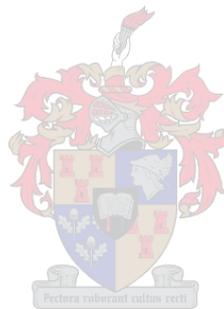


**SURVIVING A LARYNGECTOMY: THE
EXPERIENCES OF POST-OPERATIVE CANCER
PATIENTS AND THEIR FAMILIES**

by

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DECLARATION

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“You have to become used to it (laryngectomy experience) yourself. You first keep to yourself as you do not want others to know what is wrong. Later on you re-integrate and as you become used to it you totally come back again”

“Jy moet maar eers self gewoond raak daaraan (laringektomie ervaring) dan hou jy jou heel eenkant, jy wil nie hê die mense moet weet wat jy het nie.

Maar lateraan dan skuif jy weer so ‘n bietjie terug soos jy gewoond raak daaraan en dan kom jy later sommer heeltemal terug”

Dedicated to all laryngectomy patients and their families from whom I have learnt so much of life

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SUMMARY

Post-operative laryngectomy patients face various physical, psychological and social challenges. The comprehensive effects of a total laryngectomy can have an adverse impact on the patient and his or her family. Because improved medical treatment can increase the life expectancy of cancer sufferers, psychosocial guidance is required over an extended period. Unfortunately, limited information on the coping strategies of such patients is available. The social work profession could benefit from greater insight into the strengths and coping mechanisms of post-operative cancer patients in order to guide them through their survivorship journey with insight and compassion. The researcher therefore **aimed** to explore and describe the experience of a patient and his/her close family while coping with the long-term challenges of a laryngectomy. The objectives were: (1) to discuss the nature of cancer survivorship, (2) to describe the medical aspects of and physical re-adjustments to a laryngectomy, (3) to discuss principles and strategies for coping and surviving a laryngectomy, (4) to describe the comprehensive psychosocial effects during the permanent survival phase and re-entry into society; (5) to explore the survivorship journey of laryngectomy patients and their families, and (6) to analyse and interpret data obtained from the study.

Each of **the survivorship phases** as contextualised by Miller *et al.* (2008:369-374)* is discussed in the **literature review**. Both the ecological and the strengths perspective were utilised as the **theoretical framework** for this study. Principles of the **strengths perspective** focus on the inherent strengths that help patients cope with this traumatic life event, while the **ecological perspective** focuses on the utilisation of community resources in order to survive the laryngectomy experience. A combination of exploratory and descriptive **designs** was applied throughout the study to gain insight into the survival experience of post-operative laryngectomy patients and their families. The **research question** was: “What are patients’ and families’ experiences of surviving a laryngectomy with the assistance of internal and external resources within the family system and environment?”

This question was addressed by combining the quantitative and qualitative **research approaches**. Forty-five post laryngectomy patients and fifteen family members, representing one-third of these patients, were included in the study through **purposive sampling**. The study period was from June 2012 to July 2013. The inclusion criteria required: (1) Patients from the service area of the selected hospital who received a total laryngectomy as surgical treatment for an advanced stage of cancer of the larynx or hypopharynx; (2) patients who were operated on not less than three months previously; (3) patients who had already completed their initial treatment and who were attending the follow-up clinic; and (4) patients who had successfully acquired trachea-oesophageal speech.

Data obtained from the interviews were organised into themes. Four **themes** were identified: (1) the need for pre-operative information; (2) experience of physical adjustment; (3) coping and strengths used; and (4) experience of psychosocial effects of surgery and re-entry into society. These themes were divided into **sub-themes** and **categories**.

The main outcome of the study was that both patients and families mobilise a combination of inner strengths and external resources to adapt to the inevitable physical changes resulting from a laryngectomy. It is therefore **recommended** that social workers dealing with survivorship cases utilise a combination of the ecological and strengths perspectives to create an environment in which patients can explore their own inner strengths, or to help them link to community resources whilst coping with their survivorship journey.

Future research should focus on the long-term psychosocial survival of laryngectomy patients and their families, as it is likely that survivorship will increase in future; the implementation of survivorship programmes for health care professionals to equip them with skills to guide cancer survivors to full utilisation of their own strengths and available community resources; the role of pre- and primary school children/grandchildren in the rehabilitation of laryngectomy patients deserves further investigation.

*Miller, K., Merry, B. & Miller, J. 2008. Seasons of survivorship revisited. *The Cancer Journal*, 14(6):369-374.

OPSOMMING

Laringektomie-pasiënte word ná hul operasie met verskeie liggaamlike, psigiese en sosiale uitdagings gekonfronteer. Die omvattende gevolge van 'n totale laringektomie kan die pasiënt en sy of haar gesin nadelig affekteer. Aangesien verbeterde mediese behandeling die lewensverwagting van kankerpatiënte kan verleng, word psigososiale ondersteuning oor 'n langer tydperk benodig. Ongelukkig bestaan daar baie min inligting oor hoe pasiënte kanker hanteer. Die maatskaplike werk beroep kan dus voordeel trek uit beter insig in die hanteringsmeganismes van post-operatiewe kankerpatiënte om hulle met insig en empatie deur hul oorlewingsreis te kan begelei. Die navorser het ten **doel** gehad om die ondervindings van die kankerpatiënt en sy/haar naby familie tydens hul langtermynhantering van 'n laringektomie te ondersoek en te beskrywe. Verdere oogmerke van die studie was: (1) om die aard van kankeroorlewing te bespreek; (2) om die mediese aspekte van en liggaamlike aanpassing ná 'n laringektomie te beskrywe; (3) om die beginsels en strategieë vir 'n oorwinning oor 'n laringektomie te bespreek; (4) om die omvattende psigososiale gevolge van die finale oorlewingsfase en hertoetreding tot die gemeenskap te beskrywe; (5) om die oorlewingsreis van die laringektomiepatiënt en sy/haar gesin te ondersoek; en (6) om die resultate van die studie te ontleed en te interpreteer.

Elk van die **oorlewingsfases** soos deur Miller *et al.* (2008:369-374)* beskrywe, is in die **literatuuroorsig** bespreek. Die ekologiese en die sterkte-perspektiewe is tesame as **teoretiese raamwerk** vir die studie gebruik. Die beginsels van die **sterkte-perspektief** is op die inherente krag van pasiënte gemik, om te bepaal hoe hulle hierdie traumatiese lewensgebeurtenis hanteer, terwyl die **ekologiese perspektief** op hul aanwending van gemeenskapsbronne om die laringektomie te oorleef, fokus. 'n Kombinasie van ondersoekende en beskrywende **navorsings ontwerpe** is deurgaans gebruik om insig in die oorlewingstryd van laringektomiepatiënte en hul gesinne te verkry. Die **navorsingsvraag** was: "Wat is pasiënte en hul gesinne se ervarings van oorlewing ná 'n laringektomie met die hulp van interne en eksterne hulpbronne in die gesinstruktuur en omgewing?"

Kwantitatiewe en kwalitatiewe **navorsingsmetodes** is gekombineer om hierdie vraag te ondersoek. Vyf-en-veertig laringektomiepatiënte en vyftien gesinslede, wat verteenwoordigend van twee-derdes van die pasiënte was, is met behulp van 'n **doelbewuste steekproef** by die studie betrek. Die studie is tussen Junie 2012 en Julie 2013 onderneem. Die insluitingskriteria was: Pasiënte uit die diensgebied van die spesifieke hospitaal wat 'n totale laringektomie as chirurgiese behandeling vir 'n gevorderde stadium van kanker van die larinks of hipofarinks ontvang het; (2) pasiënte wat hul operasie nie meer as drie maande vantevore ondergaan het nie, (3) pasiënte wat reeds hul aanvanklike behandeling voltooi het en wat die opvolgklinik bywoon, (4) pasiënte wat tragea-esofageale spraak suksesvol bemeester het.

Die data, wat deur middel van onderhoude ingesamel is, is in temas gegroepeer. **Vier temas** is geïdentifiseer: (1) die behoefte aan inligting voor die operasie; (2) ervaring van liggaamlike aanpassing; (3) die hantering van omstandighede en innerlike krag; en (4) ervaring van die psigososiale uitwerking van die operasie en hertoetrede tot die gemeenskap. Hierdie temas is verder in **subtemas** en **kategorieë** verdeel.

Die **belangrikste uitkoms** van hierdie studie is dat beide pasiënte en gesinne 'n kombinasie van hul innerlike krag en eksterne bronne aangewend het om ná die laringektomie by die onafwendbare liggaamlike veranderinge aan te pas. Daar word dus **aanbeveel** dat maatskaplike werkers wat kankeroorlewendes hanteer, van 'n kombinasie van die ekologiese en die sterkte-perspektief gebruik maak om 'n omgewing te skep waarin die pasiënt sy of haar eie innerlike krag kan ontgin, of om pasiënte te help om kontak met gemeenskapsbronne te maak terwyl hulle die oorlewingsreis baasraak.

Toekomstige navorsing behoort te fokus op langtermyn psigososiale oorlewing van laringektomie pasiënte en familie met inagneming van die tendens dat kanker pasiënte se oorlewing toeneem; die implementering van opleidingsprogramme vir gesondheidswerkers te fokus om hulle met die nodige kennis toe te rus om kankeroorlewendes te begelei om hul volle krag en alle beskikbare gemeenskapsbronne te gebruik. Daarby verdien die rol van voorskoolse- en laerskoolkinders in die rehabilitasie van laringektomiepatiënte verdere ondersoek.

*Miller, K., Merry, B. & Miller, J. 2008. Seasons of survivorship revisited. *The Cancer Journal*, 14(6):369-374.

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CHAPTER 1

INTRODUCTION

1.1 RATIONALE FOR STUDY

This study was focused on patients who presented with an advanced stage of **larynx cancer** where a total laryngectomy was indicated, implying removal of the entire larynx (Casper & Colton, 1998:1). According to the latest statistics from the South African National Cancer Registry (NCR), 530 new patients were diagnosed with larynx cancer during 2007 (NCR, 2007:1, 2).

A laryngectomy is experienced as a **traumatic life event** by patients and their relatives (Zeine & Larson, 1999:59). For long-term survivors of head and neck cancer, many **adjustments** are necessary after treatment (Meyer, Kuhn, Campbell, Marbella, Myers & Layde, 2004:1981), as a laryngectomy heavily disrupts the patient's basic and crucial functioning in all aspects of daily life. Patients have to deal with challenges on various levels of functioning: physical (breathing, swallowing and speaking), functional, emotional and social wellbeing (Graham, 2004:126-127, 134; Kleinsasser, 1988:190-191; Zeine & Larson, 1999:52). Patients may experience difficulty in dealing with these threatening changes to the extent that a crisis may develop (Graham, 2004:125). Consequently, laryngectomy patients are confronted with special medical and psychosocial needs which inadvertently have an impact on the family (Dhooper, 1985:217; Renner, 1995:215).

Cancer survivors are **growing in number** (Ganz, Land, Antonio, Zheng, Yothers, Petersen, Wickerham, Wolmark & Ko, 2009:137,146; Pollack, Greer, Rowland, Miller, Doneski, Coughlin, Stovall & Ulman, 2005:51) and it is expected that the number of people living through and beyond cancer will continue to rise (Rowland, 2008:361). Rowland (2008:361) and Pollack *et al.* (2005:52) have described various factors as contributing factors, namely advances in screening which lead to early detection of the

disease; the improvement in the treatment of cancer; better supportive care; aging of society; as well as progress in reducing certain cancer risk factors as some of the great medical success stories of the 20th century. According to one of the cancer-related goals laid out in the Healthy People 2010 document, globally 70% of diagnosed patients can expect to be alive five years after diagnosis, while a 66% five-year survival rate (for all cancers combined) was already achieved by 2005 (Rowland, 2008:361). Neither the Cancer Association of South Africa (CANSA) nor the NCR could provide statistics for the actual number of cancer survivors in South Africa.

Previously, a survivor was **defined** as a person living with a cancer diagnosis for five years or longer (Feuerstein, 2007b:5; Pollack *et al.*, 2005:52). The National Coalition for Cancer Survivorship (NCCS) redefined survivorship as the time from diagnosis to end of life (Haylock, 2006:16; Miller, Merry & Miller, 2008:369; Pollack *et al.*, 2005:52). Miller *et al.* (2008:369-374) have referred to Fitzhugh Mullan's (1986) proposed "seasons of survivorship", referring to "acute", "extended" and "permanent survivorship". Miller *et al.* (2008:369, 372) added the season of "transitional survivorship" between "acute" and "extended survivorship", meaning the transition from active treatment to careful observation, which includes the emotional, social and medical adaptations that may occur. Within this framework, the needs and special challenges of survivors will be better understood.

This phenomenon of prolonged survivorship tends to challenge laryngectomy patients in various ways. First, **patients** have to cope with the comprehensive effects (physical, social, psychological) of surgery for a longer period of time. As a consequence of this lived reality, "being told that he or she is now cancer free does not mean that the cancer experience is over" (Rowland, 2008:364). Social workers should meet Alfano and Rowland's (2006:439) challenge that "treating cancer alone is no longer enough, we now must also focus on the goal of helping those living with and beyond a cancer diagnosis to lead full, productive, and meaningful lives".

Second, extended survivorship affects the **family system** as a whole. Patients are now dependent on and exposed to their family and other support systems for a longer period of time. Families may experience difficulty in dealing with this demand as they are not always equipped to handle the side-effects of the operation (Blanchard, 1982:240). Feuerstein (2007b:5) included families in an attempt to define survivorship. Families of cancer survivors can also be referred to as “secondary survivors”, as they too often face long-term consequences of the patient’s survivorship (Haylock, 2006:16; Kaplan, 2008:989; Rowland, 2008:362). Haylock (2006:16) and Kaplan (2008:989) emphasised that the families of patients share the impact of the experience, which is in line with the ecological perspective (Germain & Gitterman, 1996:5-6) referring to a person functioning in relation to his or her environment. Rowland (2008:362) holds the opinion that families are vital to a patient’s ultimate health and experience of wellbeing and often experience significant challenges during a family member’s cancer experience. For this reason, families of patients are included when exploring and describing the experiences of surviving a laryngectomy.

Third, prolonged survivorship also affects the role of the **social worker** functioning as part of the multi-disciplinary team in a hospital. Patients are registered within the hospital setting for a longer period while they attend the follow-up clinic, where they will require aftercare and support services of the multi-disciplinary team. The literature (Casper & Colton, 1998:35, 50; Dhooper, 1985:220, 225; Johnson, Casper & Lesswing, 1979:1816) emphasises the role of the social worker as part of the team and as being equipped with interpersonal skills to adequately address these needs. At the hospital in which the study was conducted, laryngectomy patients are routinely referred to the social worker before surgery, often directly after being informed of planned surgery. Post-operative patients are followed up at the Radiation Oncology Department on a regular basis, depending on their medical condition and needs. **Team members** rendering comprehensive care services to laryngectomy patients include the surgeon, oncologist, nursing staff, speech-language therapist, dietician, physiotherapist, social worker and radiographer (if radiotherapy is indicated).

Germain and Gitterman (1996:12) observed that a traumatic life issue (laryngectomy) can either be experienced as a **stressor** or a **challenge**. In rendering service to patients following a laryngectomy, the social worker needs to help the patient identify personal (strengths perspective) and environmental (ecological system theory) **resources** that will be needed to master this traumatic life event and also to attend to special needs that may arise following surgery. An investigation of the ways in which patients apply these resources in daily life could help the social worker understand how patients cope with their special needs following surgery, as well as how they maintain their survivorship. Patients and families need to utilise these resources to enhance personal growth and to meet the challenges posed by the laryngectomy experience (Kaplan & Hurley, 1979:57). This is especially important, considering that patients nowadays have an increased life expectancy.

My own experience as a cancer survivor, utilising resources to enhance personal growth posed by a diagnosis of cancer, inspired me to conduct this study. The researcher has twenty-seven years' experience as a social worker in the oncology unit at the specific hospital. The need to conduct research on laryngectomy patients' coping and survivorship was motivated by the fact that **limited research** in this regard is available. The Nexus database of the National Research Foundation in South Africa (Mouton, 2006:31) only refers to four studies (with no time frame) regarding laryngectomy patients (Russell, 2007; Sabri, 2006; Stellenberg, 1995). Three of the studies were conducted in the Nursing profession and one in Engineering. The ProQuest database only indicates two studies (with no time frame) on this topic. One study (Ely, 1991) compared the psychosocial adjustment of patients who received a total laryngectomy with those who only received a partial laryngectomy as treatment option. The other study (St-Hilaire, 1996) described the quality of life of spouses of laryngectomees. The limited number of studies in this field concurs with Renner's (1995:215) and Ross's (2000:14) viewpoint that a laryngectomy is apparently performed quite rarely. Statistics at the specific hospital also support this opinion.

In total, thirty-two studies regarding coping and survivorship of cancer patients were found on the Nexus database. Most of these studies were undertaken in the fields of Psychology (19, or 59%) and Medical Sciences (9, or 28%). Topics included coping with or surviving cancer in general, or with specific reference to breast cancer patients. Only two (6%) studies were conducted in Social Work. One was about the psychosocial implications of breast cancer and the other dealt with the role of support groups in assisting with the psychosocial adjustment of post-bone marrow transplant patients.

Both the Nexus and ProQuest databases showed a **lack of research** regarding the coping and survivorship of laryngectomy patients. This study will therefore help to fill this gap and make a valuable contribution to a better understanding of patients' and families' experiences of their coping strategies in mastering this traumatic life event.

1.2 PROBLEM STATEMENT AND FOCUS

Loss of the larynx, like the loss of any body part, "may be symbolic of ultimate disintegration (death) of the body" (Dhooper, 1985:222). Being confronted with the comprehensive effects (physical, social, psychological) of a total laryngectomy, both the patient and family can be plunged into a crisis (Graham, 2004:125-126; Renner, 1995:215). Due to advances in screening and detection of cancer, improved medical treatment options and better supportive care, cancer patients have an increased life expectancy (Alfano & Rowland, 2006:432; Rowland, 2008:361). Patients thus need psychosocial guidance for a longer post-treatment period (De Boer, Pruyn, Van den Borne, Knecht, Ryckman & Verwoerd, 1995:503). Little information from a social work perspective is available about the coping strategies and survivorship of laryngectomy patients. The results of this study could give social workers a better understanding of how patients and families experience surviving a laryngectomy.

1.3 THEORETICAL DEPARTURE POINTS

A combination of the ecological and strengths perspectives was utilised as theoretical framework for this study:

The **ecological system theory** (relation of the person to his or her environment) was used as a frame of reference. Within this context, systems within the laryngectomy

patients' environment (physical or social) are referred to, for example their family systems, friends, the hospital system and/or the broader community. These systems constantly influence one another's functioning (Germain & Gitterman, 1996:5-6). As a result of the laryngectomy experience, both patient and family have to adapt to various environmental changes on a continuous basis, whether it be on the physical, social or psychological level of functioning (Eadie & Doyle, 2005:115-116; Graham, 2004:125-126; Ross, 2000:13). In addition to the ecological perspective, the **strengths perspective** as developed by Saleebey (2002) was used as theoretical framework to explore how medical treatment and psychosocial factors are contributing to the laryngectomy patient's post-operative survivorship.

On the one hand, keeping in mind the principles of the **ecological system theory**, this study explored how, within this interaction between the person and his or her environment, the laryngectomee's potential is released, what its potential is to stimulate further growth (coping and continuous survivorship) and how it promotes a diverse and supportive environment which releases human potential (Germain & Gitterman, 1996:9). On the other hand, the study was also focused on what the patient's strengths are (**strengths perspective**), rather than on the patient's problems or limitations (comprehensive effects of laryngectomy, for example loss of natural voice, permanent stoma) (Sheafor, Horejsi & Horejsi, 2000:93).

The principles of the **strengths perspective** were utilised to investigate the inherent strengths that help patients cope with this traumatic life event (Saleebey, 2002:13-18; Sheafor *et al.*, 2000:93). The driving force (strengths) behind these patients' survivorship is made up of their will or desire to live; their need to survive (Rom, Miller & Peluso, 2009:27; Tominaga, Andow, Koyama, Numao, Kurokawa, Ojima & Nagai, 1998:40) and their spiritual beliefs which help to create meaning in the world (O'Baugh, Wilkes, Luke & George, 2003:268; Vachon, 2008:220). These factors can lead to the cultivation of a fighting spirit (Tominaga *et al.*, 1998:40); reordering of values and priorities; and in increased appreciation of the meaning of life (Aspinwall & MacNamara,

2005:2550; Gerlach, Gambosi & Bowen, 1990:66) and having a sense of purpose or meaning in one's life (Rowland, 2008:365).

In addition, the structure of the chapter layout was guided by the phases of survivorship as described by Miller *et al.* (2008:369-374), as illustrated in Annexure A.

1.4 GOAL AND OBJECTIVES

The **goal** of the study was to contribute to a better understanding of the survivorship experience for both the post-operative laryngectomy patient and the patient's family system. **Objectives** of the study were:

- To *discuss* the nature of cancer survivorship as experienced by the patient and various groups involved (Chapter 2).
- To *describe* medical aspects involved in a laryngectomy and physical re-adjustments for patients and their families (Chapter 3).
- To *discuss* the principles of and strategies for coping and surviving as a post-operative laryngectomy patient (Chapter 4).
- To *explain* coping with the comprehensive psychosocial effects during the permanent phase of surviving a laryngectomy as well as their re-entry into society (Chapter 5).
- To *present* the research methodology followed in conducting the study (Chapter 6).
- To *explore* laryngectomy patients' and families' own experiences of their survivorship journey (Chapters 7 and 8).
- Based on findings of the study, to *present* conclusions and recommendations with regards to patients' and families' experiences of their survivorship experience (Chapter 9).

The **research question** in this study is: "What are patients' and families' experiences of surviving a laryngectomy with the assistance of internal and external resources within the family system and environment?"

1.5 DESCRIPTION OF TERMS

For the purpose of this study, the following description of terms will be applicable and will serve as frame of reference in order to form a better understanding of information from the literature and to interpret the results of the study:

1.5.1 Combined clinic

The hospital at which the study was conducted, all newly diagnosed patients are referred to the combined clinic. For patients of the Ear Nose and Throat clinic, combined clinics are being held on a weekly basis, namely on a Wednesday. Combined decisions are taken amongst surgeons and radio oncologists regarding patients' future medical management, namely surgery, radiotherapy or chemotherapy or a combination of some of these treatment options. The treatment plan is based on medical aspects such as the diagnosis, stage of the disease, the patient's general health condition including his or her age, as described in Chapter 3. It can therefore be said that the laryngectomy survivor attends the combined clinic from the beginning of his or her survivorship journey, namely when being diagnosed and informed of planned surgery. Already at that stage in time, the patient is referred to the social worker, as part of the treatment team, for social work intervention.

1.5.2 End of initial active treatment

End of active treatment refers to the phase when treatment that was initially indicated, comes to an end. Primary treatment may refer to surgery (total laryngectomy) or radiotherapy alone, or a combination of both these treatment options. For the purpose of this study, only patients who have had a total laryngectomy were selected to participate in the study. Whether or not patients received radiotherapy treatment (before or after surgery) was not a criterion for inclusion in the study.

1.5.3 Total laryngectomy

A laryngectomy is indicated when an advanced stage or recurrence of cancer of the larynx or hypopharynx is diagnosed (Silver & Ferlito, 1996:179). During surgery, the entire larynx is removed (Casper & Colton, 1998:1). According to the NCR statistics (NCR, 2007:1), and according to the literature (Ross, 2000:13), the majority of laryngectomy patients are male patients. The researcher will therefore refer to these patients in the male form. It was also mostly male patients who participated in the study.

1.5.4 Post-operative

The post-operative phase in the laryngectomy patient's life starts from the day of surgery onwards for the rest of his or her life. In cases where radiotherapy is indicated, it is usually during this phase that patients receive their treatment although some might have been receiving the course of radiotherapy treatment prior to their surgery. From a survivorship perspective, and based on the framework suggested by Miller *et al.* (2008:369-374), the survivor therefore has to work through the following post-operative phases of the survivorship journey: the transitional phase, the extended phase and the permanent phase. Annexure A serves as an illustration of how this information can be made applicable to post-operative laryngectomy survivors. It is described in more detail in the following chapters on the literature.

1.5.5 Psychosocial aspects of survivorship

Although the literature describes the term "survivorship" as multi-dimensional (Foster, Wright, Hill, Hopkinson & Roffe, 2009:223-224), referring to physical, psychological, social and spiritual aspects of life, this study mainly focused on the psychosocial aspects involved in the survivorship of the laryngectomy patient and family members as it is conducted from a social work perspective. To some extent, attention is given to some medical aspects of the disease (Chapter 3) and the survivor's physical post-operative adjustment to the side effects of treatment (Chapter 4).

1.5.6 Survivorship, surviving, survivor

The terms “survivorship”, “surviving” and “survivor” are described in the following chapter (Chapter 2) when issues regarding survivorship of cancer patients and their families are described.

1.6 RESEARCH DESIGN AND METHOD

1.6.1 Research approach

The **quantitative approach** was useful in creating a profile of the respondents' demographic background, whilst the **qualitative approach** focused on the world of the post-laryngectomy patient from his or her own perspective (Fouché & Delpont, 2011a:65). A combination of the two approaches will be applied throughout the study (Fouché & Delpont, 2011a:63).

1.6.2 Research design

Both the exploratory and descriptive designs were applied in the study. Through the **exploratory design**, new insights were gained into psychosocial factors which may affect the patient's and family's survivorship. Within the context of the **descriptive design**, the researcher documented the course of events during the survivorship of the laryngectomy experience (Fouché & De Vos, 2011:96; Mouton, 2006:53-54).

1.6.3 Research method

The research method included the following components:

1.6.3.1 *Literature study*

The literature review contributed towards a clear understanding of the post-operative coping strategies of laryngectomy patients during survivorship and provided a logical framework within the scientific context of related studies (Babbie & Mouton, 2001:565; Fouché & Delpont, 2011c:134-135; Marshall & Rossman, 1995:28). The literature study

was used as a basis to develop a semi-structured questionnaire in a **deductive** manner, moving from the general to the specific (Grinnell, 1988:327-328). Both **local** and **international** literature was reviewed.

1.6.3.2 Population and sampling

The hospital at which the study was conducted, forty-six patients who presented with larynx cancer were surgically treated with total laryngectomy between 7 August 2007 and 14 April 2009.

Purposive sampling as a non-probability sampling technique was used (Arkava & Lane, 1983:159; Babbie & Mouton, 2001:166; Grinnell, 1993:162-163). The sample included a selection of **forty-five** laryngectomy patients who survived cancer and met the following requirements:

- Patients' medical treatment, namely a total laryngectomy as surgical treatment for an advanced stage of cancer of the larynx or hypopharynx.
- Patients from the service area of the specific hospital.
- Successful acquirement of tracheo-oesophageal voice to participate in an interview for 45 to 60 minutes.
- Patients who had completed their initial treatment (surgery and radiotherapy, if indicated) and were attending the follow-up clinic. According to Johnson *et al.* (1979:1814), a typical period of three months to two years needs to be allowed for adjustment to the laryngectomy experience. As per definition (the NCCS definition), survivorship includes any cancer patient from the stage of diagnosis to the end of life (Haylock, 2006:16; Miller *et al.*, 2008:369; Pollack *et al.*, 2005:52); no time limit is set for purposes of the study.

By using the availability sampling technique, **fifteen** family members representative of laryngectomy patients in the purposive sample, were selected to participate in face-to-face interviews with the researcher, who made use of an interview schedule.

1.6.3.3 Method of data collection

Research instruments such as **face-to-face interviews** with laryngectomy patients and a focus group consisting of their family members were used to obtain research data through **semi-structured questionnaires** (Annexure B) for patients (Babbie & Mouton, 2001:249; Greeff, 2011:353; Grinnell, 1993:268) and an **interview schedule** (Greeff, 2011:352) for the family members reporting on the patients' coping and survivorship following the laryngectomy (see Annexure C). Interviews were conducted when patients reported for treatment or attended the follow-up clinic at the hospital. In addition to patient interviews, another source of data collection was used to ensure **triangulation** in data collection (Delpont & Fouché, 2011b:442-443). To this end, a **sample** of family members, representative of patients who participated in the study, were included for exploring their experiences on coping with a laryngectomee in the family. **Special care** was taken not to exhaust patients who had limited post-operative speech ability. Professional interviewing **techniques** were used during interviews (Greeff, 2011:343-346). Interviews were **audio taped** with the permission of the participants and **transcribed** by the researcher (Greeff, 2011:359). The researcher, a qualified social worker, offered participants the opportunity to **debrief** after their participation in the study, in order to rectify possible misconceptions and to terminate the session, if they wish to do so (Strydom, 2011:122).

1.6.3.4 Method of data analysis

The data analysis model described by Marshall and Rossman (1995:113-119) was used in the study. This model entails **organising information needs**; identifying and creating **categories, themes and patterns**; formulating **linkages** among patterns; and presenting a **research report**.

1.6.3.5 Data verification

To guarantee the validity of qualitative research, some (four) participants (patients or family members) were asked to read through transcriptions and to report on the accuracy thereof.

Criteria for data verification were adopted into the following framework to guarantee the validity of qualitative research (Babbie & Mouton, 2001:276-278; Schurink, Fouché & De Vos, 2011:419-421; Marshall & Rossman, 1995:143-145):

- **Credibility:** The goal was to demonstrate that the research was conducted in a manner that assured accuracy in identifying and describing the subject. The researcher made use of triangulation whereby more than one method of data collection (semi-structured questionnaire and interview schedule) was used to obtain data from different points of view (patients' and family members' views) in order to increase the degree of credibility.
- **Transferability:** This guideline refers to the extent to which findings of the study can be applied in other contexts or with other respondents. Although the researcher applied purposive sampling to maximise the range of information that could be obtained regarding the research topic, the sample has had to be representative of the entire population of laryngectomy patients and their family members in a South African setting. Within the context of this study, generalisation of the results of the study to the entire population of laryngectomy patients will not be possible due to the size of the sample.
- **Dependability:** Within this guideline, the researcher keeps in mind the changing conditions of the topic of research, as well as changes in the understanding of the setting. If the study is repeated with the same or similar respondents in the same or a similar context, its findings would be similar. To the researcher this could be problematic, because the social behaviour and interaction of people from an ecological system is a dynamic and changing process, in which a different set of results may be obtained with a different set of respondents.
- **Confirmability:** The concept of objectivity described in the literature stresses that the findings of the study will be the product of focus and inquiry without the biases of the researcher. As a registered social worker and for the purpose of this study, the researcher was guided by a scientific process during the research. Objectivity was a basic criterion.

1.7 ETHICAL CONSIDERATIONS

Ethics in the context of social science is described as

“...a set of moral principles which is suggested by an individual or group, is subsequently widely accepted, and which offers rules and behavioural expectations about the most correct conduct towards experimental subjects and respondents, employers, sponsors, other researchers, assistants and students.”
(Strydom, 2011:114)

Within the social work discipline, it is the researcher’s (social worker’s) obligation to protect the rights and welfare of participants, as the subjects who are participating are human beings (Arkava & Lane, 1983:5). While conducting the study, the following ethical considerations were taken into account (Strydom, 2011:115-122):

- **Avoidance of harm:** The avoidance of physical and/or emotional harm has to be avoided (Strydom, 2011:115-116). Besides physical harm, Grinnell (1993:85) also added the possibility of “mental discomfort, distress, harm or danger of deprivation”. The researcher has the responsibility to inform respondents about possible harm as they have the right to withdraw at any time of the study. Within the context of this study, avoidance of harm also refers to preventing participants becoming exhausted during interviews. Also, to allow them to cough or to clean their stoma when the need arose, as it could have added to their experience of discomfort if they did not have that opportunity.
- **Voluntary participation:** Strydom (2011:116-117) emphasised that participation should always be voluntary and that no one should be forced to participate in a research project.
- **Informed consent:** Grinnell (1993:82) emphasised that consent to participate in a study must be both voluntary and informed. Not the participant only has to be protected, but also the researcher. It implies that all possible or adequate information on the goal of the investigation, research procedures, possible advantages, disadvantages and dangers to which respondents may be exposed, as well as the credibility of the researcher, has to be discussed. Explaining the term “adequate information” refers to explaining the demands of the project upon

respondents in terms of time, activities and disclosure of confidential information. Informed consent remains necessary even if the subjects do not listen to the researcher's explanation or are not really interested in knowing (Strydom, 2011:117-118). After explaining these guidelines to participants, the researcher issued participants with a written consent form to be signed before taking part in the study in which they had to declare their voluntary participation. The possibility of withdrawal from the study at any time was also discussed. Afrikaans and English versions of the consent form for patients (Annexures D & E) and family members (Annexures F & G) are attached.

- **Confidentiality:** "Confidentiality" indicates the handling of information in a confidential manner. To achieve this, it is important to respectfully negotiate with the respondents in order to request their cooperation, to explain certain aspects such as the importance of the research and refusal of consent (Strydom, 2011:119-121). Babbie (2004:66) makes it clear that confidentiality does not have the same meaning as "anonymous", as, with confidentiality, the researcher may identify a given person's responses but essentially promises not to do so publicly. The researcher approached the matter of the respondent's confidentiality with the necessary respect and responsibility. This was possible by adhering to the following rules: Keep all information confidential unless respondents have given written consent to the contrary; obtain and use only such demographic information as is necessary for the study and store the information in a safe place. Do not make identifying details of respondents known. Mark each interview with a number in stead of mentioning the respondent's identifying details.
- **Debriefing:** Debriefing refers to subjects getting the opportunity to work through their experience as a way of minimising possible harm which may have been done in spite of all precautions against such harm. With debriefing, feelings about the project are discussed immediately after the session (Strydom, 2011:122). Time was set aside to clarify any misconceptions and to terminate the session. This was done professionally by the researcher.

The researcher, being a qualified social worker, took care of the debriefing in a professional manner in line with the Ethical Code of the South African Council for Social Service Professions (1986) that is binding for social work researchers as well (Strydom, 2011:128):

Permission was obtained from the Research Ethics Committee: Human Research (Humaniora) of the University of Stellenbosch before the study commenced (Strydom, 2011:129) (Annexure H). Initial permission was valid for the period 11 October 2011 until 10 October 2012 (Annexure I). The application was renewed for the period 11 September 2012 until 10 September 2013 (Annexure J). On 14 October 2011, the Division of Research Development and Support at the Faculty of Health Sciences, of the hospital at which the study was conducted, indicated that they accepted the ethics clearance granted by Stellenbosch University Human Research Ethics Committee (Annexure K). As advised by this Committee, approval from the Manager of the specific hospital was required, as the research was conducted in a tertiary academic institution. This was in accordance with the Provincial Research Policy and the hospital's Notice Nr 40/2009. The letter of consent dated 6 February 2012 is attached (Annexure L).

The purpose of this **Committee for Human Research** (Babbie & Mouton, 2001:528; Strydom, 2011:129) is to review all research proposals involving human subjects to ensure that the rights and interests of the participant are protected.

1.8 LIMITATIONS OF THE STUDY

The following **limitations** were experienced in this research study:

- Although literature regarding cancer survivorship was available, there was a gap in **literature** regarding psychosocial aspects of the survivorship of laryngectomy patients and their families.
- Some laryngectomy survivors did not rehabilitate to such an extent that they had successfully acquired **trachea-oesophageal voice**. These patients could therefore not participate in the study as they could not participate in the face-to-face interview which was conducted to complete a semi-structured questionnaire.

- Generalisation of the results of the study can not be applied to the entire population of laryngectomy patients due to the **size of the sample**.
- **Lack of statistics** regarding the number of survivors in South Africa.

The researcher implemented the following steps to **accommodate** these limitations:

- An extensive **literature study** was done on cancer survivorship. Both national and international literature was studied.
- Patients who had not successfully mastered **trachea-oesophageal speech** were excluded from the study. The speech-language therapist assessed their communication ability.
- The researcher decided to increase the **sample size** set in the initial research proposal in order to involve the experiences of more patients and family members although this still was not adequate to be representative of the entire population of laryngectomy patients and their families.

1.9 PRESENTATION OF THE STUDY

Results of the study are compiled in this research report (thesis) which is divided into nine chapters, set out as follows:

Chapter 1 serves as an introduction to the study. Background on the motivation for the study; problem statement; theoretical departure points; goal and objectives; description of terms; research design and method, ethical considerations and limitations of the study are presented.

Information from the literature is presented in Chapters 2 to 6. In **Chapter 2**, a general overview of survivorship of cancer patients and families is presented. Reasons for increased survivorship are referred to, followed by a detailed description of the various phases of survivorship and associated challenges that various groups that are involved have to deal with.

Chapter 3 concentrates on medical aspects (acute and transitional survivorship phases of survivorship), such as the diagnosis of cancer and medical management with its challenges and feelings when active treatment comes to an end. Various aspects of the laryngectomy survivor's physical readjustment are also described, mainly concentrating on respiratory, swallowing and sensory impairment. These patients' follow-up care and challenges with reference to self-care are also attended to.

A description of coping and strengths of survivors is presented in **Chapter 4** (extended survivorship phase), focusing on recovery from initial medical treatment, coping and strategies needed for coping where the role of social support is highlighted and coping as experienced by various groups involved is described.

In **Chapter 5**, psychosocial effects of cancer and the survivor's re-entry into society (permanent survivorship phase) is described.

Chapter 6 contains a detailed presentation of the research methodology utilised for this study and also presents an overview of how it was practically applied within the context of the study.

In **Chapters 7 and 8**, data of the empirical investigation are brought into relation with the literature review to gain a better understanding of the laryngectomy patient's and the family's experiences of their own survivorship.

Based on these findings, **Chapter 9** provides conclusions and recommendations as gained from laryngectomy patients and their families regarding their cancer survivorship journey.

CHAPTER 2

SURVIVORSHIP FOLLOWING A LARYNGECTOMY

2.1 INTRODUCTION

The desire and need to survive can be seen as a central characteristic that all human beings share (Rom *et al.*, 2009:27). In this chapter, survivorship within the field of oncology is explained with specific reference to those patients whose vocal cords were removed completely following the diagnosis of an advanced stage of larynx cancer or recurrence of the disease (Stell, cited in Silver, 1991:212). This chapter **focuses** on various aspects of survivorship which will serve as theoretical basis for the interpretation of the study. By this, the first objective of the study will be addressed.

Firstly, the concepts of “survivorship”, “surviving” and “survivors” (primary and secondary) are described, followed by a discussion on the increase in the number of cancer survivors. Survivorship can be seen as a continuum with various “seasons” or “phases” of survival, with implications for health care professionals rendering services to survivors. With regard to the laryngectomy experience, the way in which various groups are challenged by this experience, are looked at. Within this cancer “journey”, survivors have to deal with long-term consequences of survivorship, referring to physical, psychological and social consequences which will be described.

2.2 DESCRIPTION OF TERMS

With reference to the experience of cancer survivorship, specific terms need to be clarified in order to better understand the survivorship experiences of laryngectomy patients and their relatives.

2.2.1 Survivorship

Survivorship in the field of oncology was ill-defined and unacknowledged until very recently (Herold & Roetzheim, 1992:779). Over the years, **cancer has changed** from

being regarded as a fatal disease into a disease that could be cured and controlled (Haylock, 2006:16; Rowland, 2008:361). This change was due to advances in treatment over the past thirty years which have led to improvement in quantity of survival and quality of life as well (Roth & Breitbart, cited in Rubin, 2001:236) and led to the formulation of various definitions describing the different phases of survivorship (Herold & Roetzheim, 1992:779-780; Hoffman, 1989:85-86; Kaplan, 2008:989; Miller *et al.*, 2008:369-374).

Shapiro, McCabe, Syrjala, Friedman, Jacobs, Ganz, Diller, Campell, Orcena and Marcus (2009:5-6) added that the **definition** of the term “survivorship” depends on the population it serves and, therefore, the purpose for which it is required. It is thus understandable that the literature has acknowledged that, although various definitions of survivorship are available, these definitions are variously defined (Feuerstein, 2007a:1; Feuerstein, 2007b:5; Griffiths, Willard, Burgess, Amir & Luker, 2007:435; Haylock, 2006:16; Jefford, Karahalios, Pollard, Baravelli, Carey, Franklin, Aranda & Schofield, 2008:20-21; Surbone, Baider, Weitzman, Brames, Rittenberg & Johnson, 2010:257). In the field of oncology, some of these definitions of cancer survivorship refer to the following terms: the experience of living **after**, **following**, **with**, **through** and **beyond** a cancer diagnosis or anybody who has **ever been diagnosed** with cancer (Foster *et al.*, 2009:224; Gerlach *et al.*, 1990:65; Haylock, 2006:16; Jefford *et al.*, 2008 20-21; Miller *et al.*, 2008:369; Pollack *et al.*, 2005:52).

For the purpose of the current study, the definition of the **National Coalition for Cancer Survivorship** (NCCS) will be used, referring broadly to **cancer survivorship** as “...the journey that a person takes from that moment of diagnosis onward” (Miller *et al.*, 2008:369). This description implies “...the experience of living with, through, and beyond a diagnosis of cancer”, and includes family members and friends being affected by the cancer experience (Jefford *et al.*, 2008:20-21). In other words, **survivorship** for the laryngectomy patient even starts before surgery, namely at the stage of diagnosis. This journey of survivorship therefore continues throughout the various phases of medical treatment, referring to surgery (laryngectomy) and the post-operative phase,

including radiotherapy (if indicated); follow-up visits at the clinic; and re-entrance into society onwards for the rest of the patient's life.

2.2.2 Survive

The South African Concise Oxford Dictionary (2007:1181) describes the term “survive” as “to continue to live or exist in spite of an accident or ordeal”. Within the contents of this study it refers to the laryngectomy patient and family who continue to live in spite of the laryngectomy experience. By this description, the principles of the strengths perspective (Saleebey, 2002:13-18) are acknowledged as it refers to continuation of life despite an injurious event like illness.

2.2.3 Cancer survivors

In 1986, Dr Fitzhugh Mullan, cancer survivors and health care providers established the **National Coalition for Cancer Survivorship** (NCCS). They composed the most commonly accepted definition of a survivor which is embraced by the National Cancer Institute (NCI) (Haylock, 2006:16; Haylock, Mitchell, Cox, Temple & Curtiss, 2007:59; Jefford *et al.*, 2008:20-21; Miller *et al.*, 2008:369; Pollack *et al.*, 2005:52; Rowland, 2008:362; Shapiro *et al.*, 2009:5-6). According to this definition, a person can be referred to as a **cancer survivor** from diagnosis onwards for the rest of his or her life. Family members and caregivers are also included in this definition. The patient who presents with cancer of the larynx, can be seen as a **cancer survivor** as from being diagnosed with larynx cancer.

The literature distinguishes between primary and secondary survivors in order to describe those involved in the survivorship experience. This distinction will also be utilised within the context of the study.

2.2.3.1 Primary survivor

Aziz and Rowland (2003) defined **primary survivors** “as those individuals who are five or more years beyond the diagnosis of their primary disease” (Haylock, 2006:16). The

Lance Armstrong Foundation defined a cancer survivor as “anybody who has ever been diagnosed with cancer” (Haylock, 2006:16). The main issue in defining a primary cancer survivor is the point at which a cancer patient can be referred to as a cancer survivor. Traditionally, a waiting period of five years following diagnosis was allowed before a person could call himself or herself a survivor (Foster *et al.*, 2009:224; Haylock, 2006:16; Pollack *et al.*, 2005:52). This definition was **redefined** by the NCCS to be applicable from the moment of diagnosis, acknowledging the late side effects of treatment decisions (Dow, 1991:59; Gerlach *et al.*, 1990:63; Miller *et al.*, 2008:369; Rowland, 2008:362). A laryngectomy patient can therefore be referred to as a primary survivor from the time of diagnosis, during surgery (laryngectomy) and after surgery (post-operatively) for the rest of his or her life.

2.2.3.2 Secondary survivor

The National Coalition for Cancer Survivorship (NCCS) included **secondary survivors** in their definition of a cancer survivor, as supported by the National Cancer Institute (NCI) (Jefford *et al.*, 2008:20-21; Miller *et al.*, 2008:373; Rowland, 2008:362). Working from the ecological perspective (Germain & Gitterman, 1996:5-6), it will be important to take into account significant others with whom the patient will share his or her survivorship experience. This ties in well with the definition by the NCCS referring to various target groups involved in their definition of survivorship. Target groups such as family members, friends and caregivers are identified as secondary survivors (Feuerstein, 2007b:5; Haylock, 2006:16; Hoffman, 1989:85; Jefford *et al.*, 2008:20-21; Kaplan, 2008:989; Miller *et al.*, 2008:369, 373; Rowland, 2008:362; Rowland *et al.*, 2001:239; Shapiro *et al.*, 2009:6). This is in accordance with the ecological perspective, in acknowledging the patient as interacting with other systems in his or her environment and during which interaction and transferral of energy occurs (Germain & Gitterman, 1996:5-6; Meyer & Mattaini, 1995:16, 21; Sheafor *et al.*, 2000:91).

Bearing the principles of the ecological perspective in mind, it seems as if secondary survivors can potentially play the following **roles** in the cancer survivor’s experience:

- They are involved in the patient's cancer experience (Haylock, 2006:16; Hoffman, 1989:85; Jefford *et al.*, 2008:20-21);
- they share the impact and challenges of the survivorship experience (Kaplan, 2008:989; Rowland, 2008:362);
- they also face the long-term consequences of cancer survivorship (Rowland *et al.*, 2001:239);
- they experience survivorship as profound and life-changing for them as well (Miller *et al.*, 2008:373) and
- they are vital to a patient's ultimate health and wellbeing (Rowland, 2008:362).

From the above-mentioned, it is clear that the role of secondary survivors ranges from being involved in the patient's cancer experience to being a vital part of the patient's ultimate health and wellbeing.

2.3 INCREASED SURVIVORSHIP

The issues of survivorship became more important to health care workers working in the field of oncology, as the number of **survivors** is constantly **increasing**. For the social worker working in a health care setting, it is important to be aware of the value of support and rehabilitation during patients' survivorship experiences.

Available **statistics** on survivorship differ. In 1971 it was estimated that there were approximately 3 million cancer survivors globally. It was then predicted that the number of survivors including men, women and children would be 20 million in 2020 (Miller *et al.*, 2008:369). In 2005 Rowland and Baker (2005:2543) referred to a global number of more than 24 million survivors worldwide in 2002, whilst Coughlin (2008:60) and Hara and Blum (2009:40), in the literature of 2008 and 2009, referred to an estimated number of 22,4 million survivors for the same year. However, Surbone *et al.* (2010:256) in 2010 estimated that approximately 25 million people worldwide could be living with a past or present diagnosis of cancer.

The current **tendency** is that the number of cancer survivors is dramatically increasing and it is expected that it will continue to rise (Coughlin, 2008:60; Golant & Haskins, 2008:420; Jefford *et al.*, 2008:20; Lemon, Prout, Barnett & Flynn, 2010:A22; Rowland, 2008:361). For this reason, cancer survivors are referred to as a growing population (Ganz *et al.*, 2009:137-138; Hara & Blum, 2009:40; Kaplan, 2008:989; McCabe & Jacobs, 2008:203, 206). As already referred to in Chapter 1, and according to one of the cancer-related goals set out in the Healthy People 2010 document, 70% of diagnosed patients globally can expect to be alive five years after diagnosis, while a 66% five-year survival rate (for all cancers combined) had already been achieved by 2005 (Rowland, 2008:361).

The literature refers to various **reasons** for the survivorship for cancer patients having **increased**, including:

- Earlier detection and diagnosis of cancer due to improvement in the technology to detect cancer (Coughlin, 2008:60; Grunfeld, 2006:5168; Pollack *et al.*, 2005:52);
- advances in cancer screening and more effective screening (Golant & Haskins, 2008:420; Hewitt, Bamundo, Day & Harvey, 2007:2270; Rowland, 2008:361);
- advances in treatment and the availability of increasingly complex primary treatments including a combination of surgery, chemotherapy and radiation (Foster *et al.*, 2009:223; Ganz, 1990:749; Harvey & Stovall, 2007:13; Mariotto, Rowland, Ries, Scoppa & Feuer, 2007:568);
- aging of the population, which implies a longer life expectancy (Mariotto *et al.*, 2007:566). This is reachable as there are fewer deaths from cardiovascular disease nowadays (Alfano & Rowland, 2006:432);
- improvement in the quality of supportive care to help patients through intense and often toxic regimes and rehabilitation interventions offered to patients (Rowland, 2008:361; Rowland *et al.*, 2001:236; Shapiro *et al.*, 2009:5);
- reduction of risk factors which can lead to a cancer diagnosis (Pollack *et al.*, 2005:52) and

- other factors such as quality of life issues, concentrating on psychological wellbeing during and after treatment (Roth & Breitbart, cited in Rubin, 2001:220); healthier lifestyles (Haylock, 2006:17; Rowland *et al.*, 2001:236) and the availability of better trained health care teams (Johnson *et al.*, 1979:1813).

With increasing survivorship it is important to take a close look at the various **phases** through which the **survivorship journey** proceeds, to empower the social worker with knowledge and a better understanding of the experiences of survivors.

2.4 PHASES OF SURVIVORSHIP

A wide variety of literature agrees to define the beginning and end points of survivorship as ranging from the time of diagnosis onward through the rest of the cancer patient's life (Griffin-Sobel, 2005:509; Haylock, 2006:16; Kaplan, 2008:989; Quigley, 1989:63; Rowland, 2008:362). Cancer survivorship is described as a continuum which can be divided into various "seasons" (Herold & Roetzheim, 1992:779; Miller *et al.*, 2008:369) or **phases** of survivorship (Shapiro *et al.*, 2009:6). Zebrack (2001:285) even referred to this continuum as from the time of cancer prevention, screening, diagnosis, treatment up to long-term survival.

Dealing with the diagnosis of cancer, Miller *et al.* (2008:369) described this experience as a "journey" that cancer survivors have to undertake. This **cancer journey** can be described as a unique experience, "passing through a common progression of events". Hoffman (1989:85-86) referred to this progression as "the seasons of survivorship", as initially described by Fitzhugh Mullan. Hoffman (1989:85) further held the opinion that "throughout each of these stages, survivors' entire lives, not just their cells, are affected by their cancer diagnosis", acknowledging the psychosocial effects of survivorship which will be described in Chapter 5.

In Figure 2.1, the phases of survivorship are conceptualised, followed by a brief theoretical description of the **various phases** and how these apply to the survivorship experience of the post-operative laryngectomy patient. Each of these phases of

survivorship will be described according to the patient's pathway through his medical management, namely the initial diagnosis, testing and staging of disease, medical treatment, aspects such as end of medical treatment, followed by physical readjustment following treatment until the phase where the patients have to report for follow-up care (acute and transitional phases - Chapter 3); recovery from initial medical treatment and coping strategies (extended phase - Chapter 4), as well as coping with long-term psychosocial effects of cancer and, eventually, the patient's re-entry into society (permanent phase - Chapter 5).

Annexure A will serve as a schematic overview of the chapter layout as referred to and will also indicate the patient's pathway throughout his or her laryngectomy experience. This will contribute towards a clearer understanding of the various phases within which the patient and family have to survive the laryngectomy experience.

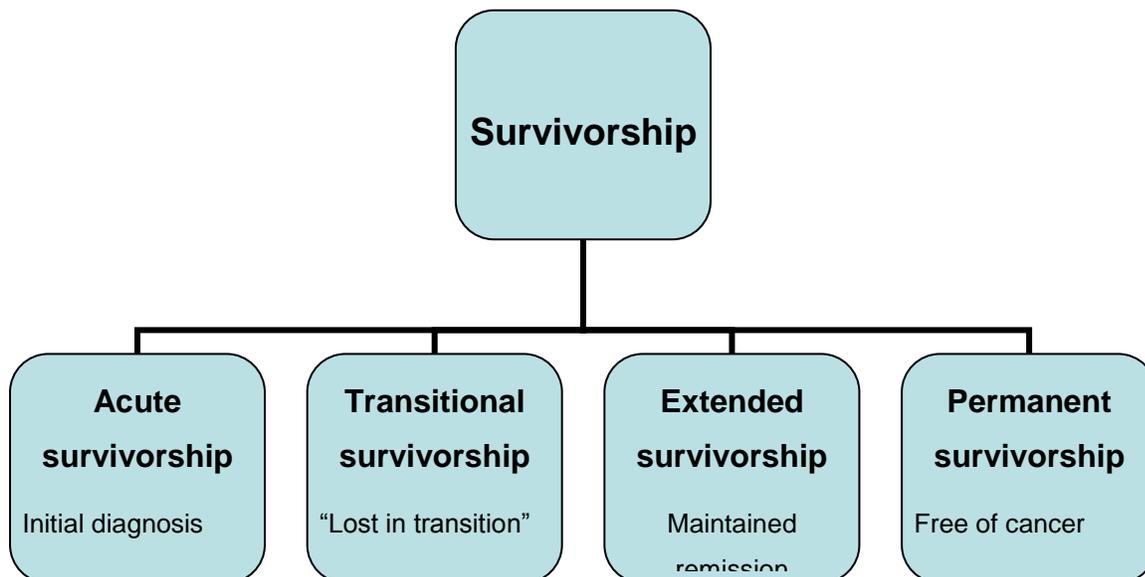


FIGURE 2.1: Model of seasons of survivorship proposed by Miller et al. (2008:371), based on the model by Fitzhugh Mullan, MD in 1986

2.4.1 Acute survivorship phase

The **phase of acute survivorship** refers to the cancer patient's experience of testing and diagnosis, treatment, and coping with the side effects of initial treatment (Herold & Roetzheim, 1992:779; Kaplan, 2008:989; Miller *et al.*, 2008:372). Referring to the hospital where the study was conducted, patients can either be treated on an in- or outpatient basis during the phase of **testing** and **diagnosis**. For **surgery** the patient will obviously be admitted and will then be referred to as an inpatient. On average, these patients will stay in hospital for ten to fourteen days, pending on the extent to which side effects may be experienced. If post-operative **radiotherapy** (6 to 7 weeks) is indicated, patients may receive this treatment on an in- or outpatient basis, depending on their location and general medical condition. Whilst coping with the **side effects** of initial medical treatment (surgery, radiotherapy, chemotherapy) patients are generally at home and are not in close contact with the hospital.

Miller *et al.* (2008:372) pointed out that, nowadays, there is a wider range of treatment options which are more effective with fewer side effects due to advances in supportive care, and a shorter treatment period. For the cancer patient, this phase implies confrontation with his own mortality (Herold & Roetzheim, 1992:779; Miller *et al.*, 2008:372). In addition, laryngectomy patients are confronted with the loss of their larynx, which, like the loss of any body part, may be symbolic of death of the patient (Dhooper, 1985:222).

2.4.2 Transitional survivorship phase

Miller *et al.* (2008:369, 372) proposed the **phase of transitional survivorship**, representing the transition from active medical treatment (surgery on an inpatient basis and radiotherapy on either an in- or outpatient basis) to careful observation of the patient's medical condition outside the hospital system. Firstly it can refer to a period of "watchful waiting" during which patients will receive some type of maintenance therapy. In the case of the post laryngectomy patient, it may include regular maintenance of speech valves. This phase has implications for the survivor as the medical hospital

team is less involved. Survivors experience ambivalence of feelings as they are relieved that treatment has ended, but the survivor, on the other hand, may experience feelings of isolation and depression. Secondly, it may refer to the phase during which the cancer survivor's medical condition has improved, although not having entered remission; has stabilised; or the survivor is experiencing progression of the disease. Transition has to occur from the knowledge that the cancer is not cured but will continue to be a significant problem. Survivors need to make various adjustments regarding their physical, psychological, social and financial functioning.

For the laryngectomy patient, this will be especially applicable as patients have to **adjust** to the **comprehensive effects** of surgery, which affect the patient's basic and crucial functioning in all aspects of daily life (Eadie & Doyle, 2005:115-116; Graham, 2004:125-126; Meyer *et al.*, 2004:1981; Ramírez, Ferriol, Doménech, Llatas, Suárez-Varela & Martínez, 2003:95; Sewnaik, Van den Brink, Wieringa, Meeuwis & Kerrebijn, 2005:95). Within the context of the ecological perspective, these adjustments need to be made on a micro (patient), meso (family) and macro (community) level (Compton & Galaway, 1999:38).

2.4.3 Extended survivorship phase

The **phase** of **extended survivorship** is described as a time of celebration with the completion of active medical treatment on an in- or outpatient basis followed by a period of "watchful waiting". Survivors now have to deal with uncertainty about their future (Heroldt & Roetzheim, 1992:779; Miller *et al.*, 2008:372). Miller *et al.* (2008:372) distinguish between three categories of patients within the phase of extended survivorship, namely survivors who are in remission and are not receiving any ongoing maintenance therapy; those living with no evidence of disease because of ongoing treatment with targeted therapy; and those who are treated and are living with advanced cancer that is not in remission but rather is in a chronic stage. During extended survivorship, survivors may experience few, moderate or more significant side effects of treatment.

Although most of these survivors are not cured, they are living with cancer by balancing the everyday challenges of “regular life” with the “ups and downs” of living with cancer and its treatment (Miller *et al.*, 2008:372). From a physical point of view, survivors learn to cope with the limitations of treatment, while psychologically they have to deal with the fear of recurrence (Heroldt & Roetzheim, 1992:779). Kaplan (2008:989) added that, during this phase, survivors are returning to normal life while being followed up regularly. Laryngectomees are constantly challenged with adaptations they have to make in daily life, like having to face the loss of their natural voice. As one’s voice is an extension of thought and the sense of oneself, the patient loses not only speech but also the ability to be heard and acknowledged (McQuellon & Hurt, 1997:234-235).

2.4.4 Permanent survivorship phase

The **phase of permanent survivorship** refers to the phase of being cured but having to deal with the comprehensive effects of cancer and its treatment on a physical, psychological and social level. Survivors have to adjust in the long term in order to live beyond their diagnosis of cancer by re-entering into society (Herold & Roetzheim, 1992:779-780; Kaplan, 2008:989).

Miller *et al.* (2008:372) are of the opinion that “there is no moment of cure but rather a gradual sense or confidence that the risk of recurrence is low and that the chance of long-term survival is great”. To support their opinion, they refer to a quote by Dr Mullan (1986) who has indicated that the cancer experience will leave an impression, both physically and emotionally. During permanent survivorship patients will feel less impaired and will again focus on involvement in the activities of normal daily life. The authors distinguish four categories of permanent survivors:

2.4.4.1 Cancer-free and free of cancer

In this group of cancer survivors, many may have had early stage cancers that were surgically cured and do not require further treatment, with little or no monitoring. In this group are those cancer survivors with advanced cancer who responded completely to

aggressive multi-modality treatment and who lead their lives without significant physical or emotional impairment (Miller *et al.*, 2008:372). Some post laryngectomy patients, for example, may be in a position to continue with their previous employment.

2.4.4.2 Cancer-free but not free of cancer

This group of survivors includes those who have to deal with long-term effects of cancer and its treatment and for whom the physical and emotional scars “serve as a daily reminder of the experience” (Miller *et al.*, 2008:372-373). This is especially true of laryngectomy patients who have to deal with dramatic physical changes, such as the presence of the tracheostoma and the absence of normal laryngeal speech, which will constantly remind them of their laryngectomy experience (DeSanto, Olsen, Perry, Rohe & Keith, 1995:768; Devins, Stam & Koopmans, 1994:608; Graham, 2004:126; Hanna, Sherman, Cash, Adams, Vural, Fan & Suen, 2004:875; Herranz & Gavilán, 1999:990). Although laryngectomy patients are free of cancer at this stage, the effects of the operation will affect them in numerous ways (Dhooper, 1985:223). During this phase, survivors may experience “posttraumatic growth” which empowers them to participate in support groups and cancer advocacy (Miller *et al.*, 2008:373).

2.4.4.3 Secondary cancers

Some survivors may develop a cancer diagnosis that is related to their treatment. Survivors then re-enter the season of acute survivorship, although their experience may be different from the previous time. Medically, prior medical treatment plans have to be taken into account when initiating new medical treatment plans. Emotionally, the survivor may experience a sense of confidence, new or unresolved anger and fear or, possibly, a combination of both (Miller *et al.*, 2008:373).

2.4.4.4 Second cancers

Various factors including genetic composition, degree of exposure and normal aging may contribute to the development of new cancers in cancer survivors (Miller *et al.*, 2008:373). Some laryngectomy patients may also be diagnosed with a second cancer,

namely cancer of the lung, as severe smoking over a long period of time is associated with both these cancer diagnoses.

2.4.5 Implications of “phases” of survivorship to health care workers

The phases of survivorship offers a **framework** for health care professionals to better understand the cancer survivorship “journey”. During **acute** survivorship, emphasis will be on dealing with posttraumatic stress associated with diagnosis and treatment. Ideally, patients will be assisted in their coping with long-term adjustment to the diagnosis and treatment. In the **transitional** phase it is important to concentrate on a reduction of confusion and fear normally associated with end of treatment. In the **permanent** phase of survivorship it will be important to focus on cancer screening to reduce the incidence of second cancers. Medical problems that develop as late or long-term complications of cancer treatment can be dealt with to improve the long-term health of patients (Miller *et al.*, 2008:373). These phases are described in the following chapters, as indicated in paragraph 2.4 - Phases of survivorship.

2.5 CHALLENGES FOR GROUPS INVOLVED WITH LARYNGECTOMY SURVIVORS

From the ecological perspective it can be said that a person functions within and **in relation to his environment** (Germain & Gitterman, 1996:5-6; Meyer & Mattaini, 1995:16; Sheafor *et al.*, 2000:91). Interaction between individuals, families, groups and their physical or social environment occurs on a continuous basis (Germain & Gitterman, 1996:6). Individuals, families and other people affected by the survivorship experience link well with the ecological perspective, as the issue of survivorship affects patients (primary survivors, on a micro level), family members (secondary survivors, on a meso level), caregivers (secondary survivors, also on a meso level) and health care workers (secondary survivors, on a macro level) (Compton & Galaway, 1999:38), as illustrated in Figure 2.2:

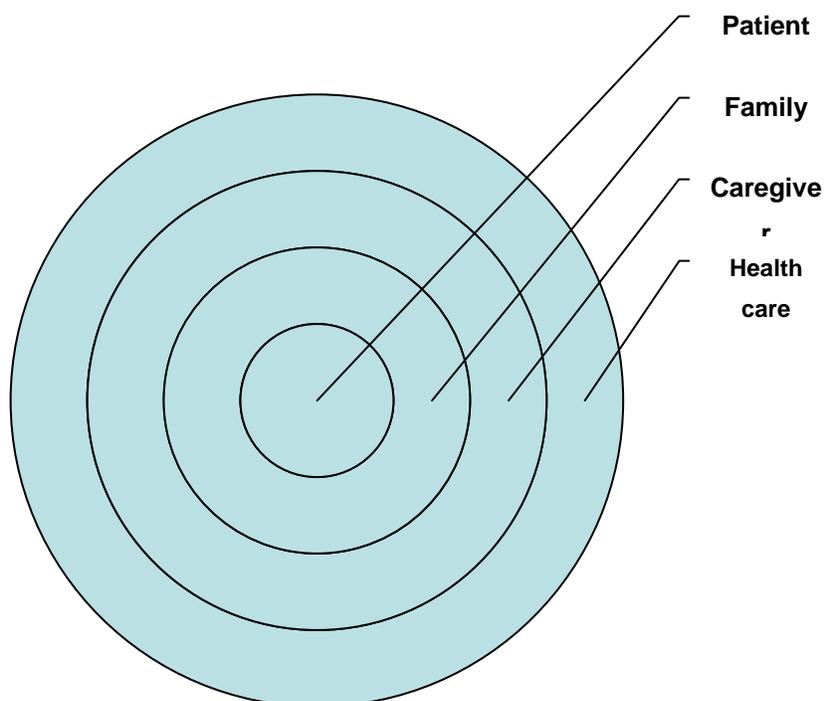


FIGURE 2.2: *Target groups affected by the survivorship experience*

People at the various levels of the ecological system may hold different viewpoints of survivorship, depending on the personal meaning it has for them. Gerlach *et al.* (1990:68) distinguished the following differences in viewpoints on survivorship according to whether they function on a primary or secondary level of survivorship, which were made applicable to the experience of the laryngectomy survivor:

2.5.1 Patients (micro level)

Primary survivors at the micro level (**patients**) have to face various challenges in coping with the disease and the effects of its treatment (Feuerstein, 2007a:4). Although many of these challenges are similar to the experience that survivors of other chronic illnesses may experience, cancer creates some unique aspects of living beyond the diagnosis (Feuerstein, 2007b:5). With increased survivorship, the long-term medical and psychosocial effects of the diagnosis and its treatment will come as a new experience to

survivors. In rendering services to primary survivors, the aim will be to maximise their long-term health and wellbeing (Feuerstein, 2007c:107; Harvey & Stovall, 2007:13).

On the one hand, the primary cancer survivors are looking forward to a disease-free future, while, on the other hand, they have to deal with certain permanent effects of the disease and its treatment. In the case of laryngectomy patients, these survivors will be confronted with permanent changes in their basic and crucial functioning like eating, speaking, breathing and swallowing (Herranz & Gavilán, 1999:993; List, Ritter-Sterr, Baker, Colangelo, Matz, Pauloski & Logemann, 1996:1; Ramírez *et al.*, 2003:95; Relic, Mazemda, Arens, Koller & Glanz, 2001:514; Sewnaik *et al.*, 2005:95). Some of the major challenges to laryngectomy patients will be to adapt to loss of voice, altered body image and functional limitations following surgery (breathing, swallowing, and speaking) (McQuellon & Hurt, 1997:239).

2.5.2 Family members (meso level)

The present study aims to explore and describe the experiences of patients and families when having to cope with the laryngectomy experience. As the laryngectomy experience does not impact the patient (primary survivor) only, but also **the family** (secondary survivors) of the patient, it will be necessary to focus on the family system from an ecological perspective. This theoretical perspective constitutes that a person functions in relation to his or her environment (Germain & Gitterman, 1996:5-6; Meyer & Mattaini, 1995:16, 21-22; Sheafor *et al.*, 2000:91). The family system can be seen as the closest of all social environments to the patient (Relic *et al.*, 2001:516). As these systems are interdependent and interrelated, energy and information are exchanged. With boundaries that are open, systems can easily react with their environment whilst preserving their structure and characteristics. Change in one part of the system will have an impact or change in all parts involved. For an understanding of the laryngectomy survivorship journey, it is important to acknowledge that change in the primary survivor's life will also impact on the system of the secondary survivor. Family members, who can be seen as secondary survivors at the meso level of the ecological perspective, are also challenged by the cancer experience.

Alfano and Rowland (2006:433-437) refer to a variety of **changes** the family needs to adapt to. On a **physical** level, families need to adapt to the effect of the patient's illness and demands caused by the illness. From a **psychological** level, families of survivors are confronted with uncertainty about the future; emotional adjustment problems after completion of treatment; adjustment to the disease; and long-term effects of treatment, stressors, distress and feelings of hopelessness. On a **social** level, family members need to adapt to change in relationships, for instance the possibility of weakened or strengthened partnerships, lack of support and communication problems. Dhooper (1985:222) and Renner (1995:216) emphasised change in family roles as an area of adjustment in families. In the case of laryngectomy patients, communication problems are especially relevant. As a result, change in family roles and breakdown in family communication may occur and may result in a crisis for both the patient and for family members (Blood, Simpson, Dineen, Kauffman & Raimondi, 1994:19; Renner, 1995:216).

2.5.3 Caregivers (meso level)

Caregivers can also be regarded as secondary survivors functioning on a *meso level*, and can often experience challenges that are similar to those of primary cancer survivors, but they often have to deal with the frustration of having no outlet for their anxieties (Golant & Haskins, 2008:421-422). Caregivers may experience impaired immunity after their care giving role has ended and may therefore develop their own risk for serious health problems (Golant & Haskins, 2008:422).

2.5.4 Health care workers (meso level)

In their offering of support services to primary and secondary survivors, **health care workers** who function on the meso level of the ecological perspective may face the following challenges:

- To *develop* a better comprehensive understanding of long-term and late effects of treatment and wellbeing of survivors in order to provide effective intervention (Feuerstein, 2007c:107);
- to *focus* on the emotional, physical and behavioural consequences of treatment and the effect on quality of life issues (Chen, Tsai, Liu, Yu, Liao & Chang, 2009:479; Roth & Breitbart, cited in Rubin, 2001:236);
- to *address* medical and psychosocial needs of the patient in order to help focus on a holistic approach and, as a result, improve service delivery (Arora, 2009:4);
- to *optimise* psychosocial as well as physical outcomes which will represent a new challenge to supportive care (Alfano & Rowland, 2006:432); and
- to *develop* a strategy for advocacy efforts that ensure the health care system's responsiveness to these needs (Zebrack, 2001:284).

On a secondary level, health professionals will **primarily focus** on the patient's survival rather than the long-term psychosocial effects of the disease and its treatment. Mohide, Archibald, Tew, Young and Haines (1992:619-622) conducted a study to compare laryngectomy patients' and health care workers' assessment of the potential impact of treatment on quality of life for these patients. Aspects such as the effect of surgery on patients' physical consequences, social activities, communication, lifestyle, functional status, self-image, self-concept, cancer control, and vocational functioning were included. The findings of the study showed a difference between the patients' and health care workers' assessments. Whilst health care workers rated impairment in patient's communication as most problematic to patients, patients ranked the physical consequences of treatment as having the most disturbing effect to them.

2.5.5 Employers (meso level)

Employers, as secondary survivors, may fear survivors' decrease in ability to work, although it was found that cancer causes less work disruption than other chronic diseases. However, patients who present with a diagnosis of cancer of the head and neck region were less likely to return to work than survivors of other cancer diagnoses (Foster *et al.*, 2009:244).

2.5.6 General public (macro level)

The **public** as secondary survivors may hold certain misconceptions about cancer as a survivable disease and may avoid survivors who experience disfigurement or disability. In the case of laryngectomy patients, this is very applicable, due to the mutilation caused by surgery and the permanent presence of the tracheostoma. Murrills (1975:55) found that these patients are sometimes mistaken by the public as being deaf. Eadie and Doyle (2005:116) reported that the public tends to refer to altered ways of communication as non-normal and less acceptable and intelligible than normal speakers. These factors, together with their altered way of speech, may add to the laryngectomy patient's tendency to withdraw from social interaction, which may increase their risk for depression.

The NCA description of primary and secondary survivors links well with the various levels of the ecological perspective, as it is representative of the micro (patient), meso (family; caregiver, employer) and macro levels (health care system, public) of functioning.

Table 2.1 summarises the **differences in challenges experienced by various groups** at levels of survivorship issues:

TABLE 2.1: Challenges of groups involved with post-operative laryngectomy survivors

Individuals and groups involved with laryngectomy survivors	Perspective of individuals / group	Perspective of laryngectomy survivor
Cancer survivor (<i>micro level</i>)	<ul style="list-style-type: none"> Looking forward to a disease-free future but having to deal with certain permanent changes 	<ul style="list-style-type: none"> Permanent change in body image (stoma), breathing, swallowing, speaking, loss of natural voice
Health professional (meso level)	<ul style="list-style-type: none"> Primarily focus on survival rather than psychosocial effects 	<ul style="list-style-type: none"> Differences between patient's and health care worker's opinion on quality of life issues regarding the effect of surgery on daily living - Mohide <i>et al.</i>, (1992:619-622)
Employer (meso level)	<ul style="list-style-type: none"> Fear of decrease in working ability 	<ul style="list-style-type: none"> Head and neck cancer patients were less likely to return to work compared to survivors of other cancers
General public (macro level)	<ul style="list-style-type: none"> Misconceptions about cancer; avoiding persons with disfigurement or disability 	<ul style="list-style-type: none"> Sometimes mistaken as being deaf Altered ways of communication are viewed as less acceptable and intelligible Patient will have an increased risk for depression as the tendency will be to withdraw from social interaction due to altered speech or shame over appearance and clumsy functioning

Following a description of differences in views held by various groups concerning survivorship, it is also important to note that survivorship comes at a cost (Curtiss & Haylock, 2006:4), which implies some consequences of increased survivorship.

2.6 CONSEQUENCES OF SURVIVORSHIP

Consequences of increased survivorship can be seen as a **problem**, a **need** or a **challenge**, depending on the consequence as experienced by the primary and/or secondary survivor.

As patients nowadays live for longer periods of time, increased survivorship can have various consequences. These consequences are described differently in the literature. Some literature (Miller *et al.*, 2008:370) regards these implications as **problems**, referring to physical, psychosocial and economic long-term effects of cancer and its treatment (Foster *et al.*, 2009:223; Lemon *et al.*, 2010:A22; Pollack *et al.*, 2005:51). Curtiss and Haylock (2006:4), in considering the psychosocial, spiritual, long-term and late effects survivorship may have on the primary survivor, warned that “survivorship often **comes with a cost**”.

Survivors may be **challenged** by psychosocial problems they experience as a result of the cancer they had survived or the treatment they receive (Lemon *et al.*, 2010:A22). With the change in the emphasis on cancer survivorship from previously being seen as a fatal disease to the present view of it as a disease that in many cases is potentially curable, survivors, too, are challenged with various changes in focus within their cancer experience. Today, cancer survivors live well beyond the time of diagnosis and treatment (Pollack *et al.*, 2005:57) and issues such as death, dying, and biological survival no longer attract sole attention during survivorship. The focus rather has shifted to the emotional, physical and behavioural consequences of treatment (Roth & Breitbart, cited in Rubin, 2001:236). Cancer survivors are also more willing to discuss and share their experience of cancer in the open, while it used to be an experience endured in silence and secrecy (Rowland *et al.*, 2001:240). The focus of cancer patients nowadays is placed on realistic hopes of recovery; knowledge about life after treatment; and how to achieve the best possible physical and psychosocial outcomes for this future (Rowland *et al.*, 2001:240). As a result of the constant change in cancer treatment, information provided to cancer survivors needs to be periodically revised and revisited,

thereby to equip patients with knowledge and tools to master survivorship challenges (Rowland *et al.*, 2001:240).

Increased survivorship also results in the **need** for comprehensive understanding of the consequences and the need to develop efficient programmes to accommodate survivorship issues (Cella, 1987:66; Gerlach *et al.*, 1990:70). There is a gap in the health care setting for handling the transition from active treatment to post-treatment care (Lemon *et al.*, 2010:A22). For the laryngectomy patient, it means a longer rehabilitation programme and a longer adjustment to physical and lifestyle changes (Johnson *et al.*, 1979:1813).

Also important to take into account is that these consequences do not **affect** the primary survivor (patient) only, but also the secondary survivors (families of survivors) (Pollack *et al.*, 2005:51), which is in line with the NCA's definition of survivorship and ties in with the ecological perspective, in acknowledging the patient's interaction with various systems (family) (Meyer & Mattaini, 1995:21-23). Cella (1987:66) was of the opinion that the problems that cancer survivors experience are "not mere extensions" of those they may experience in treatment, although it may differ in quality, being "...more diverse, less medical, difficult to anticipate, and, happily, less extreme... . [t]here [being] a trend in these problems away from illness-related ones and toward societal, interpersonal ones".

Cancer survivorship is referred to as a **multi-dimensional** concept, acknowledging the comprehensive effects of the disease and its treatment, in including the physical, psychological, social and spiritual aspects of living beyond the diagnosis of cancer (Foster *et al.*, 2009:223-224). Surbone *et al.* (2010:256) acknowledge that, although medical treatment decisions are the first priority in treating patients, the presence of both the medical and psychosocial issues of survivorship has to be acknowledged from the start. This will be especially applicable in the case of laryngectomy survivors who post-operatively present with the very obvious and visible physical effects that follow surgery (Deshmane, Parikh, Pinni, Parikh & Rao, 1995:121; Hanna *et al.*, 2004:878),

resulting in psychosocial implications for both themselves and their family members (Ross, 2000:13).

It can therefore be said that these implications are representative of effects survivors may experience on a **physical**, **psychological** or **social** level. In the discussion that follows, these implications will be stipulated, with specific reference to implications that laryngectomy survivors may experience. Taking into account the physical effects of their surgery, these survivors are being confronted with changes which occur on a permanent basis, referring to the presence of the permanent stoma, permanent inability to sing, shout, cry, laugh, sniff, taste, smell and having natural voice (Ross, 2000:16).

In the following section of the chapter, the long-term physical, psychological and social effects of cancer and its treatment are described. This is made applicable on the laryngectomy patient. Chapters 3 (medical information) and 6 (psychological and social effects) present a more detailed description of these effects as experienced by the primary and secondary laryngectomy survivor.

2.6.1 Physical consequences

Directly after being diagnosed with cancer, the primary survivor will focus on the treatability of the disease and its expected prognosis. Following treatment, the survivor's attention will be on the potential risks of invasive procedures, the effects of treatment and possible recurrence (Deimling, Bowman, Sterns, Wagner & Kahana, 2006:307). As mentioned by Pollack *et al.* (2005:52-53), various **categories of cancer treatment effects** can be distinguished, depending on the duration of the effects. These include:

- short-lived effects (hair loss, nausea, vomiting, anaemia)
- effects occurring or lasting weeks or months after treatment ends (fatigue, pain, memory problems, sexual dysfunction)
- permanent effects (lymphedema, infertility, amputation, ostomy)
- effects occurring months or years after treatment that may be life-threatening (second malignancies, cardiovascular disease, osteoporosis).

With specific reference to survivors who are representative of a head and neck or ear nose and throat diagnosis, the following specific **physical effects** will occur: arm stiffness; dental caries; taste and smell changes; difficulty with swallowing; feeding problems; bodily changes or disfigurement (loss of a body part and surgical scars) (Jefford *et al.*, 2008:21, 30). This disfigurement refers to the presence of the permanent tracheostoma through which the patient has to breathe, cough and sneeze and which is the most visible disfiguration after surgery as it is open, obvious and permanent (Belch & Beamish, 1992:60; Devins *et al.*, 1994:608; Ulbricht, 1986:133).

2.6.2 Psychological consequences

Various authors described the following potential **psychological effects** following the diagnosis and treatment of cancer: anxiety; depression; fear of end of treatment, recurrence and death; uncertainty about prognosis and future; inability to make long-term plans; psychological distress; diminished self-esteem or confidence; spiritual concerns; sadness and loneliness; mood disruption; change in self-esteem and body image; awareness of own mortality (Cella, 1987:60-61; Coughlin, 2008:61; Curtiss & Haylock, 2006:4; Gerlach *et al.*, 1990:66-68; Jefford *et al.*, 2008:21, 30; McMurchie, 1991:1450; Quigley, 1989:63-65; Roth & Breitbart, cited in Rubin, 2001:236). Although these psychological effects can potentially be experienced by any cancer patient, change in self-esteem and body image is especially applicable in the case of laryngectomy patients facing an altered appearance (permanent stoma). Again, laryngectomy survivors easily become socially isolated, which can result in depression, taking into account their initial difficulty with communicating (Dhooper, 1985:222; Graham, 2004:126).

2.6.3 Social consequences

Cancer survivors are also confronted with challenges on a **social level**, for example: change in social roles; family relations; re-orientation to altered status; re-entry into normal life; employment and financial issues; legal issues; marriage (Coughlin, 2008:61;

Dow, 1991:56-58; Gerlach *et al.*, 1990:67-68; Hara & Blum, 2009:41; Hoffman, 1989:86; Jefford *et al.*, 2008:30; Lemon *et al.*, 2010:A22; McMurchie, 1991:1450-1451; Quigley, 1989:65-66; Roth & Breitbart, cited in Rubin, 2001:236). Some of these social effects are described in Chapter 5 with specific reference to the experience of laryngectomy survivors as they, in particular, may find alteration in social or interpersonal relationships and re-entry into society a challenge (Jefford *et al.*, 2008:21; Quigley, 1989:65-66).

2.7 CONCLUSION

This chapter has described certain aspects concerning cancer survivorship with specific reference to laryngectomy survivors. A **description** of the **concepts** of “survivorship” and “primary and secondary survivors” was presented. These descriptions form the basis for implementing the ecological perspective, referring to the micro, meso and macro levels of functioning.

The population of primary cancer survivors is **increasing**, because of various reasons. Increased survivorship will raise the need for health care professionals to offer psychosocial assistance for a longer period of time.

Survivorship can be divided into **various phases** or seasons, referring to acute, transitional, extended and permanent survivorship. These seasons have to be borne in mind during service delivery as it adds to a better understanding of the cancer survivorship journey with the aim on improvement in the care and support of survivors.

Survivorship with its **multi-dimensional characteristics** can be seen as a challenging experience. Various groups such as patients, family members, caregivers and health care workers have to face survivorship challenges from different viewpoints. These challenges are experienced on various levels, namely on a physical, psychological and social level, which were briefly referred to and are discussed in more detail in the following chapter.

An understanding of survivorship issues will serve as a framework for interpretation of the surviving experience of laryngectomy patients and their families, thus meeting the first objective of the research study. The **next chapter** supplies medical information regarding this surgical procedure, including the unique context of the hospital setting in which the social worker functions as part of the inter-disciplinary team rendering services to laryngectomy patients. Physical re-adjustment of patients is also described, focusing on the respiratory, swallowing and sensory problems they may experience.

CHAPTER 3

MANAGEMENT AND EXPERIENCES OF MEDICAL TREATMENT: *Acute and transitional survivorship phases*

3.1 INTRODUCTION

The reader having been equipped with knowledge of survivorship in general, this chapter **focuses** on the experiences of laryngectomy survivors (patients and families) of medical management, starting at the stage of diagnosis and ending at the stage where the patient has to attend for follow-up care. Emotional experiences at the stage of being diagnosed with cancer and at the stage of treatment completion are also described. With reference to the various “phases of survivorship” (Miller *et al.*, 2008:369-374), this chapter is focused on both the acute and transitional phases of survivorship. By this, the second objective of the study is reached.

3.2 PHASE OF ACUTE SURVIVORSHIP

This phase starts at the initial **diagnosis** of cancer after thorough **testing and staging** of the disease, after which implementation of the patient’s prescribed **treatment** regime follows. The importance of adequate **information** being offered to the laryngectomy patient and family prior to surgery is highlighted. A description of the **treatment team** in the health care system with specific reference to the role of the social worker rendering services to these patients and their families within a hospital setting is included. The **end of initial medical treatment** has the potential to present various challenges related to emotional reactions to patients and their families which will be discussed.

3.2.1 Initial diagnosis

With the diagnosis of cancer as starting point in die cancer survivor’s journey, emotional challenges with which the patient and family will have to deal, are presented. Medical

aspects such as demographic information, risk factors and incidence of larynx cancer are discussed, followed by an outline of social trends with which these patients generally present. This information will add to a better understanding of the post-operative experiences of the laryngectomy patient and family members.

3.2.1.1 *Diagnosis as departure point in cancer survivorship*

In 1990, already, Gerlach *et al.* (1990:63) held the opinion that cancer survival starts on the day of diagnosis, which was in contrast with previous beliefs that survival only starts years after cancer treatment has been finished or years after remission. The **definition** of the National Coalition for Cancer Survivorship (NCCS) of 1996 concurs with this opinion, indicating the duration of cancer survivorship as from the moment of diagnosis for the remainder of a cancer patient's life (Miller *et al.*, 2008:369; Pollack *et al.*, 2005:52; Shapiro *et al.*, 2009:5-6). According to this definition, the cancer survivor's journey starts with the diagnosis of cancer, whilst "end of life" can be seen as the end point of this journey (Dow, 1991:59; Haylock, 2006:16; Haylock *et al.*, 2007:59; Miller *et al.*, 2008:369; Rowland, 2008:362).

For the purpose of this study, the laryngectomy patient's and family's survivorship journey starts from the time of diagnosis, and ends at the end of the patient's life. In other words, this journey of survivorship starts prior to the laryngectomy experience, namely at the stage when the patient is being informed of the diagnosis of larynx cancer. Laryngectomy patients and their families will have to face the various emotional challenges along their survivorship journey from the very start.

3.2.1.2 *Diagnosis as emotional challenge*

Patients often are unaware that they are at risk of being diagnosed with cancer and for that reason the diagnosis of cancer is often **unexpected** (Rowland, 2008:365). With this in mind, as well as the **stigma** associated with the diagnosis of cancer (DeSanto, 1994:43; Quigley, 1989:65; Richardson, Graham & Shelton, 1989:283), it is no wonder that McQuellon and Hurt (1997:231) indicated that the diagnosis and treatment of

cancer is almost always an emotionally **traumatic experience**. In addition, many **myths** and **misconceptions** are present, as cancer is still synonymous with death for many, although larynx cancer can, under some circumstances, be treated successfully (Ross, 2000:14).

Pinquart and Fröhlich (2009:416) described the stage of diagnosis and the commencement of treatment as a particularly **stressful period**. Surprisingly, many patients manage to adapt over time. These authors based their opinion on results from several studies indicating that psychological wellbeing improves over the course of treatment. Patients, who present with a diagnosis of cancer of the larynx will, in addition to this, also have to deal with unique challenges of the devastating implications of this diagnosis as they have to decide on treatment options with potentially widespread effect; the potential of surgery which may be disfiguring; and possible mortality following their decision to receive the prescribed treatment (Cady, 2002:347; McQuellon & Hurt, 1997:231). Although patients and their families have to deal with various experiences of **fear** along their survivorship journey, it is especially during the phase of diagnosis that their fear most likely will be about the treatability of the disease together with their prognosis for survival (Deimling *et al.*, 2006:307).

3.2.1.3 Demographic information of larynx cancer

According to the latest statistics collated by the **SA National Cancer Registry** (NCR) for 2007, the following information regarding the diagnosis of larynx cancer is applicable:

- The number of **new cases** of larynx cancer observed was 464 and 66 respectively for male and female patients (NCR, 2007:1, 2). The majority of these cases were from the Black population for both male (269) and female (26) patients (NCR, 2007:5, 6). This was followed by White, Coloured and Asian population groups in this sequence (NCR, 2007:3-4, 7-10).
- During 2007, cancer of the larynx was described as the thirteenth most **common cancer diagnosis** among South African males and as the thirty-sixth most

common cancer diagnosis among South African females. In both cases, the age group most at risk was 55 to 59 years (NCR, 2007:1, 2).

- Cancer of the larynx represented 1,81% (in the case of male patients) and 0,24% (in the case of female patients) **of all cancers** diagnosed during 2007 (NCR, 2007:1, 2).

The demographic information needs to be interpreted against the background of **census information**. According to statistics for South Africa in 2011, the total population of the Western Cape was 5 822 734 (census 2011:14) which included 48,8% of the Coloured population group, followed by 32,9% from the Black; 15,7% by White and 1,0% by the Asian population groups. Taking into account the NCR statistics which refer specifically to cancer of the larynx, this information has the following **implications** for the present study:

- Larynx cancer formed a **small percentage** of all cancer diagnoses especially when referring to the most common types of cancer. This information underlines the theoretical assumption that a laryngectomy is a lonely experience, as this operation is seldom performed and patients seldom know other patients who have had such an operation (Ross, 2000:14). Due to the relatively small number of laryngectomy patients, this often is a group of patients who receive little attention from a social work research perspective, which increases the need for research regarding survivorship issues.
- It is expected that the number of **female** and **younger** patients who will be diagnosed with larynx cancer will increase, mainly due to increased consumption of tobacco products and changes in drinking behaviour (Doyle, 1994:16; Eadie & Doyle, 2005:122; Renner, 1995:216; Ross, 2000:13; Smithwick, Davis, Dancer, Hicks & Montague, 2002:206).

3.2.1.4 Risk factors of larynx cancer

The most common risk factors preceding a diagnosis of cancer of the **head and neck region** include tobacco and alcohol use, although Woodard, Oplatek and Petruzzelli (2007:526) have warned that anyone can get such a cancer. Other risk factors of head

and neck cancers may include poor oral hygiene, exposure to radiation or ultraviolet light, nutritional factors, genetic susceptibility or exposure to occupational hazards (Moore, Chamberlain & Khuri, 2004:53).

In the case of **larynx cancer**, McKenna, Fornataro-Clerici, McMenamin and Leonard (1991:123) pointed out that cigarette smoking and alcohol are responsible for more than 75 percent of cases. As these risk factors are synergistic in their effects, heavy smoking combined with daily drinking leads to a relative risk of laryngeal malignancy that is 15,5 times higher than in the case of the normal population. In some cases, laryngeal cancer can be secondary to industrial and toxic exposures. Workers in railroad, farm, textile, lumber and metal industries are therefore at higher risk (McKenna *et al.*, 1991:123).

3.2.1.5 Incidence of larynx cancer

The literature (Casper & Colton, 1998:7; Ross, 2000:13) indicates that **male smokers** between the age group of 45 and 75 years are largely at risk. Due to the fact that this disease mostly occurs in late middle age, it can therefore be seen as a disease of the **elderly** (Belch & Beamish, 1992:61; Deshmane *et al.*, 1995:121; Renner, 1995:216; Ross, 2000:14). This information is in accordance with the NCR statistics for 2007, indicating that male between the age group of 50 and 69 years, and female between 50 and 64 years were most at risk of a diagnosis of larynx cancer (NCR, 2007:11, 12).

3.2.1.6 Social trends of larynx cancer

Besides substance abuse, other social factors such as low socio-economic **status**; low levels of **education**; and a generally poor **social network** and poor **coping skills** are also seen among patients presenting with cancer of the head and neck area (Cady, 2002:347; Eadie & Doyle, 2005:120).

Having said that the diagnosis of larynx cancer forms a small percentage of all cancers in general; that substance abuse plays a role in the diagnosis of cancer of the head and neck region; that this operation is not performed often; and that these patients normally

present with a generally poor social network, it can be deduced that laryngectomy patients and their families have to face various and unique challenges along the survivorship journey that starts from the moment of diagnosis.

3.2.2 Testing and staging of disease

The presence of various **symptoms** leads to the diagnosis of larynx cancer which needs to be discussed. Knowledge of these symptoms will add to a better understanding of the acute phase of these patients' survivorship journey.

The most common symptoms prior to the diagnosis of larynx cancer are alteration in voice quality or hoarseness. Other symptoms may include dysphagia (difficulty to swallow), odynophagia (painful swallowing), otalgia (ear pain), coughing, airway obstruction, neck mass and/or hemoptysis (coughing of blood). In an advanced stage of the disease, symptoms such as stridor (difficulty to breathe), anorexia or weight loss may also be present. Pain in the throat or neck may be referred to the ear and can possibly be associated with difficulty in swallowing or speaking (Dhooper, 1985:218; McKenna *et al.*, 1991:123-124).

Special medical investigations are required in order to finally diagnose the patient with cancer of the larynx. **Staging** of the disease is primarily the task of the medical team and refers to the extent to which the cancer has invaded other surrounding structures; nodal or distant spread. This information is important for the medical team to decide on an appropriate treatment plan during the patient's attendance of the combined clinic (Annexure A).

3.2.3 Treatment

Silver and Ferlito (1996:161) recommended that, especially in the case of a laryngectomy, decisions regarding patients' medical management be taken **individually**. The **holistic approach** towards the patient's treatment is thereby acknowledged, as they mention that, besides medical factors, other factors like

emotional and social factors should also be taken into consideration. Patients who, for example, present with unacceptable degrees of medical risks or with severe emotional instability, will not be good candidates for such extensive surgery. Noncompliant patients will not be good candidates for a course of radiotherapy and chemotherapy as they may not finish the prescribed duration of treatment. This type of treatment is also not recommended, if a laryngectomy will cause a previously independent elderly patient to become institutionalised. It furthermore is important to take into account the patient's probable reaction to surgery.

Before having a close look at treatment options indicated for larynx cancer, **several barriers** in the treatment of cancer of the head and neck region in general need to be stipulated (Moore *et al.*, 2004:54):

- **Late presentation** of disease as symptoms, like hoarseness, may relate to a variety of other upper respiratory abnormalities, for example: having a cold, flu, respiratory difficulties due to seasonal changes or allergies, laryngitis or smoking (Dhooper, 1985:218; Doyle, 1994:18). As pain is usually absent, patients may be treated with home remedies which may result in such patients not being prepared for a possible diagnosis of cancer (Dhooper, 1985:218). Normally, these patients also, present with a history of previous substance abuse; low socioeconomic status; low levels of education; and a generally poor social network (Cady, 2002:347; Eadie & Doyle, 2005:120), which may contribute towards late presentation of the disease.
- Treatments for cure may cause psychological and physical **morbidity**.
- Continued consumption of **alcohol and tobacco** may promote the presence of a second primary cancer diagnosis.
- **Poor compliance** for regular follow-up (Cady, 2002:347).

Having been acquainted with the various barriers which may obstruct the treatment of the patient who presents with cancer of the head and neck region, knowledge of the various modalities available in the treatment of the patient who has been diagnosed with larynx cancer will contribute to the social worker's understanding of the unique

challenges these patients and their families have to deal with along their survivorship journey.

3.2.3.1 Various modalities in the treatment of larynx cancer

Various treatment options are available, each with its accompanying implications. The treatment of laryngeal cancer is based on the extent and the location of the disease (McKenna *et al.*, 1991:125). Improving of survival remains the primary goal in treating patients with head and neck cancer, as emphasised by Woodard *et al.* (2007:529). A **combination** of treatment options may be indicated (McKenna *et al.*, 1991:125), which may include surgery, radiotherapy and/or chemotherapy.

(a) Surgery

A total laryngectomy may sometimes be accompanied by a radical neck dissection (McKenna, 1991:125). Although surgery can be seen as the standard treatment for cancer of the oral region, the literature (Chen *et al.*, 2009:474) acknowledges that it has accompanied impairment on a **physical, emotional** and **social level** of functioning. The physical effects of this operation are described in the final section of this chapter, whilst the psychosocial effects of the operation are described in the following chapter. Knowledge of a laryngectomy as surgical procedure will be important to the patient (primary survivor) and family (secondary survivor), taking into account the comprehensive effects of such an operation.

(i) Information prior to surgery

With regard to laryngectomy patients, Cady (2002:347) held the opinion that **no amount** of preoperative counselling could fully prepare patients or their families for the effects of such devastating surgery. A study conducted by Johnson *et al.* (1979:1814) showed that nearly all laryngectomy patients acknowledged the need for additional pre-operative information for both themselves and members of their families. This may be because oral cancer patients were perceived to have greater physical and daily living needs, patient care and support and information needs, compared to other cancer patients

(Chen *et al.*, 2009:474). Important to take into account, is Johnson *et al.*'s (1979:1818) warning that information being offered under circumstances of crisis may not be retained with a single session. In other words, the manner in which information is given does not always meet the patient's ability to understand it. Patients may experience high levels of stress, because of the **short time interval** between diagnosis and having to make treatment decisions and receiving surgery (Chen *et al.*, 2009:478-479). When treatment starts, the patient's fear may shift to the potential risks of treatment procedures and its accompanying side effects (Deimling *et al.*, 2006:307). The cancer survivor will therefore be challenged by fear of various experiences of loss, fear of further surgery, fear of loss of function, fear of mutilation, depression, or fear of death (Argerakis, 1990:286).

Both Kleinsasser (1988:256) and Ruiz and Crevier-Buchman (2000:173) emphasised the role of proper preoperative **counselling** of the patient and family as they believe that an understanding of the extent of the surgery and its effects on functional speech and voice will improve their prognosis for rehabilitation. **Practical guidelines** for offering this information to patients and their family members were highlighted by Kleinsasser (1988:256). It is recommended that the patient's spouse and nearest relative attend the discussion as they will be the people on whom the patient will be dependent after being discharged from hospital. Open discussion of the diagnosis and planned treatment offers the patient the opportunity to make an informed decision. In addition, Kleinsasser (1988:256-257) emphasised that patients **will need time** to consider their decision and should be allowed to discuss the proposed treatment with their family at home, if needed. The areas for which patients will need information, firstly concern their diagnosis. Feelings that may be experienced are shock and anxiety regarding their survival. Secondly, the nature and extent of the operation should be explained in simple terms. In the third place, patients need to be prepared regarding the length of treatment and expected side effects of treatment. This will include information about the use of nasogastric tube feeding shortly after having been operated; that they will have to learn to swallow again; that the normal manner of speech production will be affected; and that they will have to learn a new technique for producing speech.

Fourthly, patients and their families need to be informed that they will have to change their lifestyle following treatment. This is especially true in the case of patients who present with a diagnosis of cancer of the head and neck region where smoking and substance abuse was present (Cady, 2002:347).

From a **survivorship perspective**, the potential areas for which survivors will need information refer to medical and psychosocial issues that may arise during the various phases of cancer survivorship; the availability of sources of support; and professional assistance (Hara & Blum, 2009:41). During diagnosis and treatment, survivors may also require a need for supportive information (Chen *et al.*, 2009:478-479). The type of information offered to the patient will depend on the stage of the patient's survivorship journey (Jefford *et al.*, 2008:29-30). The purpose will be to offer adequate emotional and psychological support to the patient and family members (Jefford *et al.*, 2008:29). It is suggested that this information can be provided through educational workshops or written handouts (Argerakis, 1990:293; Hara & Blum, 2009:49). From another angle, Kreuter, Buskirk, Holmes, Clark, Robinson, Si, Rath, Erwin, Philipneri, Cohen & Mathews (2008:33) hold the opinion that survivors themselves can be seen as "messengers" of hope and information as they have personal experience of the disease themselves.

The **need to prepare** survivors for the late effects of treatment will become increasingly important in future as survivorship increases, and primary and secondary survivors will have to deal with these late effects of treatment for longer periods of time. Besides the need for information regarding the medical issues that may arise following surgery, the laryngectomy survivor and family will also need information regarding the availability of support and professional intervention as these needs may arise. This will assist them to cope with the late effects of treatment. An explanation of the medical management of the patient will be followed by a discussion of the role of the team in the health care system will therefore be discussed in part 3.2.3.2 of this sub-section dealing with the acute phase of survivorship.

(ii) Medical indications for total laryngectomy as surgical procedure

During a laryngectomy, the total or part of the larynx is removed following a diagnosis of cancer of the larynx or hypopharynx (Karamzadeh & Armstrong, 2001:528; Lennie, Christman & Jadack, 2001:668; Schuster, Lohscheller, Kummer, Hoppe, Eysholdt & Rosanowski, 2003:212; Smithwick *et al.*, 2002:204). Severe laryngeal trauma without the presence of a malignant tumour may sometimes require a laryngectomy (Casper & Colton, 1998:2). However, only patients who receive a total laryngectomy for a diagnosis of cancer were included in the study.

A total laryngectomy is described in the literature as indicated in the following situations:

- An **extended** or **advanced** cancer diagnosis where a partial resection or radiotherapy is not possible or recommended, due to the site or size of the tumour (Hanna *et al.*, 2004:875; Kleinsasser, 1988:191; Lotempio, Wang, Sadeghi, Delacure, Juillard & Wang, 2005:948; Relic *et al.*, 2001:515).
- **Spread** of the disease to adjacent structures, which results in fixation or is accompanied by nodal metastasis (spread of the disease to regional nodes) (McKenna *et al.*, 1991:125).
- **Persistent** diagnosis of cancer or recurrence of the disease after previous radiotherapy treatment or partial resection (Stell, cited in Silver, 1991:212; Jay, Ruddy & Cullen, 1991:937; Kleinsasser 1988:191).

The decision to perform a total laryngectomy should be based on careful assessment, as stressed by Kleinsassar (1988:191), as thorough consideration should be given as to whether a total laryngectomy is the best and most effective treatment.

(iii) Neck dissection as surgical procedure

Besides the nodes, with a **neck dissection** it may also be required to remove adjacent structures like blood vessels, nerves and several neck muscles, especially in the case of more advanced cancer (Lennie *et al.*, 2001:668). Following this, post-operative, patients may experience pain and limitation of movement of the shoulder due to surgical

removal of the nerve that controls the shoulder (Dhooper, 1985:218; Moore *et al.*, 2004:55).

(b) Radiotherapy and chemotherapy

Besides surgery, **radiotherapy** and **chemotherapy** can be offered, on either an in- or outpatient basis (Annexure A), depending on the geographic location of the patient. This will usually involve patients who stay far from the hospital; when a specific medical reason is indicated; or those who cannot easily make use of public transport due to their medical condition, who will be admitted during the course of their radiotherapy treatment.

Lotempio *et al.* (2005:948) remarked that treatment modalities for a diagnosis of advanced larynx cancer have changed significantly over the preceding ten years. Currently, treatment protocols usually involve either chemotherapy with radiation or total laryngectomy with post-operative radiotherapy. During the last two decades, chemotherapy and radiation therapy have formed part of treatment protocols (Woodard *et al.*, 2007:527). According to McKenna *et al.* (1991:125), chemotherapy has traditionally been used for medical palliation.

Besides the previously discussed medical management of the cancer survivor, intervention by various professionals within the health care system will be needed to support cancer survivors. This links well with the ecological perspective, acknowledging the various systems, such as on a micro, meso and macro level, in which the patient functions.

3.2.3.2 Teamwork

Teamwork in the management of treatment selection within the health care system is discussed in this section. This is followed by identification of the members of the team and the need for various professionals to form part of such a team.

(a) The role of the team within the health care system

Feuerstein (2007a:3) held the opinion that, to serve the specialised needs of the laryngectomy survivor and family, the treatment of patients who present with cancer of the larynx requires skilled teamwork by various team members, including the social worker (Casper & Colton, 1998:50-52). Feuerstein (2007a:3) distinguished between multi-disciplinary teamwork, which refers to “working side by side” and interdisciplinary teamwork, which refers to “active collaboration with one another”.

The principle that patients and families **should be involved** and **actively participate** in the treatment selection process is especially applicable to laryngectomy patients (McQuellon & Hurt, 1997:238-239). On the one hand, patients who underwent a laryngectomy may afterwards experience anger about post-operative loss experiences and may hold the opinion that they were not fully informed by the treatment team. On the other hand, patients whose larynx is removed may experience regret of their decision when a recurrence of disease occurs.

(b) Members of the team

Literature sources (Cady, 2002:347; Casper & Colton, 1998:50-51; Ganz, 1990:744; Hoffman, 1989:87; Hoops, Clarke & Martin, 1975:559; Johnson *et al.*, 1979:1816; King, Marshall & Gunderson, 1971:112, 118; McQuellon & Hurt, 1997:237) refer to various **members** of the **multi-disciplinary team** with regard to laryngectomy patients, including the social worker. Hara and Blum (2009:50) summarised this as follows: “If cancer is viewed as a kind of journey, it is clear that the person with cancer, caregivers, and members of the health care team are all co-travelers”.

At the hospital where the research study was conducted, the **team includes** the following members: surgeon, oncologist, nursing staff, speech-language therapist, dietician, physiotherapist, social worker and radiographer (if radiotherapy is indicated). When the need arises, patients may also be referred to the psychologist. Patients and their family members are also seen as part of this team. This is in accordance with the

viewpoint of Rom *et al.* (2009:25) who indicate that family (secondary survivors), friends, co-workers and neighbours can also be considered as part of the team, which links well with the ecological perspective, referring to the various ecosystems with whom the laryngectomy patient may interact (Meyer & Mattaini, 1995:25). In summary, Argerakis (1990:293) referred to team members as all the hospital personnel who come in contact with the patient.

(c) *Benefits of involvement of the multi-disciplinary treatment team*

Teamwork with laryngectomy survivors implies various benefits for both patients and their families. Some of these **benefits** are:

- encouragement and support for the patient to discontinue **habits** of alcohol abuse and smoking (Kaanders & Hordijk, 2002:304);
- prevention of **depression**, the risk of feeling alone, reliance on alcohol and possible suicidal attempts in their aim to solve problems on their own (King *et al.*, 1971:112; Rom *et al.*, 2009:25);
- prevention of **psychosocial** disturbances of the diagnosis and treatment during readjustment following the operation, taking into account the curtailment of patients' hospital stay after surgery (Argerakis, 1990:288; McQuellon & Hurt, 1997:237);
- taking care of the multiple **problems** of the laryngectomy patient with the input of various team members in a highly complicated, interactive manner (Hoffman, 1989:87; Hoops *et al.*, 1975:559, 561; King *et al.*, 1971:112);
- offering a wide range of pre-operative **information, counselling and education** from the perspective of various viewpoints (McQuellon & Hurt, 1997:237);
- making use of the skills relevant to the **needs** of the patient and family and to initiate **preventive** strategies to take care of these needs (Ganz, 1990:742; Johnson *et al.*, 1979:1816);
- offering **support** during the diagnoses, treatment and recovery period of the patient (Rom *et al.*, 2009:25); and

- identifying **rehabilitation** needs; planning for and providing and coordinating rehabilitation services by coordinating the patient's care in the hospital and community; and ensuring that the patient will follow through on the recommendations and referrals that are made (Ganz, 1990:743-744; Hoffman, 1989:87; King *et al.*, 1971:112; McQuellon & Hurt, 1997:237). By this, the patient will be assisted in reaching his optimum level of recovery (Argerakis, 1990:292).

The **value of teamwork** varies between problem solving, offering psychosocial support, providing of information relevant to the rehabilitation of the patient, including motivation to a sober lifestyle which, in the first place, was the most leading factor to the diagnosis of larynx cancer. Although the achievement of these goals would be the priority of the whole team, the social worker is in an ideal position to fulfil these roles, because of his or her specialised knowledge and skill. For this reason, the role of the social worker needs to be looked at closely.

3.2.3.3 Reasons for including the social worker in the treatment team

The literature describes various reasons why the social worker should form part of the cancer survivor's rehabilitation team. These **reasons** include:

- Social workers *are equipped* with **communication skills** which enable them to provide information to patients and family members regarding the disease, treatment, options for supportive counselling and referrals to community resources (Zebrack, 2001:286).
- Social workers *have skill* in offering **emotional support** to patients and families. Within this process they take the emotions of patients (primary survivors) and families (secondary survivors) into account and offer them the opportunity to verbalise their feelings (Argerakis, 1990:294).
- Social workers *can assist* patients and families with **adjustment problems** following treatment. These adjustments may be experienced on the level of employment, or financial, familial and emotional problems (Argerakis, 1990:294; Hoops *et al.*, 1975:562). This is especially needed in the case of laryngectomy patients who present with low socio-economic status, low levels of education and

a generally poor social network and coping skills (Cady, 2002:347; Eadie & Doyle, 2005:120).

- Social workers *can evaluate* the patient's and family's supportive care **needs** and determine what **resources** will be most appropriate (Ganz, 1990:746).
- Social workers *can promote* the patient's **rehabilitation** following treatment and refer patients to appropriate community resources (Hara & Blum, 2009:49). The social worker is an expert in evaluating the patients' supportive care needs and determining what resources are most appropriate (Ganz, 1990:746). These resources may be representative to meet patients' education, counselling, emotional support, financial assistance, legal advice or assistance needs. The social worker *can create* survivorship programmes to guide survivors to full utilisation of these resources (Hara & Blum, 2009:49) and *assist* physicians where they lack training in rehabilitation needs assessment and knowledge of applicable resources of support (Ganz, 1990:743).

From the above it can be deduced that the **social worker's role** within the patient's and family's survivorship journey covers a wide spectrum, including the offering of information, problem solving, emotional support, and linking with community resources in order to promote the patient's rehabilitation. It can therefore be said that the social worker forms an integral part of treatment in the health care system in rendering services to the cancer survivor. Involvement of the social worker also includes secondary survivors, which is in line with the ecological perspective, with reference to the patient in relation to various systems, like the family system. At the hospital where the social worker is located, the social worker's involvement starts at the stage when the combined clinic informs the patient and family (if present) of planned surgery (Annexure A).

From the above discussion regarding a patient's medical treatment, it can be said that a **holistic treatment plan** applies to the patient, as treatment does not only refer to patient's medical treatment, but also to interaction between various members of the treatment team in order to render a comprehensive service to the patient. The

completion of the initially prescribed treatment (surgery, radiotherapy, chemotherapy) brings the active initial treatment of the patient to an end.

3.2.4 End of initial active medical treatment

The end of initial active treatment may introduce its own unique challenges on various levels of functioning, namely on the micro, meso and macro levels. In surviving a laryngectomy, both primary and secondary survivors will experience these challenges.

3.2.4.1 Challenges

Challenges which are experienced at the end of the initial active treatment mostly relate to survivors' **need of support** (micro level); **differences in the experiences** and **expectations** of primary and secondary survivors (meso level) and **changes in responsibility** for prevention and detection of cancer (macro level). Each of these challenges are described in order to provide better understanding of the primary and secondary survivor's experience of surviving a laryngectomy.

(a) Challenge concerning need of support

Cancer survivors may experience the completion of treatment as a **challenging adjustment** for various reasons. On the one hand, the hospital and treatment routine offer safety, familiarity and intensive care, whilst, on the other hand, many survivors experience loss of support and community when active medical treatment is completed (Hara & Blum, 2009:47, 49).

The survivor **may need support** from family, friends, colleagues or sexual partners, referring to the meso level of functioning. This may come as a surprise, as family and friends on the meso level may expect that the survivor's need for support would diminish at the stage when active medical treatment comes to an end. As a result, the gap between the need of the survivor for support and the availability of support from family and friends may result in feelings of guilt and loneliness (Hoffman, 1989:86). On a *macro level*, survivors may also experience lack of support from the medical team,

through loss of close monitoring and less frequent contact, which may be unsettling (Hara & Blum, 2009:47, 49).

(b) Challenge of experiences and expectations

Besides **differences** between primary and secondary survivors regarding the experience of the **need for support**, the difference in the reactions of primary and secondary survivors may also add to the challenge of treatment being completed. Whilst family and friends are happy on behalf of the patient at this time, they (family and friends) are looking forward to being able “to get back to normal” and “to put it all behind them”, ignoring the long-term effects of cancer and its treatment that the patient may experience (Hara & Blum, 2009:40, 41). Such different reactions may be experienced with sadness and loneliness (Jefford *et al.*, 2008:30). Survivors may also experience difficulty in coping with the change in self-identity, as they now need to have a different outlook on life and have had to rearrange their priorities and attitudes to life, as their survivorship journey has started (Jefford *et al.*, 2008:30).

The current tendency towards a shortened hospital stay will increase the pressure on patients to adjust to their new appearance and communication skills, and to deal with the reaction of others while still in a relatively safe environment (Cady, 2002:349). In addition, families will experience pressure to cope with challenges associated with experiences of loss on various levels of functioning along the laryngectomy survivorship journey. These **challenges** relate to adaptation to changes in the patient’s physical, social and psychological functioning following surgery (Byrne, Walsh, Farrelly & O’Driscoll, 1993:173; Eadie & Doyle, 2004:753; Eadie & Doyle, 2005:115-116; Graham, 2004:125; Zeine & Larson, 1999:52).

Survivors also are not necessarily equipped with the skills to return to their **pre-operative status** or **capacity** (Rom *et al.*, 2009:33). Patients, having been exposed to a different routine for long periods of time during medical treatment, may experience feelings of being intimidated or overwhelmed. In being back to “normal”, survivors are

exposed to the possibility of the recurrence of the disease or the development of short- or long-term complications of the disease and its treatment.

Survivors sometimes experience that **significant others** (family and friends on the meso level) feel unsure in their behaviour towards the patient, with surviving **patients** experiencing the change in self-identity related to having a different outlook, priorities and attitude towards life (Jefford *et al.*, 2008:30). Taking into account the social profile of patients who normally present with a diagnosis of cancer of the head and neck region (Cady, 2002:347), laryngectomy survivors will additionally have to cope with the challenge of maintaining a sober lifestyle whilst having to adjust to their new status as a survivor.

(c) Challenge of change in responsibility

On a macro level, the **multi-disciplinary team** in the health care system no longer has the sole responsibility of prevention and detection once treatment comes to an end. After the period of close monitoring by the medical team, the survivor may experience the reduced contact as unsettling (Hara & Blum, 2009:47, 49). Responsibility shifts from the oncologist to now rest on the survivor (Hoffman, 1989:86). Taking into account that substance abuse can generally be identified as the etiological factor of a cancer diagnosis of the head and neck region (Cady, 2002:347), this will add additional pressure on the survivor to live responsibly.

3.2.4.2 Feelings about leaving the hospital system

When leaving the hospital system after completion of surgery and radiotherapy, the survivor may have “mixed feelings”, but may mainly experience **feelings** of fear and uncertainty. Feelings associated with the end of active treatment, will not affect the survivor on the micro level only, but also family and friends on the meso level and team members of the health care system on the macro level.

(a) End of treatment as source of fear

For various reasons, the end of active treatment can be experienced as a period during which survivors are challenged by feelings of fear, anxiety and uncertainty (Haylock, *et al.*, 2007:62). Fear of **recurrence** will be most prominent and this probably is the most universal and lasting effect of having been diagnosed with cancer (Deimling *et al.*, 2006:307; Foster *et al.*, 2009:241; Jefford *et al.*, 2008:20, 30; Pollack *et al.*, 2005:52) and is therefore be discussed.

In addition, fear of the risk of a **second malignancy** or **death** may also be present (Andrykowski, Lykins & Floyd, 2008:194; Coughlin, 2008:62; Hawkins, Smith, Zhao, Rodriguez, Berkowitz & Stein, 2010:21; Jefford *et al.*, 2008: 21; Miller *et al.*, 2008:370). Although these fears may diminish to some degree, it may persist in the long term, resulting in anxiety and depression (Foster *et al.*, 2009:241).

This fear of a **new** or **different type** of **cancer** may be situated within knowing that whatever predisposition “caused” the initial cancer may result in the development of another cancer. Even in the general population, the possibility of getting cancer increases with advancing age, making these survivors increasingly vulnerable to another cancer (Deimling *et al.*, 2006:307).

Other sources of fear may refer to fear of **losing** the **support** and **reassurance** of multi-disciplinary team members, fear of having to deal with uncertainty about the **future** and fear of **inability to cope** with unexpected changes in plans that may occur (Jefford *et al.*, 2008:21, 23, 26; Rom *et al.*, 2009:29).

(b) End of treatment as source of uncertainty

On a micro level, patients may experience a period of uncertainty after **leaving** the **safe environment** of the hospital setting. The multi-disciplinary team in the health care system will become less involved when treatment has finished and the patient has to leave the safety, support and close monitoring of the hospital team that functioned as a

safe environment whilst receiving treatment (Blanchard, 1982:240; Dhooper, 1985:223; Hara & Blum, 2009:47, 49; Jefford *et al.*, 2008:30; Ulbricht, 1986:133). A gap may develop between the survivor's needs and available support outside the hospital, as some survivors may still be in need of support at the time of separating from the hospital team (Hoffman, 1989:86). On the other hand, the support networks may be under the impression that the survivor's need for support has diminished, which can lead to feelings of guilt and loneliness (Hoffman, 1989:86).

Lack of effective communication or **communication problems** occurring between the various systems in which the patient functions has the potential to result in the patient and / or family experiencing uncertainty. Communication can stimulate effective coping mechanisms during the cancer survivor experience as it addresses the uncertainties of those involved. Family members may also benefit from effective communication between the various systems as this has the potential to alleviate distress and feelings of helplessness. As a result, supportive communication between survivors, families and health care professionals can reduce the uncertainties of all those involved in the survivorship journey (Gerlach *et al.*, 1990:66-68).

Survivors' experiences of uncertainty about the future (Miller *et al.*, 2008:372) may arise because there is no standard follow-up programme similar to what is experienced during treatment, and often there are no specific guidelines for the follow-up of late effects (Ganz, Casillas & Hahn, 2008:209).

(c) End of treatment as source of experiencing mixed feelings

Survivors may experience **mixed feelings** at the end of active treatment as relief and celebration are mixed with feelings of isolation and depression (Miller *et al.*, 2008:372), which could be aggravated by their speech difficulty. The laryngectomy survivor may therefore experience feelings of intense social isolation (Ross, 2000:14). This is especially applicable in the case of the laryngectomy survivor who already presents with a speech limitation. The literature (Hoffman, 1989:86) also refers to the survivor's

possible experience of “bittersweet feelings” as survivors may experience positive and negative feelings within their relationships with family, friends or healthcare workers.

For the **social worker** as member of the multi-disciplinary team, it will be important to acknowledge the challenges and feelings that survivors have to deal with. This will contribute towards a better understanding of patients’ and families’ experiences of surviving the laryngectomy, whilst having to adjust to major physical changes following surgery.

3.3 TRANSITIONAL SURVIVORSHIP PHASE

In this phase, the laryngectomy survivor’s (both primary and secondary survivors) **transition** from treatment completion to physical re-adjustment takes place. In describing this phase, physical re-adjustment caused by the disease itself and/or following treatment is looked at as from the perspective of the cancer survivor in general; those who present with a diagnosis of the head and neck region; and, more specifically, those who receive a total laryngectomy.

3.3.1 Physical re-adjustments following treatment

In general, **cancer survivors** may experience health deficits which are either directly related to their treatment or occur as a late effect of cancer treatment (Griffiths *et al.*, 2007:435; Haylock, 2006:17). These physical effects can be persistent (Jefford *et al.*, 2008:30). Various factors may contribute to the experience of such physical effects, including the cancer survivor’s age; specific diagnosis; location of the tumour; type and intensity of treatment; and the effects of time and age following cancer treatment (Miller *et al.*, 2008:370). In this regard, Dow (1991:55) emphasised the role of the specific type of cancer treatment, namely the effects of surgery, radiation therapy or chemotherapy following the diagnosis of cancer. Most survivors have to deal with bodily changes which, in the case of laryngectomy patients, will be on a permanent basis, implying loss of a body part (larynx), and surgical scars and bodily disfigurement (presence of permanent tracheotomy) (Hoffman, 1989:86; Jefford *et al.*, 2008:21).

Physically, cancer survivors may fear the management of side effects or late effects of treatment and medications once discharged from the hospital system (Deimling *et al.*, 2006:306; Jefford *et al.*, 2008:23). From a **social** perspective, this may include fear of loss of previous employment or income, fear of discrimination in the case of insurance (Gerlach *et al.*, 1990:68; Roth & Breitbart, cited in Rubin, 2001:236); fear of deterioration of family relationships (Gerlach *et al.*, 1990:67); disruption in intimate relationships or deficits in social competence (Roth & Breitbart, cited in Rubin, 2001:236). **Psychologically**, cancer survivors may experience low self-esteem or lack of confidence as a result of impairment and an altered body image (Gerlach *et al.*, 1990:66-67; Roth & Breitbart, cited in Rubin, 2001:236).

Cancer of the **head and neck region** can be described as a physically and emotionally devastating disease, taking into account its effect on daily living activities (Moore *et al.*, 2004:53-54). The diagnosis of cancer of the larynx and its treatment has far-reaching implications for physical and emotional levels as the diagnosis and treatment affect daily living, not only for the patient but also for his or her family (Cady, 2002:347; Renner, 1995:216-217). Being diagnosed and treated for cancer of the head and neck region, affect some of the most basic and vital functions of life, including speech, communication, respiration, chewing, swallowing, hearing (especially in older individuals), loss of taste and smell, and shoulder movement (D'Antonio, Zimmerman, Cella & Long, 1996:482; Jefford *et al.*, 2008:30; Moore *et al.*, 2004:55; Vartanian, Carvalho, Toyota, Kowalski & Kowalski, 2006:32,34). With regard to nutrition, patients may experience dysphagia and reduced saliva production with potential dental problems and dietary changes (Cady, 2002:348; McQuellon & Hurt, 1997:232). Problems with teeth may occur and the need to develop skills to use medical feeding equipment may also be required (Jefford *et al.*, 2008:30). Pain and discomfort on account of the cancer or as a result of surgery and radiation therapy that may follow may also be experienced (Cady, 2002:348; McQuellon & Hurt, 1997:232; Woodard *et al.*, 2007:526).

In the case of **larynx cancer**, the diagnosis impacts mainly on primary (patients) and secondary survivors (families), as the implication of treatment can be disfiguring and may cause possible mortality (Cady, 2002:347). The most obvious effects following treatment are speech and communication problems (De Boer *et al.*, 1995:511), although other disfiguring effects of treatment will necessarily result in loss of voice, change in appearance (tracheostoma) (De Boer *et al.*, 1995:512) and other functional limitations with a resulting effect on patients' self-image and identity (McQuellon & Hurt, 1997:231).

Many **laryngectomy** patients and their families have great difficulty in their attempts to adjust to the physical and lifestyle changes following surgery (Johnson *et al.*, 1979:1813). It was in this regard that Rowland and Baker (2005:2543) remarked: "Being disease free did not mean being free of the disease. Cancer has the capacity to touch all aspects of an individual's health: physical, functional, psychological / cognitive, social, economic, and spiritual". Especially in the case of laryngectomy patients an almost overwhelming number of problems which may limit optimal rehabilitation may be experienced. However, the patient has to find the best way of meeting each of these problems (King *et al.*, 1971:112).

Pre-operative **radiotherapy** may result in a greater chance of post-operative complications such as wound infections and tissue damage with poor wound healing (Woodard *et al.*, 2007:530-531). Patients who receive primary radiotherapy as treatment option may experience symptoms such as pain, dysphagia (difficulty to swallow), and continued speech disturbances as a result of post-treatment oedema (swelling) and fibrosis (Woodard *et al.*, 2007:527). Long-term consequences of radiotherapy treatment may include dryness of the mouth and a decreased sense of taste because the salivary glands and taste buds will be affected (Lennie *et al.*, 2001:667-668). As a result of surgery (laryngectomy), patients also present with a diminished sense of smell, which may contribute to nutritional problems (Cady, 2002:348).

Using the framework suggested by Steyn (2009) as departure point in describing the **psychosocial effects** of surgery, this section of the chapter describes the physical

effects following a **laryngectomy** and how it will affect the patient's and family's physical re-adjustment to their laryngectomy experience. Taking into account the tendency of increased survivorship, primary and secondary survivors now have to adjust to the side-effects of treatment for a longer period of time (Alfano & Rowland, 2006:432).

3.3.1.1 *Respiratory problems*

As illustrated in Figure 3.1, these patients have to breathe through a permanent tracheostoma (Graham, 2004:126), which is now the only airway to the lungs (Ross, 2000:15). Therefore patients no longer inhale through the nose and pharynx and exhale from the lungs to the nose and mouth. For normal speakers, pulmonary air supports both life and speech, but for the laryngectomy patient, life breathing and speech breathing are distinctly separate. Although laryngectomy patients still use air as the power source for vocalisation, this air must be voluntarily "trapped" in the esophagus and is not the same air that moves through the tracheostomy (King *et al.*, 1971:113).

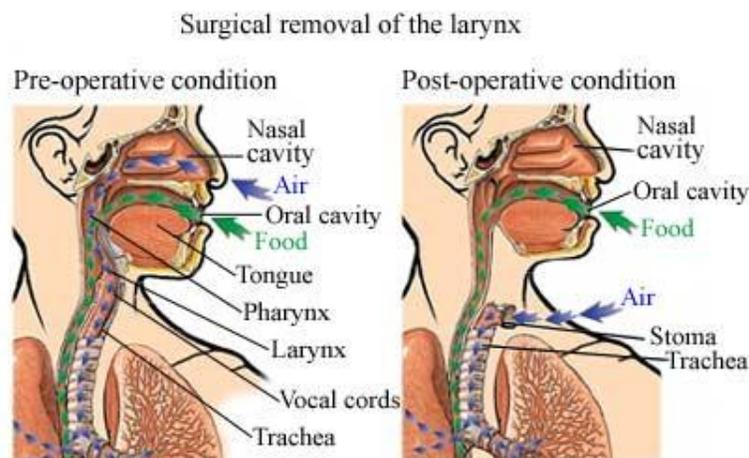


FIGURE 3.1: *Surgical removal of the larynx, pre- and post-surgery*

Source: <http://www.cnehomehealth.org/body.cfm?id=103&chunkiid=14833>

Downloaded: 18 August 2010

(Steyn, B.H.: The laryngectomy patient's need for support groups in a hospital setting: a social work perspective, 2009)

(a) *Stoma crusting and narrowing*

Patients experience loss of the humidifying function of the nose and mouth. After the operation, air is no longer warmed, cooled, cleaned, filtered and moistened after inhalation. The bronchial mucosa becomes irritated and an increased flow of mucus may lead to crusting of the stoma (Devins *et al.*, 1994:608; Dhooper, 1985:219; Ross, 2000:16).

Care of the stoma includes the following:

- **Clearing** the mucus from the stoma by wiping it away in order to avoid irritation and odour. An increase in the secretion of mucus usually occurs immediately after surgery. Previously, this function was carried out through the nose and pharynx (Ross, 2000:15, 16; Ulbricht, 1986:133).
- This cleaning process must be done **frequently**, even during night time. Cleaning of the stoma is important otherwise the patient's speaking may become strenuous. This may be bothersome and time consuming, and may also impact on social situations by leading to feelings of discomfort. (Hilgers, Aaronson, Ackerstaff, Schouwenburg & Van Zandwijk, 1991:155; Op de Coul, Ackerstaff, Van As, Van den Hoogen, Meeuwis, Manni & Hilgers, 2005:173).
- The stoma needs to be **protected** from the inhalation of foreign objects (Landis, Giger, Lacroix & Dulguerov, 2003:341).

(b) *Coughing*

Coughing is more common after a laryngectomy and the patient has to adapt to coughing mucus through the stoma (Ross, 2000:16). Increased mucus production can be caused by the lack of the cleaning, warming and moisturising effect of the upper airway on inhaled air, small particles of dust, air pollution or irritants in the air (Stam, Koopmans & Mathieson, 1991:38; Ulbricht, 1986:133) or by the change in airflow (Ross, 2000:15). Sputum production and continuous coughing have **social implications** for patients and their families. The patient may feel uncomfortable in social situations as he or she may find that it interferes with speaking. Families may find it distasteful, but might

not discuss it with the patient due to the sensitive nature of the problem (Renner, 1995:218; Ross, 2000:16).

(c) Sleep difficulties / fatigue

Respiratory problems and **difficulty with sleep** may result in fatigue, which, in turn, may have an impact on the quality of the patient's voice (Hilgers *et al.*, 1990:422, 424-425). Not being able to communicate properly may reduce social contact and result in psychological problems like anxiety and depression.

(d) Infection

The patient may experience an **increased risk** of post-operative tracheo-pulmonary infection as breathing is now through the tracheostoma instead of the nose and mouth (Landis *et al.*, 2003:341).

(e) Nasal discharge

Air now **bypasses** the **nasal cavity** during respiration (Deshmane *et al.*, 1995:123). Loss of normal nasal function results in functional limitation (Schuster *et al.*, 2003:212), which is specifically noticeable when the patient has a cold or flu and cannot blow his/her nose (Ross, 2000:16).

3.3.1.2 Swallowing problems

As cancer of the head and neck region and the treatment thereof can directly affect **eating and drinking** processes, the patient has to undergo major lifestyle changes regarding his eating habits. The ability to tolerate a regular diet will be impaired, which may result in nutritional problems, loss of appetite and weight, or malnutrition, as the patient who presents with cancer of the head and neck region is mostly linked with substance abuse. Patients may also gain weight due to loss of or decline in the sense of taste (Depondt & Gehanno, 1995:34-35; Dhooper, 1985:219; Lennie *et al.*, 2001:668, 672-673; Lotempio *et al.*, 2005:948).

Implications of the change in eating habits that affect **socialising** and are acknowledged in the literature (Lennie *et al.*, 2001:668, 672, 673; Lotempio *et al.*, 2005:948; Renner, 1995: 218-219; Ross, 2000:17; Sewnaik *et al.*, 2005:97) include the following:

- it takes longer to finish meals;
- there is a need to use liquids during meals to ease swallowing problems;
- embarrassment about eating in public due to the inability to tolerate a regular diet;
- decreased enjoyment of meals due to the loss of sense of smell and taste or difficulty in eating and swallowing;
- reduced desire to try new food; or
- restriction of conversation and socialisation during meals as it is impossible to swallow and talk simultaneously.

3.3.1.3 Sensory impairment

A laryngectomy interferes with the olfactory process (perception of odour) (Lennie *et al.*, 2001:668) because the presence of the permanent tracheostoma prevents air from being in contact with receptors in the nasal passage. The patient experiences loss of the sense of **smell**, which results in a decreased sense of taste, as the air does not flow through the nasal passages. An inability to **sniff** may be experienced following surgery (Jones *et al.*, 1992:241). As the majority of patients are elderly people, patients may also experience **hearing loss** (King *et al.*, 1971:114; Ross, 2000:17).

Loss of smell also affects social aspects of life as it may affect the following levels of functioning (Cady, 2002:348; Lennie *et al.*, 2001:673; Ross, 2000:17):

- **Safety:** Due to the inability to smell odours like smoke and natural gas, strong fumes, aerosols or toxic gasses, these may be breathed directly into the lungs, causing possibly severe danger to the patient;

- **Hygiene:** The inability to detect body odour may have an effect on the patients' social acceptance; and
- Limitations on **pleasurable odours**, like food, flowers and fragrances, also affect enjoyment of life.

3.3.1.4 Impairment of sphincter function

Loss of thoracic fixation refers to the inability of the chest to fixate when the vocal cords adduct, by drawing or pulling towards the median axis of the body (Deshmane *et al.*, 1995:125; Jay *et al.*, 1991:934). Thoracic fixation is needed when the body exerts a high degree of physical effort. The patient who suffers from loss of thoracic fixation experiences higher pressure in the intra-abdominal area while performing straining tasks, like lifting heavy weights, or other functions such as urinating or defecation. This may result in the necessity for alternative employment and financial arrangements.

3.3.1.5 Ageing and previous lifestyle

Many laryngectomees may experience additional **age-related medical problems** such as cardio-vascular or cerebro-vascular disorders, arthritis, hearing loss or dental problems, as cancer of the larynx mainly is a disease of the elderly, as already mentioned. A history of heavy smoking over a long period of time may contribute to respiratory problems (Ross, 2000:17).

Following the diagnosis and treatment of cancer and its accompanying side-effects, patients have to attend the follow-up clinic at the hospital on an outpatient basis on a regular basis.

3.4 REASONS FOR FOLLOW-UP CARE

Cancer as an illness has changed from being an acute disease to a **chronic disease**. Therefore long-term treatment and follow-up care is an important component of care, whether patients are receiving treatment aimed at cure or at palliation (Ganz,

1990:742). During the early post-discharge period, the need for more structured and supportive follow-up intervention will increase, as patients are hospitalised for shorter periods of time (Cady, 2002:349).

As cancer survivors are living longer these days, their follow-up care should include more than just monitoring their medical status (Pollack *et al.*, 2005:53). In view of survivors living longer, the importance of their needs is emphasised; these should therefore be acknowledged (McCabe & Jacobs, 2008:203). The literature acknowledges a wide spectrum of **reasons** for survivors to be followed up after treatment finishes (Coughlin, 2008:61; Feuerstein, 2007a:3; Grunfeld, 2006:5167; Hara & Blum, 2009:47; Hewitt *et al.*, 2007:2272; Kaanders & Hordijk, 2002:305; McCabe & Jacobs, 2008:203; McKenna *et al.*, 1991:125; Pollack *et al.*, 2005:53). These include:

- **Early detection** of persistent disease, recurrence, metastases or development of a second cancer such as lung cancer, taking into account the role that smoking plays in both the aetiology of head and neck and of lung cancer;
- **preventive** health maintenance;
- taking care of **late effects** of treatment or problems;
- reducing **risk of future morbidity**;
- **assessment** of cancer **risk** among family members of patients;
- **evaluation** of psychosocial effects of treatment; **providing** psychosocial support; offering **treatment** where appropriate, or **referral** for psychosocial or supportive services in order to take care of consequences of treatment;
- **health promotion recommendations** concerning smoking, alcohol, diet, exercise with the aim of risk reduction;
- **guidance** of the rehabilitation process; and
- **evaluation** of treatment outcome.

On the one hand, survivors may fear the financial impact of having to attend follow-up care on a regular basis, for example with regard to transportation (Hara & Blum, 2009:47). On the other hand, survivors may fear discharge from follow-up services and

risk a recurrence being undetected. This may lead to high levels of distress due to being without regular follow-up care (Foster *et al.*, 2009:241).

Along the cancer survivorship journey, close attention is paid to the first or acute phase, referring to the diagnosis and treatment of the cancer patient, while regular follow-up care often is not systematically planned and is only focussed on screening for the recurrence of cancer (McCabe & Jacobs, 2008:203). The ideal would be that health care professionals issue a follow-up schedule, including short- and long-term care plans for the patient (Dow, 1991:58). This follow-up plan should include the frequency of visits; types of testing to be done for recurrence; contact information for questions; and a list of the potential late effects of medical treatment (McCabe & Jacobs, 2008:204).

Survivors may easily assume that they no longer need regular follow-up care as they are cured from cancer. This poses a challenge to health care providers to clearly define the limits of cure to the patient (Cella, 1987:65). Taking into account the social profile of the laryngectomy patient, poor compliance with regular follow-up visits may result (Cady, 2002:347), which will add to the challenge of the survivorship experience.

3.5 CHALLENGES WITH REFERENCE TO SELF-CARE (LOST IN TRANSITION)

Following active treatment completion, survivors may experience a period referred to as “lost in transition”, as there are no specific guidelines for follow-up or for taking care of the late effects when treatment has ended (Ganz *et al.*, 2008:209; Haylock *et al.*, 2007:62).

Taking into account the public opinion that the diagnosis of cancer is synonymous with death, the **transition from cancer patient to cancer survivor** can be difficult for the survivor. Although the patient may experience emotional readiness to continue with his life, others may not necessarily share this experience. Fear that others may wrongly think that larynx cancer is a contagious disease, may also contribute to this conflict of

interest (Cella, 1987:62). Survivors may experience fear for lack of adequate information regarding signs of recurrence to be aware of; what to do once treatment has ended; how to improve their health; and the role they could play in preventing the recurrence of cancer. Lack of adequate practical information, such as whom to contact with questions or problems and where to find resources to meet their lack of knowledge, can also increase the cancer survivor's experience of fear (Jefford *et al.*, 2008:27).

Many survivors will experience a "new normal" instead of their previous "old normal" life, taking into account the effect of the diagnosis and treatment (Haylock *et al.*, 2007:62). Especially in the case of laryngectomy survivors, "life goes on, but will never be the same" (DeSanto, 1994:53), considering the comprehensive effect of treatment on a physical, psychological and social level.

3.6 CONCLUSION

Besides the medical aspects associated with the **diagnosis** and **treatment** of larynx cancer, emotional challenges associated with the patient's and family's experiences at the stages of diagnosis and treatment completion have been discussed within this chapter. Knowledge of these aspects are necessary for gaining better understanding of laryngectomy survivors' post-operative coping needs. As the survivorship journey of the patient who is diagnosed with larynx cancer starts at the point of diagnosis, even before his or her laryngectomy experience, the importance of sharing **information** with the patient prior to the operation has also been stressed.

That treatment does not include medical management of the patient only, but also input of various professionals of the **multi-disciplinary team** has been pointed out. The specialised needs of the laryngectomy patient require a multi-disciplinary team approach to meet the variety of needs these survivors experience. The **social worker** fulfils the role of an essential team member, being equipped with knowledge and skill in communication techniques.

Following treatment, the laryngectomy survivor has to deal with the challenge of readjustment and **post-operative effects** of the operation. The most obvious **physical changes** resulting from a laryngectomy are the presence of a permanent tracheostoma and the loss of the natural voice. Physical characteristics of a laryngectomy are mainly divided into respiratory, swallowing and sensory problems following surgery. Even when treatment has come to an end, the cancer patient has to continue the survivorship journey. Survivors remain attached to the hospital setting whilst attending the **follow-up clinic** at the hospital.

Recognition of the comprehensive impact of the diagnosis and treatment by means of a laryngectomy will necessarily lead to an awareness of the **coping strategies** of these patients and their families regarding both inner and external (community) resources. These are described in the **following chapter**.

CHAPTER 4

COPING AND STRENGTHS: *Extended survivorship phase*

4.1 INTRODUCTION

Following the phases of acute and transitional survivorship which were described in the previous chapter, this chapter **focuses** on the phase of extended survivorship. Again, Mullan's model (1986), as described by Miller *et al.* (2008:369-374), is used as framework to inform discussion. The emphasis is on the experiences of primary and secondary laryngectomy survivors along their survivorship journey. Recovery from initial medical treatment which has started following surgery now has to proceed. Rehabilitation as promoting factor towards the patient's recovery as well as the use of coping by and strengths of patients and their families in surviving the laryngectomy experience are highlighted, thus fulfilling the third objective of the study.

4.2 RECOVERY FROM INITIAL MEDICAL TREATMENT

Schuster, Hoppe, Kummer, Eysholdt and Rosanowski (2003:337) found that the diagnosis and treatment of cancer had an effect on the functional, cosmetic and social level of with the potential to cause serious stress functioning in many areas of life. For the laryngectomy survivor, effects of treatment are experienced on a **physical** level (breathing, swallowing, smell and taste) as already discussed in Chapter 3, **psychological** level (self-image due to change in body image) as well as the **social** level (communication), as is described in Chapter 4.

Post-operatively, patients have to focus on all these levels during their recovery from treatment. For example, within the extended phase of survivorship, survivors may, on a psychosocial level, experience difficulties in **cop**ing with the **behaviour of other people**, who do not know how to take care of the survivor's special needs. These difficulties may refer to "others expecting you to be back to normal" or to "put it all

behind them” and people not knowing what to say and not understanding what the cancer survivor has experienced (Hara & Blum, 2009:40; Jefford *et al.*, 2008:28). In addition, survivors may also find difficulty in relating or connecting with other people in an attempt to try to talk about how they changed because of their cancer experience. Survivors may have different outlooks, priorities, and attitudes towards life. They may have altered expectations about their physical ability and about coming to terms with their diagnosis and the change in identity as a result of not being able to continue with previous employment (Jefford *et al.*, 2008:23).

Often survivors are confronted with **long-term disability** or **late effects** from treatment. Relationships may be affected or financial problems may make life difficult for them (Hara & Blum, 2009:40). For many survivors, the “old normal” life never resumes, but will be challenged by a “new normal” (Haylock *et al.*, 2007:62).

In order to promote the laryngectomy patient’s recovery, the role of rehabilitation in the patient’s post-operative recovery from initial medical treatment is looked at first.

4.2.1 Rehabilitation as promoting factor to recovery

Following surgery, the laryngectomy patient’s **major disability** is the impairment in communication (King *et al.*, 1971:113), as patients are challenged with loss of natural voice (Ross, 2000:16). This will therefore add to their difficulty in communicating their post-operative coping needs. Rehabilitation does not refer to improving of communication ability only, but also implies other components of the survivor’s social functioning. After discussing the goal of rehabilitation, the special challenges that laryngectomy survivors have to deal with within their rehabilitation efforts, will be discussed. Factors to improve rehabilitation efforts are investigated.

4.2.1.1 Goal of rehabilitation

Cullen’s description of the **goal** of rehabilitation is conceptualised by Ganz (1990:742) in “to help each patient achieve maximum functioning in all areas within the limitations

imposed by the disease or its treatment". Whilst the laryngectomy experience will limit the patient's natural speech ability, the patient has to be helped to achieve optimal functioning. Cancer rehabilitation can be described as a process towards preventing physical and psychosocial dysfunction that could result from cancer of the larynx and the treatment thereof (Ganz, 1990:742). The goal of cancer rehabilitation can thus be seen as the strengthening of individual coping mechanisms, strengthening family and social support, and improving the physical functioning of the patient, taking into account the extent of surgery (Griffiths *et al.*, 2007:440).

Although the physical effects of surgery can not be avoided, the **goal** of the laryngectomy patient's rehabilitation will be to provide the patient with the greatest opportunity for returning to a previous level of maximum social functioning and to be re-integrated into society. For achieving this, the ideal would be that the patient is able to successfully progress to a more active emotional and social lifestyle in relation to his family, occupation and community (Casper & Colton, 1998:52-53; Deshmane *et al.*, 1995:129; Doyle, 1994:262; Keller, 1985:657).

4.2.1.2 Challenges towards rehabilitation

Following surgery and discharge from hospital, the laryngectomy patient faces **various challenges** during the rehabilitation process. Such patients have to find the best way of meeting each of these challenges. The multi-disciplinary team, in having to deal with these patients' rehabilitation challenges, has to fulfil a complex role (King *et al.*, 1971:112, 118). For instance, the rehabilitation of older laryngectomy patients is extremely complex as the laryngectomy survivor needs to master many novel and complicated tasks which demand a high level of self-care (Cady, 2002:349; King *et al.*, 1971:118). Due to the fact that substance abuse is normally associated with a cancer diagnosis of the head and neck region (Eadie & Doyle, 2005:120), treatment of substance abuse might be necessary for successful rehabilitation of some patients (Cady, 2002:349). This will add an additional challenge to the rehabilitation of the survivor. Patients will also experience a period of initial speech inability followed by limitation in their speech (Graham, 2004:126).

4.2.1.3 Components of rehabilitation

Although restoration of communication will be the most obvious aspect of rehabilitation following loss of the natural voice, various other areas of rehabilitation also need to be dealt with, including **physical, psychological, social** and **vocational** problems (King *et al.*, 1971:112-113). The literature emphasises the reciprocal relationship between speech rehabilitation and these various areas of rehabilitation (Hoops *et al.*, 1975:563; King *et al.*, 1971:113). This means that, when the laryngectomy survivor has mastered the ability to communicate successfully, improvement in other areas of social functioning will also occur.

4.2.1.4 Factors to promote rehabilitation

The following factors play an important role in **promoting** successful **rehabilitation**: open discussion of the illness in the family; the offering of adequate information by the medical team, as discussed in Chapter 3; and the presence of social support (De Boer *et al.*, 1995:503, 511), which is discussed in the following section of this chapter.

Following being equipped with knowledge regarding the post-laryngectomy patient's process of rehabilitation, focus will be on patients' coping and the strengths which will enable them to re-enter society (Chapter 5).

4.3 COPING AND STRENGTHS

In discussing the concept of coping, Moore *et al.* (2004:60-61) defined two mechanisms that regulate distress: "problem-focused" actions (information seeking, problem solving, direct action) and "emotional focused" actions (escape, seeking social support, cognitive reframing). Schuster *et al.* (2003:337) referred to **coping** as the connection between disease and the person's stress reaction that can become visible in the way a patient deals with these changes and difficulties. Cancer patients as survivors have to cope with a variety of situations throughout their survivorship. These include painful or frightening symptoms; uncertainty about their prognosis; and changes in social

relationships (Coughlin, 2008:61). In addition, laryngectomy survivors have to deal with crucial changes in their basic functioning, on a respiratory, swallowing, sensory level, and with the method of speech and communication (Ross, 2000:15).

In order to cope with the different aspects of illness and treatment and its demands, survivors employ a variety of coping strategies.

4.3.1 Coping strategies

A person's coping strategies can be seen as a complex, dynamic process that may change over time. These coping strategies can be divided according to those related to **personal** (strengths perspective) or to **social environmental** factors (ecological system theory) (Coughlin, 2008:60-61).

In conjunction with this, both Alfano and Rowland (2006:437) and Coughlin (2008:63) share the opinion that the two factors that are positively related to **resilience** and have the potential to promote successful adaptation is the person's individual **copied style** and **social support**. To illustrate their opinion, they referred to those with a positive, active coping style who do well and those who are negative and who may feel helpless and hopeless will find it more difficult to adapt (Alfano & Rowland, 2006:437). Social support has been identified as a source through which positive beliefs and emotions may influence resilience (Aspinwall & MacNamara, 2005:2554).

Quigley (1989:66) referred to Mages and colleagues (1981) who identified the following three predictive variables in coping with cancer in general, as well as in the long term: the **severity of illness**, **psychological stability** and the presence of **social support**. These variables are discussed as they also apply to laryngectomy survivors.

4.3.1.1 *The severity of illness*

Medical aspects regarding the symptoms leading to the diagnosis of larynx cancer and the criteria indicating the necessity of performing a laryngectomy were described in

Chapter 3. From this information it is clear that a total laryngectomy is indicated when an extended or advanced stage of the disease or recurrence of disease was being diagnosed (LoTempio *et al.*, 2005:948). With reference to the coping strategies of laryngectomy patients, a study conducted by Coughlin (2008) found that the coping strategies employed by cancer patients are similar to those employed by people with other difficult life events (Coughlin, 2008:61). In addition, Schuster *et al.* (2003:337) have stated that how laryngectomy patients deal with their illness does not differ from the strategies employed by patients suffering from malignant or chronic diseases of other organ systems.

4.3.1.2 Psychological stability (principles of the strengths perspective)

The principles of the **strengths perspective** as described by Saleebey (2002:13-18) were used as framework to better understand the meaning the laryngectomy patients attach to their coping ability, as this perspective focuses on the inherent strengths of the patient (Sheafor *et al.*, 2000:93-94). The laryngectomy patient and family need to deal with various changes and difficulties on a constant basis. In the discussion of the principles of the strengths perspective, parallels were found with some of the principles of the ecological perspective. An understanding of the principles of the strengths perspective can be helpful in trying to understand the laryngectomy experience as from the perspective of the patient and family.

(a) Inner strengths

The **first principle** of the strengths perspective indicates that the person and the family need to have their assets, resources, wisdom and knowledge acknowledged (Saleebey, 2002:14). For the social worker, this holds the potential of learning from and discovering the strengths of these survivors and gain a better understanding of their unique survivorship experience.

Rowland and Baker (2005:2546) refer to a study by Goodwin, who provided a review of randomised trials involving group therapy interventions and indicating that some people may be naturally more resilient than others in dealing with stressors that may occur during their lifespan, acknowledging that people may differ in how they cope with cancer and its emotional effects. In general, cancer survivors are remarkably resilient regarding the way in which they deal with the demands of their diagnosis and treatment; they may even feel pride and relief in having tolerated treatment and with what they had accomplished (Coughlin, 2008:61; Rowland, 2008:364).

(b) Challenge versus opportunity

Secondly, both the strengths principles and the ecological perspectives suggest that a traumatic life issue can possibly be experienced as either a stressor or a challenge (Germain & Gitterman, 1996:12-13). To view a traumatic life event as a challenge, personal (inner) and environmental (external) resources need to be available to master this traumatic life event. Coping occurs over time and is an expression of the relationship between a person and his or her environment, as both personal and environmental resources are required to take control of a traumatic life issue. Saleebey (2002:14) refers to Wolins' (1993) description of "survivor's pride" in experiencing a deep-dwelling sense of accomplishment through having met life challenges that resulted in positive change. This may add to one's experience of dignity as obstacles have been crossed through growth and maturing. Capacities, knowledge and skills play a role in the development and growth of a person, a group and a community. Many who struggle are already resilient, resourceful and motivated for achievement in their own terms.

When people experience great difficulties, their former coping mechanisms may break down, with the result that they discover **new ways to cope** with difficulties and re-evaluate their life goals and priorities. After being diagnosed with a potentially life-threatening illness, people may develop a more intentional way of living and therefore focus more consciously on their goals, priorities and hopes. Therefore they "may gain a clearer or more focused understanding of their values, what they really love to do, and what they are most passionate about" (Coughlin, 2008:62).

As this principle of the strengths perspective indicates, the laryngectomy experience can serve as a source of opportunity and challenge. To facilitate the process of growth while travelling the journey of survivorship can therefore be seen as one of the roles of the social worker.

(c) Capacity to grow and change

The **third principle** of the strengths perspective is also in accordance with the ecological perspective as described by Germain and Gitterman (1996:14), who found that most people have the potential to cope relatively well with serious life stressors. Growth can then be seen as a positive result of coping with stressors, which may include a traumatic life issue. Cancer may offer the experience for growth if the patient is able to view his or her future from a different and new perspective, with a positive effect on the patients' social functioning (Kaplan & Hurley, 1979:57).

Various factors contribute to one's ability to adapt to emotions which may have a profound effect on wellness and health. One's belief in one's potential to recover and prosper, hopes that are palpable, may result in the body responding optimally. In the health care system, this implies that its members have to have high expectations of people and make allegiances with their hopes, visions and values. The goal will be to reconnect people to physical and mental health in themselves and to direct them to bring forth the health of others in their community as both individuals and communities have the capacity for restoration and to rebound (Saleebey, 2002:16). Within the context of the ecological perspective, Sheafor *et al.* (2000:91) emphasised the importance to adapt to change, which is essential in coping, surviving or competing for needed resources. For the purpose of the study, this principle implies that every laryngectomy survivor has the ability to adapt to his or her situation can utilise the laryngectomy experience as an opportunity for personal growth. The health care worker, also with reference to the social worker as part of the helping profession, thus has to acknowledge this principle in order to promote the survivor's potential to the fullest.

(d) Collaboration

Fourthly, the social worker needs to connect with patients' stories and narratives, their hopes and fears, and their resources, rather than try to place the patient into a diagnostic category or treatment protocol (Saleebey, 2002:16). In order to promote the survivor's personal growth, it is important for health care professionals to work together in a team, as each discipline adds to the holistic approach in serving the needs of the survivor.

Being challenged by a potential life-threatening illness such as cancer, the **social environment** in which the person functions is of importance. Having said that social support can promote coping and resilience, reaching out to others for support reminds one of how interconnected we are with others. **Resiliency** is not only applicable on a micro level (patient), but also on meso and macro levels. On a meso level, extended family systems may contribute to resilience in many societies. A survivor who is resilient and employs positive coping strategies has the ability to do better when confronted with a serious illness. This may be particularly true of people who are members of resilient communities or networks of persons (Coughlin, 2008:63). On a macro level, community norms and resources and the common understanding of life's challenges and responsibilities, has the potential to provide support for people who are dealing with a potentially life-threatening illness or who are caring for someone who is ill. Some communities or networks of persons may be more resilient and capable of responding positively to adverse events than others due to differences in community resources, infrastructure, or social and cultural factors (Coughlin, 2008:63).

(e) Every environment is full of resources

There are individuals or groups in every environment who have something to contribute which others may desperately need, thus acknowledging the **fifth principle** of the strengths perspective. These may include knowledge, assistance and support in times of difficulty, resources, talents or time and place (Saleebey, 2002:17). Resources

available to the survivor to cope with the cancer experience are multi-faceted and can be grouped into four general categories (Andrykowski *et al.*, 2008:196-197):

- intrapersonal - resources that are personal and internal to the cancer survivor (strengths perspective)
- interpersonal - social support from various sources with the result of better psychological health in cancer survivors (ecological perspective)
- informational - access to accurate and understandable information and
- tangible - access to medical care.

For the purpose of this study, Saleebey's (2002:16-17) description of the sources of support available to the survivor in order to cope and to survive the laryngectomy experience are used, for distinguishing **inner** and **community sources**. By this, the principles of both the strengths and the ecological perspectives will be acknowledged. Inner resources refer to personal factors (strengths perspective) and community resources refer to interpersonal resources (ecological perspective). In the case of the laryngectomy survivor, different sources and types of social support are required in order to deal with post-operative issues, as remarked by Richardson *et al.* (1989:283-292).

(i) Inner resources (intrapersonal)

Various sources of inner resources are needed in order to cope or strengthen the survivor along his survivorship journey. Strengths that previously supported the patient in coping successfully have the potential to empower the survivor to use inner resources to adapt to change (laryngectomy experience) again, or to alter plans for the future. Intrapersonal factors that have the potential to enhance coping with cancer include optimism, which has the potential to mobilise resources for coping with cancer and its treatment, and positive self-esteem. This, together with optimism can be helpful in the immediate strengthening of subjective wellbeing (Pinquart & Fröhlich, 2009:408, 418). As treatment progresses however, this may probably not be stable enough for long-term change in subjective wellbeing. Initial purpose in life of the patient and perceived social support represent important resources in the course of coping with cancer. Person-

related factors such as education, age, locus of control, and illness-related factors (e.g. type of treatment) can also influence rehabilitation outcome (De Boer *et al.*, 1995:505).

The way in which a person copes with a life-threatening illness depends on numerous factors, including emotional stability, previous methods of coping, understanding of the event and its meaning for the patient, availability of resources and personal motivational forces. These factors have not been fully explored (Quigley, 1989:66).

Rowland and Baker (2005:2546), referring to a study by Goodwin, state that **people may differ** in how they attempt to cope with cancer and to deal with its emotional effects. Although many survivors manage to adapt to their post-treatment situations and successfully manage to engage in productive or meaningful activities, others may struggle to cope with its persistent psychological or physical effects, while some may experience stigmatisation or discrimination (Surbone *et al.*, 2010:257). It is for this reason that Moore *et al.* (2004:56) referred to the experience of surviving cancer as having the potential of not only causing a disparity between one's present life which is filled with coping with the cancer survivorship journey, and one's former self and future potential. The experience of stigmatisation or discrimination is especially applicable in the case of the laryngectomy survivor having to cope with physical changes such as the presence of the tracheostoma and the absence of normal laryngeal speech (Graham, 2004:126; Hanna *et al.*, 2004:875). As a total laryngectomy does affect the patient's external appearance (Herranz & Gavilán, 1999:990), patients may feel unattractive (Belch & Beamish, 1992:60).

Coughlin (2008:61) distinguished between **active** and **avoidant** ways of coping. In the case of the first mentioned, "it refers to strategies whereby persons accept the issue at hand and actively attempt to deal with it through problem solving, planning, and seeking emotional support". **Avoidant coping** refers to denial, "... to strategies whereby persons avoid facing an issue by mentally or physically distancing themselves from it". The example can be used of someone becoming busy with other things to such an extent that he or she avoids thinking about the situation. Those with a **positive**, active

coping style do well, while those who are **negative**, prone to distress, and feeling helpless or hopeless have a harder time moving forward to reorder their lives (Alfano & Rowland, 2006:437).

With regard to **personal factors** / active ways of coping, the literature (Alfano & Rowland, 2006:437; Coughlin, 2008:61; Foster *et al.*, 2009:241; Hawkins *et al.*, 2010:21; Schulz, Holt, Caplan, Blake, Southward, Buckner & Lawrence, 2008:105) describe the role of positive thinking (using positive affirmations, relaxation); confronting reality; expression of emotion; finding a positive meaning from the cancer experience; maintaining self-esteem; and faith and spirituality as helping survivors to find meaning in their cancer experience. Hopefulness and optimism may also be helpful towards tolerating or minimising stressful events. On the other hand, Coughlin (2008:61) warned that those who lack hope may be more likely to use negative coping strategies like alcohol abuse in order to deal with stressful situations. This is especially applicable in the case of laryngectomy patients, taking into account the etiological factors of the disease and their social profile, as been discussed in Chapter 3.

Positive beliefs may help people gain coping skills, knowledge, and social resources that may assist them in dealing with serious illness and other stressors (O’Baugh *et al.*, 2003:262; Rowland & Baker, 2005:2544; Vachon, 2006:28). Vartanian *et al.* (2006:35) suggested that the higher the social and cultural level of individuals, the better their capability in coping with cancer and its consequences will be. The literature (Schulz *et al.*, 2008:106; Vachon, 2006:28) also suggests a positive association between **spirituality** and coping with cancer as it is helpful in finding purpose and meaning in life.

(ii) Community resources (interpersonal)

The availability of **community resources** plays an important role in the patient’s survivorship experience (Surbone *et al.*, 2010:257) as it address issues such as programmes that provide medical services and equipment, local and national organisations and governmental agencies (Hoffman, 1989:87). Acknowledging the

ecological perspective, the environment of the patient (family, medical team) can be of help to the survivor in the role they fulfil in offering information and social support (De Boer *et al.*, 1995:505).

Andrykowski *et al.* (2008:195-196) stressed the importance to maintain a **balance** between the stress and burden posed by the cancer experience and the resources available to cope with stress and burden. A balance between these factors will determine the short- and long-term psychological health of the survivor. The greater the resources available to cope with stress and burden posed by the cancer experience, the lower the risk for poor psychological health. The availability of community resources is therefore important for the cancer patient to cope and to survive the cancer experience. Also important to take into account is the tendency that these factors may fluctuate across time, which implies that the balance must be dynamic. If the stress or burden posed by the cancer experience appears to be low and the resources are also low, it may also result in poor psychological health.

(f) Caring and caretaking

In the **sixth place**, Saleebey (2002:17-18) also referred to Deborah Stone (2000), who identified three rights to care which need to be respected, namely:

- that all families must be permitted and assisted in the care of their members, that all paid caregivers need to be able to give the support;
- quality care that corresponds with the highest ideals of care without undermining their own wellbeing; and
- that all people who are in need of care will receive the needed care.

Whilst the social work profession is about care and caretaking, the strengths perspective is about the possibility of hope which is communicated through social relationships within the family, neighbourhood, community, culture and country.

From the above it can be deduced that **social support** is both an internal and community source of support and can therefore be seen as an important factor in the survivor's experience of coping.

4.3.1.3 Presence of social support

The third predictive variable refers to the availability of **social support**. Quigley (1989:66) specifically noted that the presence of another person in the home, regardless of the relationship, was highly correlated with optimal psychosocial functioning, Quigley referred to authors who agreed that social support has the potential to limit psychosocial distress.

Social environmental factors refer to social support from various systems, namely from a spouse/partner, family, friends, neighbours or community resources (Alfano & Rowland, 2006:437; Coughlin, 2008:62-63). Helping others by sharing one's story is also viewed as an important part of coming to terms with cancer, in "*giving back to others*", whereby one's own quality of life will improve. As a result, a positive outcome will be experienced "not only by those who receive such social support, but also those who give it" (Kreuter *et al.*, 2008:34). To revert to previous social role functioning may also assist the survivor in his or her successful adaptation (Alfano & Rowland, 2006:437). Intense social support also has the potential to facilitate positive personal and social changes (Vachon, 2008:219).

(a) Role of social support

Penson, Talsania, Chabner and Lynch (2004:221) described seeking support as a natural response to stress that can be helpful in the process of coping: "By engaging with others in similar difficulty or by participating in educational or behavioral activities, it is believed that patients may develop better coping and adaptive mechanisms to the sequelae of cancer and its treatment".

(b) Sources of social support

Tracy (1990:254) identified **four main sources** of survivor support as including the household, relatives, friends and formal service providers, whilst (Coughlin, 2008:62-63) included family members, caregivers, friends, neighbours, co-workers, clergy, and patient support groups as potential sources of social support. In the case of laryngectomy survivors, these authors specifically referred to the role of “fellow sufferers” as an important source of social support (De Boer *et al.*, 1995:513). Of interest is the opinion of Coughlin (2008:62-63), referring to the possibility that in the presence of a severe illness or following a diagnosis of a potentially life-threatening illness like cancer, existing sources of social support may change as survivors may find the need to develop new sources of support. For the laryngectomy survivor, the chances of discovering new sources of support will be limited, as patients’ post-operative inability to talk may threaten the availability of entering existing or new sources of support (Richardson *et al.*, 1989:284). Also, a laryngectomy can be seen as a lonely experience as they seldom know other patients who have had such an operation (Ross, 2000:14). This may increase their coping needs.

(c) Benefits of social support

Feuerstein (2007b:5-7) claimed that social support systems have the potential to promote cancer patients’ survivorship experience. Various reasons why support systems play such an important role in this journey were identified from the literature. With reference to the ecological perspective, these **benefits** of social support as provided by various systems in which the survivor functions, namely family members, peer group, friends and health care professionals, were highlighted (Kreuter *et al.*, 2008:34; O’Baugh *et al.*, 2003:269; Surbone *et al.*, 2010:257).

Amongst other factors, **family support** is suggested as able to influence the patient’s experience of his or her survivorship journey (Surbone *et al.*, 2010:257). By sharing the story of their survivorship in order to help others, many survivors find it valuable for coming to terms with their own cancer experience. In “giving back to others”, their own

quality of life improves. In this regard, Kreuter *et al.* (2008:34) referred to studies that identified a positive psychological outcome for both those who receive and those who provide social support. Together with environmental factors, support from family, friends, fellow patients and health professionals can play an important role in maintaining a positive attitude throughout the cancer patient's journey of survivorship (O'Baugh *et al.*, 2003:269). For the survivor, a new learning process will occur, referring to the experience of being diagnosed, treatment and experiences that occur afterward (Coughlin, 2008:63).

Personal relationships and social support can be seen as "buffers" against individual distress in cancer survival. A few studies have suggested that close family ties can predict satisfactory adjustment to cancer as family usually "pulls together" in order to cope with the cancer experience. In the case of **friends or acquaintances**, this is not always the case as the lay public still tends to associate the word "cancer" synonymous with "death". For the cancer patient, this can cause difficulty in making the transition from a cancer patient to a cancer survivor (Cella, 1987:62). Whilst, on the one hand, a survivor may want to leave everything behind, friends, on the other hand, may be unable to forget. The fear of contagion, as communicated in a variety of ways and ranging from insensitive joking to outright avoidance or abandonment, may often be present (Cella, 1987:62). The laryngectomy survivor will be extremely exposed to the loss of a body part (larynx) and physical disfigurement (Kaplan & Hurley, 1979:51-52), as the effect of the operation is visible because of the permanent tracheostoma in the neck (Ross, 2000:15, 21).

Together with open discussion of adequate information, social support plays an important role in order to promote rehabilitation (De Boer *et al.*, 1995:513). Vartanian *et al.* (2006:35) recommended that, in the case of unsuccessful rehabilitation, patients should receive more comprehensive social support, as it was found that social support has the ability to promote rehabilitation.

In general, it can be said that the **benefits** of social support for survivors include the promotion of subjective wellbeing, resilience, coping, overall health and improvement in quality of life, which can be seen as essential for the experience of these positive feelings. By this, cancer survival rates may even increase (Aspinwall & MacNamara, 2005:2554; Coughlin, 2008:62-63; O’Baugh *et al.*, 2003:268; Pinguart & Fröhlich, 2009:407-409, 418). On the other hand, some survivors may experience involvement with others as not always being a positive experience, indicating that some connections have the potential to be harmful to their wellbeing (Schulz *et al.*, 2008:104).

From the above it can be deduced that social support plays an important role in the cancer survivor’s overall coping.

(d) Gaps in the provision of social support

Griffiths *et al.* (2007:435) cite research that suggests that the **provision of supportive care** is at times inconsistent, unfocused and poorly coordinated as patients’ and their carers’ needs are often unrecognised at different points of the cancer journey and therefore not met. In the case of older survivors (like laryngectomy survivors, because cancer of the larynx is mostly a disease of the elderly), survivors may lack social support, as many become isolated for various reasons. From a social perspective, they may have outlived their significant others and peers. From a geographical perspective, family and friends may live far away or may not have transport to stay in regular contact with them. When there are family members who could help, they are often hampered by their own home responsibilities, and/or their own health issues (Hara & Blum, 2009:47). In addition, laryngectomy survivors are also exposed to the limitation in communication which may add to their experience of social isolation (Graham, 2004:128; Kaplan & Hurley, 1979:52).

4.3.2 Utilisation of the strengths perspective and its meaning to social work practice

Laryngectomy survivors are in need of care while adapting to their laryngectomy experience as this can be a challenging experience through their survivorship journey. Table 4.1 presents the theoretical principles of the strengths perspective as applicable to characteristics applied by cancer survivors in general and, more specifically, to characteristics of laryngectomy survivors. References from the literature are used to illustrate the use of the strengths perspective on a practical level.

TABLE 4.1: The principles of the strengths perspective as applied to cancer survivors in general and specifically to laryngectomy survivors

General principles from the strengths perspective	Strengths perspective principles as applied to the cancer survivor's experience	Strengths perspective's characteristics as applied to the laryngectomy experience
Every individual, group, family and community has strengths	<ul style="list-style-type: none"> • Cancer survivors are remarkably resilient (Rowland, 2008:364) 	
Trauma and abuse, illness and struggle may be injurious but they may also be sources of challenge and opportunity	<ul style="list-style-type: none"> • Cancer patients and survivors have been shown to use a large variety of important strategies to cope with different aspects of their illness and treatment (Coughlin, 2008:61) • Coping strategies employed by cancer patients are similar to those employed by people with other difficult life events (Coughlin, 2008:61) 	<ul style="list-style-type: none"> • Coping mechanisms of laryngectomy patients may vary (Cady, 2002:347). • The coping of post-operative laryngectomy patients were found not to be different from patients suffering from other serious diseases (Schuster <i>et al.</i>, 2003:337) • Laryngectomy patients' post-operative adjustment is more heavily determined by their previous psychological state and coping abilities than by the severity of the surgical intervention (Ely, 1990:4046)

General principles from the strengths perspective	Strengths perspective principles as applied to the cancer survivor's experience	Strengths perspective's characteristics as applied to the laryngectomy experience
	<ul style="list-style-type: none"> • Cancer survivors were more likely to make positive than negative behaviour changes after cancer (Hawkins <i>et al.</i>, 2010:20) 	
Assume that you do not know the upper limits of the capacity to grow and change and take individual, group and community aspirations seriously	<ul style="list-style-type: none"> • Cancer may offer the experience for growth as the patient will view his future from a different and new perspective, with a positive effect on the patient's social functioning (Kaplan & Hurley, 1979:57) 	<ul style="list-style-type: none"> • Laryngectomy can offer an opportunity for growth and may see reality in new dimensions (Kaplan & Hurley, 1979:57) • For these patients, life goes on, but will never be the same again (DeSanto, 1994:53).
We best serve clients by collaborating with them		<ul style="list-style-type: none"> • Social work intervention services for the laryngectomy patient are complex and require involvement of professionals from various disciplines, including the patient, family, friends and patients who share the patient's experience (Casper & Colton, 1998:52) • Close cooperation between the patient and team members is necessary before a favourable outcome is to be expected (Dhooper, 1985:225)
Every environment is full of resources	<ul style="list-style-type: none"> • To bring people, services and resources together on behalf of the patient and to form a link between the patient and available resources (Ross, 1995:1367) 	<ul style="list-style-type: none"> • A close working relationship among multi-disciplinary team members and various community resources is advocated to best meet the needs of the laryngectomy patient (Dhooper, 1985:225)

General principles from the strengths perspective	Strengths perspective principles as applied to the cancer survivor's experience	Strengths perspective's characteristics as applied to the laryngectomy experience
Care and caretaking		<ul style="list-style-type: none"> The aim of multi-disciplinary care of the laryngectomy patient is to prevent or reduce the physical disability and emotional effect of the disease and its treatment and to enable the patient to return to his former lifestyle and routine with a means of communication that satisfactorily fulfils social, emotional and vocational needs (Casper & Colton, 1998:52)

Having acknowledged that each individual, group, family and community has **inner strengths**, it can be said that each laryngectomy patient (primary survivor on micro level), his or her family (secondary survivor on meso level) and, in broader terms, the laryngectomy community (macro level), have inner strengths. Although **illness** (diagnosis of larynx cancer) and **trauma** (laryngectomy as surgical procedure) have the potential to be experienced as a possible source of mutilation as it affects one's basic human functions, it can simultaneously serve as source of **challenge** and **opportunity** for positive growth. As the upper limits of potential for growth and change are not known, patients' **aspirations** should be taken **seriously**. Laryngectomy patients and their family's needs could be served best by **collaborating** with them by using the resources and bringing the patient in contact with them. Health care professionals need to discover these resources to bring the patient in contact with them. Caring and caretaking should be in the survivor's best interest (refer to Table 4.1). It can be deduced from Table 4.1 that the laryngectomy survivor's strengths hold the potential to empower him or her to view the laryngectomy experience as an **opportunity for growth**.

In the following subsection of this chapter, coping as experienced from the perspectives of various involved groups such as primary and secondary survivors, including the

laryngectomy survivor, is considered. The laryngectomy patient's **coping ability** needs to be interpreted within the framework of the coping of cancer survivors in general, before describing the coping of those who present with a cancer diagnosis of the head and neck region, and then, more specifically, describing coping among those who present with a diagnosis of larynx cancer.

The utilisation of the strengths perspective makes various demands on the role of the **social worker** within the health care system. Social workers should be genuinely interested in and have respect for patients' stories, narratives and accounts. Knowledge about the patients' specific situation is also of importance, as patients have learned lessons from personal experience; have hopes and interests; and can do some things masterfully, despite their illness. The social worker should also care about patients and respect patients for the difference they make by listening to them, being non-judgmental and believing in everyone's potential to grow (Saleebey, 2002:14).

The use of the strengths perspective in the **intervention process** will be to ensure that the social worker attends to patients' strengths during assessment and intervention (Sheafor *et al.*, 2000:93-94). Saleebey (2002:19-20) views the aim of the strengths perspective as to bring together individuals and communities so that they may reach their optimal potential through bringing a sense of hope and optimism to people. The goal will be to bring the patient within a particular environment to change in the direction of their hopes and aspirations.

For the social worker rendering services to primary and secondary laryngectomy survivors, it will be of relevance to be equipped with knowledge and skill for utilising the principles of the strengths perspective with regard to laryngectomy survivors.

4.4 COPING EXPERIENCED BY VARIOUS GROUPS INVOLVED

Keeping in mind the increased number of cancer patients who are surviving cancer or living with it as a chronic disease, survivors will require help to an increasing extent with adjusting to the experience. Following the diagnosis of cancer, people living after cancer

will need coping strategies in order to continue with the rest of their lives (Griffiths *et al.*, 2007:440). Vachon (2006:28) referred to **coping as a process**. De Boer *et al.* (1995:505) defined coping strategies as those efforts of the patients themselves to prevent or reduce uncertainty, negative feelings (depression, loneliness, psychological complaints), loss of control or threatened self-esteem.

The following section of the chapter describes **coping by various groups** involved in the laryngectomy patient's survivorship journey, including the laryngectomy patient himself, those cancer patients who present with a diagnosis of the head and neck region and, in a broader sense, secondary survivors in general as illustrated in Figure 4.1.

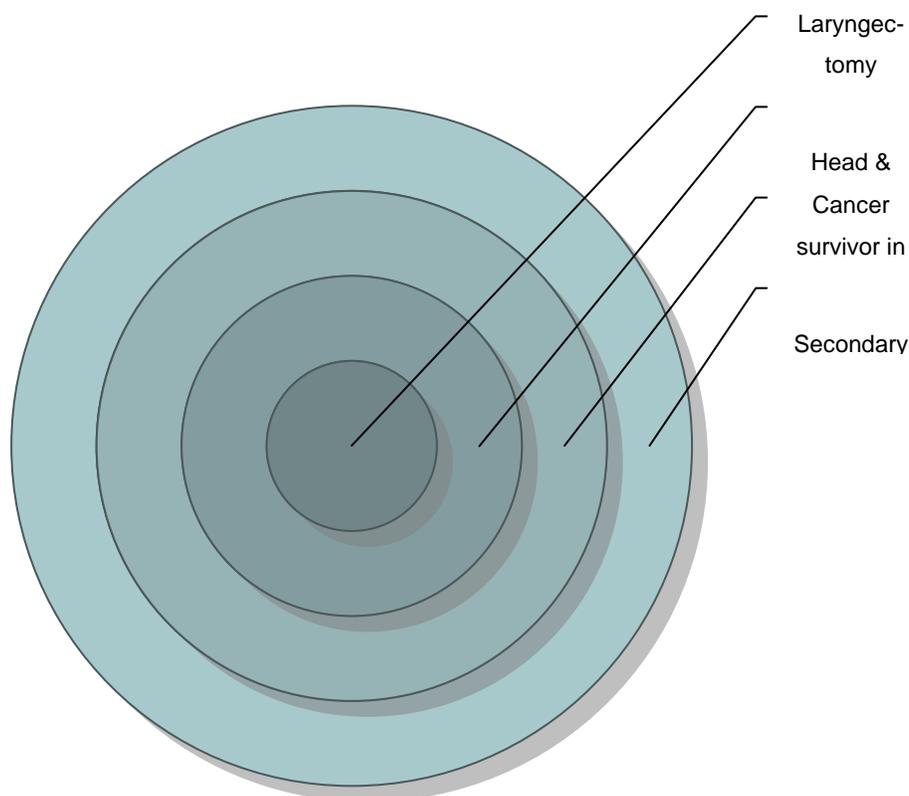


FIGURE 4.1: Schematic illustration of the various target groups of survivors

Having said that every environment is filled with strengths according to the principles of the strengths perspective, **inner** resources and **community** resources will now be described.

4.4.1 Coping by primary survivors

With reference to Schuster *et al.*'s (2003:337) **definition** of coping, when made applicable on the context of this study, it can be said that the coping of primary survivors (laryngectomy patients) becomes visible in the manner that they (primary/patients; secondary survivors/family) deal with changes caused by the laryngectomy experience.

Coping of laryngectomy survivors needs to be interpreted against the background of coping by cancer survivors in general and more specifically those who present with a cancer diagnosis of the head and neck region, followed by laryngectomy survivors.

4.4.1.1 Head and neck cancer survivors

The coping of survivors who are representative of those who present with cancer of the **head and neck region**, varies. Their coping may refer to struggling to cope, hopelessness, loss of meaning and purpose in life, or suffering. Important to take into account is the difficulty these patients' have with communication due to suffering and pain. These factors impact on their quality of life (Moore *et al.*, 2004:54).

Argerakis (1990:288) mentions three **reasons** why patients who present with cancer of the head and neck region at times readjust without the expected psychosocial disturbances. Their sources of support refer to the ecological perspective (referring to members of the health care system on the macro level) or members of the family system (meso level). Reasons for positive coping refer to:

- the quality of care and treatment patients received from the rehabilitation team in the health care system (macro level);
- patients themselves who are grateful for remaining alive so that other feelings are less important (micro level);

- psychological support received from the health care system (macro level) as well as from families and friends (meso level) taking into account the extent of their defect.

4.4.1.2 Laryngectomy survivors

In the treatment of laryngeal cancer, at least in the acute phase, the most radical change follows laryngectomy. Adaptation is an **ongoing process** that progresses at a varying pace, during which factors such as the patient's coping ability; availability of social support resources; the extent of surgery; and additional treatment required will play a role (McQuellon & Hurt, 1997:237). Not all patients with cancer of the larynx can be associated with extensive alcohol use, poor coping skills, economic resources or lack of social support as discussed in Chapter 3. For this reason, it can be said that the coping mechanisms of these patients may vary (Cady, 2002:347).

In a study conducted by Schuster *et al.* (2003:337) it was found that the **coping** of post-operative laryngectomy patients **were not different** from patients suffering from other serious diseases. Coughlin's opinion (2008:61) concurs with this study, stating that the coping strategies employed by cancer patients are similar to those employed by people with other difficult life events. Another important finding of the study by Schuster *et al.* (2003:337) was that restrictions in the ability to communicate, as in the case of laryngectomy patients, was not a determining factor in handling the disease. In the case of cancer survivors with increased life expectancy, the findings of these studies is important to take into account, as the coping skills of laryngectomy survivors will now have to be effective for longer periods of time, taking into account increased survivorship.

In another study, laryngectomy survivors indicated that they experienced **uncertainty** in their post-operative coping related to the negative consequences of the disease and treatment (56%) and in managing their own emotions (62%) (De Boer *et al.*, 1995:508). Of importance is the assumption by Cady (2002:347) that a laryngectomy has the potential to most likely exaggerate efficiencies in coping skills, rather than to improve

them. Shortly after being operated on, self-care (performance of basic hygiene and tasks related to post-operative surgical care taught by nursing staff) and re-socialisation (interaction with staff, voluntary ambulation out of room) have been identified as primary indicators of effective coping (Cady, 2002:349, referring to Dropkin, 1983). Northouse and Northouse reported that communication stimulates effective coping mechanisms during the cancer survivor experience (Gerlach *et al.*, 1990:67). Knowledge of these indicators of effective coping and the expected time frame in which they optimally should occur can be used to identify patients who are coping poorly in order to provide more intensive intervention before they are discharged (Cady, 2002:349, referring to Dropkin, 1989). **Poor coping** may contribute to many ongoing problems, such as difficulty in returning to work (with resulting financial problems); reduced participation in activities that were previously enjoyed; or social interaction contributing to depression (Cady, 2002:348; Devins *et al.*, 1994).

It is seen as the role of the **health care system** to support patients in maintaining significant relationships, activities and interests; promote development of coping strategies; and provide assistance during the recovery period (Cady, 2002:348; Devins *et al.*, 1994:614). The speech language therapist and social worker are pre- and post-operatively involved with the aim to mitigate the crisis, improve the patient's coping ability, and encourage a high level of reorganisation (Sanchez-Salazar & Stark, 1972:324). Careful and comprehensive assessment of patients' coping mechanisms, social situations, and risk factors and systematic rehabilitation efforts with ongoing counselling and support may improve outcomes for laryngectomy patients who are experiencing great difficulty with post-operative adaptation following laryngectomy (Cady, 2002:347). Patients should be trained in coping skills in order to adapt to their laryngectomy experience; make contact with the other laryngectomy patients; be introduced to a support group: and start learning speech (McQuellon & Hurt, 1997:238).

Along the road of living the survivorship journey, both primary and secondary survivors will experience **fear**. Sources of fear were discussed within the various phases of survivorship. Early in the survivorship journey, the stress of the cancer experience might

be due to the threat posed by a potentially life-threatening illness, difficulty in making treatment decisions in the presence of uncertainty and anxiety about treatment outcome. Later on, the stress experienced will be about the possibility that cancer may return, about financial difficulties due to loss of employment, difficulties with sexuality and intimacy, or recognition of persistent physical late or long-term effects of treatment (Andrykowski *et al.*, 2008:196).

Together, the severity of the disease, the psychological stability of the survivor and availability of social support are important variables that contribute to the survivor's ability to cope. Coping strategies of laryngectomy survivors as described in the literature also emphasise these variables. Variables reflect the principles of the ecological and strengths perspectives, acknowledging the inherent strengths of each individual (micro level), of family and friends (meso level) and of the community (meso level).

4.4.2 Coping of secondary survivors

Secondary survivors, like primary survivors, are affected by the laryngectomy experience as they, too, have to cope with major psychosocial implications of the diagnosis and treatment of cancer (Deshmane *et al.*, 1995:121). This is in accordance with the **ecological perspective**, which implies that a person functions in relation to his or her environment (Germain & Gitterman, 1996:5-6; Meyer & Mattaini, 1995:16; Sheafor *et al.*, 2000:91). Change in one part of the system will have an impact or result in change in all parts involved (Meyer & Mattaini, 1995:22).

Secondary survivors will experience the need to share in an experience that will help them to cope with survivorship uncertainties and issues (Gerlach *et al.*, 1990:67). As a result of extended survivorship, patients will be dependent on their family and other support systems for longer periods of time. This implies that it will be important to address the long-term wellbeing of secondary survivors and to improve their coping strategies. On the other hand, it will have the positive effect of improving their own ability to offer support to patients and to prevent burnout (Golant & Haskins, 2008:420). Open communication with members of the health care system is recommended as this

can limit family members' feelings of distress and helplessness. As a result, they will be in a position to better support the cancer survivor (Gerlach *et al.*, 1990:67-68).

In the opinion of Relic *et al.* (2001:516), the **family system** can be seen as being the closest social environment to the patient. It can thus be seen as the most important system for coping with the diagnosis and treatment of cancer. Surviving a laryngectomy can therefore be a challenging experience for secondary survivors, as these social systems (family, friends) also have to adapt to a changing environment (Sheafor *et al.*, 2000:92). In the case of the laryngectomy survivor, family members will have to adapt to changes resulting from the experience on a physical, social and psychological level (Eadie & Doyle, 2005:115-116; Graham, 2004:125-126).

4.5 CONCLUSION

Within the process of recovery from initial treatment, survivors are not necessarily equipped with the strengths needed to return to their pre-morbid lives or their earlier capacity. Rehabilitation of the laryngectomy survivor can be seen as an extremely complex process as survivors need to become used to complicated tasks which require a high level of self-care within a short period of time following surgery. Adding to this, is these patients' social profile of past substance abuse.

In discussing the process of recovery and coping, the principles of the strengths perspective were used as the basis for describing the process of coping, emphasising that every individual laryngectomy patient on a micro level, group of family or friends on a meso level, or community on the macro level has inner strengths. The coping of various groups that are involved was discussed, concentrating on the coping of primary, secondary, head and neck and laryngectomy survivors. Social support plays an important role in improving the rehabilitation and coping of cancer survivors. At the same time, laryngectomy survivors are limited regarding their ability to discover new sources of support because of their speech limitation.

From the above discussion, it can be concluded that laryngectomy patients, the primary survivors, and families, as secondary survivors, use inner (strengths perspective) and community resources (ecological perspective) in order to survive their laryngectomy experience. The fourth objective of the study has thus been addressed.

The next chapter explores the laryngectomy patients' experience of the permanent phase of survivorship, when they have to deal with a returned sense of permanence and cope with late and long-term effects of the operation on they re-entering society.

CHAPTER 5

PSYCHOSOCIAL EFFECTS AND RE-ENTRY INTO SOCIETY: *Permanent survivorship phase*

5.1 INTRODUCTION

Following the phases of acute, transitional and extended survivorship described in the two foregoing chapters, Miller *et al.*'s (2008:369-374) theoretical model of the seasons of survivorship also refers to the **permanent** phase of survivorship as the last phase of the survivorship journey. During this phase, less focus will be on cancer, as the survivor has to return to a sense of **permanence** in coping with the comprehensive effects of the diagnosis and treatment. As the medical effects of treatment have already been described in Chapter 3, the laryngectomy survivor's coping with the **psychosocial effects** of treatment, as well **re-entry** into society are described in this chapter, thus fulfilling the fifth objective of the study.

First, the survivor's coping with the long-term social and psychological effects of the diagnosis and treatment is investigated. Second, the aspect of the survivor who needs to focus less on cancer and more on re-entry into society will be described.

5.2 COPING WITH LONG-TERM PSYCHOSOCIAL EFFECTS OF CANCER

Long-term cancer survivors' experience of the effect of their diagnosis and how it changes their lives can be related to variables such as age, diagnosis, treatment, attitudes and beliefs (Miller *et al.*, 2008:371). Being treated for advanced cancer of the larynx, the laryngectomy survivor will experience the effect of surgery on some of the most basic human functions, such as breathing, swallowing and speaking (Ramírez *et al.*, 2003:95; Relic *et al.*, 2001:514; Sewnaik *et al.*, 2005:95). These effects are discussed in Chapter 3. All of these physical effects also result in **psychosocial**

implications for the patient and family. While **re-entering society**, laryngectomy survivors will realise that they are being confronted with changes of a permanent nature.

With the increased survivorship of cancer patients, emphasis is no longer solely on fear of the risk of a recurrence of cancer. Nowadays, there is greater interest in **psychosocial issues** which impact on the lives of the cancer patient and family (Miller *et al.*, 2008:371). These psychosocial effects that cancer survivors experience are related to their emotional functioning, social relationships and support, as well as factors related to the cancer and treatment (intensity and duration). With cancer patients living longer, the need arises to offer psychosocial guidance to patients (primary survivor) and families (secondary survivors) for a longer post-treatment period (De Boer *et al.*, 1995:513). Kaanders and Hordijk (2002:304) mentioned that psychosocial problems are frequent in patients presenting with cancer of the head and neck region, both before and after treatment. Laryngeal cancer is likely to have a major impact on the patient's and family's social functioning and general quality of life (McQuellon & Hurt, 1997:231).

The social worker rendering services to these patients and their families in the hospital setting thus needs to have a clear understanding of the psycho social issues that laryngectomy survivors will experience along their survivorship journey. This will contribute to a better understanding of the laryngectomy patient's readjustment following the laryngectomy experience.

5.2.1 Coping with social effects

The effect of the operation on relationships in the family context, marital relationships and other social relationships is described. Other social challenges that the laryngectomy survivor will have to deal with, including change in social roles, social isolation and rejection, and problems regarding employment and finance are also discussed.

5.2.1.1 *Family relationships*

Lewis (2006:20-21) acknowledged the influence of the **ecological perspective** when referring to the cancer patient in relation to his or her family by stating: “Cancer affects not just those who have the disease but also their caregivers and families ... family members are substantially distressed when a member has cancer”. Rowland and Baker (2005:2545) referred to a study by Rolland (2005) and emphasised cancer which can be regarded to as “a family disease” as it not only affects the cancer patient but also family members, friends, neighbours and co-workers (Hara & Blum, 2009:40). Acknowledging the influence of the ecological perspective, it can be said that a person, including the laryngectomy patient, functions in relation to his or her environment (Germain & Gitterman, 1996:5-6; Meyer & Mattaini, 1995:16; Sheafor *et al.*, 2000:91). As part of the laryngectomy patient’s environment, the family system is regarded by Relic *et al.* (2001:516) to be the closest of all relationships.

During the phase of transitional survivorship, namely at the stage of the patient’s discharge from the hospital after treatment completion, the family will experience **emotional pressure** as patients are discharged sooner from hospital as part of a cost containment strategy. The family then has to deal with patients’ care-giving needs, with an effect on their physical, emotional and social functioning (Pollack *et al.*, 2005:52-53; Rowland & Baker, 2005:2545). Ganz (1990:745-746) stressed that cancer has the potential to add stress to otherwise supportive and stable social relationships. In this regard, both Kaplan and Hurley (1979:52) and Richardson *et al.* (1989:283) mentioned that cancer and its treatment have the potential to cause problems in interpersonal relationships or to enforce previously experienced family problems. This may occur as any chronic disability has the potential to disrupt established patterns in the patient’s and family’s life (Mathieson *et al.*, 1991:162).

5.2.1.2 *Marital relationships*

Various **stressors** were reported by spouses of patients with laryngeal cancer, which may refer to any of the following: change in social role functioning; communication

patterns; financial concerns; or lack of social support. Spouses may also experience feelings of guilt or responsibility for patients' illness in not having done more to discontinue patient's smoking or alcohol habit prior to their diagnosis. They can also experience co-dependency or can assume responsibility for the patient's behaviour (Cady, 2002:350). Changes in intimacy and sexuality were also reported by McQuellon and Hurt (1997:232), although these aspects are often not discussed due to various reasons, such as reluctance by the patient and health care professionals, or the social stigma surrounding the disease (Casper & Colton, 1998:50; Deshmane *et al.*, 1995:127).

5.2.1.3 Other social relationships

The diagnosis of larynx cancer and treatment by means of a laryngectomy affects one of the most basic human functions, the patient's **speech ability** (Herranz & Gavilan, 1999:993; List *et al.*, 1996:1; Ramirez *et al.*, 2003:95; Relic *et al.*, 2001:514; Sewnaik *et al.*, 2005:95). This includes the patient feeling that he is not being understood by others; not being able to make him- or herself heard in a noisy room; and loss of self-expression with reference to expression of emotions (McQuellon & Hurt, 1997:234). Patients' experience of mutilation due to treatment may impact on their relationship with family, friends and co-workers (Argerakis, 1990:285). Many problems that laryngectomy patients experience can be related to **communication problems** (De Boer *et al.*, 1995:511), which will affect their social life (Schuster *et al.*, 2003:212). Forming new relationships does not come easily for the laryngectomy patient. Relationships with family and friends may also be altered by the patient's cancer experience (Jefford *et al.*, 2008:30). On the one hand, patients may experience that friends may remove themselves from the survivor due to discomfort with the diagnosis. On the other hand, some may become close to them because of the experience (Cella, 1987:64).

Of relevance is a study conducted with bone marrow transplantation patients, where 96% of the study group indicated that people became less supportive over time (Foster *et al.*, 2009:242). This is of significance for cancer survivors, taking into account their

prolonged life expectation. Except for this expected stress in social relationships, the social relationships of laryngectomy survivors are under additional stress.

5.2.1.4 Change in social roles

Middle adulthood has traditionally been associated with multiple adult roles (spouse, parent, friend, employee) and responsibilities. Being diagnosed with cancer during this stage of life will necessarily challenge the survivor's ability to maintain such role functioning throughout their survivorship journey (Hara & Blum, 2009:46). Patients who present with a diagnosis of larynx cancer can traditionally be seen as **elderly** people, as referred to by Ross (2000:14).

After being discharged from the hospital, the patient may feel that he or she is not in a position to **fulfil roles** that were regarded as his or her function in the family context. Their families may see their roles as diminished, and the difficulty in communication may exacerbate the frustration and other difficulties experienced by the laryngectomy survivor (Casper & Colton, 1998:3). As family roles undergo change or loss, integrity of the family system will come under threat (Dhooper, 1985:222; Graham, 2004:127; Renner, 1995:216; Ross, 2000:18-19). Although existing relationships are not easily changed during stressful situations, the equilibrium of a longstanding relationships will be disturbed (Renner, 1995:217; Richardson *et al.*, 1989:291). The adjustments that have to be made in social life could also prove to be stressful (Renner, 1995:218).

For the patient, the **loss of pre-operative status** will dawn increasingly (Graham, 2004:127). Casper and Colton (1998:47-48) pointed out the feelings of dependence, frustration and irritation experienced by patients who previously fulfilled a dominant role, but realise they are no longer able to do so and after surgery. As emotional reactions sometimes result in non-productive behaviour, stronger personalities will take charge (Renner, 1995:216). Kaplan and Hurley (1979:52) specifically referred to problems of change in social roles of the elderly as they may already struggle with adaptation to social roles and lifestyle changes.

5.2.1.5 Social isolation

Older cancer survivors of which the laryngectomy patient is representative can easily become socially isolated because they have “outlived” their significant others or peers. Geographic reasons may add to their experience of social isolation because family may stay far away and have their own home responsibilities. Problems with transport may also occur, with the result that they are not in regular contact with family (Hara & Blum, 2009:47). In addition, survivors may experience emotional difficulty in talking about their experience in a milieu that is ambivalent about death. They may avoid establishing new relationships because they are concerned about the reaction of others once they know of the cancer diagnosis (McMurchie, 1991:1450). Building new relationships will be difficult for laryngectomy patients, taking into account their speech limitation. Because most laryngectomy patients are elderly (Ross, 2000:14), they are often confronted with inevitable losses of significant relationships which can leave them turning to new peers or into themselves for continued gratification (Cella, 1987:62).

5.2.1.6 Social rejection

Patients with a “wounded appearance” or who suffer from **mutilation** are more exposed to social rejection than others. This is especially applicable in the circumstances of patients with a cancer diagnosis in the head and neck region (Argerakis, 1990:285-286), like laryngectomy patients who present with a permanent tracheostoma (De Boer *et al.*, 1995:512).

5.2.1.7 Employment and finance

Cancer survivors are confronted with **various challenges** regarding their employment and financial position. Discrimination or fear of discrimination may be present, with the resulting effect that some survivors remain in undesirable jobs because they fear that job change may result in a decrease in financial benefits or job loss (Hara & Blum, 2009:42; Hoffman, 1989:86-87). Long-term survivors with more apparent physical defects are at greater risk of discrimination at the workplace (Quigley, 1989:66). Certain myths about cancer may also impact on survivors’ employment opportunities, namely

that cancer is synonymous with death; that cancer is contagious' or that cancer survivors are unproductive workers (Hoffman, 1989:86-87; McMurchie, 1991:1450).

Patients who present with a diagnosis of cancer of the **head and neck region**, like laryngectomees, will experience certain limitations in their work environment which can be due to problems with swallowing; ability to communicate; or shoulder movement (Vartanian *et al.*, 2006:34). Examples of these limitations are airborne irritants, risk of accidental submersion in water; need to communicate above a high level of background noise, inability to shout or to lift heavy objects (King *et al.*, 1971:117).

Laryngectomy survivors' difficulty in returning to work following their diagnosis and treatment of cancer can either be due to their experience of the above-mentioned symptoms, fatigue or fear of rejection by colleagues or employers, with a direct effect on their financial position (Cady, 2002:348). Taking into account the demographic details of patients who typically present with a cancer diagnosis of the head and neck area, these patients are usually diagnosed at an advanced stage of the disease, mostly due to poor access to high-quality health care; alcohol consumption which most likely is present; and low levels of education. Late diagnosis results in an increased number of patients with disability. Taking into account the ecological perspective, it can be said that an increased rate of disability will have a socio-economic effect on the lives of patients, families and society (Vartanian *et al.*, 2006:34). Also, larynx cancer typically affects the elderly (Foster *et al.*, 2009:242) and patients with this diagnosis are therefore already retired or near the age of retirement.

In addition to the description of the social effects that the laryngectomy survivor will experience, it is also necessary to focus on the laryngectomy survivor's experience of the psychological effects of the operation, in order to form a clear picture of the comprehensive psychosocial effects that follow surgery.

5.2.2 Coping with psychological effects

Survivors who present with cancer of the **head and neck region** are seen to be more vulnerable to psychological problems than other survivors, for various reasons. Taking into account their social circumstances, these patients, as mentioned previously, often present with a history of alcohol and tobacco abuse and low social class (Foster *et al.*, 2009:241; Moore *et al.*, 2004:55). Due to the site of their cancer diagnosis, they are challenged with the potential of disfigurement, dysfunction or mutilation (Argerakis, 1990:285; McQuellon & Hurt, 1997:231).

The diagnosis and treatment for these cancers are often accompanied by multiple experiences of **fear** and **loss** (Moore *et al.*, 2004:54). Their difficulty in communicating adequately adds to this experience. They often struggle to cope and may feel hopeless because of loss of meaning and purpose in life (Moore *et al.*, 2004:54). King *et al.* (1971:116-117) mentioned that the psychological problems that laryngectomy patients may experience are inevitable, numerous and may be profound. Some of the psychological effects which the laryngectomy survivor may experience are described in the sections that follow.

5.2.2.1 Fear

One of the most common, natural, prominent, universal and lasting psychological reactions following the diagnosis of cancer, is the **fear** of recurrence or fear of a second cancer (Deimling *et al.*, 2006:307; Foster *et al.*, 2009:241; Hoffman, 1989:86; Jefford *et al.*, 2008:21; Pollack *et al.*, 2005:52). During this phase, it will be easy for the cancer patient to presume that all symptoms are related to a recurrence of the cancer until proven otherwise. Fear of recurrence and death may persist for years after curative treatment, but the degree or intensity of psychological distress generally decreases with time (McMurchie, 1991:1450-1451). Hoffman (1989:86) was of the opinion that fear of recurrence or a second cancer is normally greatest within the first two years after completion of treatment, but may persist for many years after such completion.

5.2.2.2 Experiences of loss

McQuellon and Hurt (1997:234-5) described the psychological importance of one's voice, by stating the following **loss experiences** in the absence of natural voice: It is not just our words but the way in which those words are said that convey our message through-non verbal communication by means of facial expression, voice tone and volume. Voice tone and volume give an indication of one's emotional experience and convey emotion with our message. Loss of voice will therefore reduce one's ability to express emotion. Voice is unique to a person's identity. Loss of voice is therefore more than loss of oral communication. Voice is also seen as an extension of thought and a person's sense of self. The laryngectomy patient may therefore lose not only speech but also "the ability to be heard and acknowledged".

5.2.2.3 Depression

As a result of the various experiences of loss, survivors may present with symptoms of **depression** (Dhooper, 1985:222; Renner, 1995:217; Ross, 2000:21; Stell, cited in Silver, 1991:222). Although depression is frequently under diagnosed in cancer patients, it is a common and treatable problem by which the patient's quality of life will be improved (Cady, 2002:349). Symptoms of depression may be presented with medical and treatment non-compliance; diminished decision making ability; behavioral changes; and suicide ideation (Renner, 1995:217).

5.2.2.4 Withdrawal and isolation

As a result of the experience of **loss of voice**, laryngectomy survivors may easily withdraw themselves temporarily or permanently from others (McQuellon & Hurt, 1997:234).

Throughout the survivorship journey, and while transition from cancer patient to cancer survivor occurs, the process of re-entry into society will be more important. As cancer patients are surviving for longer periods of time, re-entry into society will be of greater

relevance. For the laryngectomy survivor, the process of re-entry into society starts while the patient is still recovering from surgery.

5.3 RE-ENTRY INTO SOCIETY

For the laryngectomy survivor, re-entry into society will be accompanied by various physical, psychological and social adjustments for both the patient (micro level) and members of society (macro level).

5.3.1 Less focus on cancer as disease

During the permanent phase of the survivorship experience, patients now have to focus less on cancer and rather focus on their experience of cancer as chronic disease and their re-entry into society.

5.3.1.1 *Cancer as adjusting experience*

The diagnosis of cancer has the potential to cause challenges of adjustment in the life of the patient and his or her family. Cancer nowadays can be referred to as a chronic disease, as will be discussed.

5.3.1.2 *Cancer as chronic disease*

As shown in Chapter 2, advances in cancer treatment have led to **increasing survivorship**. As a result, the number of cancer patients surviving cancer or living with cancer as a chronic disease also increases. It can therefore be said that cancer patients are living longer and fuller lives. Although the diagnosis of cancer may imply a rapid, fatal illness for some, it will become a curable disease for more individuals and a chronic illness for most (Golant & Haskins, 2008:420; Griffiths *et al.*, 2007:440; Pollack *et al.*, 2005:52; Rowland, 2008:361; Rowland *et al.*, 2001:236). Unlike some chronic diseases that develop slowly and allow the person time to develop strategies to cope with their symptoms, the period of time from feeling relatively well to, in some cases, extremely unwell may be very short with a cancer diagnosis (Griffiths *et al.*, 2007:439).

For this reason, survivors are often not well prepared for the problems they face when treatment ends and when they try to resume their lives (Rowland & Baker, 2005:2546).

5.3.2 Process of re-entry into society

Re-entry can be seen as the process of “resuming life as an active adult”. Rowland and Baker (2005:2546) are of the opinion that survivors sometimes are not well-prepared to enter this phase. At the time of **diagnosis**, the patient has to leave his or her previous lifestyle in order to adjust to the health care system (Quigley, 1989:65). **During treatment**, the patient is out of his or her regular routine, possibly for a long period of time, with the result that it may be intimidating and overwhelming for them to **return to everyday society** (Rom *et al.*, 2009:33). By leaving the “sick role”, the survivor can experience this process as a major transition. Although there is progress in cancer treatment and cure, cancer survivors often remain associated with stigma within which context the survivor needs to redefine him- or herself in a non-health care environment (Quigley, 1989:65).

Survivors may find it difficult to manage **everyday routines** and **responsibilities** such as fitting back into normal life after treatment completion or re-entry into normal life (Jefford *et al.*, 2008:22; Roth & Breitbart, cited in Rubin, 2001:236). For various reasons, the cancer survivor may experience a lack of confidence, such as uncertainty regarding their future health condition, physical appearance or other physical problems they may experience in the future. This may result in a lack of confidence to set long-term goals or to make long-term plans (Jefford *et al.*, 2008:27).

5.3.3 Fears at the stage of re-entry

Except for the fears that cancer survivors have to deal with in general, those survivors who present with cancer of the **head and neck area**, may present with additional fears for various reasons. These may refer to fear of potential diminishment by the disease, fear of addiction, or fear of an inability to cope with the various experiences of loss associated with the disease, like loss of sight, smell and hearing (Argerakis, 1990:286;

Moore *et al.*, 2004:62). In addition, the **laryngectomy** survivor will have to deal with other sources of fear too. These may refer to fear of serious surgery resulting in potential loss of ability to communicate, loss of speech, or fear of social and economic loss following surgery (Bagshaw, 1967:54; Johnson *et al.*, 1979:1814).

Having acknowledged cancer as an adjusting experience, and that increased survivorship means that survivors have to deal with the side effects of treatment for a longer period of time, the following section of the chapter is focused on the various means of coping that the survivors will apply in order to assist their re-entry into society.

5.3.4 Themes related to coping while re-entering society

While trying to return to a **sense of permanence**, various ways in which coping with late- and long-term effects of treatment over the long term need to be looked at. In a study conducted by Foley, Farmer, Petronis, Smith, McGraw, Smith, Carver and Avis (2006:250-252) in 2006 regarding the long-term coping of cancer survivors, several **themes** were identified after interviewing fifty-eight cancer survivors who survived their cancer diagnosis for longer than fifteen years. The study found that cancer provides perspective on their daily lives for most survivors; however, it has little impact on their day-to-day functioning. For the laryngectomy survivor to deal with psychosocial changes which are of a permanent nature, various ways in which their experience will influence their lives on a permanent and lifelong basis need to be looked at as it determines their future lifestyle.

5.3.4.1 That's life

Survivors who take this approach accept their diagnosis in a **matter of fact** manner, as cancer is just one of the many issues that they had already faced or would face during life. Surprisingly, cancer does not change them much, or affects them less than other experiences of loss (Miller *et al.*, 2008:371).

5.3.4.2 Personal growth

For survivors who accept cancer as an opportunity for **growth**, cancer helps them to build on their own strengths and find new strengths (Miller *et al.*, 2008:371). This theme is in accordance with the principles of the strengths perspective, acknowledging that every individual, group or community has strengths (Saleebey, 2002:14).

The literature (Andrykowski *et al.*, 2008:193; Rowland, 2008:364) acknowledges that a combination of both positive and negative psychological adjustment can be experienced by survivors during their survivorship journey. With regard to positive adjustment, reference is made to aspects such as “benefit finding”, “post-traumatic growth”, “well-being” or “thriving” (Andrykowski *et al.*, 2008:193; Aspinwall & MacNamara, 2005:2550; Coughlin, 2008:62; Jefford *et al.*, 2008:21; Rowland, 2008:364), which may include positive mental, physical, or social outcomes. **Personal growth** may include the person who rearranges life goals and decides which are possible to attain, reviews priorities, and achieves an enhanced or deepened appreciation of life. Interpersonal roles may change and survivors may adapt to more creative, valued and engaged relationships as a result. An increased sense of mastery and self-esteem may also develop (Rowland, 2008:364; Vachon, 2008:219). As a result of personal growth, survivors frequently report new emotional depth which had been lacking and report that their life is richer following the experience of cancer (Miller *et al.*, 2008:371).

5.3.4.3 Appreciation of life

Large proportions of survivors appear to find benefit in their cancer survivorship experience (Aspinwall & MacNamara, 2005:2550). Literature (Alfano & Rowland, 2006:437; Gerlach *et al.*, 1990:66; Jefford *et al.*, 2008:21; McMurchie, 1991:1450) reported the possible positive outcome of experiencing the cancer survivorship journey, including **greater appreciation of life**. Within this period “survivors go through a period of psychosocial reorientation to their altered status” (McMurchie, 1991:1450).

5.3.4.4 Review of priorities or values

An increased sense of mastery and self-esteem may be experienced by die cancer survivor, leading to the **review** of **priorities** or **values** (Rowland, 2008:364). According to Gerlach *et al.* (1990:66), greater appreciation of life may result in a reordering of priorities. Survivors may face a period of health-promoting behaviour that is being reinforced. The laryngectomy survivor may agree to a healthier lifestyle, including maintaining a sober lifestyle.

5.3.4.5 Relinquishing control

Within the study undertaken by Foley *et al.* (2006:252), a few survivors reported that they dealt with their cancer experience by learning to let go and **relinquish control** of their lives. Within this theme, survivors view their survivorship journey from a spiritual angle, or otherwise accept that they are not in control of what life has to offer those (Miller *et al.*, 2008:371). For the survivor who experiences personal growth, it may be possible to discover a new sense of personal control and an affirmation of self through re-examination of self-identity, even in the presence of some permanent body changes (Vachon, 2008:219).

5.3.4.6 Resentment

Foley *et al.* (2006:252) reported that survivors rarely defined their cancer experience as completely negative. They reported more **positive aspects** of cancer, despite symptoms such as pain, fear of recurrence, physical effects, and health problems. Depression, anger and social isolation were identified, however, which led to the experience of reduced quality of life. Cancer has the ability to “often spur a search for deeper meaning and a fresh perspective on old problems” (Miller *et al.*, 2008:371). In the case of laryngectomy patients, physical changes will be experienced on a permanent and lifelong basis.

Confrontation with the diagnosis of cancer will necessarily provoke various ways for long-term coping by cancer survivors. Foley *et al.*'s (2006) research findings also

presented other **secondary themes**, in reporting on cancer survivors' experience of their survivorship journey. Spirituality was a common secondary theme identified from the results of their study. This is discussed first.

5.3.4.7 Heightened spirituality

Spiritual experiences are sometimes the only thing left to turn to, referring to the experience of those with cancer who present with a fatal outcome (Schulz *et al.*, 2008:114). However, spirituality is being recognised as an **essential dimension** of the cancer experience, no matter whether patients are dying or being healed (Surbone *et al.*, 2010:258). As Schulz *et al.* (2008:104) remarked, "Spirituality may address a human need for certitude in crisis". In the words of Foley *et al.* (2006:252): "Surviving cancer offered them the opportunity to begin life again in a more dedicated, spiritual way".

Spiritual concerns which have to be addressed with utmost respect may be applicable **at all stages** of the illness and survivorship. Schulz *et al.* (2008:105) referred to a qualitative study by Simon and colleagues who investigated the role of spirituality among African American women with breast cancer. When being diagnosed with cancer (acute phase of survivorship), spirituality was found to facilitate their acceptance, helped them to decide upon treatment, and provide family support. During treatment (acute phase of survivorship), spirituality aided them in coping with the effects of treatment and in finding meaning in the cancer experience. Participants reported increased spirituality and hope of survival. At treatment completion (extended phase of survivorship), spirituality gave participants a reason to survive which helped them to cope with the potential recurrence of cancer and to adjust to treatment effects (Schulz *et al.*, 2008:105).

Various literature sources (Andrykowski *et al.*, 2008:193; Aspinwall & MacNamara, 2005:2550; Coughlin, 2008:62; Hawkins *et al.*, 2010:21; O'Baugh *et al.*, 2003:268; Schulz *et al.*, 2008:105-106) reported on the variety of **benefits** attached to the role played by spirituality in the cancer experience, including coping with the experience of cancer. Other benefits referred to included creating meaning in the world; improved

interpersonal relationships; promotion of psychological wellbeing and quality of life; finding or increasing hope or physical and mental health outcomes, for example lower levels of depression, anxiety and pain; enhanced self-esteem, greater feelings of peacefulness and purposefulness.

In addition, **strength** can be drawn from spirituality. Having to cope with any serious illness, including cancer, can remind people of what they believe should be their top priorities and what they feel matters most in life. This may result in the survivor experiencing the desire to help others and to have positive relationships with other people (Andrykowski *et al.*, 2008:193; Coughlin, 2008:62-63).

Schulz *et al.* (2008:105) referred to various research studies among cancer survivors and the role of spirituality in order to further describe some of the **themes of spirituality**. In a qualitative investigation, Walton and Sullivan (2004) identified three spiritual themes among men coping with prostate cancer: prayer, coping with cancer and support. African American women with breast cancer reported that they used prayer for coping with their diagnosis. In a qualitative study undertaken by Schulz *et al.* (2008:108-112) to examine the specific nature of the relationship between spirituality and cancer coping among African Americans, semi-structured interviews with twenty-six patients were used as research method. Findings of the study identified various **themes** which included their connection with God, with others (family members, friends, church family, other cancer patients and the treatment team - meso level): with themselves (self-understanding, self-honesty or self-love, becoming a better person, new perspective on life, change in priorities - micro level); and with the world (helping others, giving to charity, volunteering, giving others a better cancer experience, sharing their story - macro level). Giving back to others frequently involved the desire among patients to give back to others with cancer, by doing anything they could to make someone else's experience easier than their own (Schulz *et al.*, 2008:113). These themes linked well with the ecological perspective, referring to the various systems in which a person functions (Sheafor *et al.*, 2000:91-92).

This tendency in the experiences of cancer survivors is representative of a **wide spectrum of experiences**. As spirituality has the ability to deepen one's faith on the one hand, survivors may also experience questions regarding their faith and anger with God, on the other (Schulz *et al.*, 2008:113-114). Those with advanced stages of faith may experience increased quality of life in comparison with those patients who present with less advanced stages of faith. Cancer survivors may often experience an increased frequency of prayer, church attendance and faith and their spirituality may become more important to them (Schulz *et al.*, 2008:106).

Survivors may experience **change** (Aspinwell & MacNamara, 2005:2550) in their spirituality due to their cancer experience, for example strengthening of faith or heightened spirituality may be present (Alfano & Rowland, 2006:437; Andrykowski *et al.*, 2008:193; Aspinwell & MacNamara, 2005:2550). Some survivors will experience spiritual transformation as their lives gain a more spiritual focus, their connection with the Higher Power deepens, they have stronger ethical convictions and need to embrace personal emotional healing and recovery (Vachon, 2008:220). Spiritual concerns may escalate during a serious illness such as cancer, to fulfil the need to deal with uncertainty caused by the diagnosis and its treatment (Schulz *et al.*, 2008:114).

Other secondary themes which were less frequently mentioned, included awareness of one's own mortality; fear of recurrence; lifestyle changes; stopping taking health for granted; changed eating habits; quitting smoking; beginning to take better care of themselves. Some survivors found that the cancer experience drew them closer to family and friends and made them more appreciative of their time together, while others described that these relationships deteriorated (Foley *et al.*, 2006:252).

Various themes of long-term coping by cancer survivors can be **summarised** by referring to Alfano and Rowland (2006:437) who referred to the survivor's renewed approach to life; positive social experiences; improved self-image; life changes; change in outlook on life; greater appreciation of life; reprioritisation of values; growth in

confidence; greater satisfaction with religious concerns and strengthened spirituality; as well as stronger interpersonal relationships.

5.3.5 Lessons learned from cancer survivors

Throughout the survivorship journey, various **lessons** can be learned from survivors, as indicated by Rowland (2008:361-368):

5.3.5.1 The importance of language

The way primary and secondary survivors **talk, think** and **approach** cancer can have a dramatic impact on the meaning attached to the cancer experience and the resources that will be mobilised in order to deal with it. The language used to describe a person with cancer had to change. One is not a “victim” of cancer, but rather a survivor, which conveys a powerful message of hope (Rowland, 2008:361-363).

5.3.5.2 Moving from active treatment to recovery

Survivors are **not always well prepared** on **treatment completion**, as little instruction is offered to survivors on how to manage when treatment ends. Anxiety can be experienced for various reasons, as already indicated in Chapter 4. On the one hand, the survivor may experience fear of recurrence; on the other hand, there may be experiences of loss on account of fellow patients or team members. Social expectations on the part of secondary survivors for the survivor to be “back to normal” on completion of treatment can add to the pressure survivors may experience. It is advisable to plan for end of treatment and also to acknowledge this to be a difficult period. Survivors need to be informed about the potential challenges they have to face during the transitional phase of survivorship (end of active medical treatment), as discussed in Chapter 3 (Rowland, 2008:363-364).

5.3.5.3 *Being cancer free*

As cancer has a comprehensive effect on the patient's physical, psychological, social, existential and spiritual functioning, the cancer experience will **never be over** (Rowland, 2008:364). This is also applicable to the life experiences of the laryngectomy survivor having to deal with various physical changes following surgery, which act as a daily reminder of various experiences of loss (permanent tracheostoma; different technique for speech production).

5.3.5.4 *Resilience*

Rowland (2008:364) described this as one of the most humbling lessons learned from the study of survivorship. Cancer survivors may feel pride in their capacity to tolerate prescribed treatment and may feel surprised with what they had accomplished. Confrontation with the cancer experience can result in **various benefits**, including an increased sense of mastery and self-esteem; the opportunity to review priorities; or an enhanced appreciation of life. Positive outcome may travel alongside the negative in the survivor's post-treatment period. In the words of Rowland (2008:364), "we help individuals see the potential positive effects of illness".

5.3.5.5 *Factors associated with good adaptation*

The following **factors** are associated with good adaptation after having to cope with the cancer experience: accessing state-of-the-art care, referring to the choice of treatment centre and aspects such as to find care reasonably close to home (for financial and social support reasons); being actively involved and participating in one's own care and a close social support network; and to have a sense of purpose or meaning in life. This is important to the cancer survivor. The situation may have a religious theme, providing relief from the stress of needing to control the cancer experience. In addition, the survivor's capacity to reduce or manage stress will also contribute towards good adaptation to the cancer experience (Rowland, 2008:365).

5.3.5.6 Cancer as “teachable moment”

People often come to this illness unaware that they are at risk. They also will not always know what had led to the cancer diagnosis, which may lead to questions of what they had done to cause the disease and what they could do to reduce the risk of recurrence (Rowland, 2008:365-366). This may be the ideal opportunity to lead the survivor to insight on **lifestyle changes**, as their specific lifestyle might have resulted in their diagnosis of cancer. This may be especially applicable to the lives of laryngectomy survivors, whose previous lifestyle normally associated with severe smoking and drinking over a long period of time may have contributed towards their diagnosis of cancer of the head and neck region (Cady, 2002:347).

The literature highlighted **various aspects** of a person’s ability to change his or her lifestyle and identified several barriers along the road of behaviour change. Hawkins *et al.* (2010:21, 29) referred to studies suggesting that behaviour change is less likely to be undertaken and maintained by men, those who are less educated, over age 65, widowed, divorced or separated, or living in urban areas. Together, these findings indicate that survivors, overall, report relatively few changes in their health behaviour after surviving cancer, and that the prevention practices and lifestyle routines of many cancer survivors may remain largely unchanged by the cancer experience in the long term (Hawkins *et al.*, 2010:29). Reasons which may motivate people to make more positive lifestyle changes may include life-threatening nature of a cancer diagnosis and its treatment; fear of recurrence of disease; one’s faith and sense of meaning in life; or the hope of improving and preserving health and quality of life (Hawkins *et al.*, 2010:20, 29, 30).

The “teachable moment” in the lives of survivors may be utilised as an **opportunity** for clinicians to discuss the effect of their previous lifestyle on their medical condition. Positive benefits to one’s health condition can be discussed and unhealthy behaviour can be discouraged (Hawkins *et al.*, 2010:20, 30).

5.3.5.7 Listening to survivors

Rowland (2008:367) highlighted the importance that the “person” should remain the key focus of cancer care. It will therefore be important to **listen to the needs** that survivors identify, including problems, resources, their fears, concerns, future expectations and how they prefer to work with multi-disciplinary team members, as it will contribute to improving the care offered to survivors.

Having learned these lessons along the road of survivorship, the cancer experience has the potential to offer an ideal opportunity for team members to lead the laryngectomy survivor to positive life changes such as to maintain a sober lifestyle, as their lifestyle contributed towards their initial diagnosis of larynx cancer.

5.4 CONCLUSION

Physical effects have potentially severe social implications, not only for the patient, but also for family members. As survivors are living longer, the **psychosocial effects** survivors have to cope with will be there for a longer period of time. The various levels on which the laryngectomy experience could affect the patient’s social functioning have been described from an ecological perspective. Families often experience these emotional reactions with greater severity than the patient does. A description of the psychological effect of this operation clearly demonstrates that the patient is vulnerable to depression in his attempt to work through various experiences of loss following surgery.

Having to cope with the comprehensive effects of the diagnosis and treatment on the long term, laryngectomy survivors’ experiences of their survivorship journey will influence their re-entry into society. This chapter presented a description of the laryngectomy survivor’s **re-entry into society** in having to cope with the late- or long-term effects of cancer and its treatment, whereby the fifth objective of the study had been reached.

The next chapter presents a description of the research methodology applicable to the present study.

CHAPTER 6

RESEARCH METHODOLOGY

6.1 INTRODUCTION

Based on the guidelines by De Vos *et al.* (2011:77, 295), five **phases** of the research process were followed, namely selection of a researchable topic, choosing formal formulations, planning, implementation and finally, data analysis, interpretation and presentation of research findings. The **steps** that were followed in each of these phases are described in this chapter. Guidelines from the literature will be illustrated by a description of how these were applied in the context of this research study.

6.2 PHASE 1: SELECTION OF A RESEARCHABLE TOPIC

In the **first phase** of the study and as starting point of the research project, the process of selecting a researchable topic was highlighted (Fouché & De Vos, 2011a:79-88).

6.2.1 Step 1: Identification of a researchable topic

The researcher identified the topic for research during her **daily practice** of service delivery to laryngectomy patients and their families on both an individual and a group level. This is in agreement with Fouché and De Vos (2011a:82-83) who remark that it is quite natural for clinically applied disciplines to identify research topics during daily practice. The survivorship journey of these patients and their families resulted in the researcher's **curiosity** (Fouché & De Vos, 2011a:84-85) about various ways in which they try to make sense of their laryngectomy experience. It became an area of interest, from which the researcher's urge to find out more regarding this topic developed.

Fouché and De Vos (2011a:84) view this method of selecting a research topic as valuable, as results gained from such a study contribute towards improved service delivery to the particular patients and will keep the researcher intellectually stimulated and interested in the topic of research (Mouton, 2006:40).

During 2009 the researcher consulted the study leader about the feasibility of the planned research project in order to determine whether the topic was researchable, scientifically acceptable and worthwhile (Fouché & De Vos, 2011a:80; Mouton, 2006:40). Practical issues such as the availability of participants for the study (patients and family members) as well as the value of the study in terms of contributing to the limited knowledge available on this topic, were discussed (Creswell, 2002:27-29). It was decided that this research topic would therefore involve exploring and describing the psychosocial experiences of laryngectomy patients and their families throughout the survivorship journey.

6.3 PHASE 2: FORMAL FORMULATIONS

Following the identification of the research topic, the choice of research approach, problem formulation, formulation of goals and objectives, writing of the research proposal and consideration of ethical aspects related to the study were described in **phase 2** of the research process (De Vos *et al.*, 2011:77).

6.3.1 Step 2: Assessing the suitability of the research approach

The choice of the topic mainly determines the appropriate approach to be chosen although it is not uncommon to use mixed method designs in a complementary manner (Fouché & De Vos, 2011b:90, 92). In this study, a **combination** of the qualitative and the quantitative approaches was used to get a better understanding of the laryngectomy patients' and families' experiences of their survivorship journey, starting from the day of diagnosis.

In the **qualitative approach**, the aim is to understand social life and the meaning people attach to everyday life (Fouché & Delport, 2011a:65). The different ways in which people try to make sense of their lives need to be understood and described (Garbers, 1996:283). The focus is on studying Human behaviour from the "perspective of the actors themselves", viewing the world "through their eyes", in order to understand

them better (Babbie & Mouton, 2001:271). Within this context, the researcher tries to understand and describe ways in which primary and secondary laryngectomy survivors make sense of their survivorship experience as from their own perspectives.

In the **quantitative approach**, the aim is to objectively measure the social world, to test hypotheses and to predict and control human behaviour (Fouché & Delport, 2011a:64) while the researcher stays in the background without becoming involved in the events or “object of study” (Garbers, 1996:282). In this study, a profile of the respondents’ demographic background has been presented to guide the interpretation of responses.

6.3.2 Step 3: Formulate the problem / question / goal / objectives

As the researcher became aware of the increased number of cancer survivors, the topic regarding survivorship became relevant. She became aware of a lack of understanding of the laryngectomy patient’s survivorship experience throughout the various phases of medical treatment, namely diagnosis, surgery, post-operative radiotherapy (if indicated) and follow-up visits at the hospital.

Mouton (2006:50-51) introduces the four steps that were followed in this study to transform research ideas into a research problem:

- Spending time on a preliminary **literature review** in order to learn more about the different ways in which this topic has been studied. This was done between April and December 2010. An article (Miller *et al.*, 2008:369-374) referring to the various seasons of survivorship that was published in an international journal was used as basis of the theoretical layout of the dissertation.
- Formulating a clear understanding of the **unit of analysis**. In this study, individual patients and some of their family members were interviewed.
- Being clear about the objectives of the research and specifying the study objectives. As discussed in Chapter 1, the **goal** of the study was to contribute to a better understanding of the survivorship experience for both the post-operative

laryngectomy patient and the family system. In order to achieve this goal, the following **objectives** were formulated:

- To *discuss* the nature of cancer survivorship as experienced by the patient and various groups involved (Chapter 2).
 - To *describe* medical aspects involved in a laryngectomy and physical re-adjustments for patients and their families (Chapter 3).
 - To *discuss* the principles of and strategies for coping and surviving as a post-operative laryngectomy patient (Chapter 4).
 - To *explain* coping with the comprehensive psychosocial effects of the permanent phase of surviving a laryngectomy (Chapter 5).
- To ensure that the formulation of the research problem was feasible in order that the study would be completed successfully, the **research question** as referred to in Chapter 1 was: “What are patients’ and families’ experiences of surviving a laryngectomy with the assistance of internal (the strengths perspective) and external resources (the ecological perspective) within the family system and environment?”

6.3.3 Step 4: Composing the research proposal

Fouché and Delpont (2011b:101) **define** the research proposal as a document that outlines how the researcher proposes to undertake a research project; this therefore can be seen as a “project planning document” (Strydom & Delpont, 2011a:283-284; Mouton, 2006:45). Tutty, Rothery and Grinnell (1996:43) emphasised the practicality of the use of the research proposal by stating that it will guide the researcher through the entire research process and that it will serve as a valuable road map. In the end, it can then be used as an outline for writing the final report. The researcher witnessed the survivorship journey through sharing the patients’ and their families’ experiences while dealing with them in individual and group settings. By conducting the research study, their experiences could be explored and described according to the various steps of the research process.

The research proposal for this study was completed in August 2010. The policy requirements of the educational institution (University of Stellenbosch) state that a research proposal should first be approved by a research panel before a student can enrol for studies and this research proposal was approved in September 2010. The researcher was registered for the study in January 2011. After minor changes, the research proposal took the form now presented in Chapter 1 of this dissertation.

6.3.4 Step 5: Ethical implications of the study

As discussed in Chapter 1, permission to conduct the research study was granted by the Ethics Committee following an oral presentation of the research proposal and a written explanation of how the researcher planned to meet all ethical requirements. After clarifying aspects that were queried by the Ethics Committee, the researcher successfully convinced the committee of her determination to adhere to strict guidelines and procedures (Strydom, 2011:127, 129). Although the Ethics Committee approved the research proposal and granted permission to continue with the study, the researcher was fully under the impression that she, as a registered social worker, held the final responsibility for conducting the study according to ethical guidelines. The researcher was not confronted with any ethical legal dilemmas while conducting the study (Strydom, 2011:129).

Ethical issues which would be upheld to during the course of the research study were discussed in Chapter 1; these issues included avoidance of harm; voluntary participation; informed consent; confidentiality; and debriefing of participants following their participation in the study (through interviews).

The researcher undertook to honour the ethical requirements at the stage when results are made public, as stressed by Strydom (2011:126). These guidelines stipulate that the researcher should provide an accurate and objective reflection of responses gained from interviews with patients and family members without impairing the principle of confidentiality. Of importance to any research is that findings of the study should not be manipulated. In addition, shortcomings of the study need to be acknowledged.

Acknowledgement has to be given throughout a study when someone else's work is incorporated within the study. In keeping with the guidelines, findings of the study will be presented in such a way that recognition is given to survivors who participated in the study and the ultimate goal of the research project will be encouraged, namely utilisation of the study by others.

6.4 PHASE 3: PLANNING

After the discussion of the research proposal, the literature study, research design and data collection, analysis and sampling were discussed as **phase 3** of the research process (De Vos *et al.*, 2011:131). Tutty *et al.* (1996:26) emphasised the role of careful planning of the study and taking into account the amount of time and resources that would be needed in order to conduct the study.

6.4.1 Step 6: Literature review

An extensive literature review regarding cancer survivorship with specific reference to the experience of laryngectomy patients and their families was conducted. A literature search revealed a lack of articles from a social worker's perspective as little previous research has been done in this regard. The researcher then studied findings of studies on cancer survivorship from various other professional fields.

A thorough literature review has several benefits, as described by Creswell (2003:29-30), Fouché and Delpont (2011c:134-135) and Mouton (2006:87). These benefits were applied to the current study. First, a literature review helps to form a clearer understanding of the nature and meaning of the topic of research as it specifically focuses on the research topic. It also helps to contextualise the study as it shows results of prior research and how the current project is linked to such research. This can indicate clearly how survivorship experiences of laryngectomy patients and family members fit into the topic of cancer survivorship in general.

Second, the literature study saves time, as it prevents duplication of research that has been done in the past. In addition, it offers the opportunity of comparing results of the current study with results of previous studies. The most widely accepted and recent findings in a particular field of research can then be identified. This was helpful when the researcher initiated the topic of research, as she identified a lack of existing information on laryngectomy survivorship from a social work perspective.

Between June and December 2009 the researcher searched for articles relevant to the research topic and started reading. As an extensive literature review was undertaken between April and December 2010, the researcher used keywords for summarising this amount of information. Organising of information according to a specific theme in exploratory studies is also suggested by Mouton (2006:93). Using a spreadsheet, provision was made for different columns, referring to the number of the article in column 1, followed by the page number in column 2 and the specific content in column 3. Chapters dealing with the literature review were composed between January and December 2011. These chapters were reviewed on a continuous basis throughout the duration of the study and the contents of the chapters were adapted as the researcher gained new insight into the field of study.

6.4.2 Step 7: Selecting a qualitative research design

A **combination** of both the exploratory and descriptive designs was applied to best reach the goal of the study as indicated in Chapter 1. An **exploratory design** helps the researcher to explore an unknown or new area of interest to obtain new insight into a field of study involving people who have had practical experience of a similar problem (the laryngectomy experience, in this instance) and this was used to gain new insights into psychosocial factors which may affect the patient's and family's survivorship journey (Babbie & Mouton, 2001:79-80; Fouché & De Vos, 2011b:95-96; Garbers, 1996:287).

A **descriptive design** focuses on the "how" and "why" questions in research. In this study, the question was: "What are the experiences of the laryngectomy patient and

family while surviving a laryngectomy?” The researcher observed the laryngectomy experience as experienced by primary and secondary survivors and afterwards described the details of the situation to present a picture of the special details of the situation (Babbie & Mouton, 2001:80; Fouché & De Vos, 2011b:96; Garbers, 1996:287).

6.4.3 Step 8: Information collection and analysis

As a registered social worker, the researcher used professional interview techniques as described by Greeff (2011:343-346) while conducting face-to-face interviews which were aided by a semi-structured questionnaire or, in the case of family members, an interview schedule. The researcher's choice of conducting in-depth face-to-face interviews was motivated by Tutty *et al.*'s (1996:56) opinion that the semi-structured interview can be useful when one wants to compare information between and among people and at the same time try to understand each person's experience.

Forty-five patients and fifteen family members were selected to share their survivorship experiences through describing their personal experience of the laryngectomy or, as in the case of the family members, their relative's laryngectomy experience. These narrative responses helped the researcher to gain better understanding of the survivorship journey as experienced by primary and secondary survivors. Thick description gained from these narrative responses enabled the researcher to enter participants' "life world" in order to provide a description of human experience as experienced by the people themselves (Fouché & Schurink, 2011:316).

Literature based on similar studies set the foundation for the formulation for the questionnaire. The problem of illiteracy was overcome by using face-to-face interviews with patients with the help of a semi-structured questionnaire (Annexure B) and an interview schedule with family members (Annexure C) (Babbie & Mouton, 2001:249; Grinnell, 1993:268). Twenty-five (55,6%) of participants in this study had no scholastic or only primary school training.

As acknowledged by Greeff (2011:353), this was an intense experience for the researcher as participants were offered the opportunity to share their deepest emotional experiences. The duration of patient interviews varied between 40 to 60 minutes and family interviews varied between 20 to 30 minutes. As these patients form part of the researcher's everyday social work practice, all participants were known to the researcher. The researcher put them at ease by interviewing them in the privacy of her office.

Initially the researcher planned to have focus group discussions with family members. Reasons for altering the choice from group discussions to individual interviews with the aid of an interview schedule (Annexure B) with family members were twofold. First, individual face-to-face interviews would produce better-quality information as participants could be offered the opportunity to discuss personal experiences of a potential sensitive nature in greater detail (Greeff, 2011:363). Second, more questions could be covered in an individual session than in a group discussion as every group member would need an opportunity to respond on each question (Greeff, 2011:341, 370).

6.4.4 Step 9: Sampling

Strydom and Delport (2011b:391) pointed out that researchers who conduct qualitative research "seek out individuals, groups and settings where the specific processes being studied are most likely to occur". The researcher chose all patients who had had a laryngectomy as the population of study. As indicated in Chapter 1, **purposive sampling** was applied as a type of a non-probability sampling technique, with the researcher using her own knowledge and judgment of the population in order to select a sample (Babbie & Mouton, 2001:166; Grinnell, 1993:162-163) while taking into account the purpose of the study. Such a sample would thus represent a good source of the information which was specially sought. By doing this, the researcher ensured that rich detail was obtained in order to collect a maximum range of specific information about the patient's and family's experience of their laryngectomy survivorship journey (Strydom & Delport, 2011b:392).

In purposive sampling, criteria for the selection of the sample are of relevance. The sample was chosen after thinking critically about the parameters of the population and then selecting the sample accordingly (Strydom & Delpont, 2011b:392). As indicated in Chapter 1, only patients who had undergone the operation not less than three months previously, who attended follow-up visits at the hospital and who had successfully acquired tracheoesophageal speech were included in the study. The speech language therapist assisted in identifying patients who had fluent speech in order to allow them to participate in an interview with duration of 45 to 60 minutes.

With reference to family interviews, marital or life partners of participants were selected to participate. If the participant was not married or did not have a life partner, another family member identified as being of significance to the patient by the participant himself, was chosen. According to the Dictionary for Social Work (2003:152, 299), a **nuclear family** refers to “the kinship group consisting of a father, a mother, and their children” and the **extended family** refers to “a kinship group comprising relatives of a nuclear family such as grandparents, uncles, aunts and second cousins”. From personal experience gained over 27 years of working with these patients, it is clear that, following the operation, the laryngectomy patient him- or herself determines who will be the most obvious person to rely on. By interviewing the family member selected by the patient, the researcher ensured that the person most exposed to the laryngectomy experience was involved in the study and had the opportunity to share their experience of the patient’s laryngectomy.

Various and unique challenges confronted the researcher in selecting the research sample. The following practical arrangements applied: Follow-up visits of participants are scheduled on a Wednesday at the Department of Radiation Oncology at the hospital where the study was conducted. On the day prior to their appointment (Tuesday) the medical folders of these patients were available in the clinic. At that stage, the researcher went through the files and identified those who met the requirements of the selection criteria. The researcher could not phone patients to discuss their willingness to

participate, as most of them did not have phones or contact numbers where they could be reached. The researcher also wanted to treat all participants equally and did not want to give some an advantage by informing them that their participation would be required.

It was not possible to predict which patients could be involved in every instance, as their ability to speak was one of the criteria. Although the previous note in the medical file could have indicated that the specific patient did have speech, it was not to say that it would be the case on the particular occasion. Patients' speech ability varies, as several factors play a role in this regard, for example their medical condition and/or the condition of the speech valve. Patients furthermore do not always keep their appointments because they are dependent on transport arrangements. Another contributory factor was the social profile of the patients, who mostly present with a previous history of substance abuse and therefore are not always compliant (Cady, 2002:347).

On the day of the patients' follow-up visit, the researcher went to the clinic to meet these patients. First she made sure about their speech ability. Patients who were unable to speak or did not make use of tracheo-oesophageal speech could not be included in the study. Two aspects were kept in mind, the first being their medical treatment which was given first priority as agreed upon in the application for ethical clearance. Another aspect to bear in mind was to allow patients who wanted to attend the laryngectomy support group to do so. With regard to patients' medical treatment, it needs to be explained that regular replacement of the speech valves at the stage when they present with leakage of the valve, is required. After consulting the doctor, those patients were sent to the Ear Nose and Throat Clinic at the specific hospital. Normally the researcher could not interview those patients on the particular day, as they were dependent on public transport arrangements and had to leave after their speech valve replacement. Participants would also have been stressed once it was late. Such participants were interviewed at the time of the next follow-up appointment at the clinic. Interviews with those who desired to attend the support group meeting were conducted in the privacy of

the researcher's office either before or after the group session. Following the group discussion, it was easy to identify those with fluent speech. Those who were able to speak, but whose speech was not fluent, were not included in the study as it would be difficult for them to participate in an interview of 45 to 60 minutes. The speech language therapist assisted in identifying those with fluent speech.

In the research proposal the researcher initially indicated that she wanted to include thirty participants in her sample. The researcher increasingly came under the impression of the valuable information gained from these interviews. As these patients were part of her everyday social work practice, the research was aimed at using the information to improve daily service delivery, as may be the case with research from everyday practice (Fouché & De Vos, 2011a:82). At the stage of application for extension for ethics clearance, the researcher indicated that she wanted to increase the sample size to a maximum of 50 participants, which was accepted. Interviews with patients started on 6 June 2012 and continued throughout the year until 10 July 2013. Interviews with family members started on 21 January 2013, continuing until 5 June 2013.

6.5 PHASE 4: IMPLEMENTATION

Phase 4 refers to implementation of the research project and therefore describes the pilot study and conducting the research (De Vos *et al.*, 2011:131).

6.5.1 Step 10: Conducting a pilot study

The purpose of the pilot study is described by Strydom and Delport (2011b:394-395) as an opportunity to determine whether the relevant data can be obtained from the participants, thereby to focus on areas that may have been unclear or to test certain questions. Following this, the researcher can adjust the contents of the questionnaire with the aim of improving the quality of interviewing participants when conducting the study. As qualitative research is usually conducted in a smaller area with fewer respondents, but in greater depth and over a longer period of time than in quantitative

research, the researcher made sure that as comprehensive and accurate an assessment as possible of the real situation to be investigated was undertaken (Strydom & Delpont, 2011b:395).

The researcher found this to be a helpful way of measuring the research instrument, namely the semi-structured questionnaire. Strydom and Delpont (2011b:395-396) distinguish four elements of a pilot study which were applied in the following ways for this research study. First, with regard to the literature review, the researcher reviewed the literature chapters on a continuous basis in order to make sure whether insight that was gained throughout the course of the study could alter or add to the existing literature, as discussed in Step 5 of this chapter.

Second, various experts were consulted before and during the pilot study, with the purpose of identifying themes and doing a more thorough literature review. For the purpose of finalising the semi-structured questionnaire, a statistician was consulted before and after the pilot study in order to discuss analysis of quantitative data in advance and to alter some questions in order to simplify analysing the data. The speech language therapist was consulted to assist with shortening of the contents of the questionnaire. After the fifth interview took place, she also consulted one of the medical specialists who did not work in the Ear Nose and Throat clinic to form an objective opinion on the contents of the questionnaire. Valuable recommendations had been made which assisted in finalising the questionnaire.

In the third place, the feasibility of the study was tested by taking an opportunity to observe the openness and willingness of participants to co-operate. All prospective participants agreed to take part in the pilot study. After finalising the interview, they indicated that it was a positive experience and that they felt honoured to be involved.

In the fourth place, the questionnaire was “tested” on six patients who successfully met the criteria for sample selection although they were not included in the study. The pilot study took place between 18 April 2012 and 24 May 2012 and included four male and

two female patients whose scholastic training varied between Grade 5 (1, or 17%); Grade 6 (1, or 17%) and Grade 10 (4, or 66%). After each of these six interviews, adjustments were made in terms of the length of the questionnaire and the terms used in the questionnaire. The two biggest challenges were to limit the length of the questionnaire, taking into account participants' speech limitation and also to ask the questions on a level that met participants on their level of education. Open-ended questions were varied with closed-ended questions in order to enable them to have a rest in-between. Time had been spent on making the contents of the questionnaire as simple and understandable as possible. No problems were experienced with the use of the digital tape recorder as it was a small, user-friendly item with the appearance of a cell phone.

6.5.2 Step 11: Implementing the design, collecting materials, recording and undertaking the literature study

The research study was conducted between June 2012 and July 2013, during which time the research design was implemented; material was collected through recording face-to-face interviews which were transcribed by the researcher.

6.6 PHASE 5: DATA ANALYSIS, INTERPRETATION AND PRESENTATION

The experiences of both the laryngectomy patient and the family throughout their survivorship journey were explored. The narratives of the 45 participants were classified into **themes**, **sub-themes** and **categories** in order to address the question "What is the experience of the participants and their relatives?" The way these themes, sub-themes and categories were classified was addressed within this phase of the research study. Schurink *et al.* (2011:404-419) distinguished the following **guidelines** that would be helpful when analysing and interpreting qualitative data, but acknowledged that the guidelines do not necessarily require the following sequence:

6.6.1 Planning for recording of data

In accordance with the opinion expressed by Tutty *et al.* (1996:67-68), the researcher found it useful to make use of audio recordings of interviews as it captures the richness of a participant's speech, from which verbatim information was gained.

As indicated in the research proposal, interviews were audio-taped by means of a digital tape recorder. Participants' consent had been asked to make use of the tape recorder before the interviews started, in order to acknowledge their rights (Annexures D, E, F and G). The reason for using the tape recorder was explained to them as useful to assist the researcher to collect information that would be valuable. It also helped with concentration, as the researcher did not have to make field notes. When answering quantitative questions, responses were marked directly on the questionnaire. Taking into account that participants had speech limitations, it was necessary to listen carefully to the contents of the interview. Using the tape recorder was very helpful to the researcher in this regard.

Interviews with patients were numbered from number one to 45 and with family members from number one to 15. In addition, the reference number of the specific patient of whom the family member was representative, was also mentioned on the questionnaire, e.g. 45 (a). The date of the interview was also documented. The respondent's name was never used during the course of the interview. Tape recordings of the interviews were stored in a safe place. These interviews were audio-taped and transcribed by the researcher.

6.6.2 Data collection and preliminary analysis

Data collection and analysis are described as systematic procedures which are inseparable and which occur continuously (Schurink *et al.*, 2011:405). The researcher transcribed the recorded interviews on the day on which the interview took place. It was a time-consuming process, as it took time to listen carefully to the contents of the interview, taking into account that participants presented with tracheoesophageal

speech. It was difficult to follow the contents of these interviews at times, as it was difficult to hear what participants had said. To ensure that the researcher typed a true reflection of the contents of the interview, the recording was listened to for a second time on the following day. It took 90 minutes each time to transcribe an interview of 45 minutes (180 minutes in total). What also challenged the researcher's ability to type the narratives of participants was that sentences were broken up into phrases when they breathed and after taking a deep breath in order to produce speech, and the contents of the sentence did not always follow chronologically.

6.6.3 Managing the data

Data analysis is described as “a process of bringing order, structure and meaning to the mass of collected data”, which means breaking up collected data into discrete parts. (Schurink *et al.*, 2011:397, 412-413; Marshall & Rossman, 1995:111). Tutty *et al.* (1996:90) describe the process of data analysis as “to sift, sort, and organise the masses of information acquired during data collection in such a way that the themes and interpretations that emerge from the process address the original research question”. The transcribed interviews were typed on the laptop. Backup copies were made of all the transcribed interviews. Interviews were numbered according to the sequence of the interviewing. The contents of the interviews were also printed in a hard copy format and kept in a safe place.

6.6.4 Reading and writing memos

Schurink *et al.* (2011:409) and Marshall and Rossman (1995:113) emphasise the importance of reading through data repeatedly in order to become familiar with the data and to help with formulation of patterns, themes and categories. After 28 interviews had been conducted, the researcher brought together the responses per question of the various participants. This process was repeated for the responses of participants number 29 to 34, and then for 35 to 45. By bringing the various responses per question together, the researcher formed a good idea of the contents of the responses she received to each question.

6.6.5 Generating categories and coding the data

Being busy with “the heart” of qualitative data was described by Schurink *et al.* (2011:410) and Marshall and Rossman (1995:114) as the most difficult, complex, ambiguous, creative and enjoyable phase in the process of research. Ryan and Bernard (in Denzin & Lincoln, 2000:780) referred to literature reviews as rich sources to generate themes, as well as the researcher’s own experience of interaction with participants.

The researcher identified keywords per participant per question in red. At the end of the quote she marked the respondent’s number in blue. Two sets of tables were then created. The first table presented an overview of responses, consisting of a column with the number of the respondent (column 1), followed by the item (column 2), motivation for the response (column 3), numbers of respondents (column 4) who responded in that way and the percentage of respondents (column 5) who responded in that way. Following this, another table was created which presented a summary of the various responses. This table consisted of two columns, for the theme, sub-theme and category.

While identifying themes, the overall goal of the study, objectives and the research question were taken into account. Themes were identified after having read the narrative responses of participants and family members repeatedly. These themes linked well with the research question, namely: “What are patients’ and families’ experiences of surviving a laryngectomy with the assistance of internal and external resources within the family system and environment?” The themes that were identified were: the nature of cancer survivorship; medical aspects and physical re-adjustments; principles and strategies for coping; coping with the comprehensive psychosocial effects. Themes were divided into different sub-themes, followed by a division into categories.

According to Schurink *et al.* (2011:411), coding is the formal representation of analytic thinking; codes can take several forms. The researcher preferred to do coding in different colours, with a specific theme being marked in the same colour throughout the data. In the preceding paragraph (step 5), the researcher referred to the organising of information gained during face-to-face interviews. Different themes were marked in different colours, which made it easier to identify the variety of themes.

6.6.6 Testing emergent understandings and searching for alternative explanations

Evaluating of data for their adequacy, credibility, usefulness and centrality needs to take place (Marshall & Rossman, 1995:116; Schurink *et al.*, 2011:415). The researcher determines how useful the data are in responding to the research question and how central data are to the topic of research, namely the experience of patients and family members in surviving a laryngectomy. Patterns of responses were identified and the researcher found linkages among identified patterns. The researcher repeatedly studied identified themes, sub-themes and categories as an ongoing process and made sure that it was relevant to the goal of the study. In some instances, consideration was given to changing and moving some categories; this occurred in cooperation with the study leader.

6.6.7 Interpreting and developing typologies

Interpretation of the collected data refers to “making sense of the data” (Schurink *et al.*, 2011:416). For the researcher, this was the most intellectually challenging phase of the research process as one has to employ heightened awareness of and focused attention on the collected data. Taking into account participants’ speech limitations, the researcher feels privileged to have gained such emotional and honest responses from participants.

6.6.8 Presenting the data

The researcher presents data in text format but in some cases also makes use of visual illustration to emphasise findings of the study. These are presented in figures or tables (Schurink *et al.*, 2011:418). The choice of method in which results are presented is determined by which format best illustrates the findings.

6.6.9 Step 12: Processing and analysing data and verifying results with literature control and participants

Schurink *et al.* (2011:397, 412-413) and Marshall and Rossman (1995:111) describe data analysis as a “messy, ambiguous, time-consuming, creative and fascinating process” in which order, structure and meaning is imposed on the mass of collected data. During this process, collected data is broken up into discrete parts. In this study, analysis of the research data took place throughout the research process. Whilst busy with the interviews, the researcher started summarising questions with a qualitative nature according to themes, sub-themes and categories. Similar themes were marked and colour-coded in order to highlight such themes. Summarising of participants’ responses occurred within various sections. Narrative responses were related to literature in order to draw conclusions. Member checking was done by asking four participants (patients and family members) to read the transcribed interviews to give their opinion on whether the transcriptions presented a true reflection of the contents of the interview.

6.6.10 Step 13: Planning narratives and writing the report

Writing of the research report can be seen as the final phase of the long research process that has been completed. Findings of the study need to be communicated to others in order to be of scientific value (Marshall & Rossman, 1995:117-119). According to Delpont and Fouché (2011a:424-425), the qualitative report is often less structured, more intertwined with the total research process and often longer and more descriptive.

In Chapter 1, the criteria, like credibility, transferability, dependability and confirmability, against which the trustworthiness of this study was assessed, were discussed. Throughout the study, these aspects received high priority as the researcher, as a registered social worker, took care of these in a professional manner in line with the Ethical Code of the South African Council for Social Service Professions. Finally, conclusions and recommendations made from the findings of the study are also presented.

6.7 CONCLUSION

During the process of doing research, it is necessary to follow particular steps within the various phases of research. The first phase refers to selection of the research topic, which can be seen as the starting point of any research project. In the second phase, the researcher has to decide upon formulation of formulas. An appropriate research approach and design need to be selected, and the formulation of the research question, goal and objectives has to be considered. In order to guide the researcher's thinking into planning, drafting of a research proposal has to follow, with an explanation of how the researcher plans to take care of ethical implications of the study. The planning phase will, in the third place, involve the literature review and selection of the research design, as well as the method of information collection and analysis. The way in which the researcher selects the sample also needs to be clearly specified. In phase four, the implementation phase, conducting a pilot study and implementation of the research design follows in the collection of information. In the final phase, the process of data analysis and writing of the research report follow.

The next chapter presents the qualitative data, which are presented according to themes, sub-themes and categories.

CHAPTER 7

IDENTIFICATION AND MEDICAL PROFILE OF LARYNGECTOMY PATIENTS DURING PHYSICAL RE- ADJUSTMENT

Acute and transitional phases of survivorship

7.1 INTRODUCTION

The previous chapter provided a description of the research methodology that was utilised in order to conduct the study. In both the current and the following chapter, an exploration of the survivorship experience of laryngectomy patients (primary survivors) and their families (secondary survivors) is presented. Data obtained from the empirical study are presented, analysed and interpreted within the context of the literature study. Themes emerging from the data analysis are identified and described and then subdivided into subthemes, followed by a division of these subthemes into relevant categories.

In the current chapter, **identifying details** (personal and medical information) of patients selected for the sample will first be presented and analysed. Two groups were involved as participants in the study, namely patients and family members representative of some of the patients who participated. A profile of family members who participated is therefore presented as well. The **focus** will be on a description of the **first two themes**, namely patients' and families' experiences of their need for pre-operative information in the survivorship experience, as well as their experience of physical adjustment following the operation (Table 7.1). These two themes are representative of the first two phases of the survivorship journey, namely the acute and transitional phases. The following chapter is focused on the last two themes that emerged from the data, namely the extended and permanent phases of survivorship.

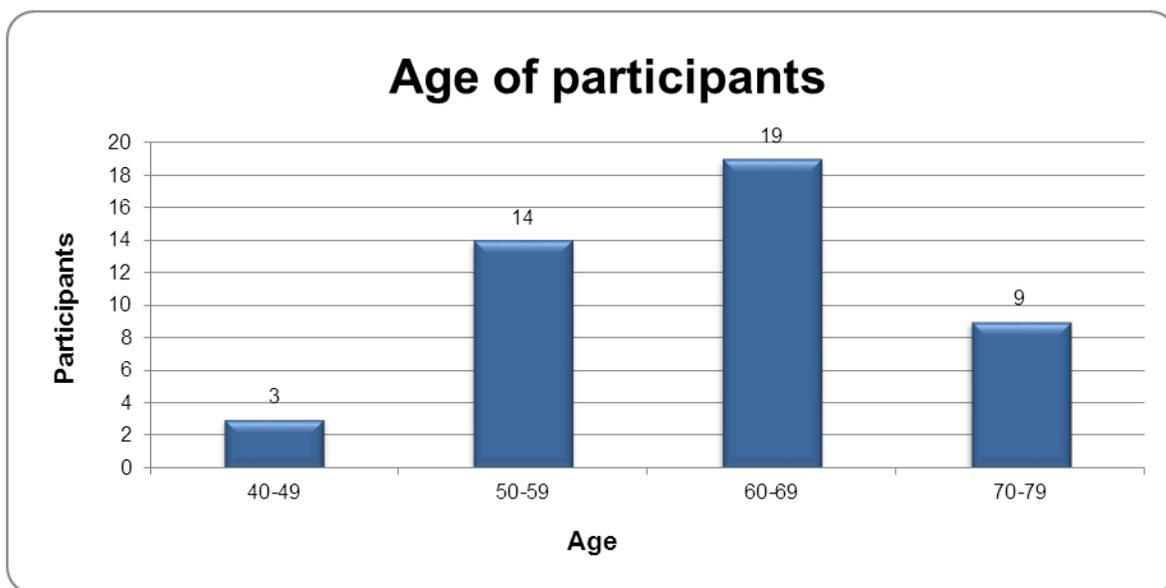
7.2 PROFILE OF PARTICIPANTS

7.2.1 Profile of patients

Identifying details of participants (patients) are presented according to the following criteria: age, marital status, race, gender, education and training, occupation (pre- and post-operative) and total monthly income, which will be linked with the survivors' survivorship journey throughout their laryngectomy experience.

7.2.1.1 Age

The ages of participants at the time of the interview are presented in Figure 7.1. Their ages varied between 42 and 79 years with an average of 62 years. The majority of participants (29, or 64,4%) were between 59 en 71 years old. Participants were between 40 and 77 years old (average of 57 years) at the time of their surgery (laryngectomy).



$n = 45$

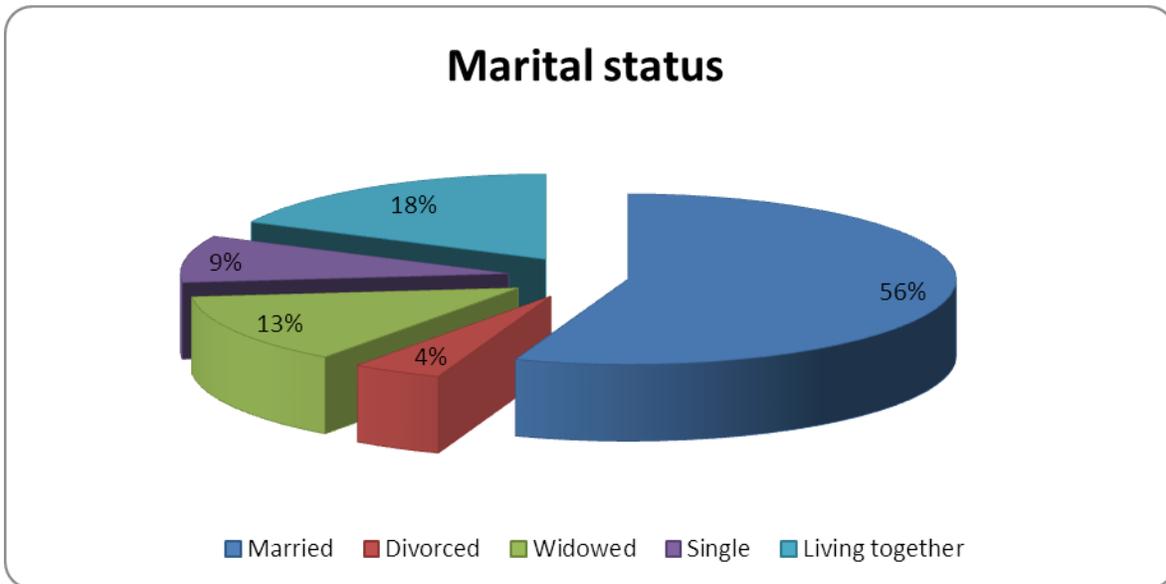
FIGURE 7.1: Age of participants at the time of the interview

Findings of the study were in line with NCR statistics for 2007 (NCR, 2007:11, 12) which confirmed that the age group most at risk of a diagnosis of cancer of the larynx is between 55 and 59 years for both male and female patients. Eleven (24,4%) of the participants in the study represented the high risk group. However, age was not a criterion for inclusion in the study.

Bearing in mind that it was mostly elderly patients who participated, literature findings which discussed the **survivorship experience** of elderly survivors has to be taken into account when describing the laryngectomy experience of patients and families. Hara and Blum (2009:47) mention various challenges that elderly survivors have to handle. One of these challenges is the comprehensive rehabilitation of older laryngectomees, which is a complex process, referring to physical, psychological, social (including communication) and vocational areas affected by such an operation (King *et al.*, 1971:112, 118). In a study from 2006 which was conducted with long-term survivors who were diagnosed more than fifteen years earlier, Foley *et al.* (2006) found that younger survivors were more likely to report personal growth from their survivorship experience, whilst older survivors were more likely to minimise the impact on their lives (Foster *et al.*, 2009:243). In addition, older survivors seemed to be less affected by their cancer experience than younger ones, as older survivors often are more accustomed to handling negative events in their lives and often do not experience the pressure of fulfilling multiple, competing roles, as will be the case with younger survivors (Hara & Blum, 2009:47).

7.2.1.2 Marital status

In the current study, more than half (25, or 55,6%) of the participants were married and eight (17,8%) were living with a partner, as shown in Figure 7.2. Six (13,3%) participants were widowed; four (8,9%) had never been married and two (4,4%) participants were divorced.



$n = 45$

FIGURE 7.2: *Marital status of participants*

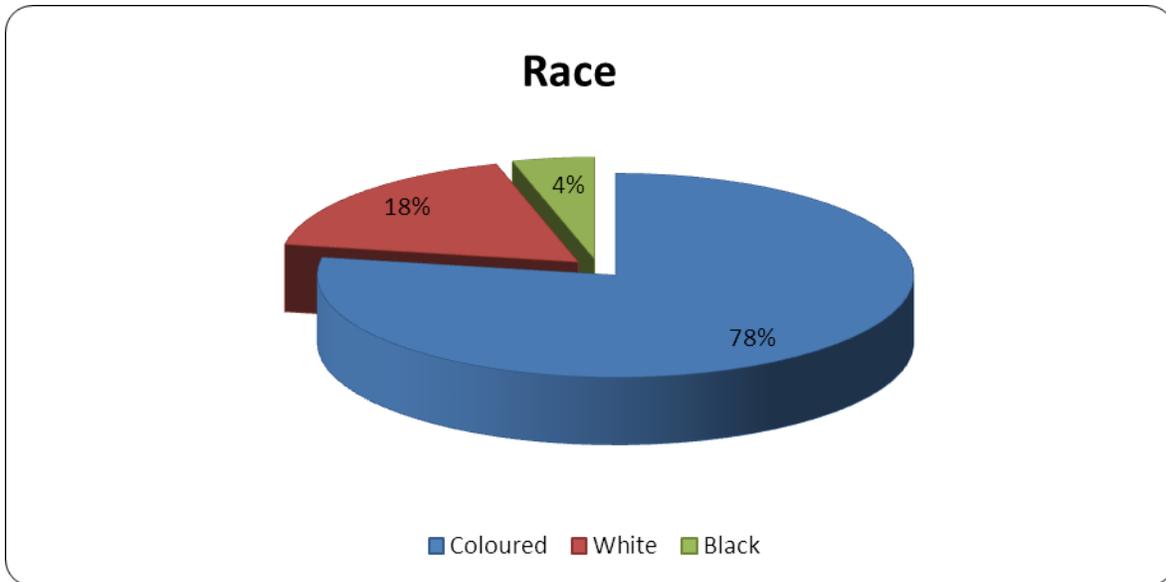
From a **survivorship perspective**, elderly survivors are often confronted with inevitable experiences of loss of significant relationships and have to face the challenge of re-entering into normal relationships or having to form new relationships (Cella, 1987:62). This may be challenging to the laryngectomy survivor, who already has to cope with the post-operative speech limitation. Cella (1987:63) also held the opinion that those survivors without significant, stable and loving relationships are at higher risk for interpersonal distress and alienation. The literature supporting the relevance and importance of spousal support (Earle, 2007:299), referred to evidence that married cancer patients live longer than unmarried cancer patients.

7.2.1.3 Race

According to the 2010 census (www.statssa.gov.za), the total population in **South Africa** is 51 770 560 (Census, 2011:15). The largest population group in South Africa is the Black (79,2%) group, followed by Coloured and White persons (8,9%) each. The smallest population group in South Africa is the Indian or Asian (2,5%) group (Census, 2011:17). It is in this context that the latest available National Cancer Registry statistics can be interpreted. NCR statistics for 2007 (NCR, 2007:5, 6) showed that the majority of patients newly diagnosed with cancer of the larynx in South Africa were from the Black population. This was followed by the White, Coloured and Asian population groups.

According to the census results of 2010 for the **Western Cape** the catchment area for patients who are treated at the hospital at which the study was conducted - the total population is 5 822 734 (Census, 2011:14). Coloured persons represent 48,8% of the total population, followed by Black (32,9%), White (15,7%) and Indian or Asian (1,0%) (Census, 2011:17). Only patients who successfully met all the criteria for inclusion in the sample were asked to participate in the study.

Although the specific hospital renders services to all population groups, two Black (4,4%), thirty-five Coloured (77,8%) and eight White (17,8%) participants took part in the study, as illustrated in Figure 7.3. The results of the study can therefore not be applied to all population groups in South Africa, as participation in the study was not representative of all population groups in South Africa. However, it can be useful when working with people from the Coloured population group as the majority (35, or 77,8%) of participants was from this population group.

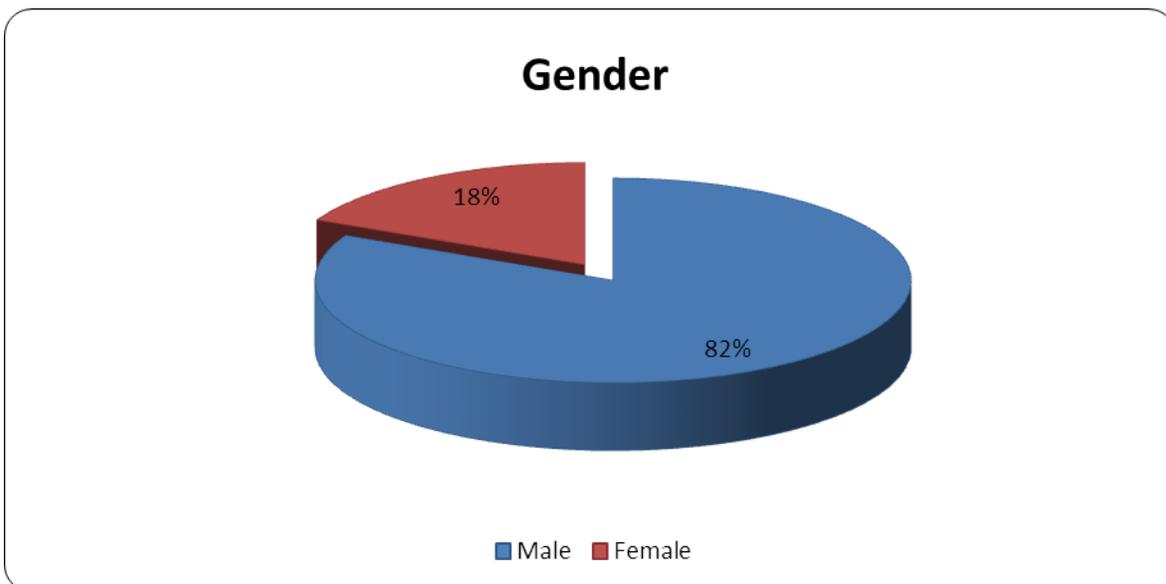


$n = 45$

FIGURE 7.3: Race of participants

7.2.1.4 Gender

Figure 7.4 shows that a majority of male patients (37, or 82,2%) participated in the study, followed by (8, or 17,8%) female participants.



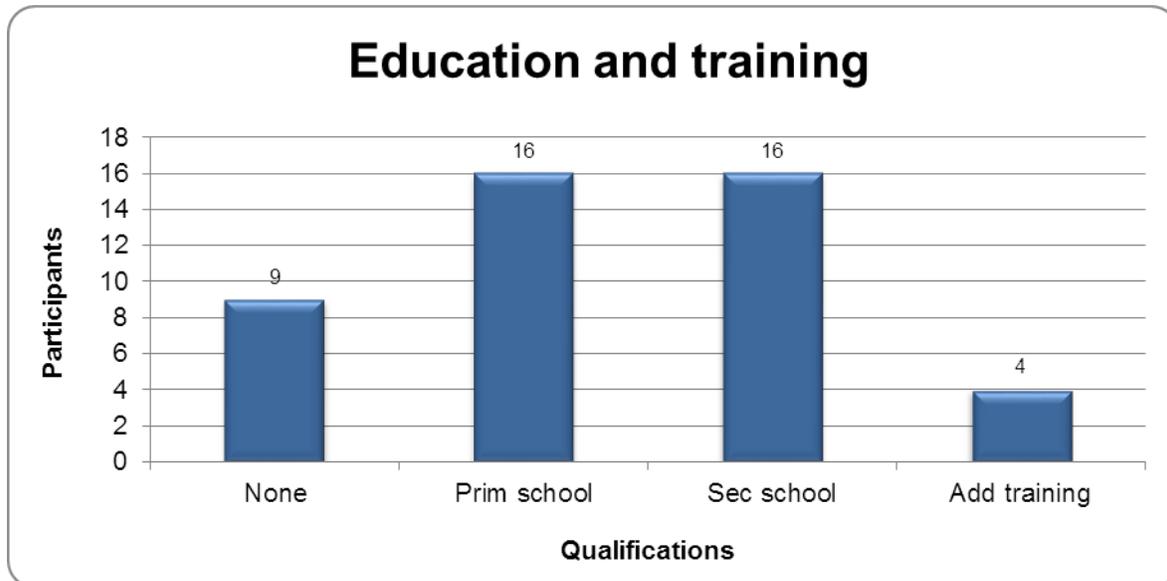
$n = 45$

FIGURE 7.4: Gender of participants

A study by Chen *et al.* (2009:474, 479) investigating the support needs of patients with oral cancer and its effect on family caregivers, found that male patients felt frustrated with their condition and did not speak out, which was in contrast with female patients who expressed themselves by crying and talking. Men are more unwilling to describe their symptoms and discomfort because of their personalities or self-esteem issues. Also, in 2006, Foley *et al.* (2006:248-258) conducted a study with cancer survivors who were diagnosed more than 15 years previously. Gender differences among long-term survivors were found as women were more likely to report personal growth, whilst men were more likely to minimise the impact of cancer on their lives. These findings had to be taken into account when describing the survivorship experience of laryngectomy patients, as it was mostly men who participated in the current study.

7.2.1.5 Education and training

Participants were asked about their level of education and training. Results from this question are graphically illustrated in Figure 7.5.



$n = 45$

FIGURE 7.5: Education and training of participants

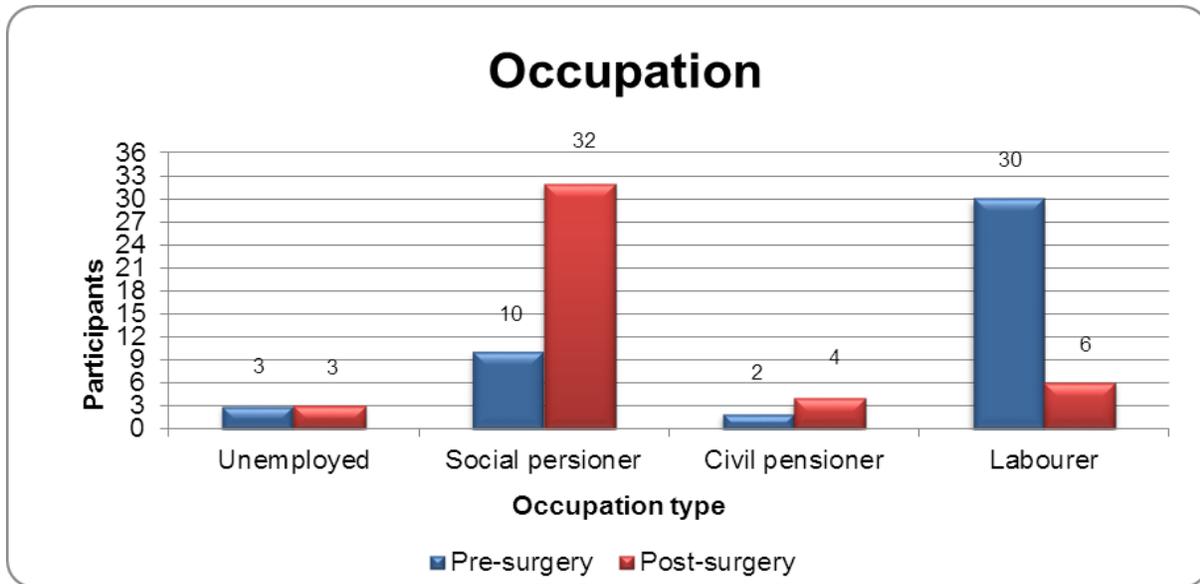
Legend: Prim school = primary school; sec school = secondary school; add training = additional training which implies that the participant also had secondary training

Nine (20%) participants had **no** scholastic training. Sixteen (35,6%) participants had **primary** school training. These included the following: two (2, or 4,4%) participants who had Grade 2 training; three (3, or 6,7%) Grade 3; two (2, or 4,4%) Grade 4; two (2, or 4,4%) Grade 5; three (3, or 6,7%) Grade 6 and four (4, or 8,9%) who passed Grade 7. Twenty (44,4%) participants had **secondary** school training, varying between seven (7, or 15,6%) participants who passed Grade 8; one (1, or 2,2%) who completed Grade 9; four (4, or 8,9%) from Grade 10 and eight (8, or 17,8%) who had Grade 12 training. Of the latter, four (8,9%) participants also had **additional training** after school (it implies that these participants also had secondary school training), such as a teaching qualification (college), diploma in business management, carpenter or a mechanical course at a technicon.

Findings of the study concur with the literature (Eadie & Doyle, 2005:120), stating that those who present with cancer of the head and neck region, mostly present with low levels of education, which was representative of more than half (25, or 55,6%) of the participants. Low educational levels of participants also need to be taken into account when analysing participants' responses concerning their experiences of surviving the laryngectomy.

7.2.1.6 Occupation (before and after surgery)

Previous and current occupations of participants were investigated in the fifth place. Figure 7.6 presents changes in participants' occupation after surgery.



$n = 45$

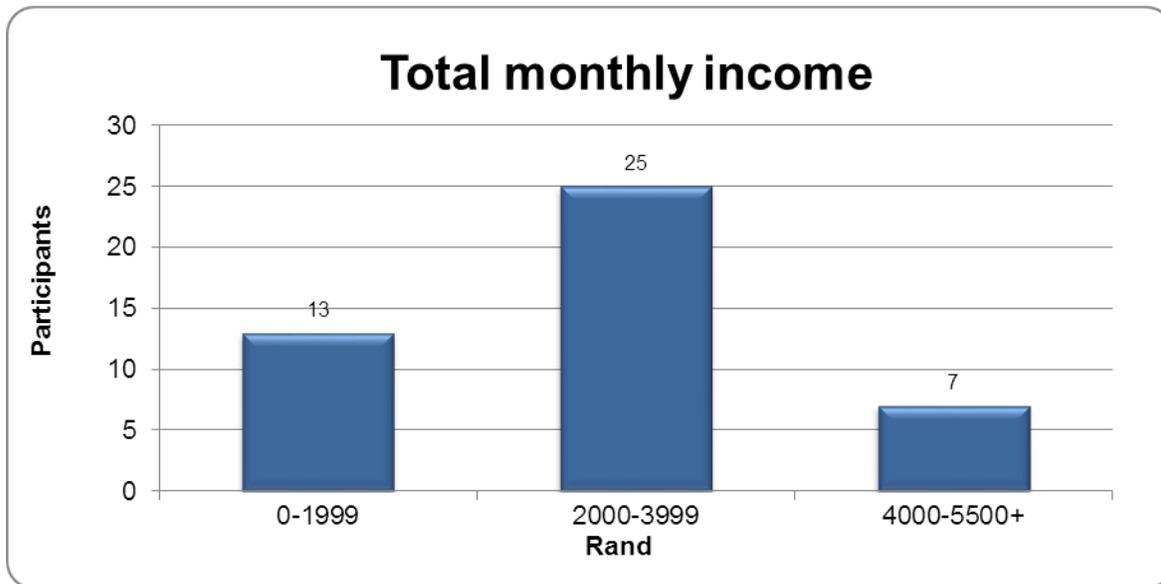
FIGURE 7.6: Pre- and post-operative occupation of participants

Legend: Pensioner includes both social and civil pensioners

Foster *et al.* (2009:244) referred to a few studies which reported on changes in income or other financial concerns experienced by survivors over time. In the case of those who presented with cancer of the head and neck region, it was found that they were less likely to return to work. As the majority of laryngectomees normally are elderly people (Ross, 2000:17), they, in many cases, already are pensioners at the time of surgery or shortly afterwards become pensioners, following their surgery. In this study, twelve (26,7%) participants were pensioners (both civil and social pensioners) before the operation. This increased to thirty-six (80%) participants following surgery. This finding implies that more than half (24, or 53,3%) of the participants became social pensioners (disability grant or old age pension) following their laryngectomy experience. According to Hara and Blum (2009:46) it can be said that a cancer diagnosis challenges one's role functioning, referring to possible change in employment and financial income after diagnosis and treatment.

7.2.1.7 Total monthly income

The total of participants' and their spouses' current monthly income was investigated, as presented in Figure 7.7.



$n = 45$

FIGURE 7.7: Total monthly income of participants

Low socio-economic status is one of the characteristics of patients who present with cancer of the head and neck region (Cady, 2002:347; Eadie & Doyle, 2005:120; Foster *et al.*, 2009:241; Vartanian *et al.*, 2006:32). This literature finding was in accordance with findings of the current study, as the majority of participants (25, or 55,6%) had a monthly income of between R 2 000 and R 3 999,00. Adding together those who were married and lived together (33, or 73,3%), it implies that this income was the total income for both the patient and spouse or life partner, which mostly consisted of a social pension for each of them.

At the hospital at which the study was conducted is a government institution, all social pensioners receive free medical treatment, including surgery, radiotherapy, speech therapy, social work services and voice prostheses. Patients who are not social pensioners are charged according to their total monthly income. Arrangements for

payment of medical bills can be made. No patient is excluded from medical treatment for financial reasons.

7.2.2 Profile of family

Fifteen family members representative of one-third of those patients (45) who participated, were selected to take part in family interviews. Families who accompanied their relative (patient) during medical appointments at the hospital as from the time that family interviews started (21 January to 5 June 2013), were included in the study. In the case of those who were married or had a life partner, the spouses or life partners were invited to participate. Nine (60%) spouses and one (6,7%) life partner participated in this study.

If the participant was not married or did not have a life partner, another family member identified by the participant himself as being of significance to the patient, was chosen. By interviewing the family member selected by the patient, the researcher ensured that the person most exposed to the laryngectomy experience was involved in the study and had the opportunity to share his or her experience of the patient's laryngectomy.

A friend (although they did not live together) and two children (daughters) of patients were included in the sample, which was representative of two widowed (13,3%) patients and one patient who was divorced (6,7%). One patient (6,7%) married four years after she had her laryngectomy (one year before the date of the interview) and therefore rather appointed her daughter to participate, as she was the one who mostly shared her mother's laryngectomy experience. In another instance a patient (6,7%) who lived with his life partner preferred his daughter to participate as she was the one he relied on and who was most involved in his laryngectomy experience.

7.3 MEDICAL ASPECTS OF A LARYNGECTOMY

Respondents' medical information related to diagnosis; date of diagnosis; type of treatment; date of laryngectomy; date of completion of treatment; frequency of follow-up visits at the hospital and current medical status was explored and is presented.

7.3.1 Diagnosis

All (45, or 100%) of the patients who participated underwent a total laryngectomy for treatment of an advanced diagnosis of cancer of either the glottis (19, or 42,2%); supraglottis (18, or 40%); hypopharynx (3, or 6,7%); transglottis (2, or 4,4%); subglottis (2, or 4,4%) and epiglottis (1, or 2,2%) as this was set as criteria for inclusion in the study.

7.3.2 Date of diagnosis

Time elapsed from **diagnosis until surgery** is discussed in the section "date of laryngectomy". As indicated in the sample selection, the minimum period of time that was allowed to elapse after completion of the patient's initial medical treatment (surgery and radiotherapy, if indicated) was three months. At this stage, survivors have had enough time to adjust to their cancer experience without getting too used to the changed situation (Graham, 2004:130). Johnson *et al.* (1979:1814) confirmed that the typical period of adjustment to the laryngectomy experience will vary between three months and two years. For inclusion in the sample, no time limit was set regarding the maximum period that could have elapsed after surgery because the **survivor's journey** starts with the diagnosis, as can be viewed in Annexure A (Miller *et al.*, 2008:369). As early as 1972 Sanchez-Salazar and Stark (1972:323) already maintained that adjustment to the laryngectomy experience starts at the time of diagnosis.

7.3.3 Type of treatment

All (45, or 100%) of the participants underwent a total laryngectomy as treatment after a diagnosis of advanced cancer of the larynx, as this was set as primary condition for

inclusion in the study. Five (11,1%) participants only underwent a total laryngectomy as primary treatment for their diagnosis of larynx cancer. Thirty-three (73,3%) participants also received post-operative radiotherapy treatment as part of their treatment regime. Twenty-three (51,1%) participants underwent additional surgery, which included block or neck dissections or, in one (2,2%) instance, a stomach pull-up. In three (6,7%) instances, participants also had previous laser treatment.

7.3.4 Date of laryngectomy

The average period of time from the **date of diagnosis** to the **date of surgery** (laryngectomy) was four months, varying from one day (minimum) to twenty-three months (maximum). Taking into account the **date of surgery** and the **date of the interview**, the intervening time following surgery until the interviews were conducted varied from between eight months to nineteen years, with an average of four years and nine months. Because participants presented a wide spectrum of post-operative time periods, the results of the study are expected to provide a true reflection of their survivorship experience.

Findings of the study agree with the opinion held by Chen *et al.* (2009:479), namely that the interval between diagnosis and making treatment decisions and receiving surgery normally is relatively short. Having to wait may challenge the laryngectomy patient and family's ability to cope with the increased stress levels under these circumstances, as the patients' **survivorship journey** starts from the date of diagnosis. On the other hand, the operation following a long period of uncertainty will bring a sense of completion for the patient (DeSanto, 1994:52).

7.3.5 Date of completion of total treatment period

The time period that elapsed between the date of **completion of treatment** and the **date of interviewing** participants, varied from three months to nineteen years, with an average period of four years and seven months. De Boer *et al.* (1995:503) reported that the longer the time that elapses after treatment, the fewer the psychosocial problems

experienced by those who presented with cancer of the head and neck area. The average time of adjustment to the laryngectomy experience was described (by Johnson *et al.*, 1979:1814) as three months to two years.

7.3.6 Frequency of follow-up visits to the hospital

As cancer survivors now live longer, Pollack *et al.* (2005:53) held the opinion that, besides monitoring for recurrence of disease, other reasons for follow-up visits should include monitoring the risk for future morbidity, new malignancies, cancer risk among family members and monitoring persistent or delayed effects of the disease. At the hospital at which the study was conducted, follow-up visits by patients vary according to the patients' medical condition and their need for supervision. Follow-up visits to the clinic form part of the patient's prescribed medical treatment plan, as illustrated in Annexure A.

The periods between of these visits varied, with patients being followed up two-monthly (7, or 15,6%); three-monthly (6, or 13,3%); four-monthly (7, or 15,6%); six-monthly (13, or 28,9%) or yearly (12, or 26,7%). Just more than half (25, or 55,6%) of the participants' follow-up visits were scheduled on a six-monthly to a yearly basis. Follow-up visits also allow patients to maintain contact with the support groups at the clinic that are available at the hospital.

Poor compliance by those survivors who present with cancer diagnoses of the head and neck region can be experienced. This may be due to significant alcohol and tobacco use commonly associated with a diagnosis of laryngeal cancer (Cady, 2002:347).

7.3.7 Current medical status

The majority (43, or 95,6%) of survivors presented absence of cancer. Although cancer was absent at the time they participated in the interview, "life goes on but will never be the same again" (DeSanto, 1994:53). For the **survivor**, there is a "new normal" (Haylock *et al.*, 2007:62). One (2,2%) participant presented with recurrence of the

disease for which he received chemotherapy and another (2,2%) participant was diagnosed with a new primary disease of the tongue.

The results of the investigation into patients' and families' experiences of the laryngectomy experience are described next, bearing participants' identifying and medical details in mind, according to themes, sub-themes and categories as mostly used in qualitative research (Table 7.1). Numbers in brackets correspond to the numbers of questions from the semi-structured questionnaire. Verbatim responses of participants are quoted to highlight participants' viewpoints.

TABLE 7.1: Summary of themes 1 and 2

THEMES	SUB-THEMES	CATEGORIES
1 Experiencing a need for pre-operative information in survivorship experience <ul style="list-style-type: none"> • <i>Explanation of information (3.1)</i> • <i>Emotional reaction to information received (3.2)</i> ACUTE PHASE OF SURVIVORSHIP	1.1 Experience of information needed in general (3.1.1)	<ul style="list-style-type: none"> • Diagnosis and survival • Nature and extent of surgery • Length of treatment and side effects • Effect on daily lifestyle • No information needed
	1.2 Benefits of team member's explanation of operation (3.1.2)	<ul style="list-style-type: none"> • Fully prepared • Partially prepared • Not at all prepared
	1.3 Emotional reactions of patients and families to information received (3.2.1 & 3.2.2)	<ul style="list-style-type: none"> • Sadness • Shock • Acceptance • Nothing or not sure
2 Experience of physical adjustment <ul style="list-style-type: none"> • <i>Physical changes (4.1)</i> • <i>Emotions regarding physical changes (4.2)</i> TRANSITIONAL PHASE OF SURVIVORSHIP	2.1 Permanent physical changes most difficult to deal with (4.1)	<ul style="list-style-type: none"> • Stoma • Physical appearance • Speech • Senses • Eating and drinking
	2.2 Emotions regarding permanent physical changes (4.2)	<ul style="list-style-type: none"> • Sadness • Acceptance • Unable to describe

7.4 MEDICAL DIAGNOSIS AND TREATMENT

The role of information in pre-operative preparation of patients and families when a laryngectomy is indicated will first be highlighted in this section of the chapter. This is followed by an exploration and discussion of their emotional reaction to information received regarding the diagnosis of cancer. This information informs the first theme to be discussed. Patients' medical diagnosis and treatment represent the **acute phase** of the **survivorship journey**, as discussed in Chapter 2.

7.4.1 Theme 1: Patients' and families' need for pre-operative information in survivorship experience

As discussed in Chapter 3, information plays a vital role in patients' pre-operative counselling. The need for information as well as their experience of information offered to them prior to the operation will now be presented from a patient's and family member's perspective, and discussed and analysed according to the relevant sub-themes and categories presented in Table 7.1. Participants' responses will be related to literature guidelines regarding the main categories of pre-operative information that patients and their families would need, as identified by Kleinsasser (1998:256-257).

7.4.1.1 Theme 1: Sub-theme 1.1: Experiencing a need for information in general

With this question, which was posed to both patients and family members, no guidance was given to participants in terms of possible responses, as this was a qualitative open-ended question. Except for one (2,2%) participant (**patient**) who could not remember as his operation was performed eleven years earlier, all other (44, or 97,8%) patients and **family members** indicated their need for pre-operative information in general. Their needs varied from wanting to find out more regarding their diagnosis and chances of survival; the nature and extent of the operation; duration of treatment and expected side effects; and effects on their daily lifestyle, to those who indicated that they had no need for pre-operative information.

Table 7.2 compares the differences in the responses of patients and family members. Each of these categories is discussed and highlighted with verbatim responses from participants.

TABLE 7.2: Comparison between patients' and families' experiences of their pre-operative need for information

Theme 1: Patients' and families' need for pre-operative information in survivorship experience		
Sub-theme 1.1: Experiencing a need for information in general		
Category	Patients (n = 45)*	Family members (n = 15)*
Diagnosis and survival	8 (17,8%)	7 (46,7%)
Nature and extent of surgery	21 (46,7%)	10 (66,7%)
Duration of treatment and side effects	20 (44,4%)	9 (60,0%)
Effect on daily lifestyle	18 (40,0%)	3 (20,0%)

**(Some participants indicated more than one opinion, therefore the total may exceed 100%)*

(a) Category: Diagnosis and survival

The first need identified by Kleinsasser (1998:256-257) refers to participants' need to be informed about their **diagnosis**, as it is not uncommon for these patients to experience feelings like shock and anxiety regarding their **survival**. From a **survivorship perspective** and in accordance with the NCR definition (Miller *et al.*, 2008:369), diagnosis can be seen as the starting point in patients' survivorship journey (Annexure A).

The following table (Table 7.3) contains the narratives related to "diagnosis and survival" of participants.

TABLE 7.3: Need for information: diagnosis and survival

Theme 1: Patients' and families' need for pre-operative information in survivorship experience	
Sub-theme 1.1: Experiencing a need for information in general	
Category	Narratives of participants
Diagnosis	<p>PATIENTS</p> <ul style="list-style-type: none"> • <i>"I just <u>wanted to know for sure</u> whether I really had cancer."/ "Ek wou net verseker weet is dit regtig kanker wat ek het."</i> • <i>"My mind already told me, <u>as I had smoked</u> ... it can only be cancer."/ "My gedagte het my klaar gesê, want ek het gerook ... dit sal net kanker wees."</i> <p>FAMILY MEMBERS</p> <ul style="list-style-type: none"> • <i>"We did not have to deal with cancer in the past, we were <u>very ignorant</u> ... you think it only happens to other people ... when you are in the same boat then it is not that far any more."/ "Ons het baie min te doen gehad met kanker, ek was baie oningelig. Jy dink altyd dit gebeur net met ander mense ... as jy in dieselfde bootjie is dan is dit nie meer so ver nie."</i>
Survival	<p>PATIENTS</p> <ul style="list-style-type: none"> • <i>"I wanted to know <u>whether</u> and how I would be <u>cured</u>."/ "Ek wil geweet het of ek hoe ek gaan gesond raak."</i> <p>FAMILY MEMBERS</p> <ul style="list-style-type: none"> • <i>"The first question is, what is her <u>chance of survival</u> ... of <u>recovering</u>, of being <u>cured</u>?" / "Die eerste vraag is, wat is haar kans op oorlewing ... die kans op herstel, op genesing ..."</i>

In this study, eight **patients** (17,8%) required further information regarding their diagnosis, including information regarding causes as well as confirmation of the diagnosis (*"I just wanted to know for sure whether I really had cancer"*), as reflected in Table 7.2. Surprisingly, some participants related their diagnosis of larynx cancer to their previous social smoking habit (*"... as I had smoked ... it could only be cancer"*). This is in accordance with literature, which lists alcohol and tobacco use as etiological factors commonly associated with a diagnosis of larynx cancer (Cady, 2002:347). On a **prognostic** level, participants also wanted to know whether they could be cured (*"I wanted to know whether and how I would be cured"*). It was Deimling *et al.* (2006:307) who referred to diagnosis as a phase during which patients and families experience fear about the treatability of the disease, as well as their prognosis for survival.

Seven **family members** (46,7%) also required further information within this category. They experienced a lack of information as they had not been exposed to such a

diagnosis in the past (“We did not have to deal with cancer in the past, we were very ignorant”). With regard to the survival of the patient, they also wondered about the success rate of the operation (“What is her chance of survival ... of recovering, of being cured?”).

(b) *Category: Nature and extent of surgery*

Narratives of participants related to “reasons for surgery; nature and extent of surgery” are reflected in Table 7.4:

TABLE 7.4: Need for information: reasons for surgery; nature and extent of surgery

Theme 1: Patients’ and families’ need for pre-operative information in survivorship experience	
Sub-theme 1.1: Experiencing a need for information in general	
Category	Narratives of participants
Reasons for surgery	<p>PATIENTS</p> <ul style="list-style-type: none"> “I wanted to know <u>why</u> they had to do the operation. Then they said because <u>I have cancer</u>.” / Ek wou geweet het die operasie, hoekom moet hulle die operasie doen toe sê hul ek het kanker.” <p>FAMILY MEMBERS</p> <ul style="list-style-type: none"> “I just wanted to know what <u>the reason</u> for the operation was.” / “Ek wil net geweet het wat is die rede op wat hulle gaan.”
Nature and extent of surgery	<p>PATIENTS</p> <ul style="list-style-type: none"> “I wanted to know <u>whether</u> there could be <u>another way</u> and whether it is really necessary to make a <u>stoma</u> in my throat.” / “Ek wou geweet het of daar nie ‘n ander manier is nie is dit nou nodig om so ‘n ‘damage’ te maak, ‘n gat te maak in my keel.” “I wanted to know <u>what it would look like</u> after I had the operation.” / “Ek wou toe weet hoe gaan dit nou lyk as ek die operasie gehad het.” “I wanted to know whether the <u>stoma</u> would be there <u>permanently</u>.” / “Ek wou geweet het of die gaatjie permanent daar gaan wees.” <p>FAMILIES</p> <ul style="list-style-type: none"> “I just wanted to know <u>how</u> they would do the operation.” / “Ek wil net geweet het hoe gaan hulle die operasie nou doen.”

Twenty-one (46,7%) patients and ten families (66,7%) indicated that they would have liked to have more information with regard to the nature and extent of surgery, which is in line with the second category identified by Kleinsasser (1998:256-257), namely their need to know more about the **nature** and **extent** of planned surgery, as reflected in Table 7.4. Some patients and families also questioned the need for the operation (“*I wanted to know why they have to do the operation*”; “*what the reason for the operation was*”).

Patients wondered about the availability of less invasive surgery and whether any alternative treatment options were available (“*I wanted to know whether there could be another way*”). In addition, patients wondered about their post-operative physical appearance (“*I wanted to know what it would look like*) with specific reference to the tracheostoma. They questioned the need for the stoma (“*...whether it was really necessary to make a stoma in my throat*”) and its permanence (“*whether the stoma would be there permanently*”). A family member also wanted to know how the operation would be done (“*how they would do the operation*”). This echoes research conducted by De Boer *et al.* (1995:507-508) regarding the rehabilitation outcome of long-term survivors treated for head and neck cancer, stating that the presence of the stoma constitutes the greater part of “damage” to laryngectomy patients’ physical appearance.

(c) Category: Duration of treatment and side effects

Participants’ responses regarding “duration of treatment and side effects of treatment” are illustrated in Table 7.5:

TABLE 7.5: Need for information: length of treatment and side effects

Theme 1: Patients' and families' need for pre-operative information in survivorship experience	
Sub-theme 1.1: Experiencing a need for information in general	
Category	Narratives of participants
Duration of treatment	<p>PATIENTS</p> <ul style="list-style-type: none"> • <i>"I just wanted to know <u>how long the operation would take</u>, <u>how long I would have to stay in hospital.</u>" / "Ek wil net geweet het hoe lank die operasie sal aanhou, hoe lank sal ek daar moet wees in die hospitaal."</i> <p>FAMILY MEMBERS</p> <ul style="list-style-type: none"> • <i>"I wanted to know <u>how long it would take ... how long he would stay in hospital.</u>" / "Ek wil geweet het hoe lank gaan dit neem ... hoe lank gaan hy in die hospitaal wees."</i>
Side effects of treatment	<p>PATIENTS</p> <ul style="list-style-type: none"> • <i>"I asked them <u>how they were going to teach me to talk</u>, <u>how they would manage to teach me to talk again.</u>" / "Ek vra toe maar hoe kan hulle my weer leer praat, hoe gaan hulle dit regkry om my weer te leer praat."</i> • <i>"I wanted to know whether I would <u>get my vocal chords</u> and my <u>voice back</u> and if it would be <u>possible for me to talk as I talked before.</u>" / Ek wou geweet het of ek my stembande en of ek my stem gaan terugkry of ek weer sal kan praat soos ek gepraat het."</i> <p>FAMILY MEMBERS</p> <ul style="list-style-type: none"> • <i>"The information I wanted to have was how the <u>whole process would work.</u>" / "Die inligting wat ek wou gehad het dat hulle vir my moes gee is hoe die hele proses gaan werk."</i> • <i>"I wanted to know what <u>the effect would be</u> and how long they would make <u>the cut.</u>" / "Ek wou geweet het wat gaan die gevolge daarna wees en hoe groot gaan hulle sny."</i>

In this study, a minority (1, or 2,2%) of participants were pre-operatively concerned about the length of treatment ("*...how long I would have to stay in hospital?*"). The side effect concerning which they mostly wanted information was the effect of the operation on their post-operative speech ability ("*...how I would manage to talk again?*"), as indicated by nineteen (42,2%) participants. This represents the third category or area concerning which patients wanted to gain more information (Kleinsasser, 1998:256-257), namely information regarding the **duration of treatment** and expected **side effects** following surgery (Table 7.5). Nine (60%) family members also indicated that they would have liked to receive more information in this regard.

A cancer diagnosis of the head and neck region may affect some of the most basic and vital functions of life, including the limitation on speech and communication (De Boer *et al.*, 1995:511). The effect of surgery on the ability to speak that necessitates the process of alaryngeal voice (voice production without vocal cords) (“*whether I would get my vocal chords and my voice back”); the process of learning post-operative speech (“...how they were going to teach me to talk”) and whether they would be able to master this altered speech method (“*would be possible for me to talk like I talked before*”) were their main areas of concern. Casper and Colton (1998:49) mentioned that in learning speech, elderly persons are reminded of their childhood. Taking into account that it was mostly elderly patients who participated in the study, the process of learning speech might have increased their levels of frustration during the **survivorship experience**. With regard to the side effects of treatment, **family members** were concerned about how the operation would be performed (“*how the whole process would work”*) and about the effect of the operation in general (“*what the effect would be*”).*

(d) Category: Effect on daily lifestyle

Participants’ responses with regard to the category “effect on daily lifestyle”, are presented in Table 7.6:

TABLE 7.6: Need for information: daily lifestyle and post-operative adaptation

Theme 1: Patients' and families' need for pre-operative information in survivorship experience	
Sub-theme 1.1: Experiencing a need for information in general	
Category	Narratives of participants
Effect on daily lifestyle	<p>PATIENTS</p> <ul style="list-style-type: none"> • <i>"I wanted to know how you would be able to <u>swallow and drink</u> ... it seemed to me they would cut your throat" / "Ek wil toe nou weet hoe sal 'n mens nou sluk daar en die drink ... lyk dan jou keel word afgesny."</i> • <i>"I just wanted to know whether I may and can <u>work again</u>." / "Ek wil net geweet het of ek kan en mag werk."</i> • <i>"I will be <u>cut off from the things I loved to do</u>" / "Ek gaan nou afgesny word van dinge waarvoor ek lief was."</i> <p>FAMILY MEMBERS</p> <ul style="list-style-type: none"> • <i>"How to <u>take care of him</u> ... you have to <u>accompany</u> him and <u>talk</u> on his behalf ... he <u>cannot shout</u> ... he <u>cannot answer you immediately</u> ... he <u>cannot bend his head to see what is lying beneath him</u>." / "Hoe hanteer jy hom ... jy moet saamgaan want jy moet vir hom praat ... hy kan nie skree nie ... hy kan jou nie dadelik antwoord nie ... hy kan nie sy kop afbuig om te sien wat is direk onder sy voete nie."</i> • <i>"The <u>after-effects</u>, will my mother be <u>able to talk</u> again, will she still be able to <u>do the things</u> she did before?" / "Die 'after-effects', gaan my ma weer kan praat, gaan sy weer die dinge kan doen wat sy gedoen het?"</i>
Post-operative adaptation	<p>PATIENTS</p> <ul style="list-style-type: none"> • <i>"How will I be able to adapt because there will be a lot of <u>changes in my life</u>." / "Hoe sal ek my moet aanpas vorentoe want daar gaan mos nou 'n klomp veranderings plaasvind in my lewe."</i> • <i>"I wanted to know whether I would be <u>like usual</u>, whether I would be able to <u>continue like normal</u>." / "Ek wil geweet het of ek nog soos ek gewoonweg gaan wees, of ek so kan wees soos normaalweg."</i> • <i>"I did not know how the <u>people would accept me</u>." / "Ek het nie geweet hoe die mense my gaan aanvaar nie."</i> <p>FAMILY MEMBERS</p> <ul style="list-style-type: none"> • <i>"I wanted to know how I had to <u>handle him</u> and whether I had to react differently to him now, compared to before. Also, about my <u>own adaptation</u>." / "Ek wou geweet het hoe moet ek hom hanteer en of ek enigsins anders teenoor hom moet optree as voor die operasie en die aanpassing vir myself ..."</i>

Kleinsasser's (1998:256-257) fourth category of needs referred to information regarding the effects of surgery on **daily living**. In this study, eighteen (40%) patients indicated that they wanted to know more about their post-operative adaptation (Table 7.6). This refers to their ability to adapt to changes caused by the operation. This correlates with

the opinion of Vartanian *et al.* (2006:32), stating that head and neck cancer treatment impacts on the patient's vital functioning such as chewing, swallowing and communication. The minority of **family members** indicated their concern in this regard (3, or 20%).

With regards to the effect of the operation **on their daily living**, they referred to the effect on their eating; drinking; swallowing (“...will you be able to swallow and drink”). Other areas on which they wanted more information included the effect of the operation on their ability to work again (“whether I may and can work again”), to continue with the pleasurable things like singing, joking, recreational activities (“I would be cut off from the things I loved to do”). The concerns of **family members** were more about the limitations on the patient's daily functioning (“...he cannot shout ... he cannot answer you immediately ... he cannot bend his head...”), including post-operative ability (“...will my mother be able to talk again...”) and whether she would be able to do the things she previously did (“...will she still be able to do the things she did before?”). They were also concerned about how to take care of the patient (“How to take care of him ...”).

Regarding **post-operative adaptation**, they realised that a lot of changes would follow (“...there will be a lot of changes in my life”) and they therefore mainly referred to how they would be able to continue with life afterwards and whether life would be normal again for them (“...whether I will be able to continue like normal”). From a survivorship perspective, their concern concurs with literature (Haylock *et al.*, 2007:62) stating that “the old normal life never resumes, rather, a new normal evolves”. On a social level, they wondered about being accepted by others and how to deal with their reaction (“I did not know how the people would accept me”). **Families** were concerned about how to take care of the patient (“how I have to handle him”) and also about their own adaptation (“I wanted to know ... about my own adaptation”).

(e) *Category: No information needed*

In contrast to the literature (Zeine & Larson, 1999:52), which stressed the importance of pre-operative information for patients, eight (17,8%) patients felt that they did not need

information. Ironically, level of education appeared not to play a role in their responses as half of these participants (4, or 50%) had secondary scholastic training, while three (37,5%) had primary training and one (12,5%) had no scholastic training. However, all participants who indicated that they did not have a need for information prior to their surgery had their operation between one year and eleven months and ten years previously, with an average period of four years and eleven months elapsing before the survey. Seven (87,5%) of these participants, in addition, were male and one (12,5%) was a female participant. As pointed out by Salva and Kallail (1989:299-301), differences in the need for information may occur between male and female patients; they, for instance, found that male laryngectomees reported strong support provided by their female spouses and they were therefore less willing to go outside the home to find additional support.

TABLE 7.7: No information needed

Theme 1: Patients' and families' need for pre-operative information in survivorship experience	
Sub-theme 1.1: Experiencing a need for information in general	
Category	Narratives of participants
No information needed	<ul style="list-style-type: none"> • <i>"I only knew I <u>could not swallow</u> and I had to go for the operation."</i> / "Ek het net geweet ek kan nie sluk nie en ek moet vir die operasie gaan." • <i>"I <u>just wanted them to do the operation and get it over.</u>"</i> / "Ek wou net gehad het hul moet dit doen en klaarkry." • <i>"I <u>left everything in their hands.</u>"</i> / "Ek het maar net in hulle hande gelos." • <i>"I said to <u>the Lord</u> I put my life in His hand, I did not ask questions."</i> / "Ek het net vir die Here gesê my lewe is in U hand, ek het maar niks vrae gevra nie." • <i>"I had too much information, I <u>know people</u> who had such operations."</i> / "Ek het al te veel inligting, ek ken mense wat sulke operasies gehad het." • <i>"Maybe if they give you all the information, then you would <u>not let them do the operation.</u>"</i> / "Miskien as hul al die inligting nou gegee het sal jy miskien nou nie die operasie sou wil laat doen het nie." • <i>"I went to the library to do my <u>own research.</u>"</i> / "Ek het gegaan na die biblioteek toe en op my eie navorsing gedoen."

To be cured and relieved from symptoms such as pain and difficulty with swallowing were the participants' main concern (*"I only knew I could not swallow and I had to go for the operation"; "I just wanted them to do the operation and get it over"*). They therefore trusted

the doctor's opinion ("*I left everything in their hands*") and put their trust in die Lord ("*I put my life in His hands, I did not ask questions*"). One participant mentioned that he felt that he had adequate information as he already knew someone else who had a similar operation ("*I know people who had such an operation*"). A participant cautioned that too much information can also be dangerous as one may not agree to the operation if you know everything beforehand ("*then you would not let them do the operation*"). Another participant highlighted his own responsibility in gaining more information himself ("*I went to the library to do my own research*").

(f) Summary

When comparing the results of patients with those of family members, it was significant that both patients and families rated their need for pre-operative information regarding the nature and extent of surgery and the length of treatment and expected side-effects as being of high priority. However, they differed with regard to the following two categories. For **patients**, it was of greater relevance to know more about how the operation would affect their daily lifestyle, whilst **family members**, prior to the operation, wanted to know more about the diagnosis and survival of the patient.

Surprisingly, only three (20%) **family members** indicated prior to the operation that they wanted to know more about how to take care of the patient ("*I wanted to know how I have to handle him*"), taking into account that patients' survivorship is increasing, with the result that family members have to take care of patients for longer periods of time, which could put pressure on them (Golant & Haskins, 2008:420). These concerns were expressed by family members of patients whose operation had been performed between twenty-three (1 year 11 months) and forty-seven (3 years 11 months) months earlier. It could therefore be that family members might have forgotten what their general need for support was at that stage.

7.4.1.2 Theme 1: Sub-theme 1.2: Experience of team members' explanation of operation

When participants were asked about their experience of the degree to which team members' explanations had helped them prior to their surgery, opinions varied, as reflected in Table 7.8:

TABLE 7.8: Experience of team members' pre-operative explanations

Theme 1: Patients' and families' need for pre-operative information in survivorship experience		
Sub-theme 1.2: Experience of team members' explanation of operation		
Fully informed	Partially informed	Not informed at all
27 (60,0%)	16 (35,6%)	2 (4,4%)

n = 45

(a) Category: Fully prepared

In contrast with the literature (Cady, 2002:347), which suggests that no amount of pre-operative counselling could fully prepare patients or their families for the effects of such an operation, most (27, or 60%) participants reported that team members' explanations of the operation fully prepared them for the process. Patients found that they were holistically prepared through information at a pre-operative stage, including their **physical**, **emotional** and **social** preparation.

Table 7.9 contains the narratives of participants to illustrate the category "fully prepared":

TABLE 7.9: Experience of team members' explanation: fully prepared

Theme 1 : Patients' and families' need for pre-operative information in survivorship experience	
Sub-theme 1.2: Experience of team members' explanation of operation	
Category	Narratives of participants
Fully prepared <ul style="list-style-type: none"> • Physical • Emotional • Social 	<p>Physical level</p> <ul style="list-style-type: none"> • <i>"The operation is very important, it is for my <u>own health</u>."</i> / "Die operasie is baie belangrik, dis vir my eie gesondheid." • <i>"The doctor told me the operation I was about to have would be a <u>major operation</u>."</i> / "Die dokter het vir my gesê die operasie wat ek gaan hê is 'n groot operasie." • <i>"They did say that they want to remove my <u>vocal cords</u> and that they will insert the <u>speech valve</u>."</i> / "Hul het gesê hul gaan my stembande verwyder en dat hul ook die spraakbuisie gaan insit." • <i>"He told me there will be a <u>stoma</u>."</i> / "Hy het my gesê daar sal 'n gaatjie wees." • <i>"I knew I <u>could not swallow</u>, I have to get the operation."</i> / "Ek het geweet ek kan niks sluk nie, ek moet die operasie kry." • <i>"They said if I am not going to accept the operation then I will <u>probably die</u>."</i> / "Hul het gesê as ek nie die operasie gaan vat nie dan kan ek moontlik sterf." • <i>"They prepared me for everything ... how to the <u>clean the trachi</u> which they replaced with the <u>speech valve</u>."</i> / "Hulle het my op alles voorberei ... hoe om die trachi skoon te maak wat hulle vervang met die spraak kleppie." • <i>"It is not that I will not be able to <u>talk again</u>. It will be a <u>process</u>; it will <u>take time</u>."</i> / "Dis glad nie dat ek nie weer kan praat nie. Dit gaan 'n proses vat, dit gaan 'n tyd neem om te kan praat." <p>Emotional level</p> <ul style="list-style-type: none"> • <i>"He said it will be a <u>big adaptation</u>, but one does <u>not</u> have <u>much of a choice</u>."</i> / "Hy het vir my gesê dit gaan 'n groot aanpassing wees, maar ek meen die keuses is nie baie nie." • <i>"The nurse told me: The path we are travelling will be a long road <u>we have to walk together</u>."</i> / "Die verpleegster het vir my gesê: die pad wat ons nou in is, dit is 'n pad wat ek en jy lank moet saamloop." <p>Social level</p> <ul style="list-style-type: none"> • <i>"He asked <u>my wife</u> to come and <u>explained to us both</u> why he had to do the operation."</i> / "Hy het my vrou laat kom en vir ons verduidelik hoekom hy die operasie moet doen." • <i>"They showed me <u>other patients</u> who already had the operation."</i> / "Hulle het ook vir my gewys die pasiënte wat dit het."

On a **physical level**, patients firstly were informed of the reason for the operation (“So the operation is very important, it is for my own health”) and the extent of the planned surgery (“The doctor told me it will be a major operation”). The surgical procedure was explained and this prepared them for the magnitude of the operation. The effects of the operation were also discussed, namely that the vocal cords would be removed (“They did say that they wanted to remove my vocal cords and that they would insert the speech valve”), resulting in a permanent stoma (“He told me there will be a stoma”). Some benefits of the operation were also referred to at that stage, namely relief from symptoms which they were experiencing, like swallowing (“I knew I could not swallow, I had to get the operation”). On the other hand, participants were warned of the possible danger of not accepting the operation (“They said if I am not going to accept the operation then I will probably die”). Even at that early stage, participants were prepared for their aftercare (“They prepared me for everything ... they taught me how to clean the speech valve”). They were assured of learning post-operative speech (“It is not that I will not be able to talk again”).

On an **emotional level**, participants reported that the team attempted to develop their insight towards deciding whether or not to accept the operation (“One does not have much of a choice”), since the aim of treatment was to cure the patient. Patients were assured that, although major adaptations would follow (“He said it would be a big adaptation”) the team would support them (“...we have to walk together”) and this assurance calmed their initial fear.

On a **social level**, one participant found it beneficial that the **family** was included in pre-operative discussions (“He asked my wife to come and explained to us both”) whilst another participant referred to the benefit of being in contact with another patient who had a similar operation (“They showed me other patients who already had the operation”).

Participants emphasised that, together with the contents of the explanation, they also found the way in which information was conveyed as helpful in preparing them for

surgery. They felt that all their questions were answered (*"I could ask them anything and they answered me"*); team members were not hesitant about answering questions, and full explanations were provided (*"They explained to me fully"*). Another aspect which was important to them was that the various steps in this process (*"They informed me about the correct steps"*) were repeatedly and continuously explained (*"The doctor did not only explain to me once, I think it was two or three times"*), and that these steps were adhered to, so they were always aware of what the doctors planned to do (*"What the operation was about and how it would be after the operation"*). In the end, they realised that they did not have much of a choice, for, although the effect of the operation was permanent, it had saved their lives, for which they were thankful (*"After they informed me what they were going to do, I felt calm"*).

Important to bear in mind is the relatively short interval between the date of diagnosis and the date of surgery. The interval for these participants who indicated that they were fully informed about the operation, was between one day and eighteen months after being diagnosed, with an average period of three months, with nine (33,3%) patients who were operated less than a month following the diagnosis and thirteen (48%) patients who were operated one to three months after their diagnosis. The majority of these participants therefore had the operation shortly after being diagnosed with cancer. According to the literature (Ross, 2000:14), one may not be able to assimilate a great deal of information prior to surgery. Johnson *et al.* (1979:1818) also warned that information given a single session under crisis may not be retained.

Findings of this study also contrast with a previous study performed by Johnson *et al.* (1979:1814), which indicated that nearly all laryngectomy patients acknowledged their need for additional pre-operative information. Because of the comprehensive effect on their physical, social and emotional functioning, one would have expected high levels of stress and therefore a heightened need for information. A possible explanation could be the that they could not recall what their need for pre-operative information was, taking into account that the period from the operation to the time of the interview varied between eight months and eleven years with an average of four years and five months.

(b) Category: Partially prepared

Sixteen (35,6%) participants reported that team members' explanations partially prepared them for what to expect. In the case of these participants, the period from the date of diagnosis to the date of surgery varied between six days and 23 months, with an average period of seven months. In addition, the interval between the date of surgery and the date of the interview varied between eight months and 19 years; an average of five years and nine months. The three areas in which participants indicated that they would have liked to have more information prior to the operation, concerned the presence of the **permanent tracheostoma**; the effect of the operation on their **speech**; **and** the effect of the operation on **daily living**.

Responses of participants are illustrated by the verbatim responses reflected in Table 7.10:

TABLE 7.10: Experience of team members' explanation: partially prepared

Theme 1: Patients' and families' need for pre-operative information in survivorship experience	
Sub-theme 1.2: Experience of team members' explanation of operation	
Category	Narratives of participants
Partially prepared <ul style="list-style-type: none"> • Stoma/speech • Symptoms • Daily living 	<p>Stoma / speech</p> <ul style="list-style-type: none"> • <i>"I did not know what I would <u>look like after the operation</u> and <u>how serious it was</u>, the <u>effects</u> of the operation."/ "Ek het nie geweet hoe gaan ek lyk na die operasie nie of hoe ernstig dit was nie, die nagevolge van die operasie."</i> • <i>"I was <u>not aware</u> that I would have a <u>stoma</u> ... after the operation I wanted to say something and then I <u>could not talk</u> ..."/ "Ek was nie bewus ek sal 'n gaatjie hê nie ... maar toe ek nou klaar operasie is toe wil ek iets sê en ek kan nie praat nie ..."</i> • <i>"I did not realise that I would not be able to <u>breathe</u> through my nose and mouth."/ "Ek het nie besef ek sal nie asem kan haal deur my neus en deur my mond nie."</i> • <i>"I do not know whether there will be a <u>chance</u> that they <u>can close the stoma</u>."/ "Ek weet nou nie of daar 'n kans is of hul weer die plek weer kan toemaak nie."</i> <p>Other physical symptoms</p> <ul style="list-style-type: none"> • <i>"They did not explain to me ... that I <u>could eat</u> although I <u>had the pipe</u>."/ "Hy het nie 'explain' vir my nie ... ek kan eet ook saam met die 'pipe'."</i> • <i>"Afterwards I I experienced lots of problems with <u>heartburn</u>."/ "Agterna het ek uitgevind ek het baie probleme met sooi brand."</i> • <i>"I had to rush to hospital when a thing stuck in my throat ... if you have a problem with your valve ..."/ "Ek moes na die hospitaal jaag toe iets in my keel vassteek ... as jy probleme met jou spraaklepel ondervind ..."</i> • <i>"I did not ask everything I wanted to hear from them ... only <u>how long</u> I will have to <u>stay in hospital</u>."/ "Ek het nou nie alles wat ek wil gehoor het vir hulle uitgevra nie ... net hoe lank ek nog gaan bly in die hospitaal"</i> <p>Daily living</p> <ul style="list-style-type: none"> • <i>"There were a few things that I had to learn [by] myself ... they didn't tell that I would not be able to swim."/ "Daar was 'n paar dinge wat ek vir myself moes leer ... hul het nie gesê dat ek nie sal kan swem nie."</i> • <i>"I did not know what was <u>lying ahead</u>."/ "Ek het nie geweet wat voorlê nie."</i>

The needs of those who wanted to know more about the presence of the **permanent tracheostoma** varied from those who wanted to know more about their physical appearance (*"I did not know what I would look like after the operation"*); the ability to **have speech** immediately after the operation (*"I wanted to say something and then I could not*

talk"); their new way of breathing (*"I did not realise that I would not be able to breathe through my nose and mouth") to those who doubted the permanency of the tracheostoma (*"I do not know whether there will be a chance that they can close the stoma"*).*

Participants also felt that they would have liked to have more information about **physical effects** of the operation in general. These uncertainties varied from wanting to know more about their eating and drinking (*"They did not explain to me ... that I could eat although I had the pipe"*); the incidence of heartburn (*"I experienced lots of problems with heartburn"*); how to manage a blocked stoma; how to deal with problems associated with the speech valve (*"If you have a problem with your valve ..."*) to those who wanted more information on the length of their stay in hospital after the operation (*"... how long I will have to stay in hospital"*).

They felt inadequately prepared regarding the effect of the operation on their **daily living** (*"There were a few things that I had to learn by myself ..."; "I did not know what was lying ahead"*).

However, they felt well informed about the need for the operation with the aim to extend their life expectancy (*"I will live longer if I get the operation"*). They also appreciated information on their ability to have post-operative speech (*"you will learn to talk"*):

"He explained to me that I will live longer if I get the operation."

"Hy het 'explain' dat ek langer gaan lewe as ek die operasie kry."

"Then I asked the doctor how I will be able to talk, then the doctor said, you will learn to talk."

"Toe vra ek hoe gaan ek dan kan praat, toe sê die dokter, jy sal weer kan praat."

An explanation for why they felt that doctors only informed them partially may be that it would be too time consuming or that patients may not be able to fully absorb a complete explanation (*"It would take too long and I would not understand it"*). However, in contrast with literature (Zeine & Larson, 1999:59-60) that emphasises the importance of adequate pre-operative counselling, three (6,7%) participants warned about the danger

of too much information, resulting in them refusing the operation (*"Maybe they thought it will frighten me"*). These were the participants who had a brief interval between the date of diagnosis and the date of surgery (49 days; 29 days; 49 days) with an average period of 42 days.

Patients said that they were either too shocked or scared to ask questions. They also felt that they were to deal with it themselves; therefore the best way was to learn through their own understanding (*"It is something I have to deal with as a patient"*). Johnson *et al.* (1979:1818) explain that information offered at the time of a crisis may not be retained from a single session. The manner therefore in which information is given does not always meet the patient's ability to understand it. This is confirmed in the words of one of the participants:

"...everything went so quickly, the shock was past the shock."

"... dit het so vinnig gegaan, die skok was verby die skok."

(c) Category: Not at all prepared

Finally, a minority of participants (2, or 4,4%) experienced that team members did not prepare them at all for what to expect. However, the period between the date of diagnosis and date of surgery for these two participants was six and 43 days respectively with an average of 25 days. The period between the date of surgery and the interview varied from ten months to one year and nine months, with an average of one year and five months. The brief interval between these two dates could therefore have added to the level of stress experienced at that stage (Chen *et al.*, 2009:478-479). Ross (2000:14) mentioned that patients and families may not be able to assimilate a great deal of information shortly before surgery. The emotional state of the patient and spouse may affect their ability to "hear" or accept this information (Zeine & Larson, 1999:59). Table 7.11 represents the category "not at all prepared" as indicated by patients:

TABLE 7.11: Experience of team members' explanation: not at all prepared

Theme 1: Patients' and families' need for pre-operative information in survivorship experience	
Sub-theme 1.2: Experience of team members' explanation of operation	
Category	Narratives of participants
Not at all prepared	<ul style="list-style-type: none"> • <i>"I was not conscious ... <u>I did not know anything.</u>" / "Ek was nie by my bewussyn nie ... ek weet niks nie."</i> • <i>"I just thought that they <u>kept it away</u> from me ... I heard about cancer, that you <u>will not stay alive for long</u> after you had cancer." / "Ek dink toe maar net hulle steek seker iets weg ... ek het al gehoor van kanker, jy gaan nie lank lewe na die kanker nie."</i>

One participant felt that his wife was better informed before the surgery, as he himself was very ill at that stage (*"I was not conscious ... I did not know anything"*). Another participant felt that professionals may have preferred to keep information regarding their cancer confidential, since a diagnosis of cancer is often associated with having a poor prognosis (*"You will not stay alive for long after you had cancer"*).

(d) Summary

Both patients and family members found pre-operative preparation helpful for the purpose of their emotional, physical and social preparation. Also, It helped them in preparing for their post-operative adjustment. This finding agrees with literature (Jefford *et al.*, 2008:29-30) stating that, from a **survivorship perspective**, adequate information as to what to expect during the various phases of survivorship is necessary. This is especially applicable in the case of those patients who present with a diagnosis of oral cancer, whose physical and daily living needs will be greater than those of others (Chen *et al.*, 2009:474).

7.4.1.3 Theme 1: Sub-theme 1.3: Emotional reactions of patients and families to information received

Patients and family members supplied a wide variety of responses to describe their feelings at the time of diagnosis and on being informed of their planned operation. Patients were first asked about their own emotional reaction at the time. They were then asked to describe how they thought their families felt. Lastly, families had the

opportunity to describe their emotional reactions at this stage. Their reactions ranged from “feeling nothing” (“*I felt nothing*”) to “feeling heavy” (“*first I felt heavy*”). McQuellon (1997:231) pointed out that a diagnosis and the treatment of cancer almost always are emotionally traumatic experiences. This is especially true in the case of cancer of the head and neck area, because of its life-threatening nature and the threat of potential disfigurement and dysfunction.

The most prominent reactions experienced by patients and families are summarised in Table 7.12 and a discussion of the three most commonly experienced emotional reactions, namely sadness, shock and acceptance, follows.

TABLE 7.12: Comparison of emotional reactions to information received as reported by patients and family members

Theme 1: Patients' and families' need for pre-operative information in survivorship experience			
Sub-theme 1.3: Emotional reactions of patients and families to information received			
Emotional reactions	Patients' responses (<i>n</i> = 45)*		Family's responses as reported by family members (<i>n</i> = 15)*
	Patients' own reactions	Family's reactions as perceived by patients	
Sadness	23 (51,1%)	24 (53,3%)	7 (46,7%)
Fear	5 (11,1%)	0 (0,0%)	0 (0,0%)
Shock	8 (17,8%)	13 (28,9%)	4 (26,7%)
Acceptance	15 (33,3%)	6 (13,3%)	3 (20,0%)
Nothing/not sure	9 (20,0%)	8 (17,8%)	3 (20,0%)

**(Some participants indicated more than one reaction, therefore the total may exceed 100%)*

(a) Category: Sadness

According to patients, the most prominent emotional response experienced by themselves (51,1%) and their family members (53,3%) at time of diagnosis, was sadness. This was confirmed by family members. The ratings in these three circumstances were more or less the same and varied between 46,7% and 51,1%, which implies that patients were in line with their description of their own and their families' emotional reaction at that time. The narrative responses of participants which illustrate the category of “sadness” in response to pre-operative information received are reflected in Table 7.13.

TABLE 7.13: Emotional reactions by patients and families: sadness

Theme 1: Patients' and families' need for pre-operative information in survivorship experience	
Sub-theme 1.3: Emotional reactions of patients and families to information received	
Category	Narratives of participants
Sadness <ul style="list-style-type: none"> • Fatal disease • Loss • Future adaptation 	<p>PATIENTS</p> <p>Cancer as fatal disease</p> <ul style="list-style-type: none"> • <i>"When I heard that it was cancer it was as if <u>my whole world tumbled</u>." / "Toe ek hoor dit is kanker toe is dit asof my hele wêreld in mekaar getuimel het."</i> • <i>"I felt bad because I thought that I <u>would not recover</u>, I <u>would die soon</u>." / "Ek het toe sleg gevoel want ek het gemeen ek gaan nie weer regkom nie, ek gaan sommer gou oorlede raak."</i> <p>Experience of loss</p> <ul style="list-style-type: none"> • <i>"You feel sad to know that the things you loved you will <u>not be able</u> to do any more ... there will be the feeling that you are going to <u>lose something</u>." / "Jy voel darem hartseer om te weet die dinge wat jy nou altyd so lief was om te doen en waarmee jy jou besig hou sal dit nie meer kan doen nie ... daar gaan 'n gevoel wees dat jy sal iets verloor."</i> • <i>"<u>How</u> the people will <u>accept</u> you" / "Die vrese hoe jy aanvaar sal word"</i> • <i>"I did not know <u>how to continue</u> with my life." / "Ek het nie geweet hoe ek nou met die lewe gaan vorentoe gaan nie."</i> • <i>"<u>Nothing can prepare you</u> on how it will feels <u>not to have voice</u> and not to be able <u>to talk</u>." / "Niks kan jou voorberei op hoe dit voel om nie stem te het en nie te kan praat nie."</i> <p>FAMILY MEMBERS ACCORDING TO PATIENTS</p> <p>Cancer as fatal disease</p> <ul style="list-style-type: none"> • <i>"I think they <u>believed</u> that I am <u>not going to live for long</u>." / "Ek dink hulle het geglo ek gaan nie meer lank lewe nie."</i> <p>FAMILY MEMBERS</p> <p>Cancer as fatal disease</p> <ul style="list-style-type: none"> • <i>"When you hear cancer then you only <u>think of death</u> and that person <u>will not live</u> ... cancer is like a notification of death." / "As jy hoor kanker dan dink jy net aan sterfte en die persoon gaan dit nie maak nie ... 'because why' kanker is mos nou 'n doodstydning."</i> <p>Experience of loss</p> <ul style="list-style-type: none"> • <i>"It was very sad ... I have to go back home and have to <u>leave him here</u>." / "Dit was vir my baie hartseer ... ek moet terug huis toe gaan maar ek moet hom nou hier agterlos."</i> • <i>"You feel sad ... because he was used to talking all those years and <u>now he cannot talk</u>." / "Mens voel maar hartseer, ... want hy was nou gewoond al die jare kan hy gepraat het en hy kan nou nie praat nie."</i>

Patients linked their experience of sadness to the diagnosis of cancer (“...it was as if my whole world tumbled”) and the association between cancer and having a poor prognosis (“I thought that I would not recover”) and the loss of daily activities and hobbies as a result of the disease (“... the things you loved you will not be able to do any more”). Findings of the study correspond with literature (Ross, 2002:14), which states that the diagnosis of cancer may raise many myths and misconceptions for many, for people easily see it as synonymous with death. Dhoooper (1985:222) specifically referred to loss of the larynx which may be seen as symbolic of the death of the body. Patients were also concerned about their social acceptance following surgery (“How the people will accept you”). The experience of the limitation of their speech as well as daily activities added to the experience of loss (“There will be the feeling that you are going to lose something”). This finding agrees with the opinion expressed by Dhoooper (1987:222) that patients may experience grief when attempting to work through their experience of loss. Some participants felt overwhelmed by not knowing how to deal with future challenges (“I did not know how to continue with my life”). McQuellon (1997:232, 239) pointed out that, in the case of larynx cancer, impairment with regard to disfigurement as well as dysfunction (loss of voice) results from the treatment which requires major adaptations by most patients.

Family members also indicated that the perception of cancer as having a potential fatal outcome (“...you only think of death and that person will not live”) shocked them at the stage of diagnosis and on being informed of planned surgery. They also referred to other loss experiences, such as leaving the patient at the hospital (“I have to go back home and have to leave him here”) and the limitation in speech (“...and now he cannot talk”). Cady (2002:347) also stated that a diagnosis of larynx cancer can be devastating for both patients and families as they have to face decisions regarding complex treatment choices, potentially disfiguring surgery (laryngectomy) and possible mortality.

Furthermore, families wondered about the patient’s ability to cope with their diagnosis and the necessary adaptations following surgery, as can be observed from the following narrative response by a family member:

“I just thought how it would affect us ... it was terrible, it was very very sad and I nearly experienced depression because how would he cope, how would I cope. It was a very big operation and a huge adaptation for him and for me and for the children, but for him the most.”/

“Ek het net gedink ... hoe gaan dit dan vir ons almal affekteer ... dit was verskriklik, dit was ontsettend ontsettend terneergedruk en amper soort van in ‘n depressie gegaan want hoe gaan hy ‘cope’, hoe gaan ek ‘cope’. Dit is ‘n vreeslike groot operasie en dit is ‘n vreeslike aanpassing vir hom en vir my en vir die kinders, maar vir hom natuurlik die meeste.”

(b) Category: Shock

Family members reported that they felt shocked on being informed about the the patient’s diagnosis and planned surgery (*“I did not expect it”*). This was also what patients pointed out when they had to comment on how they thought their families felt at that stage. Patients’ rating of family members (28,9%) corresponded well with family members’ own ratings (26,7%). Interestingly, however, only 17,8% of **patients** reported that they themselves felt shocked at this stage. Narrative responses of both patients and families are recorded in Table 7.14:

TABLE 7.14: Emotional reactions by patients and families: shock

Theme 1: Patients' and families' need for pre-operative information in survivorship experience	
Sub-theme 1.3: Emotional reactions of patients and families to information received	
Category	Narratives of participants
Shock <ul style="list-style-type: none"> • Unexpected • Fatal disease • Limitation • Stigma 	<p>PATIENTS</p> <p>Unexpected</p> <ul style="list-style-type: none"> • <i>"I was shocked as I <u>did not know</u> that something like that <u>could happen to me.</u>" / "Ek was geskok want ek het nie geweet ek sou so iets oorkom."</i> • <i>"When you hear that C word ... it was just like <u>it never sunk in</u> ... maybe I <u>did not know</u> how to react to this thing and then all of a sudden it just hits me ... then I felt very downhearted, sad about it." / "Wanneer jy die K woord hoor ... dit was asof dit nie ingesink het nie ... dalk omdat ek nie geweet het hoe om te reageer nie en toe skielik toe tref dit my ... toe voel ek baie teleurgestel, hartseer oor dit."</i> <p>Cancer as fatal disease</p> <ul style="list-style-type: none"> • <i>"Then you think you are not going to live for long. I felt <u>this is the end</u>. Now I cannot be of meaning any more." / "Dan dink jy jy gaan nie lank lewe nie. Ek het gevoel dit is nou klaar, ek kan niks meer beteken nie."</i> <p>FAMILY MEMBERS ACCORDING TO PATIENTS</p> <p>Cancer as fatal disease</p> <ul style="list-style-type: none"> • <i>"Everyone is shocked, they believe you are <u>going to die.</u>" / "Vir almal is dit 'n skok, hulle glo jy gaan nou dood."</i> <p>Limitation on physical abilities</p> <ul style="list-style-type: none"> • <i>"They were shocked ... because they do not know you like that and they knew the <u>things you did previously.</u>" / "Hul het dit met skok ingeneem ... omdat hulle jou mos nou nie so ken nie en hulle weet wat jy waarmee jy eintlik besig was."</i> <p>Stigma</p> <ul style="list-style-type: none"> • <i>"They were shocked because <u>no one else in the family had the same disease</u> ... they asked whether I <u>drank with someone else who had such a disease.</u>" / "Hulle het baie geskrik 'because' nie een in die familie het daai selfde siekte gehad nie ... hulle vra of ek saam met iemand gesit en drink het wat ook so 'n siekte het."</i> <p>FAMILY MEMBERS</p> <p>Unexpected</p> <ul style="list-style-type: none"> • <i>"I was shocked because I <u>did not expect it.</u>" / "Ek was geskok gewees want ek het mos nou nie dit verwag nie."</i> <p>Experience of loss</p> <ul style="list-style-type: none"> • <i>"How will he be able to <u>communicate</u>, how will I <u>understand</u> him when he will get the operation, I felt a bit bad." / "Hoe gaan ek en hy dan nou weer kommunikeer, hoe gaan ek hom verstaan as hy nou moet hierdie operasie kry, ek het 'n bietjie terug gevoel."</i> <p>Cancer as fatal disease</p> <ul style="list-style-type: none"> • <i>"It was terrible, all that I could see was that my husband is <u>going to die</u> ... it was a shock ... / "Dit was vir my verskriklik, al wat ek gesien het is my man gaan sterf ... dit was vir my skokkend."</i>

Patients mostly linked the experience of shock to the fact that the diagnosis of cancer was unexpected (“*I did not know that something like that could happen to me”). This correlates with literature (Rowland, 2008:365) stating that the diagnosis of cancer is often made unexpectedly. Patients also comment that they did not know how to react (“*I did not know how to react to this thing*”) and reported shock about the potentially fatal outcome (“*I felt this is the end”*) of the disease. Patients referred to family members who might have experienced shock due to limitations to the patients’ physical abilities (“*...they knew the things you previously did”*), as well as social stigma associated with the diagnosis of cancer (“*...no one else in the family had the same disease*”). **Family members** mainly referred to the unexpectedness of the diagnosis (“*I did not expect it”*) and the association between cancer and death (“*All that I could see was that my husband is going to die”*).*

(c) *Category: Acceptance*

An interesting finding that differs from the literature, was that one third of patients (15, or 33,3%) were left with feelings which varied between satisfaction, acceptance or thankfulness and calmness. Patients’ and families’ experiences are illustrated in Table 7.15:

TABLE 7.15: Emotional reactions of patients and families: acceptance

Theme 1: Patients' and families' need for pre-operative information in survivorship experience	
Sub-theme 1.3: Emotional reactions of patients and families to information received	
Category	Narratives of participants
Acceptance <ul style="list-style-type: none"> • Thankfulness • Belief in God • Inner strength 	<p>PATIENTS</p> <p>Thankfulness</p> <ul style="list-style-type: none"> • <i>"When the doctor told me I have cancer I <u>accepted</u> it because I knew <u>there was hope.</u>" / "Toe die dokter vir my sê ek het kanker toe het ek dit aanvaar want ek het geweet daar is hoop."</i> • <i>"I was <u>thankful for the operation.</u>" / "Ek was baie bly vir die operasie."</i> <p>Belief in God</p> <ul style="list-style-type: none"> • <i>"When I heard about the cancer I was <u>satisfied</u> because I knew it was <u>God's disease.</u>" / "Toe ek van die kanker hoor toe was ek tevrede want ek het geweet dit is God se siekte."</i> <p>Inner strength</p> <ul style="list-style-type: none"> • <i>"The doctor told me that they will support me all the way. And that set <u>my mind at ease.</u>" / "Die dokter het vir my gesê ons is bereid om die lang pad saam met jou te loop. En daai het vir my tevrede gestel."</i> • <i>"I was <u>very strong.</u> I prayed to be <u>calm</u> when I heard what disease I have, I must not be frightened but I <u>have to accept</u> it." / "Ek was baie sterk. Ek het maar net gebid ek moet kalmte kry as ek hoor watter siekte ek kry, ek moet nie skrik nie ek moet dit maar net aanvaar."</i> <p>FAMILY MEMBERS ACCORDING TO PATIENTS</p> <p>Thankfulness</p> <ul style="list-style-type: none"> • <i>"They were also <u>glad</u> ... they felt that I <u>did not pass away.</u>" / "Hulle is ook maar bly ... hulle voel natuurlik daar was nog nie dood in die familie nie."</i> • <i>They were satisfied because they also <u>wanted me to be healthy.</u>" / "Hulle was tevrede want hulle wil ook hê ek moet gesond wees."</i> <p>FAMILY MEMBERS</p> <ul style="list-style-type: none"> • <i>"I was <u>glad</u> that he came in time and that he agreed to the operation. I felt that he <u>would be cured.</u>" / "Ek was net bly hy het gou gekom en hy het ingestem vir die operasie. Ek het gevoel hy gaan gesondraak."</i> • <i>"I put my <u>mind at ease.</u>" / "Ek het my maar tevrede gestel."</i>

Since they felt very ill at the time of diagnosis, they viewed the operation as an opportunity to give them hope (*"I knew there is hope"*). For the survivor, the driving force (strength) for their survivorship is made up of their will or desire to live, or their need to survive (Rom *et al.*, 2009:27; Tominaga *et al.*, 1998:40). Following a long period of uncertainty, the diagnosis of cancer and information regarding planned treatment can also bring a sense of completion (DeSanto, 1994:52). This is also applicable in the case

of the laryngectomy survivor. However, diagnosis is seen as the starting point in the survivorship journey (Annexure A).

(d) Category: Nothing or not sure

A significant finding was that a certain proportion of patients did not know how their relatives felt as they did not discuss their feelings openly. The majority of patients were male and Chen *et al.* (2009:474, 479) have warned that male patients often do not speak out. This differs from female patients who express themselves by crying and talking. The following table (Table 7.16) illustrates these patients' viewpoint:

TABLE 7.16: Emotional reactions of patients and families: no emotion

Theme 1: Patients' and families' need for pre-operative information in survivorship experience	
Sub-theme 1.3: Emotional reactions of patients and families to information received	
Category	Narratives of participants
Nothing	<p>PATIENTS</p> <ul style="list-style-type: none"> • <i>"I felt <u>nothing</u>. I took it... it is like that and it will be like that."</i> / "Ek het niks gevoel nie. Ek het dit so gevat dit is nou so en dit moet nou seker so wees." • <i>"I only said: The <u>worst</u> that can happen to me is <u>that I may die</u>."</i> / "Ek het net gesê: Die ergste wat met my kan gebeur is ek kan doodgaan." • <i>"I did not worry, I knew that <u>even if you are a baby you can also get cancer</u>."</i> / "Ek het nie ge-worry nie, ek weet net jy kan 'n babetjie wees dan kry jy ook daai siekte." • <i>"It is not my problem, I took it and <u>gave it in the hands of the Lord</u>."</i> / "Die probleem is nie my probleem nie, ek gee hom in die Here se hande."
Do not know	<p>FAMILY MEMBERS ACCORDING TO PATIENTS</p> <ul style="list-style-type: none"> • <i>"I <u>do not know</u> how she felt inside."</i> / "Ek weet nie hoe sy binnekant gevoel het nie." • <i>"I <u>do not experience</u> their feelings, I <u>can say nothing</u>."</i> / "Ek het mos nou nie hulle gevoelenthed nie, ek kan niks sê nie." • <i>"My familie <u>did not show me</u> how they felt, they <u>talked around it</u> ... they did not want to talk about it in my presence ... maybe they thought it will let me feel depressed or they thought it will make me more sick."</i> / "My familie wil nie eintlik vir my gewys het hoedat hulle voel nie, maar altyd 'around' dit gepraat ... hulle wil nou nie voor my daarvoor praat nie ... seker maar hulle gaan nou dink dit gaan my nou 'depress' laat voel of hulle dink dit gaan nou vir my siek maak."
Can not say	<p>FAMILY MEMBERS</p> <ul style="list-style-type: none"> • <i>"I <u>can not say</u> how I felt."</i> / "Ek kan nie sê hoe ek gevoel het nie."

Patients who said that they “felt nothing” (“*I did not feel anything*”) (9, or 20%) expressed the attitude of “that’s life” (“*It is like that and it will be like that*”). They also revealed resignation regarding the knowledge that they could only die from the diagnosed condition (“*The worst that can happen to me is that I may die*”). Miller *et al.* (2008:371) referred to these survivors as those who accept their diagnosis in a matter-of-fact manner, with cancer just being one of the many issues that they had already faced or would face during life. Their cancer experience did not change them much, or less than other experiences of loss. The realisation that anyone can be affected by cancer (“...even a baby”), resulted in them not experiencing the intensity of feeling associated with the diagnosis. They also found it helpful to put their trust in the Lord (“*I took it and gave it in the hands of the Lord*”).

(e) Summary

Emotional experiences of patients and families at the stage of being informed about the diagnosis of cancer varied: some experienced sadness, shock or acceptance and others could not specify their emotional reaction. Responses from patients and their families were mainly in accordance with one another. A significant finding was that **families** experienced shock to a greater extent than patients, whilst **patients** experienced a greater extent of acceptance than families. A possible explanation could be that the patients who participated mainly were elderly male people. On the one hand, elderly survivors are more likely to minimise the impact on their lives (Foster *et al.*, 2009:243) or, on the other hand, appear to be less affected by their cancer experience than younger ones as they often are more accustomed to handling negative events in their lives and often do not experience the pressure of fulfilling multiple, competing roles, as will be the case with younger survivors (Hara & Blum, 2009:47).

7.5 PHYSICAL RE-ADJUSTMENT

During the **transitional phase** of their survivorship journey, patients and families have to deal with the reality of certain permanent physical changes, which face them from the time of surgery (Miller *et al.*, 2008:372).

7.5.1 Theme 2: Patients' and families' experiences of their physical re-adjustment

Those physical changes most difficult to deal with by patients and family members were explored first, followed by an exploration of emotional reactions caused by the experience of these physical changes. These are described as the second theme of the results of the study.

7.5.1.1 Theme 2: Sub-theme 2.1: Permanent physical changes most difficult to deal with

Patients were required to indicate (Question 4.1 in questionnaire for patients) which of the permanent physical changes they identified as the most difficult to cope with. They were tested with regard to their experience of the presence of the stoma, physical appearance, speech, senses and ability to eat and drink.

TABLE 7.17: Permanent physical changes most difficult to deal with (patients)

Theme 2: Patients' and families' experiences of their physical re-adjustment			
Sub-theme 2.1: Permanent physical changes most difficult to deal with (for patients)			
Physical adjustment	Extreme	Mild	Not at all
Stoma	21,1%	35,0%	43,9%
Physical appearance	22,2%	31,1%	46,7%
Speech	33,0%	40,4%	26,7%
Senses	44,4%	20,0%	35,6%
Eating and drinking	27,4%	15,6%	57,0%

(Some participants indicated more than one opinion therefore the total may exceed 100%)

n = 45

It can be deduced from Table 7.17 that **patients** mostly experienced extreme difficulty with their **sensory functioning**, namely their inability to smell and taste (44,4%). According to literature (Lennie *et al.*, 2001:668, 673), decreased ability to taste and smell is due to the olfactory process which is destroyed during surgery. Loss of smell has far-reaching implications with results concerning issues of safety, issues of hygiene and the limitation of responding to pleasurable odours. This was followed by extreme problems with post-operative **speech** (33,0%) and, thirdly, problems with **eating and drinking** (27,4%). More or less of equal value and less importance were problems experienced with physical appearance (22,2%) and the **permanent tracheostoma** (21,1%).

The same question was posed to **family members**, but as an open-ended question. Table 7.18 reflects families' responses:

TABLE 7.18: Permanent physical changes most difficult to deal with (families)

Theme 2: Patients' and families' experiences of their physical re-adjustment	
Sub-theme 2.1: Permanent physical changes most difficult to deal with (for families)	
Category	Narratives of participants
Speech	<ul style="list-style-type: none"> • <i>"I <u>could not clearly understand</u> what he wanted to say."</i> "Ek kon nie mooi verstaan wat hy wou sê nie." • <i>"She <u>did not want to talk</u>, she thought she had to make gestures with her hands ... she <u>became angry</u> when we did not understand her, she <u>reacted hysterically</u>."</i> / "Sy wou nie praat nie, sy het net gedink sy moet nou met haar hande gebare maak ... sy het kwaad geword want ons verstaan nou nie vir haar nie, dan raak sy nou histeries." • <i>"When I talked to her she <u>could not answer me properly</u>."</i> / "As ek met haar praat dan kon sy nie so lekker teruggepraat het nie."
Stoma	<ul style="list-style-type: none"> • <i>"The <u>stoma</u>, because of all the <u>mucous</u> that exits through it, it was not easy in the beginning to live with it."</i> / "Die gaatjie, want met die baie slym wat daar uitkom, dit was nie maklik om in die begin daarmee saam te leef nie." • <i>"<u>Cleaning of the stoma</u> was the most difficult part."</i> / "Die skoonhou van die gaatjie was vir my die moeilikste gewees."

The majority (10, or 66,7%) acknowledged that they found the adaptation to the patient's post-operative **speech ability** (*"I could not clearly understand what he wanted to say"*) the most difficult physical change to adjust to, followed by the presence of the **permanent tracheostoma** (6, or 40%) (*"The stoma, because of all the mucous that exits through the stoma"*).

One family member (6,7%) referred to the fact that her husband reacted "like a child" as he did not want to be alone. Taking into account that it is mostly elderly people who undergo a laryngectomy (Ross, 2000:13), this reaction may lead to confusion regarding role functioning and frustration for other family members. In the words of the participant:

"My husband cannot talk now. He is almost like a child ... he does not want to be alone, he does not want to be with people ... because he was always a man who could talk."/

"My man kan nou nie praat nie. Hy's amper soos 'n kind, hy wil nie eintlik alleen wees nie, hy wil nie by mense wees nie ... want hy was mos altyd gewees 'n man wat kan gepraat het."

7.5.1.2 Theme 2: Sub-theme 2.2: Patients' and families' emotional experiences regarding inevitable permanent physical changes

Having obtained an indication from both patients and family members of the most difficult physical changes they had to deal with following the operation, their emotional experiences in having to deal with these inevitable permanent physical changes caused by the operation were also explored. The results from the question that was posed are presented in Table 7.19. The majority of **patients** found it difficult to describe their emotional experiences. They either referred to the fact that they felt "different" or did not specify (18, or 40%). This was followed by their experience of sadness (16, or 35,6%). **Family members**, on the other hand, mostly experienced acceptance (7, or 46,7%).

TABLE 7.19: Patients' and families' emotional experiences regarding inevitable permanent physical changes

Theme 2: Patients' and families' experiences of their physical re-adjustment		
Sub-Theme 2.2: Emotional experiences regarding inevitable permanent physical changes		
Emotional reaction experienced	Patients' responses (n = 45)*	Family's responses (n = 15)*
Sadness	16 (35,6%)	4 (26,7%)
Shock	2 (4,4%)	2 (13,3%)
Acceptance	7 (15,6%)	7 (46,7%)
Could not describe	18 (40,0%)	1 (6,7%)

**(Some participants indicated more than one opinion, therefore the total may exceed 100%)*

(a) Category: Sadness

More than one third (16, or 35,6%) of the **patients** indicated that they responded with sadness when they realised that had to deal with inevitable permanent physical changes, whilst four (26,7%) of the **family members** also indicated that they shared this emotional reaction. This is in accordance with the literature, indicating that patients mourn their experience of loss (Dhooper, 1985:218). This category is illustrated by verbatim responses of participants as presented in Table 7.20:

TABLE 7.20: Physical re-adjustment: sadness

Theme 2: Patients' and families' experiences of their physical re-adjustment	
Sub-Theme 2.2: Emotional experiences regarding inevitable permanent physical changes	
Category	Narratives of participants
Sadness <ul style="list-style-type: none"> • Reactions • Loss experience • Adjustments 	<p>PATIENTS</p> <p>Other people's reactions</p> <ul style="list-style-type: none"> • <i>"Because you are <u>feeling "abnormal"</u> and <u>people do not accept you.</u>" / "Omdat jy nie meer normaal is en nie meer aanvaar word deur die mense nie."</i> • <i>"I <u>felt inferior</u> when I was with other people. You cannot explain yourself clearly as you would like to." / "Jy voel minderwaardig as jy tussen ander mense is. Jy kan jou nie duidelik uitspreek soos jy wil nie."</i> • <i>"I felt <u>a bit uncomfortable</u> among other people. They always looked <u>strangely at me.</u>" / "Dit het my 'n bietjie ongemaklik laat voel tussen die ander mense. Hulle het my altyd so snaaks aangekyk."</i> <p>Loss experience</p> <ul style="list-style-type: none"> • <i>"I <u>cannot taste</u> the food, I also cannot taste the coffee and tea." / "Ek kan nie die smaak van die kos kry nie, ook nie die smaak van die tee of koffie nie."</i> • <i>"I <u>do not have friends any longer ... no one talks to me.</u>" / "Ek het nie meer vriende nie ... niemand gesels met my saam nie."</i> • <i>"I was a bit afraid because I <u>cannot do the things as I did it before.</u>" / "Ek was bietjie teleurgesteld want ek kan mos nou nie meer die dinge doen soos ek dit kan gedoen het nie."</i> <p>New adjustments</p> <ul style="list-style-type: none"> • <i>"In the beginning it was quite hard. It was due to the new circumstances." / "Aan die begin was dit nogal moeilik. Dit is weens daardie nuwe omstandighede."</i> • <i>"It was a <u>lonely change.</u>" / "Dit was so 'n eensame verandering gewees."</i> • <i>"I <u>feel heavy</u>, I have to struggle to talk, I cannot talk spontaneously ... I have to search how to talk." / "Ek voel swaar, ek moet sukkel ek kan nie sommer praat nie ... nou moet ek soek om te praat."</i> <p>FAMILY MEMBERS</p> <p>Loss experience</p> <ul style="list-style-type: none"> • <i>"I was sad to think that he would <u>no longer be normal.</u>" / "Ek was hartseer om te dink hy is nou nie meer normaal nie."</i> • <i>"It is sad to think he was healthy and today he has <u>that disease</u> and that disease is for a <u>lifetime.</u>" / "Dis hartseer om te dink hy was 'n gesonde man gewees en vandag is hy in daai siek en daai siek is nou vir lewenslank."</i>

The most prominent reasons were that they had to deal with various experiences of loss, were different from other people's reactions ("*...people do not accept you*"); acknowledgment of the things they could not do ("*I cannot do the things as I did it before*") and also having to face the reality of adaptation to new adjustments ("*It was a lonely change*"). From a **survivorship perspective**, adjustment to these post-operative changes will be of ever greater relevance as survivorship increases and survivors have to deal with new experiences for longer periods of time (Golant & Haskins, 2008:420). Patients furthermore are hospitalised for shorter periods of time following the operation. Patients therefore have a shorter interval for "testing out" their new appearance and communication skills, including the reaction of others, which previously happened in the safety of the hospital (Cady, 2002:349).

(b) Category: Acceptance

On the other hand, seven (15,6%) **patients** and two (13,3%) **family members** reacted with positive feelings of thankfulness and acceptance when having to deal with inevitable permanent physical changes. Table 7.21 presents how participants motivated their acceptance of their physical re-adjustment:

TABLE 7.21: Physical re-adjustment: acceptance

Theme 2: Patients' and families' experiences of their physical re-adjustment	
Sub-theme 2.2: Emotional experiences regarding inevitable permanent physical changes	
Category	Narratives of participants
Acceptance <ul style="list-style-type: none"> • Explanation • Faith • Cannot change • Positive strengths • Time 	<p>PATIENTS</p> <p>Pre-operative explanation</p> <ul style="list-style-type: none"> • <i>"Before the operation you <u>were prepared</u> for how it will be after the operation."/ "Hulle lig jou mos voor die tyd in hoe jy gaan wees."</i> • <i>"<u>I knew how it would work and what would happen</u>. I already accepted it so it was not a big deal for me."/ "Voor die tyd ek het geweet hoe dit werk ek het geweet wat kom. Ek het dit klaar aanvaar gehad so dit is nie vir my te 'n groot 'issue' nie."</i> <p>Trust in the Lord / faith</p> <ul style="list-style-type: none"> • <i>"Then I said, Lord, that vision that I had in the cloud ... You did say you will carry me, and <u>I believed that the Lord will carry me</u>."/ "Toe het ek gesê Here, daai visie wat ek gesien het in daai wolk ... U het gesê U gaan my dra, en ek het geglo die Here gaan my dra."</i> <p>One cannot change it</p> <ul style="list-style-type: none"> • <i>"I just felt <u>this is the way I am and I will stay like that</u>."/ "Ek het maar net gevoel ek is nou so en ek gaan maar nou so bly."</i> <p>Concentrate on positive strengths</p> <ul style="list-style-type: none"> • <i>"I can still work a bit, I can talk, some things will not be possible but I <u>can still do the things</u> any person can do."/ "Ek kan bietjie werk, ek kan praat, sommige dinge kan daar nie meer wees nie maar als wat die normale ou kan doen kan ek ook doen."</i> • <i>"The stoma is nothing, <u>as long as I am alive</u>, I was not angry"/ "Die gat is niks, solank ek lewe, ek was nie kwaad nie."</i> <p>FAMILY MEMBERS</p> <p>Trust in the Lord / faith</p> <ul style="list-style-type: none"> • <i>"If you put it in the <u>Hands of the Lord</u> then it is so easy. You realise you just have to."/ "As jy dit in die Hand van die Here sit dan is dit so maklik. Jy besef net, jy moet."</i> <p>One cannot change it</p> <ul style="list-style-type: none"> • <i>"I had to accept it as I realised that <u>nothing could be done to change it</u>. I <u>decided I just have to continue</u>, if he can manage, then I can also."/ "Ek moes maar aanvaar want ek weet mos daar kan nou niks aan gedoen word nie. Ek het besluit ek moet daardeur, as hy kan daardeur dan moet ek ook, ek kan nie agterbly nie."</i> • <i>"We accepted it because it was <u>just another thing which had happened with which we had to live</u>."/ "Ons het dit geaanvaar 'because why' vir ons was dit maar net nog 'n iets wat gebeur en ons moet daarmee saamleef."</i> <p>Time as healing factor</p> <ul style="list-style-type: none"> • <i>"It cost a lot of prayer, lots of tears, but <u>with time</u> it becomes <u>easier</u>, and now, I do not see it anymore"/ "Dit het baie bid gekos, baie trane en met tyd, dan word dit makliker en nou nog, ek sien dit nie raak nie."</i>

Patients linked this experience to being well-prepared by the pre-operative counselling (“*Before the operation you were prepared”; “...and knew how it would work and what would happen””) and putting their trust in the Lord (“*I believed that the Lord will carry me”*). They also accepted that one cannot change (“*This is the way I am and I will stay like that”*) one’s situation. They then concentrated on positive strengths (“*I can still do the things any person can do*”), which could help them to overcome the limitations of the permanent physical changes.*

Families accepted these inevitable permanent physical changes by utilising various sources of energy, which varied from spirituality through putting their trust in the Lord (“*If you put it in die Hands of the Lord then it is so easy*”), by accepting that one could not change the effects of the operation (“*nothing can be done to change it”*), to acknowledging that, with time, it became easier (“*...but with time it becomes easier”*).

Survivors, who respond with acceptance towards inevitable permanent physical changes following the laryngectomy, utilise these positive emotions in order to adapt to changes caused by the operation. This is in accordance with the principles of the strengths perspective (Saleebey, 2002:14-15), in viewing positive emotions to promote patients’ optimal recovery.

(c) Category: Unable to describe

Another portion (13, or 28,9%) of the patients and one family member (6,7%) found it difficult to describe their emotions when having to deal with inevitable permanent physical changes. Some (5, or 11,1%) only referred to the fact that they felt “*different*” or “*nothing*”. Two contributory variables could have played a role. First, taking into account that the majority of participants (patients) had either no or only primary school education (25, or 55,6%) and that it was mostly male (37, or 82,2%) patients who participated, it was difficult for them to describe their emotional reactions, more so as males are not eager to speak out. Men also are more unwilling to describe their symptoms and discomfort because of their personalities or issues around self-esteem. In the case of family members, mainly females participated (13, or 86,7%). They therefore found it

easier to describe their feelings, as they cry or talk about their feelings more easily (Chen *et al.*, 2009:474, 479).

(d) Summary

Emotional experiences of **patients** at the point of having to deal with inevitable permanent physical changes varied from not being able to specify their emotional reaction to those who experienced sadness. **Family members** felt it easier to describe their emotions in this regard. This could probably be linked to gender differences. Family members to a large extent experienced acceptance.

(e) Summary of emotional reactions (diagnosis; inevitable physical changes)

When comparing the emotional reactions of primary (patients) and secondary (families) survivors at the stage of being informed about the cancer diagnosis (Table 7.12) and having to adjust to inevitable permanent physical changes caused by the operation (Table 7.19), interesting changes were found between the reactions of primary and secondary survivors. A summary of these responses is highlighted in Table 7.22:

TABLE 7.22: Summary of patients' and families' emotional reactions at diagnosis and when having to deal with inevitable permanent physical changes

Theme 2: Patients' and families' experiences of their physical re-adjustment				
Sub-theme 2.2: Emotional experiences regarding inevitable permanent physical changes				
Emotional reactions	Patients' responses (n = 45*)		Families' responses (n = 15*)	
	Information re diagnosis and surgery	Inevitable permanent physical changes	Information re diagnosis and surgery	Inevitable permanent physical changes
Sadness	23 (51,1%)	16 (35,6%)	7 (46,7%)	4 (26,7%)
Fear	5 (11,1%)	0 (0,0%)	0 (0,0%)	0 (0,0%)
Shock	8 (17,8%)	2 (4,4%)	4 (26,7%)	2(13,3%)
Acceptance	15 (33,3%)	7 (15,6%)	3 (20,0%)	7 (46,7%)
Nothing/not sure	9 (20,0%)	18 (40,0%)	3 (20,0%)	1 (6,7%)

**(Some participants indicated more than one opinion therefore the total may exceed 100%)*

When diagnosed with cancer, **patients** initially experienced feelings of sadness, When being diagnosed with cancer, which shifted to what they “could not describe” after being operated. They similarly also experienced feelings of sadness when they had to face the reality of the inevitable permanent physical changes resulting from the operation. **Family members** initially experienced sadness when informed about the operation, which, on the other hand, shifted to acceptance when they had to deal with those inevitable permanent physical changes that were due to the operation.

When bearing in mind the **profile of family members** who participated, the time period between the date of the patient’s laryngectomy and date of interview with the family member varied between ten and 138 months, with the average period that had elapsed after surgery being five years. A study by Blood *et al.* (1994:19-35) reported that high levels of stress and perceived burden had been recorded by spouses of patients following surgery, which appeared to be greatest in the first six months following surgery. A plateau is usually found following the twelve-month benchmark. It could therefore be that family members at the time of the interview indicated that they accepted these inevitable permanent physical changes as they had become used to it over the long term. Research conducted by De Boer *et al.* (1995:503) found that the greater the period that elapsed since treatment, the fewer the psychosocial problems associated with head and neck tumour. As the patient’s family is part of the ecological system within which the patient functions, it is also of relevance on the family member involved.

Pre-operatively, it also was more relevant for family members to know more about the diagnosis and survival of the patient prior to the operation than for the patients themselves (Table 7.2). It can therefore be said that it was more important for the family that the patient is cured from cancer than to be emotionally affected by the inevitable permanent physical changes caused by the operation.

7.6 CONCLUSION

In this chapter, a profile of patients' **identifying** and **medical information** first was presented and analysed. Four themes emerged from the data collected from the transcripts. The first two themes that emerged from laryngectomy patients' and families' recorded survivorship experiences were explored and described. These are representative of the acute and transitional phases of the survivorship journey.

Nearly all participants indicated their need for pre-operative information, as reflected in **Theme 1**. This included information needed in general; their experience of team members' explanation of the operation; opinions on the need for information on specific levels; and emotional reactions of both patients and families to information received.

In **Theme 2** participants indicated that they generally found the adaptation to changes in their senses as the most difficult aspect to manage. Again, emotional reactions of patients and families regarding their adaptation to these permanent physical changes were explored.

Themes 3 and **4**, which are representative of the extended and permanent phases of the survivorship journey, are explored and described in the following chapter.

CHAPTER 8

COPING AND STRENGTHS

PSYCHOSOCIAL EFFECTS AND RE-ENTRY INTO SOCIETY:

Extended and permanent phases of survivorship

8.1 INTRODUCTION

The need for pre-operative information felt by laryngectomy patients and their families and the patients' physical adjustment following the operation were described in the previous chapter. This was representative of the first two phases of the survivorship journey. In the current chapter, **coping and strengths** utilised in order to cope with the various phases of medical treatment, their experience of the **psychosocial effects** of surgery and their **re-entry into society** during the extended and permanent phases of their survivorship journey will now be described. Themes that emerged from participants' responses are summarised in Table 8.1. These themes are presented according to sub-themes and categories. Numbers in brackets correspond to the numbers of questions from the semi-structured questionnaire. This information will be highlighted by referring to participants' verbatim responses.

TABLE 8.1: Summary of themes 3 and 4

THEMES	SUB-THEMES	CATEGORIES
3 Experience of coping and strengths used <ul style="list-style-type: none"> • <i>Coping with physical changes (5.1)</i> • <i>Coping with treatment completion (5.2)</i> • <i>Coping with readjustment after operation (5.3)</i> 	3.1 Coping with physical changes (5.1)	<ul style="list-style-type: none"> • Inner strengths • Environmental resources
	3.2 Feelings experienced with treatment completion (5.2)	<ul style="list-style-type: none"> • Thankfulness • Fear and uncertainty • Mixed feelings
	3.3 Patients' and families' most difficult adaptation to cope with post-operatively (5.3.1. & 5.3.2)	<ul style="list-style-type: none"> • Speech • Physical effects • Psychosocial effects

THEMES	SUB-THEMES	CATEGORIES
<ul style="list-style-type: none"> <i>Coping with aftercare (5.4)</i> <i>Coping with laryngectomy experience (5.5)</i> <p>EXTENDED PHASE OF SURVIVORSHIP</p>	3.4 Coping with hospital's expectation after being discharged (5.4.2)	<ul style="list-style-type: none"> Did know exactly Did not know exactly Did not know at all
	3.5 Coping with laryngectomy experience in general by utilising strengths and resources (5.5.1-5.5.4 and 5.5.5.1-5.5.5.2)	<ul style="list-style-type: none"> Strengths <ul style="list-style-type: none"> Inner strength Challenge vs opportunity Grow & change Collaboration Resources Social support
<p>4 Experience of psychosocial effects of surgery and re-entry into society</p> <ul style="list-style-type: none"> <i>Social effects and adjustment (6.1)</i> <i>Emotional effects and adaptation (6.2)</i> <i>Re-entry into society (6.3)</i> <p>PERMANENT PHASE OF SURVIVORSHIP</p>	<p>Social effects 4.1 Social effects and adjustment (6.1.1-6.1.6)</p> <ul style="list-style-type: none"> Life partner Children / grandchildren Other family Previous friends New friends Employment / finance Role functioning 	<p>Relationships:</p> <ul style="list-style-type: none"> Remained the same Improved Affected negatively
	<p>Emotional effects 4.2 Experience of loss of natural voice (6.2.2)</p>	<ul style="list-style-type: none"> Loss experience Acceptance
	<p>Re-entry into society 4.3 Experience of adjustment to society (6.3.1)</p>	<ul style="list-style-type: none"> Easy Difficult Uncertain
	<p>4.4 Things that made re-entry into society easier (6.3.2-6.3.3)</p>	<ul style="list-style-type: none"> Inner strength External resources <ul style="list-style-type: none"> Social support Speech Children / grandchildren Hobbies
	<p>4.5 Sources of fear and uncertainty (6.3.4)</p>	<ul style="list-style-type: none"> Physical aspects Lifestyle and aftercare
	<p>4.6 Lessons learned</p> <ul style="list-style-type: none"> Cancer experience Laryngectomy Previous strengths used <p>(6.3.5.1-6.3.5.3)</p>	<ul style="list-style-type: none"> Healthy lifestyle Appreciation of life Spirituality

8.2 COPING AND STRENGTHS

It is during the **extended phase** of survivorship that patients have to cope with various aspects of their medical treatment (Miller *et al.*, 2008:372). For laryngectomy survivors (patients and families), it implies that they have to cope with emotions connected to physical changes caused by the operation, treatment completion and re-adjustment after the operation, followed by their aftercare (Annexure A).

8.2.1 Theme 3: Patients' and families' experiences of coping and strengths used

The third theme that was explored was patients' and their family members' experiences of coping and the strengths they have utilised in order to survive various phases of the laryngectomy experience.

8.2.1.1 Theme 3: Sub-theme 3.1: Coping with permanent physical changes caused by the operation

Patients were asked to describe how they managed to cope with permanent physical changes resulting from the operation. Participants referred to their use of both inner resources (inner strength) as well as environmental resources (social support). This represents a combination of utilising both the strengths (Saleebey, 2002:13-18) and ecological perspectives (Germain & Gitterman, 1996:9-14) in an attempt to cope with the changes.

Responses to this question link well with follow-up questions within the same theme, by which participants were asked which strengths they had utilised in order to cope with the laryngectomy experience in general (Sub-theme 3.5) and also, which resources they utilised in order to assist them in their post-operative coping (Sub-theme 4.4). A full description of both internal and external resources is presented in Sub-theme 3.5 of this chapter.

(a) *Category: Strengths*

On the basis of the principles of the strengths perspective (Saleebey, 2002:13-18), thirty-one (68,9%) patients acknowledged that they utilised their inner strength to deal with inevitable physical changes resulting from the operation. These strengths varied from having a fighting spirit (“...you have to fight back”) and willingness to adapt to changed circumstances (“And then my own will ... I want to go ahead”) to the ability to come to terms with one’s own limitations (“I realised that I will not be able to do the things I did before”). To have a positive attitude of acceptance (“... to accept yourself the way you are now”; “You have to become used to it yourself”) and to deliberately decide to continue with life despite the operation (“I decided ... I just have to continue with life”) were also referred to. Within this category, the role of one’s own personality in utilising these strengths was also emphasised (“I think your personality will help”). These categories are representative of the principles of the strengths perspective as stressed by Saleebey (2002:13-18), namely to have inner strength; to see cancer as a challenge and opportunity; to utilise cancer as opportunity for growth and change and the ability to collaborate.

Table 8.2 presents “inner strength” as a way of coping with permanent physical changes following the operation.

TABLE 8.2: Ways of coping with permanent physical changes: inner strength

Theme 3: Patients' and families' experiences of coping and strengths used	
Sub-theme 3.1: Coping with permanent physical changes caused by the operation	
Category	Narratives of participants
Strengths <ul style="list-style-type: none"> • Inner strength • Challenge and opportunity • Growth and change • Collaboration 	<p>INNER STRENGTH</p> <p>Fighting spirit</p> <ul style="list-style-type: none"> • <i>"I just said to myself, this is <u>not the end of the road</u>, you have to <u>fight back</u>." / "Ek het net vir myself gesê, dit is nie die einde van die pad nie. Jy moet terugbakei."</i> <p>Own personality</p> <ul style="list-style-type: none"> • <i>"It is part of your life, you have to adapt. I think your <u>personality</u> will help ... I easily adapt in any situation" / "Dis maar deel van jou lewe, jy moet aanpas. Ek dink dit is jou persoonlikheid wat daar help ... ek pas my aan in enige situasie baie maklik"</i> • <i>"I <u>have that ability</u> to block it out, to put it in segments. I store it in my memory and it can stay there ... I will deal with it later ..." / "Ek het daai vermoë om hom te blok, jy kan hom in segmente sit. Dan pak ek hom in my 'memory' en daar kan hy nou maar sit ... ek hanteer dit later ..."</i> <p>CANCER AS CHALLENGE AND OPPORTUNITY</p> <p>Willingness to adapt to change</p> <ul style="list-style-type: none"> • <i>"And then <u>my own will</u>. I will not just sit there, I <u>want to go ahead</u>." / "En dan nou my wilskrag. Ek gaan nie op 'n hophie sit nie, ek gaan vooruit."</i> <p>CAPACITY FOR GROWTH AND CHANGE</p> <p>Came to terms with limitations</p> <ul style="list-style-type: none"> • <i>"I realised that I will not be able <u>to do the things I did before</u> ... you just have to encourage yourself." / "Jy sal nie meer die dinge doen wat jy voorheen gedoen het nie ... jy moet maar nou net vir jou opbeur."</i> <p>Acceptance</p> <ul style="list-style-type: none"> • <i>"<u>Acceptance</u> is very important, to <u>accept yourself as you are now</u>." / "Aanvaarding is baie belangrik, om te aanvaar soos jy nou is."</i> <p>COLLABORATION</p> <p>Will to continue with life</p> <ul style="list-style-type: none"> • <i>"I <u>decided</u> it will be of no use if I am angry, I just have <u>to continue</u> with life." / "Ek het besluit dit baat nie ek gaan kwaad wees of iets nie, ek moet maar net voortgaan met die lewe."</i>

(b) Category: Social support

To a lesser extent (7, or 15,6%), the role of social support in order to adapt to changes resulting from the operation was also highlighted. Participants identified support from various sources, such as from family, friends and people of the church (*"I got lots of*

support from the church and the family). This refers to patients' interaction with the resources within their environment in terms of the ecological perspective (Germain & Gitterman, 1996:9-14). However, environmental resources can also be informal, to include relatives, friends (“...a friend who also had a stoma ...she always came to me...”) and neighbours (Germain & Gitterman, 1996:5). It is in this regard that Saleebey (2001:17) mentioned that every environment has individuals or groups who have something to give that others may desperately need. The following examples with regard to the role of social support in coping with permanent physical changes can be viewed from participants' narrative responses (Table 8.3):

TABLE 8.3: Coping with permanent physical changes: social support

Theme 3: Patients' and families' experiences of coping and strengths used	
Sub-theme 3.1: Coping with permanent physical changes caused by the operation	
Category	Narratives of participants
Social support <ul style="list-style-type: none"> • Family • Friend • Church 	<ul style="list-style-type: none"> • “It was not difficult for me to adapt because I got lots of <u>support from the church and the family</u>.” / “Dit was nie vir my moeilik om aan te pas daarmee nie want ek het baie ondersteuning ook gekry soos van die kerk af en die familie.” • “I had <u>a friend who also had a stoma</u>. She always came to me and sat by me and then I felt better.” / “Ek het ‘n vriendin gehad wat ook so ‘n gaatjie het. Sy het altyd oorgekom na my toe en by my kom sit en dan voel ek weer beter.”

8.2.1.2 Theme 3: Sub-theme 3.2: Coping with end of active medical treatment

Patients experienced the end of medical treatment with various emotions, which varied from thankfulness and sadness to a combination of emotions.

(a) Category: Thankfulness

The majority of patients (32, or 71,1%) experienced emotions of gratitude following their medical treatment. These were the patients who had been operated from eight months

to nineteen years (with an average of four years and seven months) prior to the date of the interview. They mainly referred to the fact that the treatment improved their condition (*"I feel much better than before the operation."*). They also reported support received from the hospital team as a reason for their thankfulness (*"... thankful for the people at hospital ..."*). Their ability to re-enter their family cycle (*"I was very thankful ... that I could go home and to be with my children"*); their ability to master post-operative speech (*"I am thankful to talk"*); and their future expectations (*"...thankful that I could continue with my life"*) helped them to experience treatment completion as reasons for thankfulness. Jefford *et al.* (2008:30) and Hara and Blum (2009:40) acknowledge that families and friends will experience feelings of happiness at the stage of the patient's treatment completion. Another reason for their thankfulness which was supported in literature (Hara & Blum, 2009:40) was that some patients acknowledged the financial benefit of treatment completion as it implies that they do not have to spend money on travelling in order to report at the hospital so often (*"... then I spend less money"*). This can be linked to the finding that twenty-nine participants (64,4%) **earned** less than R2 499 per month. Patients may also experience the feeling of pride in managing to complete their prescribed medical treatment (Coughlin, 2008:61; Rowland, 2008:364).

TABLE 8.4: Coping with treatment completion: thankfulness

Theme 3: Patients' and families' experiences of coping and strengths used	
Sub-theme 3.2: Coping with end of active medical treatment	
Category	Narratives of participants
Thankfulness <ul style="list-style-type: none"> • Health • Support • Family • Speech • Future • Financial 	<p>Improved health</p> <ul style="list-style-type: none"> • <i>"I <u>feel very good, much better</u> than before the operation."</i> / "Ek voel nou baie goed, baie beter as wat ek voor die operasie gevoel het." <p>Support of hospital team</p> <ul style="list-style-type: none"> • <i>"I am thankful for the <u>people at hospital</u> who helped me."</i> / "Ek is dankbaar vir mense by die hospitaal wat vir my gehelp het." <p>Reintegration with family</p> <ul style="list-style-type: none"> • <i>"I was very thankful ... that I could go home and <u>to be with my children.</u>"</i> / "Ek het bly gevoel ... dat ek weer by die huis by my kinders kan wees." <p>Post-operative speech</p> <ul style="list-style-type: none"> • <i>"I am thankful to talk, that I can have a <u>conversation with you.</u>"</i> / "Ek is dankbaar dat ek kan praat, dat ek 'n gesprek met jou kan voer." <p>Future expectancy</p> <ul style="list-style-type: none"> • <i>"I was very thankful that I could <u>continue with my life...</u>"</i> / "Ek het bly gevoel dat ek nou kan aangaan met my lewe ..." <p>Financial reasons</p> <ul style="list-style-type: none"> • <i>"It made me feel good when I did not have to come here so often, then you <u>spend less money.</u>"</i> / "Dit het my lekker laat voel toe ek nou nie meer so baie hiernatoe kom nie, dan gee jy minder geld uit."

(b) *Category: Fear and uncertainty*

Fear and uncertainty were experienced by six (13,3%) patients. With these participants, the period from the date of surgery to the date of the interview varied between sixteen months and eleven years, the average being five years and eleven months. This is supported in the literature (Haylock *et al.*, 2007:62). Patients mainly referred to fear for social rejection by others ("*...I thought [about] how they are going to accept me*"). To a lesser extent, this was followed by the fear of recurrence of the cancer ("*...will it come back ... you are always afraid ...*") and uncertainty when leaving the safety ("*I was afraid to leave the hospital*") and the support of the hospital ("*I must say I miss you a lot*"). This is supported in literature (Jefford *et al.*, 2008:21, 23, 26), stating that patients may experience anxiety about separating from the health care system. Rowland (2008:363-364) has also emphasised that moving from active treatment to recovery can be stressful, taking into account the above-mentioned reasons.

Table 8.5 presents patients' narrative responses to the question how they coped with treatment completion in the category of "fear and uncertainty":

TABLE 8.5: Coping with treatment completion: Fear and uncertainty

Theme 3: Patients' and families' experiences of coping and strengths used	
Sub-theme 3.2: Coping with end of active medical treatment	
Category	Narratives of participants
Fear and uncertainty <ul style="list-style-type: none"> • Others • Recurrence • Leaving hospital • Absence of support 	<p>Reaction of others</p> <ul style="list-style-type: none"> • <i>"I felt <u>nervous</u> as I thought <u>how</u> they are going to <u>accept me</u>. How do I have to react?" / "Ek het senuweeagtig gevoel want ek het gedink hoe gaan hulle nou vir my aanvaar. En hoe moet ek nou reageer."</i> <p>Cancer recurrence</p> <ul style="list-style-type: none"> • <i>"Regarding the disease, <u>will it come back</u> ... you are always <u>worrying</u>." / "Wat die siekte betref gaan dit terugkom ... jy is altyd bekommerd."</i> <p>Leaving the safety of the hospital</p> <ul style="list-style-type: none"> • <i>"I was <u>afraid to leave</u> the hospital ... I turned back, I wanted to go back. I am afraid of being outside. I had an eternal <u>fear for my acceptance</u> ... because I did not have confidence in myself ... while I was walking I thought, <u>will my wife accept me the way I am?</u>" / "Ek was bang om uit die hospitaal uit te gaan ... toe draai ek om, ek wil teruggaan. Ek is bang om buite te wees. Ek het 'n ewige vrees gehad vir die aanvaarding daarvan ... want ek het nie vertrou in myself gehad nie ... toe ek daar afgeloop kom toe dink ek gaan my vrou my aanvaar soos wat ek is?"</i> <p>Absence of support from hospital</p> <ul style="list-style-type: none"> • <i>"I must say I <u>miss you a lot</u>, I just want to be with you." / "Ek moet sê ek verlang vir julle baie, ek wil sommer net saam wees ..."</i>

(c) *Category: Mixed feelings*

Only seven (15,6%) patients experienced mixed feelings of happiness and sadness when leaving the hospital system, which is in accordance with the opinion of both Hoffman (1989:86) and Miller *et al.* (2008:372). In the current study, mixed feelings included feelings of thankfulness together with sadness (*"A bit of sadness ... but also a bit of thankfulness ..."*); shame (*"...glad to be out of hospital, but actually I was ashamed of what the people will say"*) or feelings of discomfort (*"I felt very satisfied ... a bit uncomfortable to be at home"*). Table 8.6 reflects responses on the question regarding patients' coping with treatment completion in the category of "mixed feelings":

TABLE 8.6: Coping with treatment completion: mixed feelings

Theme 3: Patients' and families' experiences of coping and strengths used	
Sub-theme 3.2: Coping with end of active medical treatment	
Category	Narratives of participants
Mixed feelings Thankfulness vs <ul style="list-style-type: none"> • Sadness • Shame • Discomfort 	<p>Thankfulness and sadness</p> <ul style="list-style-type: none"> • <i>"A bit of <u>sadness</u> to leave the people behind who supported you ... but also a bit of <u>thankfulness</u> as you are on your way home ... sadness and thankfulness, it goes together ..."</i> / Darem 'n tikkie hartseer om die mense wat vir jou heeltyd ge-ondersteun het nou agter te los ... maar ook 'n tikkie blydschap want jy kan nou huis toe ... die hartseer en blydschap hulle gaan so saam ..." • <i>"I would say I was <u>glad</u> ... when they discharged me I had tears in my eyes and I was <u>sad</u> to leave them ... when I left I looked back and told them, we leave one another now, but in my heart I will never forget you."</i> / "Ek sal sê ek was bly ... toe hulle my ontslaan toe was daar trane in my oë en ek was hartseer om hulle te verlaat ... en toe ek weggaan het ek nog weer omgekyk en vir hulle gesê, ons los nou mekaar, maar in my hart sal ek julle nooit vergeet nie." <p>Thankfulness and shame</p> <ul style="list-style-type: none"> • <i>"I was <u>glad</u> to be out of hospital, but actually I was <u>embarrassed about what the people would say</u>"</i> / "Ek was bly om uit die hospitaal te gaan, maar eintlik, ek was skaam want wat gaan die mense sê." <p>Thankfulness and discomfort</p> <ul style="list-style-type: none"> • <i>"I felt very <u>satisfied</u> ... it made me feel a <u>bit uncomfortable to be at home</u>"</i> / "Ek het baie tevrede gevoel ... dit het my bietjie ongemaklik laat voel by die huis."

Some variables of participants' identifying details could have contributed to their response. With regard to their level of education, the majority (71%) of these participants had secondary and additional **training**. They therefore found it easier to specify their feelings as experienced at the stage of treatment completion. Furthermore, the **age** of participants who experienced mixed feelings at the time of treatment completion was between 49 and 73 years, with five of them being younger than sixty years. Survivors in the middle age group may be involved in fulfilling multiple social roles (Cella, 1987:62). The laryngectomy experience then may lead to the feeling of having more to lose than survivors of an older age (Hara & Blum, 2009:47). Taking into account the period from **surgery** to the **date of interview**, this varied between eight months and ten years with an average of four years and seven months.

8.3.1.3 Theme 3: Sub-theme 3.3: Coping with post-operative readjustment

In coping with post-operative readjustment following surgery, **patients** were first asked about their own experience concerning the most difficult adjustments they had to make (Question 5.3.1). This was followed by the **patients' opinions of their family's** most difficult adjustment (Question 5.3.2). Lastly, **family** members themselves had the opportunity to comment on this question (Question 3.1).

TABLE 8.7: Patients' and families' most difficult post-operative adaptation

Theme 3: Patients' and families' experiences of coping and strengths used			
Sub-theme 3.3: Coping with post-operative readjustment			
Most difficult post-operative adaptation	Patients' responses (n = 45)*		Family's responses as reported by family members themselves (n = 15)*
	Patients' own reactions	Family's reactions as perceived by patients	
Speech	29 (64,4%)	29 (64,4%)	6 (40,0%)
Physical effect (including presence of stoma)	12 (26,7%)	9 (20,0%)	3 (20,0%)
Social effect	6 (13,3%)	0 (0,0%)	1 (6,7%)
Emotional effect	0 (0,0%)	8 (17,8%)	2 (13,3%)
Nothing / not sure	3 (6,7%)	6 (13,3%)	3 (20,0%)

**(Some participants indicated more than one opinion, therefore the total will exceed 100%)*

Patients' responses were in line with the literature (McQuellon & Hurt, 1997:233-234) referring to Pruyn *et al.* who reviewed literature on psychological aspects of head and neck cancer and who summarised studies of post laryngectomy patients concerning problems pertaining **speech**; embarrassment about **physical appearance** and the experience of **psychological** problems.

(a) *Category: Speech*

In all three categories reflected in Table 8.7, patients' speech was the most difficult to adapt to following the operation, as indicated by twenty-nine patients (64,4%) and six families (40,0%). This correlates with literature (Graham, 2004:127) stating that loss of speech and an altered method of speech is considered the most traumatic and challenging consequence of a laryngectomy. When participants (patients) were asked about their family's most difficult post-operative adjustment, again, twenty-nine (64,4%) indicated that family members must have found it difficult to adapt to their new way of communication and speech. Findings of patients' responses thus correlated well with families' responses.

Patients found it difficult to become used to their experience of loss of voice (*"The worst was not being able to talk"*). They also had to learn a new way of speech production and communication (*"To learn to talk was the most difficult"*). Not being heard (*"To express yourself in a situation where no one can hear you"*) was another concern whilst they referred to their own feelings (*"...you feel self-conscious"*) in this regard. Acceptance from others (*"...you never know how they are going to accept you"*) was also difficult for them, as some people felt sorry for them and others made fun of them. **Patients** indicated that it must have been difficult for **family members** to become used to their loss of voice (*"...as I cannot talk like before"*); loss of self-expression (*"I've lost my ability to laugh"*), their new method of speech production (*"...which process I have to go through so that I produce voice"*) and initial difficulty in understanding them (*"...when they did not understand what I tried to say"*).

Six (40,0%) **family members** referred to adjustment to the patients' post operative speech. They referred to the new technique of communication (*"I learned not only to hear but to listen"*). In some instances it also resulted in the patient's anger towards their family members (*"I could not understand him then he became angry"*). This is supported by McQuellon and Hurt (1997:233-234) who referred to Pruyn *et al.*'s study, concerning problems pertaining to speech, which could include not being understood; not being

able to make oneself heard in a noisy room; and feeling inhibited regarding the ability to express themselves. Difficulty with adjustment to the patient's post-operative speech will be reflected in Table 8.8.

TABLE 8.8: Most difficult post-operative adaptation: speech

Theme 3: Patients' and families' experiences of coping and strengths used	
Sub-theme 3.3: Coping with post-operative readjustment	
Category	Narratives of participants
<p>Speech</p> <ul style="list-style-type: none"> • Loss of voice • New technique • Not heard • Not understood • Own feelings • Others • Self-expression • Frustration • Anger 	<p>PATIENTS</p> <p>Loss of voice</p> <ul style="list-style-type: none"> • <i>"The worst was <u>not being able to talk</u>. When others talk you only look at them. You want to say something but you cannot talk."/ "Die slegste was dat jy kan nie praat nie. As ander praat dan kyk jy net vir hulle. Nou wil jy ook graag iets sê maar jy wil nie nou sê nie, want jy kan nie praat nie."</i> <p>Technique of learning speech production</p> <ul style="list-style-type: none"> • <i>"At times, some <u>speech runs along one side between my fingers then you can hear the speech is not right</u>."/ "Soms dan hardloop van die geselskap by die een kant by die vinger deur, dan kan jy hoor die sprake is nie reg nie."</i> <p>Not being heard</p> <ul style="list-style-type: none"> • <i>"To express yourself in a situation where <u>no one can hear you</u>."/ "Om jou uit te druk in 'n situasie waar niemand jou kan hoor nie."</i> <p>Own feelings</p> <ul style="list-style-type: none"> • <i>"... your voice that has changed when you talk people's attention is on you ... <u>you feel self-conscious</u>."/ "... jou stem wat verander het as jy praat dan is mense se aandag op jou ... jy is selfbewus."</i> <p>Reaction of others</p> <ul style="list-style-type: none"> • <i>"... You never know how they are <u>going to accept you</u>."/ "... jy weet nooit hoe gaan die mense jou aanvaar nie."</i> • <i>"<u>Some feel sorry for you and others see you as a joke</u>."/ "Party Kan jou bejammer en vir ander kan jy 'n 'joke' wees."</i> <p>FAMILY MEMBERS ACCORDING TO PATIENTS</p> <p>Loss of voice</p> <ul style="list-style-type: none"> • <i>"Probably to talk ... as I <u>cannot talk as I talked before</u>."/ "Seker maar die praat ... want ek kan mos nie meer praat soos ek gepraat het nie."</i>

Theme 3: Patients' and families' experiences of coping and strengths used	
Sub-theme 3.3: Coping with post-operative readjustment	
Category	Narratives of participants
	<p>Loss of self-expression</p> <ul style="list-style-type: none"> • <i>“When they make a joke, you can only ‘smile’, I’ve <u>lost my ability to laugh.</u>” / “As hulle grappe maak, jy moet nou maar net ‘smile’ ek het my lag alles verloor.”</i> <p>Technique of learning speech production</p> <ul style="list-style-type: none"> • <i>“To see, whenever I want to talk, which <u>process I have to go through so that I produce voice for them to understand.</u>” / “Om te sien elke slag as ek wil praat, watter proses ek moet deurgaans dat daar kan klank uitkom dat hulle kan verstaan.”</i> <p>Not being understood</p> <ul style="list-style-type: none"> • <i>“Your speech may not be as clear as it always was and it makes them a bit <u>uncertain or nervous.</u> Did they hear you correctly or how will you react if they answer wrongly to what you have asked them.” / “Jy praat miskien nie so duidelik soos altyd nie en dit maak hul bietjie onseker of dit maak hul bietjie senuweeagtig. Hoor hulle nou reg of hoe gaan jy nou optree as hul nou die verkeerde antwoord [gee] op dit wat jy nou gevra het.”</i> <p>FAMILY MEMBERS</p> <p>Becoming familiar with new technique of communication</p> <ul style="list-style-type: none"> • <i>“I learned <u>not only to hear but to listen.</u> Before the operation we walked past each other and then we talked, communicated. Now I have to stand still, look him into the eyes.” / “Ek het geleer om nie net te hoor nie, maar om te luister. Voor die operasie het ons bymekaar verbygestap, en dan het hy en ek gepraat, gekommunikeer. Nou moet ek gaan stilstaan, hom in die oë kyk.”</i> <p>Taking care of patient’s frustration or anger</p> <ul style="list-style-type: none"> • <i>“I <u>could not understand him,</u> and then he became <u>difficult.</u>” / “Ek hom nie kan lekker verstaan het nie, en dan het hy so moeilik geraak”.</i>

(b) Category: Physical effects

Within this category, **patients** (12, or 26,7%) mostly referred to the presence of the stoma and their experience of limited physical ability. Besides the absence of normal laryngeal speech, authors (DeSanto *et al.*, 1995:768; Devins *et al.*, 1994:608; Graham, 2004:126; Hanna *et al.*, 2004:875; Herranz & Gavilán, 1999:990) agreed that the

presence of the tracheostoma is the most dramatic physical change following the operation. McQuellon and Hurt (1997:233-234), refer to Pruyn *et al.*'s study about embarrassment about physical appearance, including food intake; impairment of taste and sucking; mucous discharge (“...when you talk you have to go away to clean it”); coughing (“I was afraid to cough”); hygiene; blowing nose; colds; breathlessness; reduced physical capacity (“Now I cannot do too much then I become tired”) and fear in covering stoma with the potential of experiencing difficulty with breathing; fear of water entering the stoma. Within this category, one patient also referred to loss of previous physical recreational activities (“My most difficult adaptation was my sport”).

Patients also referred to their family's (9, or 20,0%) difficulty to accept the presence of the stoma (“The most difficult was to look at me ... because they look into the stoma”) and to take care of the stoma in the presence of others (“...to go outside to cough”). Also, patients reported that their families were afraid of a potential fatal outcome of the disease (“...that I would not make it”). **Families** confirmed (3, or 20,0%) their difficulty with regard to the patients' physical appearance, which was in correlation with how patients thought that family members would feel about the stoma (“...to clean it and to keep it clean”).

Table 8.9 presents the responses of participants regarding the most difficult post-operative adaptation with specific reference to “physical effects”.

TABLE 8.9: Most difficult post-operative adaptation: physical effects

Theme 3: Patients' and families' experiences of coping and strengths used	
Sub-theme 3.3: Coping with post-operative readjustment	
Category	Narratives of participants
Physical effects <ul style="list-style-type: none"> • Cough/stoma • Physical ability • Recreational • Appearance • Fatal disease • Taking care 	<p>PATIENTS</p> <p>Coughing / Stoma care</p> <ul style="list-style-type: none"> • <i>"Shortly after the operation is the <u>regular cleaning</u> ... when you talk you have to go away to clean it."</i> / "Net ná die operasie is hierdie gereelde skoonmakery ... as jy praat dan moet jy opstaan en skoonmaak." • <i>"I was afraid <u>to cough</u> because it comes through the stoma."</i> / "Eintlik was ek bang om te hoes ook want die goed kom mos deur die gaatjie." <p>Less physical ability</p> <ul style="list-style-type: none"> • <i>"Now I cannot do too much then I <u>become tired</u>."</i> / "Nou kan ek nie te veel woel nie dan raak ek moeg." <p>Loss of recreational activities</p> <ul style="list-style-type: none"> • <i>"My most difficult adaptation was my <u>sport</u>. That I could not participate actively."</i> / "My moeilikste aanpassing was nou my sport. Dat ek nie meer so aktief kan deelneem nie." <p>FAMILY MEMBERS ACCORDING TO PATIENTS</p> <p>Becoming used to changed physical appearance</p> <ul style="list-style-type: none"> • <i>"The most difficult was to look at me ... because they look into the <u>stoma</u>."</i> / "Die moeilikste was gewees die aanskouing ... want hulle kyk binne in die gat." • <i>"During meals I have to excuse myself from the table to go outside <u>to cough</u>."</i> / "Etenstye dan moet ek van die tafel opstaan om uit te gaan om te gaan hoes." <p>Fear for cancer as fatal disease</p> <ul style="list-style-type: none"> • <i>"They thought at the time I had the operation that I would <u>not make it</u>."</i> / "Hulle het gedink die tyd dat ek die operasie gehad het ek sal dit nie anderkant enduit kom nie." <p>FAMILY MEMBERS</p> <p>Taking care and observing of physical effects</p> <ul style="list-style-type: none"> • <i>"The most difficult was <u>to clean it</u> and to <u>keep it clean</u>."</i> / "Die moeilikste was om daai ding skoon te kry en skoon te hou." • <i>"I could not accept that he was lying there with such a <u>long cut</u>, it was terrible for me. I cannot clean it because it seems <u>as if I hurt him</u>."</i> / "... toe kon ek dit nie aanvaar dat hy met die lang sny lê nie, dit was vir my verskriklik. En kan nie skoonmaak nie, want dit lyk ek maak vir hom seer."

(c) *Category: Psychosocial effects*

Whilst patients (6, or 13,3%) mainly identified problems they experienced on a social level, they referred to their family's problems that they experienced on an emotional level (8, or 17,8%). With reference to Pruyn *et al.*'s study (McQuellon & Hurt, 1997:233-234), psychological problems such as anxiety, uncertainty, depression, loss of self-esteem, suicidal thoughts, uselessness, shame, irritability, fear of recurrence and a sense of inferiority were identified. They also referred to vocational problems, social withdrawal (*"The most difficult was the people closest to you ... they ignored me"*) and tension in relationships (*"For me the most difficult was to be among other people"*) as was found in the current study.

Patients referred to problems they experience when socialising with others (*"The most difficult was to be among other people"*) and also their decision to change their previous social habits (*"I had to change my whole way of living ... I drank and smoked..."*). This is especially applicable in the case of those who present with a cancer diagnosis of the head and neck area, as social habits such as severe drinking and smoking can be seen as etiological factors contributing to the diagnosis (Cady, 2002:347).

Interestingly and in accordance with the literature (Blanchard, 1982:240), patients referred to families' inability to take care of them once they were at home as they were not always equipped to take care of their post-operative needs (*"...they wondered whether they would be able to take care of me"*). They also referred to problems their families may have experienced regarding their post-operative adjustment (*"...they did not know me like that"*) and especially their aftercare.

Family members confirmed this information as three (20,0%) said that they mainly experienced problems on an emotional level. Emotional problems that were experienced varied from temporary separation during treatment (*"...he was far... it was difficult because we had never been separated for so long"*) to having to deal with the

reaction of others (“When we went out there were people who turned their noses up at him...”). Responses are reflected in Table 8.10:

TABLE 8.10: Most difficult post-operative adaptation: psychosocial effects

Theme 3: Patients’ and families’ experiences of coping and strengths used	
Sub-theme 3.3: Coping with post-operative readjustment	
Category	Narratives of participants
Psycho social effects <ul style="list-style-type: none"> • Socialisation • Social habits • Aftercare • Adjustment • Separation • Others 	<p>PATIENTS</p> <p>Socialisation</p> <ul style="list-style-type: none"> • “The most difficult was to be <u>among other people</u>. You <u>feel ashamed</u> as the <u>saliva</u> is running when you are talking.” / “Die moeilikste was om tussen ander mense te kom. Jy voel skaam ... vir die slyme wat uitloop as jy praat.” • “The most difficult was the <u>people closest to you</u> ... they <u>ignored</u> me. They <u>felt sorry</u> for me. They kept me at a <u>distance</u>.” / “Die heel moeilikste is die mense die naaste aan jou ... hulle het vir my altyd geïgnoreer. Hulle het my jammer gekry. Hulle het my op ‘n afstand gehou.” <p>Change in social habits</p> <ul style="list-style-type: none"> • “I had to <u>change</u> my whole <u>way of living</u> ... I <u>drank</u> and <u>smoked</u> and hung around with the other men.” / “Ek moes my hele manier van lewe ge-‘change’ het ... ek het gedrink en gerook en saam met die ander manne in die rondte geloop.” <p>FAMILY MEMBERS ACCORDING TO PATIENTS</p> <p>Aftercare</p> <ul style="list-style-type: none"> • “When they heard I will be discharged they <u>wondered</u> whether they would <u>be able to take care of me</u>. They were <u>scared</u>.” / “Toe hulle hoor ek kom huis toe, toe het hulle gesê hulle het gewonder of hulle sal kan werk saam met my. Hulle was bangerig gewees.” <p>Adjustment</p> <ul style="list-style-type: none"> • “They did not feel good because they said they <u>felt sore on my behalf</u>.” / “Hulle het nie lekker gevoel nie want hulle sê hulle kry seer vir my part.” • “It was <u>difficult</u> for them because they <u>did not know me like that</u>.” / “Dit was vir hulle moeilik want hulle ken mos nou nie vir my so nie.” <p>FAMILY MEMBERS</p> <p>Separation</p> <ul style="list-style-type: none"> • “The fact that he was <u>in hospital</u> for such a <u>long time</u>, he was far... it was difficult because we were never separated for so long.” / “Die feit dat hy so lank in die hospitaal moes gebly het, en hy was ver ... dit was baie moeilik gewees want ons was nooit lank uitmekaar uit nie.” <p>Reaction of other people</p> <ul style="list-style-type: none"> • “There were <u>people</u> who <u>turned their noses up at him</u>...” / “Daar was baie mense wat hul neus opgetrek het.”

8.2.1.4 Theme 3: Sub-theme 3.4: Coping with hospital's expectations after treatment completion

Participants (**patients**) were asked about whether they knew what the hospital team expected from them in order for them to cope on their own at home. They received guidance in their response to this question as they were given the option to indicate whether they knew exactly, did not exactly know or did not know at all. They then had to motivate their response.

As reflected in Table 8.11, the majority (34, or 75,6%) of the participants indicated that they knew exactly. To a lesser extent, some (6, or 13,3%) indicated that they did not know exactly. Five (11,1%) participants said that they did not know at all what was expected of them. **Family members**, on the other hand, were asked an open-ended question on the same issue. They mainly (9, or 60%) felt that they did not know exactly what was expected of them, whilst the other six (40%) felt that they did know exactly what was expected of them. Responses of patients are summarised in Table 8.11:

TABLE 8.11: Knowledge of hospital's expectations after treatment completion

Theme 3: Patients' and families' experiences of coping and strengths used		
Sub-theme 3.4: Coping with hospital's expectations after treatment completion		
Knew Exactly	Did not know exactly	Did not know at all
34 (75,6%)	6 (13,3%)	5 (11,1%)

n = 45

(a) Category: Knew exactly

Those patients who exactly knew what was expected of them at home referred to their preparation in general (“*I knew exactly as I received information on how to manage myself*”), which they felt was helpful. They were prepared in how to take care of the stoma (“*They did say how I have to clean the valve...*”) and also what was expected of them in terms of their new lifestyle (“*I knew I had to give my full co-operation ... stop smoking ... Alcohol and*

those things I have to leave”). Another factor contributing to their knowing exactly what was expected of them in terms of their aftercare, concerned the utilisation of their inner strength in having a positive attitude (*“I was very prepared as I had a positive attitude”*) as well as their motivation to be independent (*“... not to be dependent on any person”*). This links well with the strengths perspective conceptualised by Saleebey (2002:14), stating that every individual has strengths. They also found that faith helped them to feel prepared (*“...with God’s will I have to go on with my life”*). In a study conducted by Schulz *et al.* (2008:105) to determine the role of spirituality in coping with cancer it was found that spirituality gave patients a reason to survive and helped them to adjust to the effects of treatment following their treatment.

Family members felt prepared regarding what was expected of them in terms of physical care (stoma care; nasogastric tube feeding; general assistance at home; avoiding exposure to water, like swimming or showering) (*“They showed us how to clean the stoma and how to help him”*) and also the patient’s post-operative adaptation (*“The doctors showed us very well how it will be, how he will adapt”*). They emphasised the importance of this preparation even before the patient’s discharge. Being in a position to visit the patient during his hospitalisation, they found it useful to observe what was expected of them in this regard.

Responses of both primary and secondary survivors indicating that they did not know exactly what was expected of them with regard to the patients’ aftercare, is in contrast with literature (Ganz *et al.*, 2008:209; Haylock *et al.*, 2007:62), indicating that following treatment, survivors may experience a period of being “lost in transition”, with no specific guidelines for their aftercare. Those patients who indicated that they knew exactly what was expected of them in terms of their aftercare, **medical treatment completed** between three months and 19 years prior to the **interview** with an average of five years and one month.

Table 8.12 shows the responses to the question regarding survivors’ knowledge of expectations regarding their aftercare, “knew exactly”.

TABLE 8.12: Knowledge of expectations regarding aftercare: exactly knew

Theme 3: Patients' and families' experiences of coping and strengths used	
Sub-theme 3.4: Coping with hospital's expectations after treatment completion	
Category	Narratives of participants
Knew exactly <ul style="list-style-type: none"> • Aftercare • Lifestyle • Attitude • Independency • Faith • Information • Physical care • Adaptation 	<p>PATIENTS</p> <p>Preparation on aftercare</p> <ul style="list-style-type: none"> • <i>"I knew exactly as I <u>received information</u> on how to <u>manage myself</u>." / "Ek het presies geweet omdat 'n mens inligting gekry het oor hoe om jouself te hanteer."</i> • <i>"They <u>did tell</u> me how I have to keep <u>cleaning the valve</u> when I am at home and also how to take my <u>tablets</u>." / "Hulle het gesê by die huis moet ek aangaan met die skoonmaak van die kleppie en die pille wat ek gedrink het, hoe om dit te drink."</i> <p>Lifestyle</p> <ul style="list-style-type: none"> • <i>"I knew I had to give my <u>full co-operation</u> ... <u>stop smoking</u>." / "Ek het geweet ek moet my volle samewerking gee ... op te hou rook."</i> • <i>"<u>Alcohol</u> and those things I have to leave, I must not use it." / "Die drank en daai goed moet ek los, ek moet nie daai goed gebruik nie."</i> <p>Positive attitude</p> <ul style="list-style-type: none"> • <i>"I was very prepared as I had a <u>positive attitude</u>." / "Ek was baie gereed omdat ek positief ingesteld was."</i> <p>Own independency</p> <ul style="list-style-type: none"> • <i>"To be independent and <u>not be dependent</u> on any person ... I want to be <u>as normal as possible again</u>." / "Om onafhanklik te wees en nie afhanklik te wees van enige persoon nie ... ek wil so normaal moontlik weer wees."</i> <p>Role of faith</p> <ul style="list-style-type: none"> • <i>"I just accepted the fact that this was what had happened and <u>with God's help</u> I will go on with my life. Life does not stop there, it goes on and it moves forward." / "Ek het net aanvaar die feit dat dit is nou wat gebeur het en met die hulp van God gaan ek aan met my lewe. Die lewe stop nie hier nie, dit gaan aan en dit beweeg vorentoe."</i> <p>FAMILY MEMBERS</p> <p>Role of information</p> <ul style="list-style-type: none"> • <i>"The doctors often <u>talked</u> with us and <u>explained</u> to us." / "Die dokter het baie keer met ons gepraat en hy het baie dinge verduidelik aan ons."</i> • <i>"The doctor did not talk to us but he talked to my father. <u>My father told us, therefore we knew</u>." / "Die dokter het nie self met ons gepraat nie"</i>

Theme 3: Patients' and families' experiences of coping and strengths used	
Sub-theme 3.4: Coping with hospital's expectations after treatment completion	
Category	Narratives of participants
	<p>maar hy het saam met my pa gepraat. En my pa het weer vir ons gesê en op so 'n manier het ons geweet.”</p> <p>Physical care</p> <ul style="list-style-type: none"> • “They told her there would be certain things that she will not be able to do again, like <u>swimming</u> or <u>showering</u>.” / “Hulle het vir haar gesê daar is sekere dinge wat sy nie weer sal kan doen nie, soos swem of ‘shower’.” • “They showed us how to <u>clean the stoma</u> and how to <u>help him</u>.” / “Hulle het vir ons gewys hoe om die gaatjie skoon te hou en om hom te help.” <p>Post-operative adaptation</p> <ul style="list-style-type: none"> • “The doctors explained very well <u>how it would be</u>, <u>how he will adapt</u>.” / “Die dokters het vir jou baie mooi verduidelik hoe dit nou vir jou gaan wees, hoe hy die aanpassing gaan maak.”

(b) *Category: Did not know exactly*

Responses from those who indicated that they did not know exactly what was expected of them in terms of their aftercare, differed from those who did not ask (“*I did not ask them what and how...*”) to those who indicated that, although they were informed, would themselves be the persons to practise it at home (“*...and now you have to do it for yourself at home*”). These responses are presented in Table 8.13. The time between **treatment completion** and the **date of the interview** ranged from sixteen months to fifteen years with an average of four years and seven months. Participants who indicated that they did not know exactly what was expected of them once discharged from hospital, correlate with the literature (Cady, 2002:349), indicating that a shortened stay in hospital adds to patients' and families' pressure in performing post-operative self-care. One participant recommended the use of handouts and also joining a support group in order to prepare patients on what would be expected from them regarding their aftercare.

TABLE 8.13: Knowledge of expectations regarding aftercare: did not know exactly

Theme 3: Patients' and families' experiences of coping and strengths used	
Sub-theme 3.4: Coping with hospital's expectations after treatment completion	
Category	Narratives of participants
<p>Did not know exactly</p> <ul style="list-style-type: none"> • Did not ask • Lack of information • Uncertain 	<ul style="list-style-type: none"> • <i>"I did not ask them what and how. At times I wanted to do something and then I did not know whether I could."/ "Ek het mos nie vir hulle gevra wat en hoe en wat nou nie. Partykeer wil jy 'n ding doen en nou dink ek ek kan nie daai ding doen nie."</i> • <i>"I do not know what they expect of me, to keep the stoma clean and whether I have to attend the follow-up visits regularly."/ "Ek weet nie wat verwag hulle van my om die plek skoon te maak en skoonhou en moet ek gereeld die opvolg nakom."</i> • <i>"I only knew a bit because they taught us how to clean and now you have to do it for yourself at home."/ "Ek het maar net 'n bietjie geweet want hulle het vir ons geleer hoe om skoon te maak en dit moet jy nou self doen by jou huis."</i> • <i>"I was afraid something could happen to me and I would be far [from hospital]."/ "Ek was bang, ek het gevrees iets kan gebeur en ek is ver."</i>

(c) Category: Did not know at all

The five **patients** who indicated that they did not know at all what was expected of them when their treatment was finished and they had to cope on their own at home referred to the fact that they did not realise that the effect of the operation would be experienced on a continuous basis (*"I thought that when the operation is over then everything is over"*). They were ignorant as to what was expected from them in general and also in terms of their future employment (*"I did not know exactly what to do with my work, for example"*). Cady (2002:349) emphasised that, taking into account a shortened stay of patients in the safe environment of the hospital, would result in an increased level of pressure on patients to adjust to their laryngectomy experience in a relatively short time.

Family members also emphasised that there were both physical (*"One night he coughed and then the valve came out... what does one do in such a case?"*) and emotional effects (*"I had to learn to deal with his different moods"*) for which they were unprepared. These

included the following: diet; stoma care; care of the Provox, especially during an emergency; inability to scream or to sing (physical); mood swings; aftercare; self-centeredness; anger (emotional). Taking into account the increased survivorship of cancer patients, informal caregivers are likely to provide more complex care for a longer period of time, which may increase their levels of stress (Goland & Haskins, 2008:420). They found out for themselves (“*We found out for ourselves what worked best for us*”) or learned from the patient (“*He explained what they said to me*”) how to take care of the patient. Those who indicated that they did not know at all, had **completed their treatment** between six months and ten years prior to the **date of the interview**; an average of four years and two months elapsing between completion and being interviewed. Responses in the category “did not know at all” when asked about their knowledge of expectations regarding their aftercare, are presented in Table 8.14.

TABLE 8.14: Knowledge of expectations regarding aftercare: did not know at all

Theme 3: Patients’ and families’ experiences of coping and strengths used	
Sub-theme 3.4: Coping with hospital’s expectations after treatment completion	
Category	Narratives of participants
<p>Did not know at all</p> <ul style="list-style-type: none"> • Lack of information • Own experience 	<p>PATIENTS</p> <ul style="list-style-type: none"> • “<i>I <u>did not know at all</u>. I thought that when the operation is over, then everything is over.</i>” / “<i>Ek het glad nie geweet nie. Ek het gedog dat as die operasie klaar is dan is dit klaar dis verby.</i>” • “<i><u>No one told me</u> what was going on. I did not know exactly what to do with <u>my work</u>, for example.</i>” / “<i>Niemand het vir my mos nou gesê wat aangaan eintlik nie. Ek het nie presies geweet wat ek moet doen met my werk byvoorbeeld.</i>” <p>FAMILY MEMBERS</p> <p>Lack of knowledge regarding physical care</p> <ul style="list-style-type: none"> • “<i>He struggled <u>to eat</u>, it was an adaptation.</i>” / “<i>Hy het gesukkel om te eet en daar was ‘n aanpassing.</i>” • “<i>One evening he sneezed and then the <u>valve came out</u>. What does one do in such a case, and then also the <u>bleeding</u>.</i>” / “<i>Een aand het hy genies toe val die kleppie uit. Wat maak mens in so ‘n geval, en dan mos ook die bloeiery.</i>” <p>Lack of knowledge regarding emotional effects</p>

Theme 3: Patients' and families' experiences of coping and strengths used	
Sub-theme 3.4: Coping with hospital's expectations after treatment completion	
Category	Narratives of participants
	<ul style="list-style-type: none"> • <i>"I had to learn to deal with his <u>different moods</u>, I had to read it. In the beginning it was very difficult."</i> / "Ek moes geleer het om sy verskillende gemoedstoestande te hanteer en ek moes dit gelees het. Dit was baie moeilik aan die begin." <p>General</p> <ul style="list-style-type: none"> • <i>"<u>No, not at all</u> because things <u>came naturally</u>, how I have to take care of him."</i> / "Nee glad nie want kyk dinge het maar net vanself gekom, hoe ek vir hom moet behandel." • <i>"<u>No not really</u>. We continued as we do now. We <u>found out for ourselves</u> what worked best for us."</i> / "Nee nie rêrig nie. Ons het maar aangegaan soos ons nou ook aangaan. Ons het maar vir onself uitgevind dit werk beter so en dit werk beter sus." • <i>"No, they <u>did not say anything</u>. They <u>did not explain</u> to me, he explained me to what they said."</i> / "Nee hulle het vir my niks gesê nie. Hulle het nie vir my verduidelik, het hy vir my 'explain' wat hulle vir my gesê het."

8.2.1.5 Theme 3: Sub-theme 3.5: Coping with the laryngectomy experience in general by utilising strengths and resources

As referred to under Theme 3.1 in this chapter, patients mobilise a combination of the principles of the strengths and the ecological perspective in order to cope with their laryngectomy experience. With Theme 3.5, the utilisation of both the strengths and ecological perspectives will now be explored and described in more detail.

(a) Category: Strengths perspective

When asked about patients' utilisation of strengths in order to cope with their laryngectomy experience, the following responses were gained from a closed-ended question:

TABLE 8.15: Principles of the strengths perspective

Theme 3: Patients' and families' experiences of coping and strengths used			
Sub-theme 3.5: Coping with laryngectomy experience in general (strengths)			
Principles	Degree to which you utilise inner strengths		
5.5.1 Inner strengths	Extreme	Moderate	Not at all
I do not let the operation get me down	45 (100%)	0 (0,0%)	0 (0,0%)
I have hope for the future (optimism)	45 (100%)	0 (0,0%)	0 (0,0%)
I have a sense of purpose or meaning	44 (97,8%)	1 (2,2%)	0 (0,0%)
The support I receive from people or resources help me to feel strong	45 (100%)	0 (0,0%)	0 (0,0%)
AVERAGE %	99,4%	0,6%	0,0%
5.5.2 Cancer as challenge and opportunity	Extreme	Moderate	Not at all
I have plans for my life	41 (91,1%)	4 (8,9%)	0 (0,0%)
I think of the operation as an opportunity from which I could learn	43 (95,6%)	2 (4,4%)	0 (0,0%)
I decided to use strengths which had helped me in the past	44 (97,8%)	1 (2,2%)	0 (0,0%)
I have incorporated the experience into daily life	45 (100%)	0 (0,0%)	0 (0,0%)
AVERAGE %	96,1%	3,9%	0,0%
5.5.3 Capacity for growth and change	Extreme	Moderate	Not at all
To adapt to a more healthy lifestyle	40 (88,9%)	3 (6,7%)	2 (4,4%)
I realise what is most important in life	45 (100%)	0 (0,0%)	0 (0,0%)
I appreciate life and is thankful for my health	45 (100%)	0 (0,0%)	0 (0,0%)
Heightened spirituality	45 (100%)	0 (0,0%)	0 (0,0%)
AVERAGE %	97,2%	1,7%	1,1%
5.5.4 Collaboration	Extreme	Moderate	Not at all
To attend follow-up visits at hospital on a regular basis	45 (100%)	0 (0,0%)	0 (0,0%)
AVERAGE %	100%	0,0%	0,0%

n = 45

Responses to this question will now be discussed, based on the principles of the strengths perspective as conceptualised by Saleebey (2002:13-18):

(i) Inner strengths

All patients (45, or 100%) utilised strengths such as **not be let down** by the operation, **hope** for the **future** and **benefitted from support** in order to feel strong. In addition, almost all (44, or 97,8%) relied on a sense of **purpose and meaning**.

De Boer *et al.* (1995:505) verified this, indicating that, for the patient, purpose in life and perceived social support represent important resources in the course of coping with cancer. The literature (Alfano & Rowland, 2006:437; Coughlin, 2008:61; Foster *et al.*, 2009:241; Hawkins *et al.*, 2010:21; Schulz *et al.*, 2008:105) also describes the role of positive thinking, finding positive meaning in the cancer experience, hopefulness and optimism as helpful to tolerate or minimise stressful events which, in this regard, will be the diagnosis and treatment of cancer.

(ii) Cancer as challenge and opportunity

All participants (45, or 100%) indicated that they had **incorporated** their laryngectomy experience into **daily life**, whilst nearly all (44, or 97,8%) patients decided to utilise strengths which had helped them in the **past** in order to master this experience. Strengths that previously supported the patient in successful ways of coping have the potential to empower the survivor to use inner resources to adapt to change or to alter future plans (Pinquart & Fröhlich, 2009:408, 418; Roth & Breitbart, cited in Rubin, 2001:223). Forty-three (95,6%) participants indicated that they experienced the operation as an **opportunity** from which they could **learn**.

In addition, the majority of participants (41, or 91,1%) still had **plans** for the **future**. This was a positive finding, as uncertainty about one's future and an accompanying inability to make long-term plans occurs easily when having to deal with a cancer diagnosis (Jefford *et al.*, 2008:21).

(iii) *Capacity for growth and change*

All participants (45, or 100%) indicated that they experienced **heightened spirituality** following their operation, as well as that it promoted their **appreciation for life** and made them realise what is **most important in life**.

In a study conducted by Schulz *et al.* (2008:104-106), it was found that there is a positive association between **spirituality** and cancer coping, as spirituality may address a human need for certitude in crisis. Based on the various phases of survivorship as composed by Miller *et al.* (2008:369-374), it can be said that spirituality will help with acceptance at the stage of initial diagnosis and decision upon treatment (acute phase). Having to find meaning during the phase of treatment (acute phase), to cope with the effects of treatment (transitional phase) and during the post-treatment period (transitional and permanent survivorship phase), spirituality gave participants a reason to survive. It also helped them to cope with the potential for cancer recurrence and, in the end, to adjust to the effects of treatment (permanent phase).

Greater appreciation of life is a common finding among people who have experienced a life-threatening illness like cancer in an attempt to find benefit in their experience (Aspinwell & MacNamara, 2005:2550). According to Rowland (2008:364), in referring to “benefit finding” and “posttraumatic growth”, these positive effects often travel alongside negative effects in survivors’ lives post-treatment. This was followed, for the majority of the participants (41 or 91,1%), by an experience that the operation made their **life better**.

Most participants (40, or 88,9%) indicated that they decided to adapt to a more **healthy lifestyle** and to quit previous smoking and drinking habits. This was supported by Jefford *et al.* (2008:21) stating that not all consequences of a cancer experience are negative, as many people reported positive outcomes, such as positive lifestyle changes. Cancer can be seen as a “teachable moment”, which will be described under Theme 4.6 of this chapter.

(iv) Collaboration

All participants (45 or 100%) indicated their agreement to regular attendance of the **follow-up clinic**. Participants were offered the opportunity to give a reason for attending the follow-up clinic after their treatment. In response to being asked how they view the role of follow-up visits at the clinic, participants mostly (24, or 53,3%) indicated that they view it as an opportunity to assess their **cancer status** or to evaluate their **medical condition in general** (18, or 40,0%).

In the words of one of the participants, cancer can be seen as “a thief” as it “can easily come back to another place”. It is therefore of relevance to report for follow-up visits in order to assess their **cancer status**.

With regard to assessment of their **general medical condition**, eight (17,8%) participants referred to observation of possible stoma narrowing or leakage of the trachea during these visits at the hospital.

The literature (Coughlin, 2008:61; Feuerstein, 2007a:3; Grunfeld, 2006:5167; Kaanders & Hordijk, 2002:305) emphasises the importance of regular follow-up visits for survivors, for reasons ranging from taking care of late effects of treatment and assessment for a new primary disease or recurrence of disease to offering support and promotion of rehabilitation opportunities for survivors. Surprisingly, one (2,2%) participant referred to the benefit of social support when attending the follow-up clinic and whilst joining the support group. One (2,2%) participant was not sure about the purpose of follow-up visits at the clinic.

(b) Category: Social support

Participants were asked to identify the people with whom they had shared a house at the time of their operation (Table 8.16). This was followed by a request to describe what community resources, in their opinion, were available and had helped them in their post-operative coping with the laryngectomy experience.

TABLE 8.16: People in the same home at time of laryngectomy

Theme 3: Patients' and families' experiences of coping and strengths used	
Sub-theme 3.5: Coping with laryngectomy experience in general (social support)	
Person(s)	Number (%)
Life partner	34 (75,6%)
Parents	3 (6,7%)
Children / grandchildren (younger than 6 years)	15 (33,3%)
Children / grandchildren (7 - 12 years)	13 (28,9%)
Children / grandchildren (13 - 18 years)	8 (17,8%)
Children 18+ years	26 (57,8%)
Siblings	2 (4,4%)
Friends	1 (2,2%)
No other	2 (4,4%)

n = 45

More than half (26, or 57,8%) of participants indicated that their life partner shared the house with them at the time of their operation. This was followed by children above the age of 18 years (26, or 57,8%). A significant finding was that twenty-eight (61,9%) participants indicated that children at pre-school or of primary school age lived in the house where they were living at the time of surgery. The role of pre- and primary school children in these patients' laryngectomy experience is described under Theme 4.1 of this chapter.

Participants were then given the opportunity to indicate which resources in the community contributed towards their post-operative coping. As this was an open-ended question, no guidance was given. The following community resources were mentioned:

TABLE 8.17: Community resources

Theme 3: Patients' and families' experiences of coping and strengths used		
Sub-theme 3.5: Coping with laryngectomy experience in general (social support)		
Community resources	Patients' responses % (n = 45)*	Family's responses % (n = 15)*
Family members	17 (37,8%)	8 (53,3%)
Church friends	13 (28,9%)	5 (33,3%)
Day hospital	12 (26,7%)	0 (0,0%)
Friends	9 (20,0%)	0 (0,0%)
Neighbours	7 (15,6%)	0 (0,0%)
Hospital team	0 (0,0%)	8 (53,3%)
Support group	0 (0,0%)	2 (13,3%)

**(Some participants indicated more than one opinion therefore the total will exceed 100%)*

Participants (**patients**) identified family members as the most (17, or 37,8%) supportive resource in the community during their post-operative coping. This was followed by church friends (13, or 28,9%), the staff of the day hospital (12, or 26,7%); friends (9, or 20%) and neighbours (7, or 15,6%). Other sources of support mentioned by participants (patients) were the staff of the hospice or CANSA; welfare organisations; people from the community; the old age home where the specific patient was a resident; previous employers and people living on the farm.

Family members experienced support from the family as most helpful (8, or 53,3%), followed by hospital team members (8, or 53,3%); church friends (5, or 33,3%) and the support group (2, or 13,3%). Other sources of support with equal importance (3, or 20%) as identified by family members were the staff of the hospice, friends and neighbours. They also referred to their general practitioner, the society for disabled people and the day hospital.

Richardson *et al.* (1989:283-292) conducted a study with sixty laryngectomy patients in order to determine social environmental factors which could possibly minimise the effect

of a laryngectomy. It was found that different sources and types of social support contribute towards a reduction of physical and psychosocial dysfunction, and contribute to the learning of new skills to overcome limitations of surgery. For the laryngectomy survivor it implies that social support can contribute to learning new skills to overcome their speech limitation. Taking into account the age of participants - mostly elderly patients - the literature (Moore *et al.*, 2004:47) refers to lack of social support which is often experienced due to the fact that such persons had outlived their significant others and peers, and also due to geographic reasons, including lack of transport.

From the above it is clear that patients to a large extent utilised the principles of the **strengths perspective** in order to cope with their laryngectomy experience. This is supported by Saleebey (2002:14), who has referred to people's ability to build something of value with the resources within and around them, although illness may cause stress. Within the context of surviving a laryngectomy, the source of support can either be from the strengths or from the ecological perspective, or from a combination of both of these perspectives as seen from the responses of participants.

8.3 PSYCHOSOCIAL EFFECTS AND RE-ENTRY INTO SOCIETY

The final phase of survivorship, as described by Miller *et al.* (2008:372), is the **permanent phase** of survivorship. Participants in this phase were asked about their experience of the psychosocial effects of the operation and their re-entry into society. Rowland (2008:364), referring to the psychosocial and spiritual effects of the diagnosis of cancer, mentioned that "being cancer free does not mean being free of cancer".

8.3.1 Theme 4: Patients' and families' experiences of psychosocial effects of laryngectomy and re-entry into society

In the first sub-theme (4.1), an exploration of the **social effects** of the operation will be discussed. This will be followed (sub-theme 4.2) by a discussion of the **emotional**

effect against the importance of voice and their experience of their loss of voice. In the last place, the **re-entry into society** (sub-theme 4.3) will be presented.

8.3.1.1 Theme 4: Sub-theme 4.1: Social effects and adjustment

When asked about the effect of the operation on various social levels, the following social relations were tested: relationship with life partner; children or grandchildren; other family members; previous friends; ability to form new relationships; employment and financial position and fulfilment of social roles within the family. Participants mostly indicated that these relationships **remained the same** or even **improved** (relationship with other family members), as can be seen from Table 8.18. The minority acknowledged that their laryngectomy experience **affected** social relationships **negatively** with regard to previous friends, as well as their employment and finance.

TABLE 8.18: Effect of laryngectomy on social relationships (patients)

Theme 4: Patients' and families' experiences of psychosocial effects and re-entry into society					
Sub-theme 4.1: Social effects and adjustment					
Item	N/A	Did not comment	Improved	Remained the same	Affected negatively
Life partner	10 (22,2%)	0 (0,0%)	8 (17,8%)	22 (48,9%)	5 (11,1%)
Children/ grandchildren	2 (4,4%)	8 (17,8%)	11 (24,4%)	20 (44,4%)	4 (8,9%)
Other family members	0 (0,0%)	2 (4,4%)	19 (42,2%)	14 (31,1%)	10 (22,2%)
Previous friends	0 (0,0%)	0 (0,0%)	5 (11,1%)	20 (44,4%)	20 (44,4%)
New relationships	0 (0,0%)	1 (2,2%)	0 (0,0%)	30 (66,7%)	14 (31,1%)
Employment and finance	0 (0,0%)	1 (2,2%)	2 (4,4%)	18 (40,0%)	24 (53,3%)
Social role fulfilment	0 (0,0%)	4 (8,9%)	2 (4,4%)	29 (64,4%)	10 (22,2%)
TOTAL	12 (3,8%)	16 (5,1%)	47 (14,9%)	153 (48,6%)	87 (27,6%)

n = 45

(a) Category: Relationship remained the same

Participants mostly indicated that their relationships with their life partners; children and grandchildren and previous friends, their ability to form new relationships and their social role fulfilment **remained the same**. In Table 8.19, narrative responses of participants illustrate their viewpoint on relationships that had remained the same with regard to the various relations involved:

TABLE 8.19: Social effects (patients): relationships remained the same

Theme 4: Patients' and families' experiences of psychosocial effects and re-entry into society	
Sub-theme 4.1: Social effects and adjustment	
Category	Narratives of participants
Life partner	<ul style="list-style-type: none"> • <i>"He always said: 'Although you look like this, as long as you can talk and you are still alive then <u>you will be on my side.</u>' / "Hy het altyd gesê: 'Al lyk jy so, net solank jy kan praat en jy leef nog is jy altyd aan my kant."</i>
Grandchildren	<ul style="list-style-type: none"> • <i>"It <u>motivates one to recover sooner and to adapt sooner.</u>" / "Dit 'motivate' ook 'n mens om gouer te wil gesond raak en gouer aan te pas."</i> • <i>"That child made me feel <u>as if I did not have the operation.</u>" / "Daai kind het vir my gelaat voel dat ek amper nie eens voel ek het die operasie gehad nie."</i>
Ability to form new relationships	<ul style="list-style-type: none"> • <i>"I make new friends at <u>church.</u>" / "Ek maak baie nuwe vriende by die kerk."</i> • <i>"I make new friends here in <u>hospital.</u>" / "Ek maak sommer nuwe vriende hier in die hospitaal."</i> • <i>"... they come to the house and some of my friends bring <u>new friends with them</u>" / "... hulle kom daar by die huis en van my vriende kom kuier vir my en dan bring hulle miskien 'n vriend saam."</i>
Social role fulfilment	<ul style="list-style-type: none"> • <i>"I still do the same things which I did in the <u>past. I do it with appreciation ... to say thank you that I can still do it.</u>" / "Ek doen nog dieselfde dinge wat ek in die verlede gedoen het. Ek doen dit met waardering ... ek moet eintlik dankie sê dat ek dit vir hulle kan doen."</i> • <i>"It is not that my role in my family is difficult, <u>I can handle it. I cannot find that they excluded me.</u>" / "Dis nie dat my rol binne my gesin vir my moeilik is nie, ek kan dit hanteer. Ek kan nie agterkom of uitvind dat hulle my opsy gesit het nie."</i>

As can be seen in Table 8.19 and with regard to social **role fulfilment**, participants mostly referred to the physical ability affected by the operation (*"I still do the same things which I did in the past"*) instead of their role fulfilment. This could probably be linked to the fact that the majority (25 or 55,6%) of participants had either no or only primary school education. They therefore found it difficult to respond to a question with an abstract nature, such as their role fulfilment.

However, according to Cella (1987:62), the role of the survivor in the traditional nuclear family depends upon the age of the survivor. The majority (27, or 60%) of patients who participated in the study was between 60 and 78 years of age, and was therefore representative of the elderly age group. According to Cella (1987:62), each of the psychosocial stages of development poses unique challenges and concerns for its survivors. However, all will face the common problem of "re-entry" into normal relationships. **Elderly survivors** will be confronted with inevitable loss of significant relationships. This may result in them turning to new peers or retreating within themselves for continued gratification. For the laryngectomy survivor, turning to new peers will be challenging, taking into account the speech limitation.

Also of relevance are those who were representative of the **middle adulthood group**, as eighteen (40%) participants' ages varied between 42 and 59 years. According to Hara and Blum (2009:46), this is the phase when one fulfils multiple adult roles and responsibilities, particularly those involving supporting a family. A cancer diagnosis at this time challenges one's ability to multitask effectively, which can undermine one's self-image as an adult in society.

(b) Category: Relationship improved

The majority of participants (see Table 8.19) indicated that their relationship with **other family members** improved. Reasons for such improvement were, on the one hand, that they, by experiencing acceptance and support, found that family members contributed positively to this improvement (*"They went out of their way to make things easier for me"*) and also that they felt sorry (*"They felt sorry for me"*) for them because of their cancer

diagnosis. The fact that more than one family member suffered from cancer also result in greater closeness between family members (“... *it brought our family closer to one another*”). Patients on the other hand also commented on how they worked at this positive and improved relationship by leaving behind their previous social habits such as drinking and smoking (“*They asked me to stop smoking but I did not stop ... now I’ve stopped. Now everyone likes me*”). Cella (1987:62) referred to studies that have suggested that close family ties can predict satisfactory adjustment to cancer, as the family usually “pulls together” to cope with the challenges resulting from cancer. Table 8.20 illustrates the contribution of family members, as well as of patients themselves, in order to improve relationships.

TABLE 8.20: Social effects (patients): relationships improved

Theme 4: Patients’ and families’ experiences of psychosocial effects and re-entry into society	
Sub-theme 4.1: Social effects and adjustment	
Category	Narratives of participants
Other family members <ul style="list-style-type: none"> • Reasons • Own role 	<p>Reasons for improvement</p> <ul style="list-style-type: none"> • “<i>They went out of their way to make things easier for me ... this <u>inspired me to do better</u>.</i>” / “Hulle het uit hulle pad gegaan om dit vir my makliker te maak ... dit het my geïnspireer om maar net nog beter te doen in die lewe.” • “<i>They <u>became closer to me</u>. They <u>felt sorry for me</u> because cancer is something huge in society.</i>” / “Hulle het lieverste nader beweeg. Hulle het my bejammer want kanker is mos iets groot in die samelewing.” • “<i>My father also had cancer and my sister died of breast cancer ... now it is me ... it <u>brought our family closer</u> to one another.</i>” / “My pa het ook kanker gehad destyds, en my suster is dood aan borskanker ... nou ek ... dit het ons as familie nader aan mekaar gebring.” <p>Patients’ role to promote improvement</p> <ul style="list-style-type: none"> • “<i>They talked a lot to me and asked me to <u>stop smoking</u> but I did not stop ... now I’ve stopped. Now everyone likes me.</i>” / “Hulle het baie met my gepraat en gesê die rokerie moet ek los maar ek het nooit opgehou nie. Nou het ek opgehou. Almal hou nou van my.”

(c) Category: Relationship affected negatively

Social areas in which patients experienced a negative effect was in the area of their previous **employment and finance** as well as their **previous friendships**.

(i) Employment and financial situation

The category most affected by the laryngectomy experience was their **employment and financial situation**, as they experienced limited physical ability or could not continue with their previous employment. This finding correlates with literature (Graham, 2004:127; Ross, 2000:20) stating that, following surgery, laryngectomy patients may need to alter their previous employment to exclude certain employment conditions or due to the loss of natural speech, especially when employment is dependent on verbal communication (Graham, 2004:127; Ross, 2000:20). The effect of the operation on participants' employment and financial situation can be viewed clearly from Figure 7.6 as discussed in the previous chapter, taking into account that the portion of participants who were pensioners before the operation (12, or 26,7%) increased (to 36, or 80%) after the operation. Surprisingly, some participants indicated that they learned to be more responsible (6, or 13,3%) with spending money, mainly due to the fact that they stopped previous social habits (*"I do not smoke or drink any longer. With that money I buy food"*). Narrative responses of participants recorded in Table 8.21 illustrate their opinion on reasons for change in their employment and financial situation, as well as financial benefits gained following the operation.

TABLE 8.21: Social effects (patients): negative effect: employment and finance

Theme 4: Patients' and families' experiences of psychosocial effects and re-entry into society	
Sub-theme 4.1: Social effects and adjustment	
Category	Narratives of participants
Employment and finance <ul style="list-style-type: none"> • Negative effect • Responsible 	<p>Negatively affected</p> <ul style="list-style-type: none"> • <i>"The operation <u>changed my work</u> situation because I cannot do the type of work I did previously ... it had a big <u>effect</u> on my <u>finances</u>."</i> / "Die operasie het baie van my werk verander want ek kan mos nou nie meer die tipe werk doen wat ek gedoen het nie ... dit het 'n baie groot effek op my geld gehad." • <i>"We had our own business but I <u>had to close it</u> because I could not communicate with people."</i> / "Ons het ons eie besigheid gehad en ons moes dit los want ek kon nie kommunikeer met mense nie." <p>More responsible</p> <ul style="list-style-type: none"> • <i>"I <u>do not smoke or drink</u> any longer. With that money I <u>buy food</u>."</i> / "Ek rook en drink nie meer nie, daai geldjies kan maar almal gaan vir kos." • <i>"I did not have a lot of respect for money ... my <u>income</u> is now <u>less</u> but I know <u>how to spend it</u>."</i> / "Ek het baie min respek gehad vir geld ... my inkomste is nou baie minder maar ek weet hoe om dit te spandeer."

(ii) Previous friends

An equal number of participants indicated that their relationship with **previous friends** either remained the same or was affected negatively. Stated reasons for this negative effect was that their previous friends continued their previous social habits (7, or 15,6%) (*“They all left me ... we do not travel the same road. In the past we drank a lot”*); that they had difficulty to talk (*“Most of them stayed away because I could not talk”*) and also that friends felt sorry for them and mistakenly thought that speaking was uncomfortable (*“They do not want me to talk a lot, they feel sore on my behalf”*) for the patient. Also, since they were not used to this way of communication, they found it hard to adapt to it. Lastly, they found it difficult to understand the patient (*“... they did not understand me”*) (6, or 13,3%), or had the irrational fear that the patient may die unexpectedly whilst with them (*“... they are afraid that I will die any moment”*). However, participants indicated that once their speech ability improved, they were accepted again. Yet it was difficult to cope with the effect of the operation and to see the patient is in that condition (*“They said they cannot see me like that, they are not used to me like that”*). As a result, they started to exclude them from social events (*“They do not visit me, they wrote me off”*).

This is supported in literature (Cella, 1987:62) stating that friends still tend to equate the word “cancer” with “death”, and this can make the transition from cancer patient to cancer survivor extremely awkward. A survivor may want to leave everything behind, but friends may be unable to forget. Often there also is an irrational fear of contagion, which can be communicated in a variety of ways, ranging from insensitive joking to outright avoidance or abandonment. Table 8.22 presents patients’ opinions on how the laryngectomy experience impacted on their relationship with previous friends.

TABLE 8.22: Psychosocial effects (patients): relationships negatively affected: previous friends

Theme 4: Patients' and families' experiences of psychosocial effects and re-entry into society	
Sub-theme 4.1: Social effects and adjustment	
Category	Narratives of participants
Previous friends <ul style="list-style-type: none"> • Social habits • Speech • Surgery 	Social habits <ul style="list-style-type: none"> • <i>"They <u>all left me</u> ... we do not travel the same road. In the past we drank together."</i> / "Hulle het hulle van my af weggebreek ... ons loop mos nie meer saam op die een paadjie nie. Ons het mos maar altyd 'n dop gedrink." Speech limitation <ul style="list-style-type: none"> • <i>"They came less because I <u>could not talk</u> to them ... they <u>did not understand</u> me."</i> / "Hulle het so 'n bietjie skaars geraak want hulle kan nie lekker gesels nie ... hulle kry my nie lekker verstaan nie." • <i>"They do not want me <u>to talk a lot</u>, they <u>feel sore</u> on my behalf"</i> / "Hul wil nie hê ek moet praat nie want hulle kry seer" Effect of the operation <ul style="list-style-type: none"> • <i>"They do not visit me ... they are <u>afraid that I might die</u> any moment."</i> / "Hulle kom nie meer by my nie ... hulle is bang soos ek is nou ek gaan enige tyd dood." • <i>"They do not visit me, <u>they wrote me off</u>. They said they cannot see me like that, they are not used to me like that."</i> / "Hulle kom nou glad nie meer by my nie, hulle het my ook seker afgeskrywe. Hulle sê hulle kan my nie so sien nie, hulle is nie gewoond aan my so nie."

When the same question regarding the effect of the operation on social relations was posed to family members, six (40%) **family members** referred to the fact that family relationships improved since the operation, whilst five (33,3%) could not indicate any difference from what they experienced before the operation. Negative effects (4, or 26,7%) referred to financial problems (transport to visit the patient in hospital) (*"When he could not work there was no income"*) as well as the emotional effects of the operation, including the change in method of speech (*"There was a change in the family because of his speech"*). These included stress due to the uncertainty about whether the cancer was cured (*"Maybe he was afraid of the cancer"*) as well as the patient's social isolation (*"My father does not attend functions because of the stoma and people staring at him"*). They also were concerned about the possibility of something happening to him during the night and therefore also did not sleep well at night (*"We had difficulty to sleep in the beginning.*

We were afraid, anything could happen”). Table 8.23 reflects the responses of family members regarding the psychosocial effects of the operation.

TABLE 8.23: Psychosocial effects (families): effect on relationships

Theme 4: Patients' and families' experiences of psychosocial effects and re-entry into society	
Sub-theme 4.1: Social effects and adjustment	
Category	Narratives of participants
Remained the same	<ul style="list-style-type: none"> “<i>I forget that she had the operation. I <u>live absolutely past that</u>. It is not a burden for me, no, definitely not a stumbling block.</i>” / “<i>Ek vergeet dat sy die operasie gehad het. Ek leef absoluut verby dit. Dis nie vir my ‘n las nie, nee definitief nie ‘n struikelblok nie.</i>”
Relationship improved	<ul style="list-style-type: none"> “<i>We lean on one another and that has <u>brought us closer</u> as a family ... it brought us nearer to one another.</i>” / “<i>Ons het maar op mekaar gesteun en ons het nader aan mekaar gekom as ‘n familie ... ons het meer hegger uit die situasie gekom.</i>”
Negative effect	<p>Financially</p> <ul style="list-style-type: none"> “<i>When he could not work there was <u>no income</u>. We always had to make plans to ensure that there is money.</i>” / “<i>Toe hy nou nie meer werk nie toe is die inkomste nou minder. Ons moet maar altyd ‘n plan gemaak het dat daar altyd geld is.</i>” <p>Effect of speech limitation</p> <ul style="list-style-type: none"> “<i>There was a change in the family because of his <u>speech</u>. I could not get over it that he could not speak as he used to.</i>” / “<i>Dit was so ‘n verandering in die huis gewees oor die praat. Ek kan dit net nie oor my hart gekry het oor die man nie kan gepraat het soos hy gepraat het nie.</i>” <p>Stress about cancer status</p> <ul style="list-style-type: none"> “<i>There was a bit of stress between us. Later on we decided that we have to carry on living. Perhaps he was <u>afraid of still having cancer</u>.</i>” / “<i>Dis ‘n bietjie stremming tussen ons. Maar later het ons besluit mens moet maar aangaan met die lewe. Miskien was hy nog bang hy is nog vol kanker.</i>” <p>Social isolation</p> <ul style="list-style-type: none"> “<i>My father does not attend functions because of the stoma and <u>people staring at him</u>.</i>” / “<i>My pa gaan nie meer na gebeurtenisse toe nie as gevolg van die gaatjie omdat die mense vir hom kyk.</i>” <p>Fear and uncertainty</p> <ul style="list-style-type: none"> “<i>We had <u>difficulty with sleeping</u> in the beginning. We were afraid, something might happen.</i>” / “<i>Ons het baie moeilik geslaap in die begin. Ons was skrikkerig, enigiets kan gebeur.</i>”

8.3.1.2 Theme 4: Sub-theme 4.2: Emotional experience of loss of natural voice

As loss of voice is one of the most prominent consequences of this operation (Graham, 2004:127), participants were asked about their experience of the loss of their voice. This question was also posed to family members. In the attempt to describe how they experienced the loss of natural voice following the operation, **patients** mainly referred to it as a negative experience (26, or 57,8%). The minority (18, or 40%) did not experience their loss of voice as problematic. Participants described ways of coping in compensating for this loss of natural voice. When the same question was posed to **family members**, they were mainly thankful (10, or 66,7%) for their relative's (patient) health, despite the loss of his or her natural voice. Those for whom it initially was a negative experience (3, or 20%) also found that it changed to a positive experience. Two (13,3%) did not identify any problems in this regard. Table 8.24 summarises these different responses of patients and family members:

TABLE 8.24: Comparison between patients' and families' experiences of loss of voice

Theme 4: Patients' and families' experiences of psychosocial effects and re-entry into society		
Sub-theme 4.2: Emotional experience of loss of voice		
Experience	Patients' responses % (n = 45)*	Families' responses % (n = 15)*
Experience of loss	26 (57,8%)	3 (20,0%)
Acceptance	18 (40,0%)	10 (66,7%)
Did not comment	1 (2,2%)	2 (13,3%)

*Some participants indicated more than one opinion therefore the total will exceed 100%

(a) Category: Experience of loss

Participants' concentrated on their experience of loss ("... very uncomfortable as I could not talk") and also described negative feelings evoked within themselves following their loss of voice ("...you feel strange..."; "... I felt bad ..."; "... for me it was difficult ..."). It was Dhooper (1985:222) who said that loss of the larynx, like the loss of any body part, may

be seen as symbolic of death of the body. Patients also referred to the aspect “not being heard” (*“It seemed as if no one heard me when I talked”*) and the behaviour of other people (*“...at times my voice sounded bass and then you got those who teased you...”*) who affected them negatively. McQuellon and Hurt (1997:234-235) held the opinion that voice can be seen as an extension of thought and a person’s sense of self. Loss of voice thus implies loss of the ability to be heard and acknowledged. As a result, the person loses his or her ability to express him- or herself. Temporary or permanent dislocation from social relationships may occur. The need will arise to establish a new social support system that can understand the patient’s new voice.

TABLE 8.25: Experience of loss of voice: experience of loss

Theme 4: Patients’ and families’ experiences of psychosocial effects and re-entry into society	
Sub-theme 4.2: Emotional experience of loss of natural voice	
Category	Narratives of participants
Experience of loss <ul style="list-style-type: none"> • Loss • Emotions • Not heard • Others 	<p>Loss experiences</p> <ul style="list-style-type: none"> • <i>“It then was <u>very uncomfortable</u> for me as I could not talk.” / “Toe was dit vir my baie ongemaklik want ek kan mos nou nie praat nie.”</i> <p>Negative emotions</p> <ul style="list-style-type: none"> • <i>“You also <u>feel strange</u> as you are not used to the sound.” / “Jy voel ook maar snaaks want jy is nie gewoond aan die geluid nie.”</i> • <i>“I <u>felt bad</u> as I did not have my own voice.” / “Ek het nogal sleg gevoel want omdat ek nie my eie stem het nie.”</i> • <i>“It was <u>difficult</u> for me. One night I dreamed I could talk, I heard myself so clearly ... then I started to cry. For me it was a big shock. I said to my wife: ‘Hear how I am talking’, and I could not talk.” / “Vir my is dit swaar. Ek het een aand gedroom ek praat, ek het so duidelik myself hoor praat ... ek het begin huil daai oomblik. Vir my was dit ‘n groot skok. Ek sê vir my vrou: ‘Hoor hoe praat ek’, en ek kan nie praat nie.”</i> <p>Not being heard</p> <ul style="list-style-type: none"> • <i>“I suffered. When my voice disappeared then they talked and then they <u>could not hear me talking</u>” / “Ek het maar moeilik gekry. Toe my stem nou weggraak dan praat hulle dan kan hulle nie my hoor praat nie.”</i> • <i>“It felt strange because it seemed as if <u>no one heard me</u> when I talked, I seemed as if I talked too softly.” / “Dit het snaaks gevoel want dit lyk al niemand hoor my nie as ek praat nie, dan lyk dit al ek praat te sag.”</i> <p>Behaviour of other people</p> <ul style="list-style-type: none"> • <i>“At times my voice sounded like a bass and then you got <u>those who teased you</u>.” / “Somtyds het ek amper soos ‘n rapser bas stem geklink dan het jy gekry die persone wat jou gekoggel het.”</i> • <i>“In the beginning it was frustrating. Many people <u>thought</u> as I am talking like this, <u>I am deaf as well</u>.” / “Aan die begin dit was ‘frustrating’ om te sukkel. Want baie mense het gedink ek is half doof ook.”</i>

(b) Category: Acceptance

Time as a healing factor was mentioned by participants in dealing with their loss of natural voice (“...with time you accept it”). This links with a study to determine rehabilitation outcomes of long-term survivors treated for head and neck cancer conducted by De Boer *et al.* (1995:503; 512-513), who found that the greater the time that elapses after treatment, the fewer the psychosocial problems that patients experience. **Patients** also learned to focus on positive aspects such as their health (“...it is for your own health”) and were thankful for still having a voice (“I am thankful that I still have a voice”), as they utilised the principles of the strengths perspective (Saleebey, 2002:14). **Family members**, on the other hand, were thankful for the patient’s improved health (“I was very thankful that he was healthy”), as well as the patients’ ability to talk again (“To me it was he had a voice. It did not matter to me how it sounded and how it came out”). The opinions of both patients and families are presented in Table 8.26:

TABLE 8.26: Experience of loss of voice: acceptance

Theme 4: Patients' and families' experiences of psychosocial effects and re-entry into society	
Sub-theme 4.2: Emotional experience of loss of natural voice	
Category	Narratives of participants
Acceptance <ul style="list-style-type: none"> • Time • Positive aspects • Health • Speech 	<p>PATIENTS</p> <p>Time as healing factor</p> <ul style="list-style-type: none"> • <i>"It was a bit difficult because it was not the voice you were used to having. I was a bit disappointed <u>but with time</u> you have to accept it."</i> / "Dit was 'n bietjie moeilik want kyk dit is nie meer die stem wat jy gewoond is wat jy het nie. Ek was ietwat van teleurgesteld maar mettertyd moet jy dit mos nou aanvaar." • <i>"I felt down. It <u>took time to recover</u> but I did manage."</i> / "Ek het 'down' gevoel. Dit het tyd gevat om reg te kom maar ek het daarby uitgekome." <p>Concentrate on positive aspects</p> <ul style="list-style-type: none"> • <i>"I did not feel good, but you have to accept it is <u>for your own health</u>."</i> / "Ek het nogal nie lekker gevoel nie maar 'n mens moet maar tevrede wees, dit is vir jou gesondheid." • <i>"I am only aware of <u>still having a voice</u>."</i> / "By my gaan dit nou net nog oor omdat ek darem nog 'n stem het." • <i>"I am <u>satisfied</u> with it. I now talk a bit different but now they know what I said, <u>they now understand you</u>."</i> / "Ek is tevrede daarmee. Nou praat ek bietjie anderste maar nou kan hulle weet wat ek sê, nou kan hulle jou verstaan." <p>FAMILY MEMBERS</p> <p>Health as reason for thankfulness</p> <ul style="list-style-type: none"> • <i>"I was just very <u>thankful</u> that he was <u>healthy</u>, that nothing happened to him, it could easily have been different."</i> / "Ek was net bitter dankbaar dat hy gesond is, dat hy nie iets oorgekom het nie, dit kon so maklik anders gewees het." <p>Ability to talk as reason for thankfulness</p> <ul style="list-style-type: none"> • <i>"It did not matter to me how it sounded and how it came out ... I was just <u>thankful</u> that he still had a <u>voice</u>."</i> / "Dit het nie vir my saak gemaak hoe dit klink nie en hoe dit uitkom nie. Ek was net dankbaar daar was weer 'n stem." • <i>"We are just <u>thankful</u> that he is <u>healthy</u>."</i> / "Ons is net bly dat hy gesond is." • <i>"Only that he <u>could talk to me again</u> ... that very first day that he could say (he looked at me): 'hello', I thought heaven opened for me, it was fantastic!"</i> / "Net dat hy weer met my kon praat ... daai eerste dag wat hy weer vir my kon sê (hy het vir my gekyk): 'hello', ek het gedog die hemel gaan oop, dit was vir my fantasties!"

8.3.1.3 Theme 4: Sub-theme 4.3: Experience of adjustment to society

Participants (**patients**) were asked how they experienced their adjustment to society following their medical treatment. They were given the option to indicate whether it was easy, difficult or whether they felt uncertain. Participants were then asked to motivate their response. This same question was also posed to **family members**.

(a) Category: Easy

More than half (26, or 57,8%) of the patients indicated that they experienced their adjustment to society as easy. Aspects which helped them in their adjustment were successful mastery of speech (*"It was very easy when I started to talk"*); acceptance by others (*"Easy because the people around me accepted me"*); support (*"... my family was there for me"*); their own attitude (*"It was easy as it felt for me after the operation that I was still the same as I was before the operation"*) and their inner strength (*"I will not let it get me down"*). Patients' responses correlate with them utilising a combination of both the strengths and the ecological perspectives, referring to external (speech; behaviour and support of other people) and internal factors (own attitude; inner strength). According to Sanchez-Salazar and Stark (1972:323), adjustment begins from the time the patient learns that he has cancer. The impact of cancer will require that the patient utilises all coping resources in order to cope with the life-threatening implications of cancer, both intra- and interpersonal. When this same question was posed to **family members**, six (40%) indicated that it was not difficult for them as they continued as before (*"We did not do any adaptation, we continued as before"*). Table 8.27 presents both patients and families' opinions on why they found their adjustment to society "easy".

TABLE 8.27: Experience of adjustment to society: easy

Theme 4: Patients' and families' experiences of psychosocial effects and re-entry into society	
Sub-theme 4.3: Experience of adjustment to society	
Category	Narratives of participants
Easy <ul style="list-style-type: none"> • Speech • Acceptance • Support • Own attitude • Inner strength 	<p>PATIENTS</p> <p>Successful mastering of speech</p> <ul style="list-style-type: none"> • <i>"It was very easy when I <u>started to talk again.</u>" / "Dit was vir my baie maklik gewees toe ek eers weer kan begin praat."</i> <p>Acceptance by others</p> <ul style="list-style-type: none"> • <i>"Easy because the people around me <u>accepted me.</u>" / "Maklik want die mense rondom my het my aanvaar."</i> <p>Support</p> <ul style="list-style-type: none"> • <i>"It was not difficult after the operation ... <u>my family</u> was there for me." / "Dit was nie moeilik na die operasie gewees nie ... my familie was daar vir my."</i> • <i>"It was not difficult because when we are together <u>as a group</u> we can talk together." / "Dit was nie moeilik nie omdat as ons groepie bymekaar [is] dan kan jy nou lekker gesels nou saam met hulle."</i> <p>Own attitude</p> <ul style="list-style-type: none"> • <i>"I do not think it was difficult because I <u>could cope with other people before</u> ... I am a people's person." / "Ek dink nie dit was vir my moeilik nie omdat ek voorheen met mense kan klaargekom het ... ek is 'n mens-mens."</i> • <i>"I felt that I was <u>still the same</u> as before the operation." / "Dit het vir my gevoel ek is maar net soos ek gewees het voor die operasie."</i> <p>Inner strength</p> <ul style="list-style-type: none"> • <i>"I always was a spontaneous person and I <u>will not let it suppress me.</u>" / "Ek was maar altyd 'n spontane persoon en ek gaan nie vir my laat afdruk nie."</i> • <i>"It to a great extent is <u>the way you live your life.</u>" / "Dit is meerendeels die manier hoe jy die lewe aanvat."</i> <p>FAMILY MEMBERS</p> <ul style="list-style-type: none"> • <i>"We did not need to adapt, we <u>continued as before.</u>" / "Ons het geen aanpassings gemaak nie, ons gaan aan soos wat dit was voor die tyd."</i> • <i>"There is <u>not much difference</u>, it's only that we have to be more observant of him ... you have to keep an eye on him." / "Daar's nie veel verskil, dit is nou maar net ons is meer opletterend vir hom ... jy moet hom altyd dop hou."</i>

(b) Category: Difficult

Seventeen patients (37,8%) acknowledged that, for them, the post-operative adjustment was difficult. The two main areas concerned their altered manner of communication (“*I felt lonely because I could not communicate*”) and dealing with other people’s behaviour (“*Some of them made fun of me, others felt sorry for me*”). as will be presented in Table 8.28. Argerakis (1990:296) acknowledged that disruption of one’s ability to express attitudes and feelings may result in feelings of worthlessness and being burdensome to family and friends. Cella (1987:62), in addition, warned that people often have an irrational fear of contagion, ranging from insensitive joking to outright avoidance or abandonment.

TABLE 8.28: Experience of adjustment to society: difficult

Theme 4: Patients’ and families’ experiences of psychosocial effects and re-entry into society	
Sub-theme 4.3: Experience of adjustment to society	
Category	Narratives of participants
Difficult <ul style="list-style-type: none"> • Communication • Rejection 	<p>Communication</p> <ul style="list-style-type: none"> • “<i>It is as if you are new ... I felt lonely because <u>I could not communicate</u>.</i>” / “Dit is amper soos jy’s nuut ... ek voel amper soos eensaam omdat jy kan nie meer gesels nie.” • “<i>People <u>did not understand me</u>, I used gestures. At times they asked me a question and then it took a couple of seconds before I could answer and then they forgot what they asked.</i>” / “Die mense het mos nie vir my verstaan nie, dan was dit nou gebaretaal. Somtyds het die mense ‘n vraag gevra en dan vat dit ‘n paar sekondes om te antwoord en dan het hy vergeet wat hy gevra het.” <p>Other people’s behaviour / social rejection</p> <ul style="list-style-type: none"> • “<i>Some people <u>believe that you are different</u> now as you ‘act’ differently... so he cannot bear with you who are a bit different.</i>” / “Party glo jy is anderste want jy ‘act’ nou anderste ... nou kan hy nie vir jou verdra wat bietjie anderste is nie.” • “<i>People did not treat me well. It almost seemed as if I had a <u>contagious disease</u> according to them.</i>” / “Die mense het my nie so lekker gehanteer nie. Dit lyk amper of dit ‘n aansteeklike siekte is volgens die mense.” • “<i>Some <u>made fun</u> of me, others <u>felt sorry</u> for me.</i>” / “Party vat jou vir ‘n ‘joke’ ander bejammer jou.”

(c) *Category: Not sure*

Two (4,4%) patients were not sure how they found their adjustment to society following their treatment.

- *“I am not sure. I do not know what to say now” / “Ek is nie seker nie. Ek kan nou nie weet hoe om nou te sê nie”*

(d) *Summary*

Two variables have to be taken into account when interpreting these findings. With reference to those patients who indicated that their post-operative adjustment was **easy**, the average time lapse between **treatment completion** and **time of interview** was four years and six months. More or less the same average period was found with reference to those patients who indicated that their post-operative adjustment was **difficult**, namely a period of five years. Those who indicated that they were **not sure** about their post-operative adjustment completed treatment one year and ten months before. It was therefore difficult for them to give an indication of how they experienced their post-operative adjustment. Another variable was the **gender** of patients who participated. As the majority of the participants was male (37, or 82,2%), it could be said that they were more likely to minimise the impact of cancer on their lives in comparison to female patients. This was found in a study by Foley *et al.* (2006:248-258) with cancer survivors who were diagnosed more than fifteen years previously.

8.3.1.4 Theme 4: Sub-theme 4.4: Things to help making re-entry into society easier

Participants (**patients**) were asked to identify those things that had helped to ease their re-entry into society. They distinguished between inner resources and community resources. A traumatic life stressor (like illness) can possibly be experienced either as a stressor or as a challenge (Germain & Gitterman, 1996:12-14). In order to experience it as a challenge, both inner and external resources were mobilised by laryngectomy survivors in order to master this traumatic life event. DeSante (1994:53), in

acknowledging the role of inner strength and social support, held the opinion that what the patient brings to treatment in terms of personal resources is as important as what is done in terms of medical treatment.

(a) Category: Inner resources

Within the category of inner resources, participants referred to the role of self-acceptance (“Because I accepted myself who I am”); inner strength (“...my own will, yes my will and positive thinking”); appreciation of life (“...it is a second chance”); and faith (“Faith helped me a lot”). These participants actively decided to continue with their lives (“You have to tell yourself you have to continue with life”). Family members also mobilised their inner resources in order to help them with their re-entry into society (“I took it day by day”). The use of inner resources was discussed under Theme 3.5. With reference to the use of the strengths perspective, Saleebey (2002:14) stressed that, although disease may cause disruption, people have assets, resources, wisdom and knowledge that professionals sometimes are not aware of, which they utilise in order to master traumatic events such as cancer (“I decided...”; “you have to tell yourself...”; “my own will and positive thinking”). Table 8.29 presents the category of “inner resources” as reported when patients were asked about what had helped them with their re-entry into society.

TABLE 8.29: Re-entry into society made easier: inner resources

Theme 4: Patients' and families' experiences of psychosocial effects and re-entry into society	
Sub-theme 4.4: Things to help making re-entry into society easier	
Category	Narratives of participants
Inner resources <ul style="list-style-type: none"> • Self acceptance • Inner strength • Appreciation • Faith 	<p>PATIENTS</p> <p>Self acceptance</p> <ul style="list-style-type: none"> • <i>"I <u>accepted myself</u> who I am, therefore other people can also accept me."/ "Ek aanvaar wie ek is, daarom kan ander mense my nou ook aanvaar."</i> <p>Inner strength</p> <ul style="list-style-type: none"> • <i>"I <u>decided</u> that I am going to adapt to everything, I will not be ashamed."/ "Ek het by myself besef dat ek gaan vir my by alles gaan ek vir my aanpas, ek gaan nie skaam wees nie."</i> • <i>"You have to tell yourself <u>you have to continue</u> with life."/ "Jy moet vir jouself sê jy moet maar aangaan met die lewe."</i> • <i>"My <u>own will</u> and <u>positive thinking</u>."/ "My wilskrag en my positiewe denke."</i> <p>Appreciation</p> <ul style="list-style-type: none"> • <i>"The three 'G's': Patience, faith and the opportunity you have ... it is a <u>second chance</u>."/ "Die drie G's: Geduld, geloof en die geleentheid wat jy het ... dis 'n tweede kans."</i> <p>Faith</p> <ul style="list-style-type: none"> • <i>"<u>Faith</u> helped me a lot."/ "My geloof het vir my baie gehelp."</i> <p>FAMILY MEMBERS</p> <p>Inner strength</p> <ul style="list-style-type: none"> • <i>"I took it <u>day by day</u>. At times it was <u>difficult</u> and other times it was <u>easy</u>."/ "Ek het dit maar elke dag gevat dag vir dag. Partykeer was dit moeilik partykeer was dit maklik gewees."</i>

(b) Category: External resources

With reference to external resources that eased their re-entry into society, participants first referred to the **role of support** from various sources. Other external resources which contributed to their easier adaptation were the role of **gaining speech**, the role of **pre- and primary school children** and **grandchildren** towards their survivorship, and the role of **recreational activities**.

(i) Sub-category: Social support

Various sources of support referred to include a life partner, children, employers, friends and grandchildren as well as support received within the support group (*"I sat and listened to them and looked at how fluently they talked"*). Social support as external source of support was discussed under Theme 3.5. Gerlach *et al.* (1990:67) refer to Cella who held the opinion that successful cancer survivor adjustment often correlates with the support of close family members. Therefore families need to share in an experience that will help them to cope with the uncertainties and issues in survivorship. Findings of Tracy's (1990:252) study with at-risk families showed that most families had at least one network member on whom they could rely for help. Table 8.30 demonstrates the various sources of support indicated by patients.

TABLE 8.30: Re-entry into society made easier: external resources

Theme 4: Patients' and families' experiences of psychosocial effects and re-entry into society	
Sub-theme 4.4: Things to help making re-entry into society easier	
Category	Narratives of participants
External resources (social support) <ul style="list-style-type: none"> • Various sources • Support group 	Support from various sources <ul style="list-style-type: none"> • <i>"My wife helped me a lot, my children also supported me. It made me feel good. My employer also, they accepted me ..."</i> / <i>"My vrou het my baie gehelp, die kinders het my ondersteun. Dit het my laat goed voel. Dis my werk ook, hulle aanvaar my ..."</i> • <i>"My friends, they helped me a lot. They took me out and talked."</i> / <i>"My vriende, hulle het my baie gehelp. Hulle vat my uit en gesels."</i> • <i>"Because they [grandchildren] asked a lot of questions and could not understand my gestures, it forced me to talk."</i> / <i>"Deurdat hulle [kleinkinders] vrae gevra en nie gebaretaal kon verstaan het nie, toe het hul my forseer om te praat."</i> Support group <ul style="list-style-type: none"> • <i>"The group. I sat and listened to them and looked at how fluently they talked."</i> / <i>"Die kringetjie. Ek het baie gesit en luister hier en dan kyk ek dan kyk ek hoe mooi lekker praat die mense."</i>

(ii) Sub-category: Enhancement of socialisation

The factor which helped them in their adjustment to society following their treatment was enhancement of their socialisation. Taking into account that loss of speech can be seen as the most traumatic effect of the operation (Graham, 2004:127), successful mastering of speech can be seen as beneficial for these patients' post-operative adaptation.

TABLE 8.31: Things to help making re-entry into society easier: promotion of speech

Theme 4: Patients' and families' experiences of psychosocial effects and re-entry into society	
Sub-theme 4.4: Things to help making re-entry into society easier	
Category	Narratives of participants
Enhancement of socialisation	<ul style="list-style-type: none"> • <i>"When I heard my voice, I thought it is a strange voice but the more I practiced the more confidence I had. I said to myself, <u>life is going to get better for me.</u>" / "Toe ek hoor my stem, toe dink ek dis darem 'n baie snaakse stem maar hoe meer soos ek geoefen het so meer het ek myself nou vertrouwe gehad en het ek vir myself gesê, nee die lewe gaan vir my weer beter word."</i> • <i>"If I could not talk, it would have been different. But <u>I can talk now.</u>" / "As ek nou nie kon gepraat het nie, dan sou dit anderste gewees het. Maar nou kan ek darem nou praat."</i>

(iii) Sub-category: Role of grandchildren

An unexpected and interesting finding which could not be found in literature was the role of pre- and primary school children and grandchildren in the rehabilitation of these patients. The age of grandchildren commonly referred to ranged between a few months and three years of age. This can be seen in view of the observation of the changed structure of the nuclear family as grandchildren of this age group are often raised by their grandparents. Citing a study by Mages *et al.*, Quigley (1989:66) referred to variables that were predictive of psychosocial adjustment in cancer patients in general, as well as in long-term cancer survivors. With regard to the role of social support, it was noted that the presence of another person in the home regardless of the relationship was highly correlated with optimal psychosocial functioning.

Regarding the **role of grandchildren** in laryngectomy patients' survivorship experience, their contribution during the following phases of survivorship was acknowledged and will be highlighted by participants' verbatim responses:

Pre-operative preparation (acute phase)

- *"I realised that I have four grandchildren who are very fond of me. It is for them I have to **give my cooperation.**" / "Ek het net besef ek het vier kleinkinders wat baie lief is vir my ... vir hulle moet ek my samewerking doen."*
- *"The children encouraged me ... she was 2 years old ... she was the person **who made me accept the operation** ... I said I still want to raise her." / "Die kindertjies het vir my so 'n hele aanmoediging gegee ... sy was 2 jaar oud ... dis die persoon wie my laat instem met die operasie ... ek het gesê ek wil haar grootmaak."*

Post-operative adaptation (transitional phase)

- *"She always **stepped in for me**; she was two or three years old. Many people told me - this child interpreted a lot for you. Yes they help you because they let you talk, she **motivated me** a lot." / "Sy het altyd vir my ingetree, sy was nog so klein, so twee drie. Baie vir die mense sê vir my - die kind het baie getolk vir jou. Ja hulle help jou mos maar want hulle laat jou mos praat, sy het my baie gemotiveer."*
- *"The small one, he **gave me a lot of strength** ... he was the one to push me and say that I will become strong." / "Die kleintjie, hy gee vir my sterk krag ... hy was nou eintlik die man wat my nou vorentoe gestoot het en vir my gesê het jy sal sterk word."*

Learning speech (extended phase)

- *"My grandchildren, they were very inspiring. They **motivated me to be what I am today**, that I can talk. I am looking forward to my future." / "My kleinkindertjies hulle was vir my inspirerend. Hulle het vir my gemaak dat ek so is vandag, dat ek kan praat. Ek het sommer lus vir die lewe."*
- *"There was no one at home, only me and the grandchild. Because they asked a lot of questions and could not understand my gestures, they **forced me to talk.**" / "Daar was niemand by die huis gewees nie, net ek en die kleinkind. Deurdat hulle vrae gevra en nie gebaretaal kon verstaan het nie, toe het hul my forseer om te praat."*

- *“In the beginning it was difficult because I could not talk to them. I felt ashamed and I did not want them to hear that I could talk, so I spoke to myself alone my room until I became used to my voice. That little one **made me talk a lot.**”* / “Aan die begin was dit swaar om nie met hulle te kon praat nie. Ek was nog skaam en aan die begin ek wou nie gehad het hulle moet hoor ek kan praat nie, toe het ek altyd alleen so in die kamer gepraat tot ek gewoon geraak het aan die stem. Daai kleintjie het my baie laat praat”.
- *“If it was not for them, then my father would not have been **able to talk.**”* / “Was dit ook nie vir hulle nie dan sou my pa ook nie kon gepraat het nie.” (family).
- *“They were small, they turned one in that year. Then my mother said they would not be able to talk if he did not talk. They had a **great influence**, especially with the **talking.**”* / “Hulle is mos maar nog klein, in daai jaar het hulle ‘n jaar geword. Toe sê my ma hulle gaan nie kan praat as jy nie praat nie ... Hulle het regtig ‘n groot invloed gehad, veral van die praat” (family).

Motivation to continue with life - re-entry into society (permanent phase)

- *“It motivates one to recover sooner, it is through the little ones that I adapted sooner. I did it **and life continued for us**”* / “Dit ‘motivate’ ook ‘n mens om gouer te wil gesond raak, dit is deur die kleintjies ook wat ek gouer moes aangepas het. Ek het dit gedoen en die lewe het vir ons weer aangegaan.”
- *“They motivated me. They could not understand that their grandfather had to talk like this. He did not want to talk, he wanted to step aside and was shy. And in this manner I **stepped within the community**”* / “Hulle het liewer vir my gemotiveer. Hulle kan nie dit verstaan dat oupa nou so moet praat nie. Want oupa wil mos nou nie gepraat het nie, wou wegstroom en was skaam vir praat. En so het ek toe voetjie vir voetjie uit gemeenskap toe geloop.”
- *“He just laughed at them and I think it **encouraged him to continue** like that. He is very fond of that one, she was one and now she is five years old.”* / “Hy het net gelag vir hulle en ek dink dit het vir hom ge-encourage dat hy moet aangaan so. Want hy is verskriklik baie lief vir daai enetjie. Sy was ‘n jaar en sy is nou vyf jaar oud” (family).

Role of social support

- *“My grandchildren ... those two children **encouraged me** ... the little girl was four years old at the time, the boy only one ... I was alone [with them] at home.”* / “My kleinkinders ... daai twee klein kindertjies het vir my aangespoor ... die meisiekindjie was daai tyd vier, en die seuntjie was maar een ... want ek is alleen by die huis.”
- *“She **meant a lot to me.** That child made me feel as if I did not have the operation.”* / “Sy het baie vir my beteken. Daai kind het vir my gelaat voel dat ek amper nie eens voel ek het die operasie gehad nie.”

(iv) Sub-category: Recreational activities

In response to the question about hobbies that they practised or creative ways they found to accommodate the inevitable and permanent changes caused by the operation and to continue with their survivorship, the majority of participants referred to practical tasks such as gardening or cleaning their houses. Again they found innovate ways to keep themselves busy, either with practical tasks or creative activities. Those who indicated that they love birding could either do it for financial reasons (sell chickens) or to promote their speech (parrots). Many of these hobbies did not demand the ability to talk. In a study conducted by Tominaga *et al.* (1998:40) regarding family environment, hobbies and habits as psychosocial predictors of survival for surgically treated patients with breast cancer, it was found that various hobbies such as painting and keeping a garden beautiful may strengthen patients and promote opportunities for social contact, which, in turn, reduce feelings of loneliness and isolation.

TABLE 8.32: Hobbies

Theme 4: Patients' and families' experiences of psychosocial effects and re-entry into society		
Theme 4.4: Things to help making re-entry into society easier		
Item	Description	Number (%)
Gardening	None	23 (51,1%)
Cleaning the house	Inside and outside the house	22 (48,9%)
Creative activities	Motivate others (sketches of woodwork); needlework; sight-seeing; painting; crocheting; knitting; (woodwork); playing games; manufacturing ornaments to sell	14 (31,1%)
Practical tasks	Broker; handyman; work; taking care of children; selling sweets; staying busy; shopping; visiting friends or elderly people; socialising; hospice activities; helping others	11 (24,4%)
Birding	Budjies; canaries; finches; parrots; chickens; pigeons	5 (11,1%)

(Some participants indicated more than one therefore the total may exceed 100%)
n = 45

8.3.1.5 Theme 4: Sub-theme 4.5: Sources of fear and uncertainty

Participants received guidance in answering a question on their experience of sources of fear and uncertainty following their operation. Table 8.33 summarises the results from this question. Haylock *et al.* (2007:62) warned that the transition from patient to survivor is a time of anxiety, uncertainty and fear for many patients, as the “old normal” life never resumes; rather, a new “normal” evolves. This is especially applicable in the case of laryngectomy survivors having to deal with multiple challenges following the operation.

TABLE 8.33: Sources of fear and uncertainty

Theme 4: Patients' and families' experiences of psychosocial effects and re-entry into society				
Sub-theme 4.5: Sources of fear and uncertainty				
Sources of fear and uncertainty	Presence of fear and uncertainty		If “yes”, to what extent did you experience fear and uncertainty?	
	Yes	No	Plenty	Few
Physical aspects				
To take care of my stoma	15 (33,3%)	30 (66,7%)	5 (11,1%)	10 (22,2%)
Recurrence of disease	19 (42,2%)	26 (57,8%)	9 (20,0%)	10 (22,2%)
Loss of ability to communicate	23 (51,1%)	22 (48,9%)	10 (22,2%)	13 (28,9%)
AVERAGE %	42,2%	57,3%	17,8%	24,4%
Emotional aspects				
To adjust to changed physical appearance (stoma)	14 (31,1%)	31 (68,9%)	6 (13,3%)	8 (17,8%)
Health concerns	21 (46,7%)	24 (53,3%)	10 (22,2%)	11 (24,4%)
To set long-term goals or to make long-term plans	15 (33,3%)	30 (66,7%)	7 (15,6%)	8 (17,8%)
Uncertainty about future	15 (33,3%)	30 (66,7%)	9 (20,0%)	6 (13,3%)
AVERAGE %	36,1%	63,9%	17,8%	18,3%
Social aspects				
To take care of own health at home without the availability and support of the hospital	15 (33,3%)	30 (66,7%)	6 (13,3%)	9 (20,0%)
Fear of inability to cope with loss experiences (speech, communication, employment, finances)	15 (33,3%)	30 (66,7%)	8 (17,8%)	7 (15,6%)
AVERAGE %	33,3%	66,7%	15,6%	17,8%

From the above it can be deduced that patients mainly are in fear and uncertainty regarding **physical** aspects (42,2%). This was followed by fear and uncertainty regarding **emotional** aspects (36,1%) and, lastly, **social** aspects (33,3%). With regard to **physical aspects**, their first source of fear and uncertainty concerned their post-operative ability to communicate. This was followed by fear of recurrence of disease, or that the cancer may recur. In a study conducted by Gerlach *et al.* (1990:66-67) to identify cancer survivors' needs as reported by survivors and their families, various sources of fear were reported, such as fear of recurrence of disease; effect of the cancer diagnosis on family relationships; fear of the effect on communication as well as on employment and insurance.

On an **emotional level** and of equal importance, they experienced fear and uncertainty about setting long-term goals or making long-term plans; inability to adjust to unexpected changes in plans which could occur; and uncertainty about the future. **Socially**, they were concerned about taking care of their own health at home without the availability and support of the hospital (Jefford *et al.*, 2008:30) and fear of inability to cope with experiences of loss (Moore *et al.*, 2003:62).

Family members had no guidelines regarding possible responses to this question. However, twelve (80%) participants (family members) mainly expressed the following reasons for experiencing fear and uncertainty: the presence of the permanent tracheostoma (*"Then I experience that fear that she probably will not be able to breathe"*); potential to recover (*"...will he be able to stay alive?"*) and of the recurrence of the cancer (*"The uncertainty, will the cancer come back"*); how the operation would change their lives (*"Will he be the same spontaneous person he was before the operation?"*) and how to take care of the patient (*"How will you cope, how will the people around you cope?"*). The other three (20%) family members did not identify any fear or uncertainty.

From a survivorship perspective, Lewis (2006:20) referred to the various aspects one has to take into consideration when referring to the effect of cancer survivorship on families and caregivers. These referred to family members who are substantially distressed when a member has cancer. They then have to cope with the impact of the diagnosis as well as tension in the family caused by the diagnosis. Family members do not always know or understand how to support the patient as they themselves struggle to maintain their core functions, taking into account the needs of the survivor. For secondary survivors (family) of the laryngectomy patient, this will be especially applicable, as Chen *et al.* (2009:473) found that the supportive needs of those with oral cancer impact on the burden of family caregivers.

(a) Category: Physical aspects

With regard to physical aspects, fears and uncertainties indicated by families were discussed under Theme 3.3. They referred to difficulty in accepting the presence of the stoma and how to take care of the stoma, as well as fear and uncertainty regarding the potential of a fatal outcome. Similar information was shared by family members in response to this question, as families again referred to their fear and uncertainty in this regard.

TABLE 8.34: Sources of fear and uncertainty (families): physical effect and prognosis

Theme 4: Patients' and families' experiences of psychosocial effects and re-entry into society	
Sub-theme 4.5: Sources of fear and uncertainty	
Category	Narratives of participants
Physical effect and prognosis <ul style="list-style-type: none"> • Stoma • Recovery • Recurrence 	<p>Stoma</p> <ul style="list-style-type: none"> • <i>"We definitely experience fear ... will we know what to do, do we <u>clean</u> him properly ... if that '<u>plastic thing</u>' falls out, what will we do, will there be blood?"</i> / "Ons het dit definitief gehad daai bang ... gaan ons nou weet hoe om te maak, maak ons hom nou reg skoon? Sê nou maar daai 'plastic' dingetjie val uit, wat maak ons, daar gaan bloed wees". • <i>"Then I experience that fear that she probably will <u>not be able to breathe</u> ... especially after the operation the stoma was very small."</i> / "Dan kry ek daai bang gevoel in my dat sy miskien nie gaan kan asem kry nie ... en veral na die operasie was haar gaatjie baie klein gewees." <p>Potential to recover</p> <ul style="list-style-type: none"> • <i>"I was a bit worried, will he be able to <u>stay alive</u>? Because when we saw him after the operation, the pipes and things..."</i> / "Ek was bietjie bekommerd, gaan hy lewe? Want vir my het dit so gelyk wat ek hom sien wat hy gelê het wat hy geopereer is, die pype en goeters." <p>Cancer recurrence</p> <ul style="list-style-type: none"> • <i>"The uncertainty, <u>will the cancer come back</u>? Will we be strong enough when it comes back?"</i> / "Die onsekerheid, gaan die kanker nou weer kom? Gaan ons sterk genoeg wees as dit weer kom?" • <i>"I was a bit scared, <u>will the cancer start again</u>? ... once he coughed blood ... when I see blood I think there must be a cause for it."</i> / "Ek was half skrikkerig, gaan die kanker weer begin? ... een slag het hy bloed gehoes ... as ek bloed sien dan dink ek daar moet 'n oorsaak wees."

(b) Category: Lifestyle and aftercare

Families experienced fear and uncertainty about patients' lifestyles and expectations of aftercare. This may be because of increasing survivorship of patients (Rowland, 2008:361), as well as shortened stay of patients in hospital, with the result that caregivers (families) may experience difficulty in dealing with the demands of patients'

aftercare as they are not always equipped to take care of the side effects of the operation (Blanchard, 1982:240). The narrative responses of some of the patients are presented in Table 8.35.

TABLE 8.35: Sources of fear and uncertainty: lifestyle and aftercare

Theme 4: Patients' and families experiences of psychosocial effects and re-entry into society	
Sub-theme 4.5: Sources of fear and uncertainty	
Category	Narratives of participants
Lifestyle and aftercare <ul style="list-style-type: none"> • Lifestyle • Self care 	<p>Change in lifestyle</p> <ul style="list-style-type: none"> • <i>“Whether he would be able to talk, whether we would be able to understand and whether he would be able to accept it. Whether <u>he would be the same spontaneous person</u> he was before the operation?” / “Of hy sal kan praat dat ons hom sal kan verstaan en of hy dit gaan aanvaar. En of hy dieselfde spontane mens gaan wees as wat hy gewees het voor die operasie.”</i> <p>How to take care of him</p> <ul style="list-style-type: none"> • <i>“I did not know <u>what to expect, what you would do next? How would you cope, how would the people around you cope?</u> The people stare, what would you say? Will you become aggressive or will you just leave it at that?” / “Ek het nie geweet wat verwag, wat kan jy volgende doen nie, wat is jou volgende stap nie. Hoe gaan 'n mens dit hanteer nie, hoe gaan die mense om jou dit hanteer nie. Die mense kyk, wat gaan jy vir hulle sê. Gaan jy aggressief raak en gaan jy dit net los?”</i>

8.3.1.6 Theme 4: Sub-theme 4.6: Lessons learned during the survivorship journey

Participants were asked what they had learned from cancer in general, and then from their laryngectomy experience. As stated in the literature (Surbone *et al.*, 2010:257), the experience of survivorship is different for each cancer patient and is related to individual and societal variables. Central themes that were identified from the responses of both patients and family members are reflected in Table 8.36.

TABLE 8.36: Lessons learned during the survivorship journey: summary of patients' and families' responses

Theme 4: Patients' and families' experiences of psychosocial effects and re-entry into society				
Sub-theme 4.6: Lessons learned during the survivorship journey				
Lessons learned	Cancer in general		Laryngectomy experience	
	Patients (n = 45)*	Families (n = 15)*	Patients (n = 45)*	Families (n = 15)*
Healthy lifestyle (drinking; smoking)	21 (46,7%)	5 (33,3%)	6 (13,3%)	3 (20,0%)
Appreciation of life Positive attitude Thankfulness Acceptance	14 (31,1%)	3 (20,0%)	21 (46,7%)	7 (46,7%)
Heightened spirituality	4 (8,9%)	1 (6,7%)	6 (13,3%)	2 (13,3%)

**(Some participants indicated more than one opinion, therefore the total may exceed 100%)*

In general, **patients** mainly (21 or 46,7%) learnt to maintain a sober lifestyle by quitting previous social habits with regard to smoking and drinking as they realised that this was the cause of their disease. From the laryngectomy experience they (21, or 46,7%) mainly learned to appreciate life and to maintain a positive attitude, which included thankfulness and acceptance of circumstances which cannot be changed. **Family members**, on the other hand, also learned from the patient's cancer experience about the importance of maintaining a healthy lifestyle (5, or 33,3%) and that cancer can be cured. The laryngectomy experience mainly taught them to have a positive attitude and to appreciate life (7, or 46,7%). These categories are described next.

(a) Category: To maintain a healthy lifestyle

The literature refers to cancer as a "teachable moment" (Rowland, 2008:361-367) in terms of trying to reduce the risk of the disease recurring, by refraining from smoking, watching their diet ("to eat more vegetables and food with vitamins") and exercising ("and to do exercises"). In the case of laryngectomy patients, quitting their previous habits of

smoking and drinking (*“If you smoke and drink you must not do it”*) is applicable as these can be seen as etiological factors contributing to their diagnosis of cancer of the head and neck area (Cady, 2002:347). Patients also indicated that they give their cooperation in terms regular attendance of the follow-up clinic (*“You have to attend your follow-up visits”*). Patients’ and families’ decision to maintain a healthier lifestyle is presented in Table 8.37:

TABLE 8.37: Lessons learned: healthy lifestyle

Theme 4: Patients’ and families’ experiences of psychosocial effects and re-entry into society	
Sub-theme 4.6: Lessons learned during the survivorship journey	
Category	Narratives of participants
Maintain a healthy lifestyle <ul style="list-style-type: none"> • Social habits • Healthy lifestyle • Medical treatment 	<p>PATIENTS</p> <p>Social habits</p> <ul style="list-style-type: none"> • <i>“The lesson that I learned, if you <u>smoke</u> and <u>drink</u> you must not do it because that is the cause of the disease.” / “Die les wat ek geleer het, as jy rook en jy drink jy moet dit nie meer doen nie want daaruit ontstaan die siekte.”</i> <p>Healthy lifestyle</p> <ul style="list-style-type: none"> • <i>“Cancer taught me to eat more <u>vegetables</u> and <u>food with vitamins.</u>” / “Die kanker het my ook geleer dat ek moet baie groente kos eet en kosse wat soos vitamieene in het”.</i> • <i>“To <u>stop smoking</u>, not to eat <u>unhealthy food</u>. To use your <u>medication</u> and to do <u>exercises.</u>” / “Ophou rook, ophou verkeerde goeters eet. Jy moet jou medikasie gebruik wat jy kry, baie oefening doen.”</i> <p>Medical treatment</p> <ul style="list-style-type: none"> • <i>“You have to attend your <u>follow-up visits.</u>” / “Jy moet jou ‘check ups’ vat.”</i> <p>FAMILY MEMBERS</p> <ul style="list-style-type: none"> • <i>“I have to maintain a healthier <u>lifestyle</u> and <u>stop smoking</u> because <u>smoking causes cancer.</u>” / “Ek moet ‘n meer gesonde leefstyl handhaaf en ophou met rook want rook veroorsaak kanker.”</i>

(b) Category: Positive attitude and appreciation of life

Patients also learned to maintain a positive attitude (*“I learned you have to have self-confidence and to stay positive...”; “...to think positive and to stay positive”*) in order to master this traumatic event. They also learned to be thankful (*“From the operation I learned to accept things”*). In addition, research conducted by Quigley (Gerlach *et al.*, 1990:66) emphasised that, together with uncertainty about the possibility of a recurrence of the disease and the risk of a second malignancy, increased appreciation of life often occurs

in cancer survivors. These may include appreciation of improved health (“*You must not take your health for granted*”) as well as having a second chance in life (“*you have to appreciate your second chance*”). Responses related to the question that was asked are reflected in Table 8.38.

TABLE 8.38: Lessons learned: appreciation of life

Theme 4: Patients’ and families’ experiences of psychosocial effects and re-entry into society	
Sub-theme 4.6: Lessons learned during the survivorship journey	
Category	Narratives of participants
Appreciation of life <ul style="list-style-type: none"> • Positive attitude • Appreciation 	<p>PATIENTS</p> <p>Positive attitude</p> <ul style="list-style-type: none"> • “<i>I learned you have to have <u>self-confidence</u> and to <u>stay positive</u> and <u>adapt</u>.</i>” / “<i>Ek het geleer dat jy moet selfvertroue het en dat jy moet positief bly en jy moet vir jou aanpas.</i>” • “<i>The Lord gave me <u>the vision</u> to <u>think positively</u> and to <u>remain positive</u>.</i>” / “<i>Die Skepper het vir my die visie gegee dat ek moet positief dink en moet positief bly.</i>” • “<i>From the operation I learned to <u>accept</u> things. There <u>is hope</u>, you can be cured.</i>” / “<i>Uit die operasie het ek geleer ek aanvaar ander dinge. Daar is hoop, jy kan genees.</i>” <p>Appreciation of life</p> <ul style="list-style-type: none"> • “<i>You must not take your <u>health for granted</u>.</i>” / “<i>Dat jy nie die gesondheid as vanselfsprekend moet aanvaar nie.</i>” • “<i>You have to <u>treasure your life</u> ... you have to take life one day at a time</i>” / “<i>Jy moet jou lewe oppas, jy moet kyk na jou gesondheid ... jy moet maar lewe dag vir dag vir dag.</i>” • “<i>You’ve got a second chance in life; therefore you have to <u>appreciate your second chance</u>.</i>” / “<i>Mens het ‘n tweede kans gekry in die lewe daarom waardeer ek die tweede keer.</i>” <p>FAMILY MEMBERS</p> <p>Positive attitude</p> <ul style="list-style-type: none"> • “<i>You have to take it <u>day by day</u> ... you have to make the best out of the bad.</i>” / “<i>Jy moet maar dag vir dag vat ... jy moet maar die beste maak van ‘n slegte saak.</i>” • “<i>Your <u>vision of life</u> changes, you have more respect for what you have now.</i>” / “<i>Jou visie van jou lewe ‘change’, jy kry nou meer respek vir wat jy nou het.</i>” • “<i>To say thank you every day for everything ... life is short, it can easily turn against you.</i>” / “<i>Om elke dag dankie te sê, dankie vir alles ... want die lewe is so kort, dit kan so vinnig teen jou draai.</i>” <p>Appreciation of life</p> <ul style="list-style-type: none"> • “<i>Cancer is not synonymous with death, it is only a word. You get a <u>second chance</u>.</i>” / “<i>Kanker is nie ‘n doodsvonniss nie, dis maar net ‘n woord. Mens kry ‘n tweede kans.</i>”

(c) Category: Heightened spirituality

O’Baugh *et al.* (2003:268) found that, together with a positive attitude, spirituality can help patients to create meaning from what has happened to them. Schulz *et al.* (2008:114) said that when people are faced with a failing body (in this case an altered body image), the spiritual is sometimes the only thing left to turn to (“...the Lord will carry me”). Participants realised their dependency upon the Lord (“...you are nothing”, “I am not my own boss, the Lord is your boss”). Table 8.39 reflects the lesson of “appreciation of life” as learned by patients and families.

TABLE 8.39: Lessons learned: heightened spirituality

Theme 4: Patients’ and families’ experiences of psychosocial effects and re-entry into society	
Sub-theme 4.6: Lessons learned during the survivorship journey	
Category	Narratives of participants
Heightened spirituality	<p>PATIENTS</p> <ul style="list-style-type: none"> • “When I looked there was a very dark cloud. In the cloud was an image, a perfect face. I then doubted. Something said to me: Lord, if it is you, look at me. While I looked I realised: I must not be afraid, <u>the Lord will carry me.</u>” / “Toe ek opkyk is daar ‘n pikswart wolk. En in die wolk staan ‘n beeld, die volmaakte gesig. Ek het toe getwyfel. En iets sê vir my: Here, as dit U is, kyk na my. En terwyl ek so kyk kom dit op na my: jy moet nie bekommerd wees nie, ek dra jou.” • “I was not very religious. The operation taught me that you must never forget that <u>you are nothing, you have to know there is Someone Greater.</u>” / “Ek was nie baie godsdienstig nie. Die operasie het my geleer jy moet nooit vergeet die mens is maar ‘n niks, jy moet maar weet daar is iemand Hoër.” • “From the operation I learned that <u>you are not your own master, the Lord is your master. When you go for the operation and when you come back, then you pray and you ask for the help of the Lord, you pray to be cured.</u>” / “Die operasie het jy geleer jy is nie jou eie baas nie, die Here is jou baas. As jy vir die operasie gaan of jy kom noutet uit die operasie, dan bid jy en dan vra jy vir die Here om vir jou te help, dan bid jy, sodat jy kan gesond word.” <p>FAMILY MEMBERS</p> <ul style="list-style-type: none"> • “I was always afraid of an operation, I thought when you are going to theatre you will not come back, it <u>taught me to trust.</u>” / “Ek was altyd bang gewees vir ‘n operasie, ek het gedink as jy teater toe gaan dan kom jy nie weer terug nie, en dit het my geleer om te vertrou.”

Participants were then asked to describe to what extent previous strengths they had discovered within themselves, or lessons they had learned in the past, helped them to cope with their laryngectomy experience. Responses to this question are presented in Table 8.40. Participants (20, or 44,4%) mainly referred to the role that **strength** within themselves (*“The strength within you is what I believe in”*) and **spirituality** (12, or 26,7%) (*“My faith in the Lord, that is actually the spirit that gave me strength”*) had played in this regard. Ten (22,2%) participants could not specify or did not respond to the question. Taking into account the scholastic training of participants and the large proportion that had either no (9, or 20%) or only primary school education (16, or 35,6%), it might have been difficult for them to respond to a question of such an abstract nature.

TABLE 8.40: Lessons learned: Previous strengths used

Theme 4: Patients' and families' experiences of psychosocial effects and re-entry into society	
Sub-theme 4.6: Lessons learned during the survivorship journey	
Category	Narratives of participants
Inner strength	<ul style="list-style-type: none"> • <i>“The <u>strength within me</u> is what I believe in. Nothing is impossible, you can achieve things if you have a <u>strong will</u>.” / “Die krag binne myself dit is dinge waarin ek glo. Niks is onmoontlik nie, ‘n mens kan dinge bereik as jou wilskrag net daar is.”</i> • <i>“After the operation I thought to <u>stay strong</u> to survive the disease.” / “Na die operasie het ek gedink om sterk te bly dat ek die siekte kan oorwin.”</i> • <i>“You have to try to make the <u>best out of the bad</u> ... but wasn't it for my own will then I would not have made it.” / “Jy moet probeer om van die slegte iets goed te maak ... was dit nie vir my wilskrag nie dan sou ek dit seker nie gemaak het nie.”</i> • <i>“The <u>will to go on with life and not to let it put you down</u>.” / “Die wil om aan te gaan met die lewe en jou nie te laat onderkry nie.”</i>
Spirituality	<ul style="list-style-type: none"> • <i>“My faith in the Lord, that is actually the power that <u>gave me strength</u>.” / “My geloof in die Here, dit is nou eintlik die krag wat vir my baie sterk gemaak het.”</i> • <i>“I only decided the Lord is <u>always with me</u> and I need not fear.” / “Ek het maar net altyd besluit die Here is altyd saam met my en ek hoef nie bang te wees nie.”</i>

8.4 REMARKS

Participants were first asked how they felt about being approached to do the interview in order to complete the questionnaire. This was a positive experience for all (45, or 100%) participants. They felt proud to be of help to others who still have to undergo this operation.

- *“Well, some things went out which always stayed inside, because you asked questions and I answered them. Wonderful, now I feel free.” / “Wel hier het dinge nou uitgegaan wat altyd binne gebly het, omdat u vrae gevra het en ek die vrae geantwoord het. Wonderlik, nou voel ek weer skoon.”*
- *“It now let me feel very good that you actually made use of me, that I can describe the way I feel, the way I am.” / “Dit laat my goed voel dat u gebruikmaak van my, nou kan ek beskryf hoe ek voel.”*

In response to the question about their feelings when they had to think back about their operation, all (45, or 100%) participants again agreed that it was a positive experience for them:

- *“For me I feel good to talk about my disease. It gives one encouragement and strength to continue.” / “Vir my voel dit lekker om te praat oor die siekte. Dit gee ‘n man weer ‘n hupstoot vorentoe en dit maak jou weer sterk om aan te gaan.”*
- *“I feel good. There is a bit of ups and downs but the wind will blow it all away.” / “Ek voel goed. Daar is nou so ‘n bietjie ‘ups and downs’ maar die wind waai dit weer later weg.”*
- *“I refer to myself as a cancer survivor ... you can only encourage someone if you yourself went through it.” / “Ek noem myself ‘n kanker ‘survivor’ ... jy kan alleen iemand bemoedig as jy self daardeur gegaan het.”*

8.5 CONCLUSION

Within **Theme 3**, patients and families’ experiences of coping and strengths used in order to survive the laryngectomy experience were described. This included coping with physical changes resulting from the operation, completion of treatment, coping with the most difficult post-operative adaptation, coping with the hospital’s expectations after discharge and the laryngectomy experience in general. It was clear that both primary and secondary survivors utilise a combination of strengths and ecological perspectives in order to survive the laryngectomy experience.

Their experience of psychosocial effects of the operation and re-entry into society was discussed under **Theme 4**. The effects of the operation on various social relationships, as well as the experience of loss of natural voice, were also explored. It became clear that previous relationships mostly remained the same. The only two levels that were negatively affected were survivors' previous employment and financial position and their relationship with former friends. Although loss of natural voice was experienced as a loss, both primary and secondary survivors were thankful for improved health following the operation.

Re-entry into society was described in terms of their adjustment to society; things that made their re-entry easier; sources of fear and uncertainty; and lessons learned from cancer in general and their laryngectomy experience in particular. The majority of participants found their adjustment to society to be easy. Both inner and external sources of support helped them with the re-entry into society. The contribution of pre- and primary school children in this regard was highlighted. Patients and families mostly learned from both the cancer and the laryngectomy experience to maintain a sober lifestyle and to have a positive attitude with appreciation for life, and experienced heightened spirituality.

In Chapter 9 the conclusions will be explained and recommendations will be made.

CHAPTER 9

FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

9.1 INTRODUCTION

The survivorship experience of laryngectomy patients and their families was investigated in this study. The **aim** of this **chapter** is to present a summary of the findings in order to make conclusions based on the findings of the study and to make relevant recommendations. These recommendations could be used by social workers in the field of oncology, especially those who are involved with rendering services to laryngectomy patients.

The **goal** of the proposed study was to gain an understanding of the survivorship experience of laryngectomy patients and their families, as starting from the moment of diagnosis onward. Within this journey of survivorship, the survivor applies both personal (strengths perspective) and environmental (ecological perspective) resources to experience this traumatic life issue either as a stressor or as a challenge. This goal was reached as the following objectives as specified in **Chapter 1** were reached:

- In **Chapter 2**, a theoretical overview of the nature of cancer survivorship as experienced by the patient and various groups involved was presented. This provided insight and a better understanding of the various phases of survivorship.
- In **Chapter 3**, the medical aspects involved in a laryngectomy and physical re-adjustments for patients and their families were described.
- In **Chapter 4**, the principles of and strategies for coping and surviving as a post-operative laryngectomy patient were discussed.
- In **Chapter 5**, coping with the comprehensive psychosocial effects of the permanent phase of surviving a laryngectomy was explained, as well as patients' re-entry into society.

- In **Chapters 7 and 8**, the findings obtained from the study were analysed and interpreted.
- In this chapter (**Chapter 9**), findings of the study, from which conclusions are drawn and recommendations will be made, are presented.

The **research question** of the study was: “What are patients’ and families’ experiences of surviving a laryngectomy with the assistance of internal (strengths perspective) and external resources (ecological perspective) within the family system and environment?” This question was addressed in the previous two chapters.

9.2 FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

9.2.2 Identifying details

Findings of the study regarding patients’ and family members’ identifying details, as well as patients’ medical details, are as follows:

9.2.1.1 *Patients*

The **age** of participants (patients) who were selected for the study varied between 42 and 79 years with an average of 62 years. Both **male** and **female** patients were involved; however, more males (37, or 82,2%) than females (8, or 17,8%) took part. This is in line with the current tendency, namely that mostly elderly male persons are affected by the diagnosis of cancer of the larynx. The majority of participants were **married** (25, or 55,6%) or lived with a partner (8, or 17,8%). With the exception of eight White (17,8%) and two patients from the Black **population group** (4,4%), all other participants (35, or 77,8%) were from the Coloured population group. The catchment area of the hospital where the study was conducted extends to patients from the Western Cape. Statistics of laryngectomy operations being performed showed that the majority of these patients were from the Coloured population group. Patients who participated in the study were therefore representative of the statistics recorded at the specific hospital. The majority of participants (16, or 35,6%) had primary school or no (9

or 20,0%) **education**, were pensioners (civil or social) following their surgery (36, or 80%) and earned a total monthly income of between R 2 000 and R 2 499 (16, or 35,6%) and therefore fell into a low-income group.

9.2.1.2 Family members

Fifteen family members, representative of one-third of those patients (45) who participated, were selected to participate in family interviews. Family members who participated mainly comprised spouses or life partners (10, or 66,7%). These family members were appointed by patients as those who were most exposed to their laryngectomy experience.

9.2.2 Medical information

All the participants (patients) (45, or 100%) in the study received a total laryngectomy for treatment of an advanced cancer diagnosis (cancer of the glottis or supraglottis). This was mostly followed up with post-operative radiotherapy treatment (33, or 73,3%). Nearly all the participants (43, or 95,6%) presented with the absence of cancer. The average period of time that elapsed between the **date of diagnosis** and the **date of surgery** (laryngectomy) was four months, the average period of time that elapsed between the **date of surgery** and the **date of the interview** was four years and nine months whilst the average time period between the date of **completion of treatment** and the date of **interviewing** participants, was four years and seven months. Most of the participants (25, or 55,6%) attended the follow-up clinic on a six- to twelve-month basis.

From these findings it can be **concluded** that the general profile of laryngectomy patients who participated in the study varied in age, gender, marital status, race, education, occupation and income. Characteristics associated with patients who present with cancer of the head and neck area, are that they are elderly, male, of low education and low socio-economic status (Eadie & Doyle, 2005:120). Findings of the study were in accordance with information from the literature.

RECOMMENDATIONS

It is recommended that social work service providers involved in survivorship issues of cancer patients who are aiming at intervention with laryngectomy patients and their families (as was discussed in Chapter 3 paragraph 3.2.3.3), should have:

- Knowledge of **medical aspects** involved in the diagnosis and treatment of cancer of the larynx
- Knowledge of the **etiological factors** of larynx cancer (substance abuse like severe smoking and drinking over a period of time), to initiate community precaution programmes.

9.2.3 Theme 1: Patients' and families' need for pre-operative information in survivorship experience

9.2.3.1 *Nature of need for information*

The following **findings** regarding patient' and families' need for information before the operation are of importance:

- Both patients and families indicated their main need to be for pre-operative information in the categories of the **nature** and **extent** of **surgery** (21, or 46,7%, and 10, or 66,7%, respectively), as well as the **length** of **treatment** and expected **side-effects** (20, or 44,4% and 9, or 60% respectively) of treatment.
- For patients, it was of greater relevance to know more about how the operation would affect their **daily lifestyle** (18, or 40,0%), whilst family members (7, or 46,7%) wanted to know more about the **diagnosis** and **survival** of the patient prior to the operation, as being cured and relieved of symptoms such as pain and difficulty with swallowing were their main concern.
- Eight (17,8%) patients required further information regarding their **diagnosis**, including causes and confirmation of the diagnosis.
- Three family members (20,0%) wanted more information with regard to the effect of the operation on their **daily lifestyle**.

- Three family members (20,0%) indicated that, prior to the patient's operation, they wanted to know more about **how to take care** of the patient, taking into account that survivorship increases with the result that family members would have to take care of patients for longer periods of time.
- Eight patients (17,8%) felt that they experienced **no need** for information prior to their operation because to be cured and relieved of their symptoms such as pain and difficulty with swallowing were their main concern.
- Twenty-seven participants (60,0%) felt that they had been **fully informed** pre-operatively about the operation. They found that this preparation was on a physical, emotional and social level.
- Sixteen patients (35,6%) felt that they had been **partially informed**. Pre-operatively, they would have liked to have more information regarding the presence of the permanent tracheostoma, and the effect of the operation on their speech as well as on their daily living.
- Two patients (4,4%) were of the opinion that they were **not informed at all**.

CONCLUSION

The **conclusion** can be drawn that both patients and families experienced a need for information pre-operatively, although levels on which they required information may have differed to some extent. The majority of participants found the information they received prior to surgery to be adequate and helpful towards their emotional, physical and social preparation for the operation, as well as for their post-operative adjustment.

RECOMMENDATIONS

With regard to the role of the social worker in offering information to patients and families pre-operatively (Chapter 3 paragraph 3.2.3.3), it is recommended that:

- The social worker should have thorough knowledge of the **various levels** of patients' and families' needs for pre-operative information.

- The social worker, as part of the **multi-disciplinary team**, should play a significant role in providing information to patients and families, taking into account their communication skills.
- The social worker should have knowledge of the **strengths perspective** in order to respect patients for their knowledge as they know exactly what they are talking about and are experts regarding their own lives.
- The social worker should have skill in **listening** to patients' and families' need for information.
- The social worker should advocate for **open discussion** of information between patients, families and health care workers.

9.2.3.2 Emotional reactions of patients and families at the time of diagnosis and being informed about surgery

Findings of the study regarding patients' and families' emotional reactions at the time of diagnosis and when being informed about surgery, are as follows:

- Patients mostly experienced **emotional reactions** such as sadness (23, or 51,1%) and acceptance (15, or 33,3%) in response to received pre-operative information.
- **Emotional reactions** of family members as perceived by patients at the time of diagnosis and being informed of the operation mostly involved sadness (24, or 53,3%) or shock (13, or 28,9%).
- Family members themselves indicated that they pre-operatively mostly experienced **emotional reactions** such as sadness (7, or 46,7%) or shock (4, or 26,7%).
- Nine (20,0%) patients **could not describe** their emotions at the stage of being informed of their diagnosis and also could not indicate how they thought their families felt at the stage of diagnosis (8, or 17,8%).

It can be **concluded** that emotional reactions to the received information as perceived by patients to a large extent correlated with their family's reactions and this was also confirmed by family members themselves. These emotional reactions mostly involved sadness, shock and acceptance.

RECOMMENDATIONS

Taking into account the role of the social worker in offering support to patients and families (Chapter 3 paragraph 3.2.3.3), it is recommended that:

- The social worker dealing with survivorship issues of oncology patients should feel comfortable with and be sensitive to **personal feelings** and **experiences** in dealing with cancer patients in general, and laryngectomy patients in particular, as the process of interviewing these patients at times requires a high degree of professional skill.
- The social worker should be aware of the **emotional reactions** patients and families will experience at the stage of being informed of their diagnosis and planned treatment.
- The social worker should have expert knowledge and skills to take care of identified **emotional reactions**.
- The social worker should have knowledge of the **ecological perspective** and skills in the implementation of this perspective when rendering service to patients and families, as they function within various ecological systems and interact with one another in order to cope or survive.
- The social worker should have the potential to **offer support** to patients and families at the stage of diagnosis and when being informed about surgery, as the family can be seen as the closest system in which patients function, and change in one system will affect the others.

9.2.4 Theme 2: Patients' and families' experiences of physical re-adjustment

The following are **findings** with regard to patient's and families' experiences of physical adjustment:

- The most difficult **physical changes** patients have to adapt to following the operation, are on the level of their sensory functioning (20, or 44,4%), followed by their speech limitation (15, or 33,3%).
- For families, the most difficult **physical change** following the operation was adaptation to the patient's post-operative speech ability (10, or 66,7%), followed by the presence of the permanent tracheostoma (6, or 40,0%).
- Eighteen (40,0%) participants could not describe their emotional reactions regarding having to adapt to inevitable permanent **physical changes** caused by the operation. This was followed by their experience of sadness (16, or 35,6%).
- Families mostly responded with **feelings** of acceptance (7, or 46,7%) or sadness (4, or 26,7%) regarding adapting to inevitable permanent **physical changes** caused by the operation .

From the above-mentioned findings, the **conclusion** can be drawn that patients and families differ regarding their experience of the most difficult physical post-operative adaptation. While most patients found it difficult to describe their emotional reactions to these changes or experienced sadness, families responded with acceptance and thankfulness.

RECOMMENDATIONS

Taking into account the role of the social worker throughout the patients' and families' survivorship journey (Chapter 3 paragraph 3.2.3.3), the following recommendations can be made:

- The social worker should have knowledge of the various **physical effects** of the operation as it impacts on patients' and families' psychosocial functioning.
- The social worker should have knowledge of these **physical effects** as both patients and families will have to deal with the effects of the operation for a longer period of time as survivorship increases.
- The social worker should be sensitive to **differences** between patients' and families' experiences of inevitable permanent physical changes after the operation in order to offer appropriate social support.
- The social worker should assist patients and families with their post-operative **adjustment**, as problems experienced on a physical level have the ability to impact on a psychosocial level.
- The social worker should find innovative ways to **encourage communication** with patients and families who may have difficulty with their ability to express their emotional reactions to inevitable permanent physical changes following surgery due to their level of education.

9.2.5 Theme 3: Patients' and families' experiences of coping and strengths used

Findings regarding coping and strengths utilised throughout the various phases of participants' medical treatment, which is also representative of the various phases of patients' and families' survivorship journey, are presented next, followed by conclusions and recommendations regarding each of these phases:

9.2.5.1 Coping with permanent physical changes caused by the operation

In the **acute phase** of survivorship, patients have to cope with inevitable permanent physical changes resulting from the operation. The following **findings** were determined from the study:

- Thirty-one (68,9%) patients utilised their **inner strength** to deal with inevitable physical changes following the operation. Experiences in this regard were based on the principles of the strengths perspective.
- Seven (15,6%) patients referred to the role of **social support** in order to adapt to the inevitable physical changes post-operatively. They referred to support received from family members, friends, people from the church and their grandchildren.

The **conclusion** can be drawn that patients mobilise a combination of both inner strength and social support in order to adapt to inevitable physical changes post-operatively. Various sources of social support can be seen as valuable for these patients' post-operative adaptation in order to deal with these changes.

RECOMMENDATION

Being involved in patients' and families' survivorship journey from the stage of diagnosis to shortly after surgery, it is recommended that:

- The social worker should be aware of the experience of patients and families having to deal with **inevitable permanent physical changes** resulting from the operation.

9.2.5.2 *Coping with end of active medical treatment*

While still in the **acute phase** of survivorship, patients and families have to cope with challenges at the stage when medical treatment is completed. The study **found** that:

- Thirty-two patients (71,1%) experienced emotions of **gratitude** following their medical treatment. Reasons for their gratitude were their improved health condition; support from a hospital team; reintegration in family; successful mastering of post-operative speech; future life expectancy; and financial aspects.

- Six patients (13,3%) experienced **fear** and **uncertainty** at the time of treatment completion due to fear of social rejection; possible recurrence of disease; or loss of support from the hospital.
- Seven (15,6%) experienced **mixed feelings** at the end of their medical treatment, referring to feelings of thankfulness together with sadness, shame, or feelings of discomfort.

In **conclusion** it can be said that a variety of emotional reactions experienced at the stage of treatment completion varied from gratitude to fear and uncertainty, or a combination of emotions.

RECOMMENDATION

At the stage of treatment completion, it could be recommended that:

- The social worker should have insight in patients' emotions at the stage of **treatment completion** to prepare them prior to their discharge from hospital regarding how to deal with these emotions.

9.2.5.3 Coping with most difficult adaptation post-operatively

During the **transitional phase** of survivorship, physical readjustment following their treatment will occur. **Findings** of the study are:

- Twenty-nine patients (64,4%) and six families (40,0%) indicated that **post-operative speech** was the most difficult to deal with. This was also in accordance with family's reactions as perceived by patients (29, or 64,4%).
- Twelve patients (26,7%) found the presence of the **stoma** and their experience of limited **physical ability** to be problematic after the operation. Three families (20,0%) confirmed their difficulty with regard to the patients' physical appearance. This correlated with to how patients thought family members would feel (9, or 20,0%).

- Six patients (13,3%) identified problems they had experienced on a **social level**, and referred to their family's problems experienced on an **emotional** level (8, or 17,8%). Problems on a **social level** referred to problems in socialising with others and also to their decision to change their previous social habits. **Emotional problems** experienced by families involved patients' aftercare and adjustment.
- Three families (20,0%) reported experiencing problems on a **psychosocial** level. This referred to separation from the patient whilst being in hospital and having to deal with the reactions of other people.

From the above-mentioned findings it can be **concluded** that, following the operation, post-operative speech was the most difficult adaptation to make for both patients and families. It can also be **concluded** that, to a lesser extent, physical aspects such as the presence of the stoma and limited physical ability present another area of difficulty related to their adaptation. Another **conclusion** was that psychosocial effects of the operation were experienced by both patients and families, and this mainly involved the challenge of having to deal with the reactions of others.

RECOMMENDATION

Social work with laryngectomy survivors should take into account that:

- The social worker should have knowledge of, insight in and sensitivity towards the **most difficult** post-operative **adjustment** patients and families have to make, in order to assist them throughout their survivorship journey.

9.2.5.4 *Coping with aftercare*

Still within the **transitional phase** of survivorship, **findings** of the study were:

- Thirty-four patients (75,6%) indicated that they **knew exactly** what was expected of them after being discharged. They felt prepared for their aftercare and requirements in terms of their future lifestyle. They also emphasised the role of their own positive attitude, their own independency and the role of their faith.

- Six patients (13,3%) held the opinion that they **did not know exactly** what was expected from them, as they did not request information from team members or felt that no one could prepare one for what to expect, because you have to experience it yourself.
- Five patients (11,1%) **did not know at all** what was expected of them after being discharged; they either felt unprepared for the continuous effect of the operation and had to deal with unanswered questions in terms of their future employment.

It can be **concluded** that most patients knew what was expected of them after being discharged. Taking into account the increased survivorship of cancer patients, this is of significance with regard to patients' aftercare and families who have to deal with patients' aftercare for longer periods of time.

RECOMMENDATION

At the stage of discharge planning, the social worker should take care of survivors' need for knowledge regarding their aftercare:

- The social worker, as member of the multi-disciplinary team, should guide patients and families to increased knowledge of what the **hospital's expectations** are of patients following their medical treatment.

9.2.5.5 Coping with the laryngectomy experience in general

With regard to coping abilities, patients utilised principles of the strengths perspective (Saleebey, 2002:13-18) to the following extent:

- All patients (45, or 100%) utilised strengths such as **not being let down** by the operation and **hope** for the future, and benefited from **support** in order to feel strong.
- Forty-four patients (97,8%) relied on a sense of **purpose and meaning**.
- Forty-five (100%) had incorporated their laryngectomy experience into **daily life**.

- Forty-four patients (97,8%) decided to utilise **strengths** which had helped them in the **past** in order to master this experience.
- Forty-three (95,6%) view the operation as an **opportunity from which they could learn**.
- Forty-one (91,1%) patients indicated that they have **plans** for their **future**.
- Forty-five patients (100%) experienced **heightened spirituality** following their operation, and that it promoted their **appreciation in life** and made them realise what is **most important in life**.
- Forty patients (88,9%) decided to adopt a more **healthy lifestyle**.
- Forty-five patients (100%) agreed to attend regular **follow-up visits** at the clinic.
- Twenty-four (53,3%) viewed attendance of **follow-up visits** as an opportunity to assess their **cancer status**.
- Eighteen (40%) viewed attendance of **follow-up visits** as necessary to evaluate their **medical condition in general**.

In **conclusion**, patients utilised strengths based on the various principles of the strengths perspective (Saleebey, 2002:13-18) in order to survive their laryngectomy experience; these included their inner strength; seeing cancer as a challenge and viewing it as an opportunity for growth and change and to collaborate.

With regard to support provided in terms of the **ecological perspective** (Germain & Gitterman, 1996:13), patients referred to the use of the following sources of support within the community in the following ways:

- Seventeen patients (37,8%) and eight family members (53,3%) identified their **family members** as the most important source of support in the community during their post-operative coping.
- Thirteen patients (28,9%) and five family members (33,3%) viewed their **friends in the church** as supportive.
- Twelve patients (26,7%) identified personnel of the **day hospital** as helpful to them.

- Nine patients (20,0%) found their **friends** to be supportive.
- Seven patients (15,6%) said that their **neighbours** were supportive.
- Eight family members (53,3%) experienced **hospital team members** as helpful to them, whilst two families (13,3%) referred to the role of **support groups**.

In **conclusion**, patients utilise various sources of social support in order to deal with the laryngectomy experience in general. In general, the overall **conclusion** can be made that patients utilised a combination of both inner strength and external resources in order to cope and survive.

RECOMMENDATIONS

Regarding being involved in survivorship issues of laryngectomy patients and their families, it is recommended that throughout the various phases of the survivorship journey of patients:

- The social worker should have insight in patients' coping through the various **phases of medical treatment** and survivorship.
- The social worker should have knowledge of the principles of both the **strengths** and the **ecological perspectives**, as patients demonstrate the use of a combination of the principles of both in order to survive the laryngectomy experience.
- The social worker should assess **inner strengths** of patients and families and respect them for being experts in their experience of the laryngectomy.
- The social worker should have knowledge of **community resources** available in order to link these patients with relevant resources.
- The social worker should be **innovative** in creating an environment for patients to explore their own inner strengths or to be linked with community resources.

9.2.6 Theme 4: Experience of psychosocial effects of surgery and re-entry into society

The following **findings** were determined with regard to patients' and families' experience of the psychosocial effects of the operation and re-entrance into society:

9.2.6.1 *Psychosocial effects of the operation*

The psycho social effects of the operation refer to a combination of both social and emotional effects experienced by patients:

(a) *Social effects*

- Patients mainly indicated that their relationships with their life partners; children or grandchildren; other family members; previous friends; their ability to form new relationships and fulfilment of social roles **remained the same**.
- Relationships with regard to other family members **improved** after the operation.
- Relationships that were **negatively affected** were those with **previous friends**, while their employment and finance were also affected.

It can be **concluded** that a laryngectomy experience has the ability to affect the patients' and families' social functioning. Although most relationships remained the same, the areas which were most affected were the relationship with previous friends and their employment and finance. On the other hand, the laryngectomy experience was also beneficial for their relationship with other family members, this being the area that improved after the operation.

RECOMMENDATION

- The social worker should be sensitive to and have insight in the potential effect of a laryngectomy on the patient's social functioning, for instance the relationship with **previous friends** and practical issues like **employment** and **finance**.

(b) *Emotional effects*

- Twenty- six patients (57,8%) indicated that they were negatively affected by their loss of voice and their experience of it was one of **loss**. Not being heard and also having to deal with the behaviour of others added to their feeling of loss.
- Ten family members (66,7%) managed to experience the patient's loss of voice as a positive experience of **acceptance**, because they were thankful for the patient's improved health and their ability to talk after surgery.

It can be **concluded** that, although loss of voice is experienced by patients as a loss, families managed to overcome this loss experience through acceptance and thankfulness.

RECOMMENDATIONS

- The social worker should have sensitivity for and insight into the experiences of loss (such as **loss of voice**) that patients have to deal with.
- The social worker should be aware that patients and families experience the patient's loss of voice differently. During social work intervention, these differences have to be considered.

9.2.6.2 *Re-entry into society*

With regard to participants' re-entry into society, **findings** indicated that:

- Twenty-six patients (57,8%) found their re-entry into society **easy**. Factors promoting this were successful mastering of speech; acceptance of others; the social support they received; their own positive attitude; and their inner strength.
- Seventeen patients (37,8%) experienced **difficulty** with their adjustment to society, mainly due to difficulty in communication and having to deal with other people's behaviour.
- Two (4,4%) patients were **not sure** how they experienced their re-entry into society.

- Patients mobilised both **inner** and **external resources** in order to ease their adjustment to society.
- With regard to **inner resources**, patients referred to the positive role of self-acceptance, inner strength, appreciation of life, and the role of faith.
- **External resources** referred to the role of speech in order to promote patients' post-operative adjustment; the role of pre- and primary school children and grandchildren, as well as recreational activities.
- Sources of **fear** and **uncertainty** mainly involved those aspects related to physical issues (presence of the stoma and how to take care of the stoma; potential fatal outcome of the disease), lifestyle and aftercare. Similar information was reported by family members responding to this experience.
- From their **cancer experience**, twenty-one patients (46,7%) indicated that they learned to follow a healthier lifestyle, as was also experienced by five family members (33,3%).
- Twenty-one patients (46,7%) and seven family members (46,7%) learned from their **laryngectomy experience** to be thankful.
- To a lesser extent, **heightened spirituality** was mentioned by patients and families with regard to their experience of cancer in general (patients: 4, or 8,9%; families 1, or 6,7%) and specifically with reference to the laryngectomy experience, patients 6, or 13,3%; families 2, or 13,3%).

In **conclusion**, most patients found their re-entrance into society easy. They mobilised both internal and external resources to assist them in this regard. Another **conclusion** is that the experience of fear and uncertainty mainly involved their physical appearance, lifestyle and aftercare. This can be related to increased survivorship and the shortened stay in hospital. It can also be **concluded** that a diagnosis of cancer can be seen as a teachable moment, as patients and families learned from their cancer experience to maintain a healthy lifestyle. With regard to the laryngectomy experience, they learned to be thankful.

RECOMMENDATIONS

With regard to patients' **re-entry into society**, the following recommendations are made:

- The social worker should, as member of the multi-disciplinary team, prepare patients and families for their **aftercare** before the patient is discharged.
- The social worker should enhance the mobilisation of both inner strength and external resources to make the patient's **re-entry** into society **easier**.
- The social worker should have knowledge of the theoretical departure points of both the **strengths and ecological perspectives**.
- The social worker should be aware of patients' **inner strengths** as well as **strengths** they had utilised in the **past** to overcome problems, as this could be utilised again in their experience of surviving a laryngectomy.
- The social worker should be aware of the various potential **sources of support** which may be beneficial for patients.
- The social worker should be involved in opportunities to promote patients' **post-operative speech** rehabilitation as this helps them with their re-entry into society.
- The social worker should emphasise the role of pre- and primary school **children or grandchildren** in patients' post-operative adjustment, as this was found to be of help in the study.
- The social worker should encourage patients to participate in **recreational activities**, as this helps them with their post-operative adaptation.
- The social worker should be sensitive regarding sources of **fear** and **uncertainty** involving physical and lifestyle aspects and aftercare, in order to assist patients through their laryngectomy experience.
- The social worker should look into opportunities to promote the cancer patient's experience of cancer as a **teachable moment** in order to promote a healthier and sober lifestyle.

9.3 FURTHER RESEARCH

In view of the results of this explorative and descriptive investigation, it is suggested that further research regarding the survivorship issues of laryngectomy patients and their families should focus on:

- Further research on the long-term psychosocial survival of laryngectomy patients and their families, as it is likely that survivorship will increase in future.
- Initiation of survivorship programmes for health care professionals to guide survivors to full utilisation of their own strengths and available community resources.
- The role of pre- and primary school children/grandchildren in the rehabilitation of laryngectomy patients shortly after their discharge from hospital.

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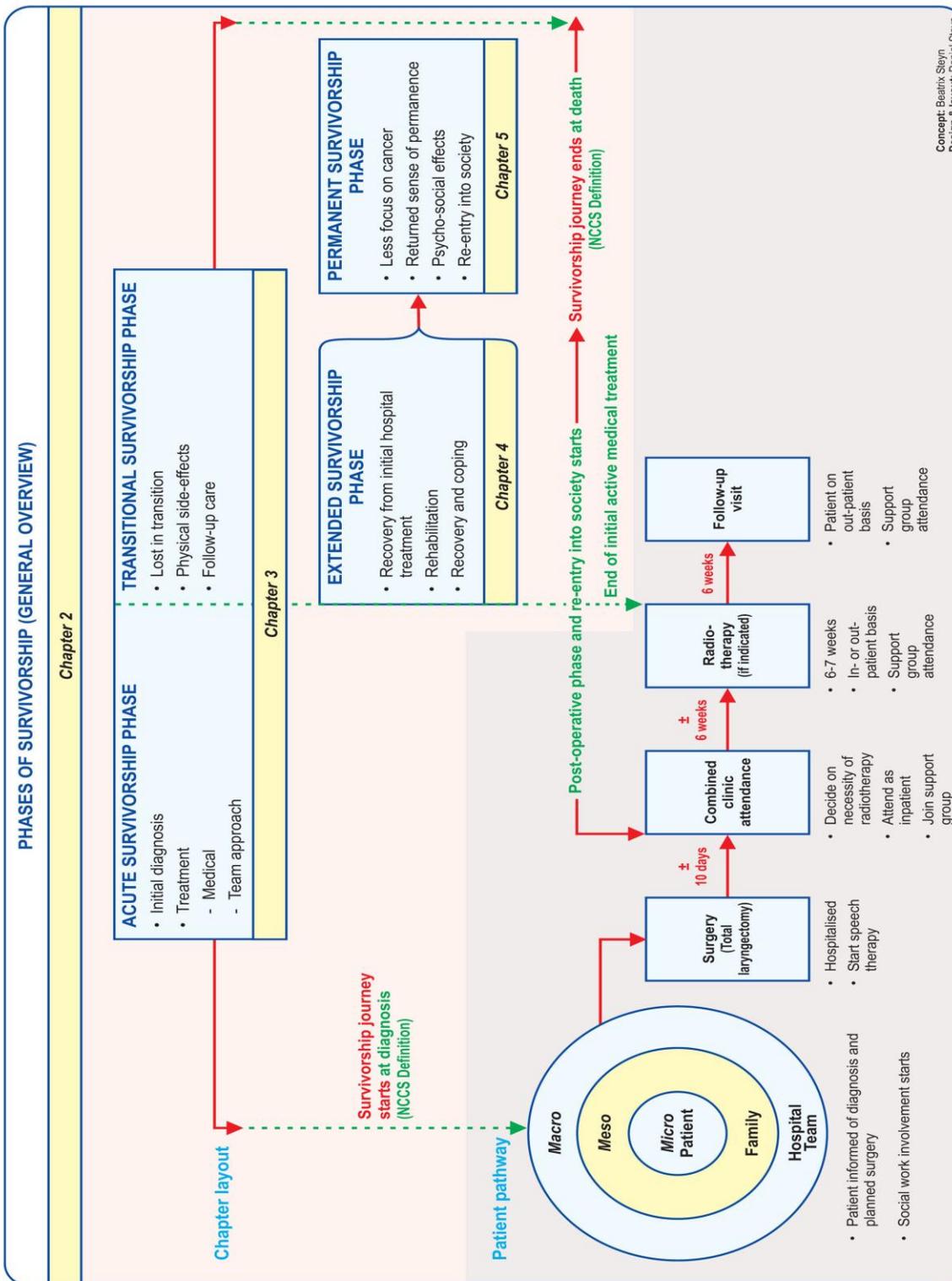
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ANNEXURE A – The laryngectomy patient’s survivorship experience (chapter layout and phases of survivorship)

[Based on the model of Miller, K., Merry, B. & Miller, J. 2008. Seasons of survivorship revisited. *The Cancer Journal*, 14(6):369-374]



ANNEXURE B – Semi-structured Interview schedule (patients)

UNIVERSITY OF STELLENBOSCH /
UNIVERSITEIT VAN STELLENBOSCH

DEPARTMENT OF SOCIAL WORK /
DEPARTEMENT MAATSKAPLIKE WERK

SEMI-STRUCTURED INTERVIEW SCHEDULE / SEMI-GESTRUKTUREERDE ONDERHOUDSKEDULE

Surviving a laryngectomy: The experience of post-operative cancer patients and their families / *Oorlewing van 'n laringektomie: Die ervaring van post-operatiewe kankerpatiënte en hul families.*

All information will be regarded as confidential. Individual views or respondents' names will not be made known. / *Alle inligting is vertroulik. Individuele standpunte of respondente se name sal nie bekend gemaak word nie.*

1. IDENTIFYING DETAILS / IDENTIFISERENDE BESONDERHEDE

1.1 Age / Ouderdom

1.2 Marital status / *Huwelikstatus*

Married / <i>Getroud</i>	Living together/ <i>Leef saam</i>	Single/ <i>Ongetroud</i>	Separated/ <i>Vervreemd</i>	Divorced / <i>Geskei</i>	Widow(er)/ <i>Weduwee/ Wewenaar</i>

1.3 Race / *Bevolkingsgroep*

Black / <i>Swart</i>	Coloured / <i>Kleurling</i>	White / <i>Blank</i>	Asian / <i>Asiër</i>

1.4 Gender / *Geslag*

Male / <i>Manlik</i>	Female / <i>Vroulik</i>

1.5 Education and training / *Opleiding*

No school training/ <i>Geen skoolastiese opleiding</i>	Highest school Std passed/ <i>Hoogste skoolst. geslaag</i>	Trade / <i>Ambag</i>	Technicon, college, university (specify) / <i>Technikon, kollege, universiteit (spesifiseer)</i>

1.6 Occupation (specify) / *Beroep (spesifiseer)*

	Before surgery / <i>Voor chirurgie</i>	After surgery / <i>Na chirurgie</i>
Unemployed <i>Werkloos</i>		
Social pensioner / <i>Maatskaplike pensioenaris</i>		
Civil pensioner / <i>Siviele pensioenaris</i>		
Skilled or unskilled labourer / <i>Geskoolde of ongeskoolde arbeider</i>		
Professional <i>Professioneel</i>		

1.7 Specify your and your life partner's current **total** monthly income / *Spesifiseer u en u lewensmaat se huidige gesamentlike maandelikse inkomste*

R 0 - R 499		R3 000 - R3 499	
R 500 - R 999		R3 500 - R3 999	
R1 000 - R1 499		R4 000 - R4 499	
R1 500 - R1 999		R4 500 - R4 999	
R2 000 - R2 499		R5 000 - R5 499	
R2 500 - R2 999		R5 500+	

2. MEDICAL INFORMATION / MEDIESE INLIGTING2.1 Diagnosis / *Diagnose* 2.2 Date of diagnosis / *Datum van diagnose* 2.3 Type and period of treatment / Tipe en tydperk van behandeling

	Neck dissection/ <i>Nek- disseksie</i>	Stomach pull-up/ <i>Maag optrek</i>	Radio- therapy/ <i>Radio- terapie</i>	Chemo- therapy/ <i>Chemo- terapie</i>
Treatment already received / <i>Behandeling reeds ontvang</i>				
Current treatment / <i>Huidige behandeling</i>				
Planned treatment / <i>Beplande behandeling</i>				

2.4 Date of laryngectomy / *Datum van laringektomie* 2.5 Date of completion of total treatment period as indicated in (2.3) /
*Datum waarop volle behandelingsperiode soos aangedui in (2.3)
voltooi is* 2.6 What is the frequency of your follow-up visits to the clinic? /
Hoe gereeld doen u opvolgbesoeke aan die kliniek?

6-weekly / <i>6-weekliks</i>	<input type="checkbox"/>	4-monthly / <i>4-maandeliks</i>	<input type="checkbox"/>
2-monthly / <i>2-maandeliks</i>	<input type="checkbox"/>	6-monthly / <i>6-maandeliks</i>	<input type="checkbox"/>
3-monthly / <i>3-maandeliks</i>	<input type="checkbox"/>	Yearly / <i>Jaarliks</i>	<input type="checkbox"/>

2.7 Current medical status / *Huidige mediese status*

Cancer status / <i>Status van kanker</i>	Yes / <i>Ja</i>	No / <i>Nee</i>	Not determined / <i>Nie bepaal nie</i>
• *Absent / <i>Afwesig</i>			
• Persistent disease / <i>Voortgesette siekte</i>			
• Recurrence of disease / <i>Hervatting van siekte</i>			
• New primary disease / <i>Nuwe primêre siekte</i>			
• Metastatic disease / <i>Metastatiese siekte</i>			

3. MEDICAL DIAGNOSIS AND TREATMENT / *MEDIESE DIAGNOSE EN BEHANDELING*

3.1 Explanation of information / *Verduideliking van inligting*

3.1.1 What information did you need and were you looking for prior to your operation? / *Watter inligting wou u hê en het u voor u operasie nodig gehad?*

3.1.2 How did you experience the team member's pre-operative explanation of the operation? Please tick one of the following blocks and motivate your answer/ *Hoe het u die spanlede se verduideliking van die operasie voor die operasie ervaar?*
Merk asseblief een van die onderstaande blokkies en motiveer u antwoord.

It prepared me for all I should have known. / <i>Dit het my voorberei vir alles wat ek moes weet.</i>	It prepared me partially for what I should have known. / <i>Dit het my gedeeltelik voorberei vir wat ek moes weet.</i>	It did not prepare me at all for all I should have known. / <i>Dit het my glad nie voorberei vir alles wat ek moes weet nie.</i>

Motivate your answer / *Motiveer u antwoord* _____

3.2 Emotional reaction to information received / *Emosionele reaksie op inligting ontvang*

- 3.2.1 What emotional reaction(s) did you experience and for what reason(s) did you experience these reactions after being diagnosed and when informed of the proposed operation? / *Watter emosionele reaksie(s) het u ervaar na u diagnose en nadat u ingelig is oor die beplande operasie, en om watter rede(s)?*

Emotional reaction(s) of yourself / <i>Emosionele reaksie(s) van uself</i>	Reason(s) / <i>Rede(s)</i>

- 3.2.2 In your opinion, what emotional reaction(s) did your family experience and for what reason(s) did they experience these reactions after being informed of your diagnosis and proposed operation?

Na u mening, watter emosionele reaksie(s) het u familie na u diagnose en inligting oor die beplande operasie ervaar, en om watter rede(s)?

Emotional reaction(s) of your family/ <i>Emosionele reaksie(s) van u familie</i>	Reason(s) / <i>Rede(s)</i>

4. PHYSICAL RE-ADJUSTMENT / LIGGAAMLIKE HERAANPASSING

4.1 Physical changes / Liggaamsveranderinge

Which permanent physical changes were the most difficult to cope with? / *Watter permanente liggaamsveranderinge was die moeilikste om by aan te pas?*

Permanent changes / <i>Permanente veranderinge</i>	Degree of difficulty to adapt / <i>Moeilikhedsgraad van aanpassing</i>		
	Extreme / <i>Baie</i>	Moderate / <i>Bietjie</i>	Not at all/ <i>Glad nie</i>
Stoma / Stoma			
Presence of permanent stoma / <i>Teenwoordigheid van permanente stoma</i>			
Breathing through the stoma / <i>Asemhaling deur die stoma</i>			
Coughing through the stoma / <i>Hoes deur die stoma</i>			
Cleaning of stoma / <i>Skoonmaak van stoma</i>			

Physical appearance / <i>Fisieke voorkoms</i>			
Changed physical appearance / <i>My liggaam wat nou anders lyk</i>			
Speech / <i>Spraak</i>			
Loss of natural voice / <i>Om nie meer my natuurlike spraak te hê nie</i>			
Learning of new method of speech / <i>Aanleer van nuwe manier van praat</i>			
Sound of my new voice / <i>Klank van my nuwe stem</i>			
Ability to express my feelings (laughing, crying, singing, whistling) / <i>Vermoë om met my stem uitdrukking aan my gevoelens te gee (lag, huil, sing, fluit)</i>			
Speaking over the telephone / <i>Om oor die telefoon te praat</i>			
To be heard when speaking in a noisy environment / <i>Om gehoor te word wanneer jy in 'n raserige omgewing praat</i>			
Senses / <i>Sintuie</i>			
To smell and taste / <i>Om te ruik en te proe</i>			
Eating and drinking / <i>Eet en drink</i>			
To eat and drink in the presence of others / <i>Om in die teenwoordigheid van ander mense te eet en te drink</i>			
To take liquids with your meals in order to swallow / <i>Om vloeistowwe saam met maaltye te drink sodat ek makliker kan sluk</i>			
Inability to eat and drink during conversation/ <i>Om nie te kan praat terwyl ek eet nie</i>			

4.2 Emotions regarding physical changes / *Emosies rakende liggaamsveranderinge*

Describe your initial emotions when you discovered the inevitable permanent physical changes caused by this operation (stoma, smell, taste, breathing, speech) / *Beskryf hoe u aan die begin gevoel het toe u uitgevind het van die permanente veranderinge in u liggaam wat nie weer gaan wees soos voor die operasie nie (stoma, reuk, smaak, asemhaling, spraak) _____*

5. COPING AND STRENGTHS

5.1 Coping with physical changes /

Hantering van liggaamsveranderinge

How did you cope with the permanent physical changes caused by your operation (stoma, smell, taste, breathing, speech)? / *Op watter maniere het u by die permanente liggaamsveranderinge wat deur u operasie veroorsaak is, aangepas (stoma, reuk, smaak, asemhaling, spraak)?* _____

5.2 Coping with treatment completion /

Hantering van die einde van behandeling

5.2.1 What feelings did you experience when your medical treatment (surgery; radiotherapy) was completed and for what reason(s) did you experience these feelings (where applicable)? / *Watter gevoelens het u ervaar toe u mediese behandeling (chirurgie; radioterapie) voltooi is en om watter rede(s) het u hierdie gevoelens ervaar?*

Feelings experienced / Gevoelens ondervind	Reason(s) / Rede(s)

5.3 Coping with readjustment after your operation /

Hantering van heraanpassing na die operasie

5.3.1 In your opinion, what, post-operatively, was the most difficult part of your adjustment to normal life? / *Volgens u, wat was die moeilikste aanpassing wat u na afloop van die operasie moes maak?* _____

5.3.2 In your opinion, what, post-operatively, was the most difficult part of your family's adjustment in continuing with their lives? / *Volgens u, wat was die moeilikste aanpassing wat u familie ná die operasie moes maak?*

5.4 Coping with aftercare / Hantering van nasorg

5.4.1 Why do you have to attend the follow-up clinic at the hospital when your treatment has finished? / *Hoekom moet u vir opvolgbesoeke na die hospitaal kom noudat u behandeling klaar is?* _____

5.4.2 Did you know what the hospital team expected from you after your medical treatment finished and you had to cope on your own at home? / *Het u geweet wat die hospitaalspersoneel van u verwag noudat u mediese behandeling klaar is en u op u eie by die huis met u lewe moet aangaan?*

I knew exactly/ <i>Ek het presies geweet</i>	I did not know exactly / <i>Ek het nie presies geweet nie</i>	I did not know at all / <i>Ek het glad nie geweet nie</i>

Motivate your answer / *Motiveer u antwoord* _____

5.5 Coping based on principles of the strengths perspective /
Oorlewing gebaseer op beginsels van die sterkte perspektief

To which extent did you utilise your inner strengths in order to manage the diagnosis and treatment of your cancer? / *Tot watter mate kon u die krag en sterkte binne uself (u innerlike krag) gebruik in die hantering van u siekte en behandeling?*

Principles / Beginsels	Degree to which you utilise inner strengths / <i>Mate</i> waarin u innerlike sterkte gebruik		
	Extreme / Baie	Moderate/ Bietjie	Not at all/ Glad nie
5.5.1 Inner strengths / Innerlike sterkte			
I do not let the operation get me down. / <i>Ek laat nie toe dat die operasie my onder kry nie.</i>			
I have hope for the future (optimism). / <i>Ek het hoop vir die toekoms (optimisme).</i>			
I have a sense of purpose or meaning. / <i>Ek glo dat ek 'n doel in die lewe het en iets vir iemand kan beteken.</i>			
The support I receive from people or sources help me to feel strong. / <i>Die ondersteuning wat ek van ander kry, help my om sterk te voel.</i>			
5.5.2 Cancer as challenge and opportunity / Kanker as uitdaging en geleentheid			
I think of the operation as an opportunity from which I could learn. / <i>Ek dink aan die operasie as 'n geleentheid waaruit ek kon leer.</i>			
I have plans for my life. / <i>Ek het planne vir my lewe.</i>			
I decided to use strengths which helped me in the past. / <i>Ek gebruik my innerlike krag wat ek in die verlede gebruik het, ook nou om by die operasie aan te pas.</i>			
I have incorporated the experience into daily life. / <i>Ek het my siekte en operasie aanvaar as deel van my lewe.</i>			
5.5.3 Capacity for growth and change / Geleentheid tot groei en verandering			
To adapt to a more healthy lifestyle / <i>Om 'n meer gesonde lewenstyl te handhaaf</i>			
I realise what is most important in life. / <i>Ek besef wat belangrik is in die lewe.</i>			
I appreciate life and am thankful for my health. / <i>Ek waardeer die lewe en is dankbaar vir my gesondheid.</i>			
Heightened spirituality / <i>My geloof voel versterk.</i>			
5.5.4 Collaboration / Samewerking			
To attend follow-up visits at hospital on a regular basis / <i>Om gereeld vir opvolgbesoeke by die hospitaal op te daag</i>			

5.5.5 Resources / Hulpbronne5.5.5.1 Resources within personal environment / Hulpbronne binne persoonlike omgewing

Identify the people with whom you shared a house at the time of your operation:
/ *Identifiseer die persone wat dieselnde huis tydens die operasie met u gedeel
het:*

People / Persone	Yes/ Ja	No/ Nee	People / Persone	Yes/ Ja	No/ Nee
Life partner <i>Saamleefmaat</i>			Children / grandchildren (secondary school) <i>Kinders / kleinkinders</i> (sekondêre skool)		
Parents / Ouers			Brothers / sisters <i>Broers / Susters</i>		
Children / grandchildren (pre-school) <i>Kinders / kleinkinders</i> (voorskools)			Friends / <i>Vriende</i>		
Children / grandchildren (primary school) <i>Kinders / kleinkinders</i> (primêre skool)			Other (specify) / <i>Ander (spesifiseer)</i>		

5.5.5.2 Community resources / Gemeenskapshulpbronne

What resources in your community were available to you and have helped you
in your post-operative coping? / *Watter persone of instansies in u omgewing
was beskikbaar vir u en het u na u operasie gehelp?*

6. PSYCHOSOCIAL EFFECTS / RE-ENTRY INTO SOCIETY *PSIGO-MAATSKAPLIKE GEVOLGE / HERINSKAKELING IN GEMEENSKAP*

6.1 Social effects and adjustment / Maatskaplike effekte en aanpassing

Describe the influence of the operation on the following social relationships in
your life and how you adjusted to it: / *Beskryf die invloed van die operasie op die
volgende maatskaplike verhoudinge in u lewe en hoe u daarby aangepas het:*

6.1.1 Relationship with your life partner / *Verhouding met u lewensmaat*

6.1.2 Relationship with children / grandchildren / *Verhouding met kinders / kleinkinders*

6.1.3 Relationship with other family members / *Verhouding met ander familielede*

6.1.4 Relationship with friends / *Verhouding met vriende*

6.1.4.1 Friends I had in the past / *Vriende wie ek vantevore gehad het*

6.1.4.2 Ability to form new relationships / *Vermoë om nuwe vriende te maak*

6.1.5 Your employment and financial position / *U werk en finansiële posisie*

6.1.6 Fulfillment of your role within your family / *Die uitvoer van u rol binne u gesin*

6.2 Emotional effects and adaptation / *Emosionele uitwerking en aanpassing*6.2.1 How did you experience the loss of your natural voice after the operation? / *Hoe het u die verlies van u natuurlike stem na die operasie ervaar?*

6.3 Re-entry into society / *Herinskakeling by gemeenskap*6.3.1 After completion of treatment, how did you experience your adjustment to society? / *Na afloop van u mediese behandeling, hoe het u u aanpassing by die gewone lewe ervaar?*

Easy / <i>Maklik</i>	Difficult / <i>Moeilik</i>	Uncertain / <i>Onseker</i>

Motivate / *Motiveer*.

6.3.2 What helped you to make your re-entry into society easier? / *Wat het u gehelp om u aanpassing by die gewone lewe makliker te maak?*

6.3.3 Which hobbies do you practise or which creative ways have you found to accommodate these inevitable and permanent changes caused by the operation and to continue your survivorship? / *Watter stokperdjies beoefen u in u vrye tyd of watter maniere het u uitgedink om die veranderinge wat altyd as gevolg van die operasie daar gaan bly, te hanteer en elke dag met u lewe aan te gaan?*

6.3.4 For a laryngectomy patient, it is not unusual to experience fear and uncertainty. Please indicate whether you experienced the following sources of fear and uncertainty and to what extent / *Vir 'n laringektomie-pasiënt is dit nie ongewoon om bang en onseker te voel nie. Gee asseblief 'n aanduiding of u die volgende oorsake van bangheid en onsekerheid ondervind het en hoe erg was dit?*

Sources of fear and uncertainty / Bronne van vrees en onsekerheid	Presence of fear and uncertainty / Aanwesigheid van vrees en onsekerheid		If "yes", to what extent did you experience fear and uncertainty? <i>Indien "ja" - tot watter mate het u vrees en onsekerheid ervaar?</i>	
	Yes/ Ja	No / Nee	Plenty/ Baie	Few/ Bietjie
Physical aspects / Fisieke aspekte				
To take care of my stoma / <i>Die versorging van my stoma</i>				
Recurrence of disease / <i>Dat die siekte mag terugkeer</i>				
Loss of ability to communicate / <i>Om nie te kan kommunikeer nie</i>				
Emotional aspects / Emosionele aspekte				
To adjust to changed physical appearance (stoma) / <i>Om by veranderde liggaams voorkoms aan te pas (stoma)</i>				
Health concerns / <i>Bekommernis oor my gesondheid</i>				
To set long-term goals or to make long-term plans / <i>Om planne vir my toekoms te maak</i>				
Uncertainty about future / <i>Onsekerheid oor toekoms</i>				
Social aspects / Maatskaplike aspekte				
To take care of own health at home without the availability and support of the hospital / <i>Om weg van die hospitaal alleen by die huis met die lewe aan te gaan en nou self te moet aanpas by die gevolge van die operasie</i>				
Fear of inability to cope with loss experiences (speech, communication, employment, finances) / <i>Vrees om dit wat ek met die operasie verloor het, nie te kan hanteer nie (spraak; kommunikasie; werk; finansies)</i>				

6.3.5 What did you learn from / *Wat het u geleer uit:*

6.3.5.1 Your cancer experience in general? / *U belewenis van kanker in die algemeen?*

6.3.5.2 Your laryngectomy experience? / *U laringektomie-ervaring?*

6.3.5.3 To what extent did previous strengths you have discovered within yourself or lessons you have learned, help you to cope with your laryngectomy experience? / *In watter mate het krag wat u binne uself ontdek het, of lesse wat u in u lewe geleer het, u gehelp om u aanpassing by die operasie makliker te maak?*

7. **COMMENTS / KOMMENTAAR**

THANK YOU VERY MUCH FOR YOUR CO-OPERATION /
BAIE DANKIE VIR U SAMEWERKING

ANNEXURE C – Interview schedule for family members

UNIVERSITY OF STELLENBOSCH / UNIVERSITEIT VAN STELLENBOSCH

DEPARTMENT OF SOCIAL WORK / DEPARTEMENT MAATSKAPLIKE WERK

**INTERVIEW SCHEDULE FOR FAMILY MEMBERS / ONDERHOUDSKEDULE VIR
FAMILIELEDE**

Surviving a laryngectomy: The experience of post-operative cancer patients and their families / *Oorlewing van 'n laringektomie: Die ervaring van post-operatiewe kankerpatiënte en hul families.*

1. MEDICAL DIAGNOSIS AND TREATMENT / MEDIESE DIAGNOSE EN BEHANDELING

- 1.1 What information did you want and were looking for prior to the patient's operation? / *Watter inligting wou u kry en het u nodig gehad voor die pasiënt se operasie?*
- 1.2 How did the team members' explanation help you to prepare for the operation and the effects of the operation? / *Hoe het die spanlede se verduideliking u gehelp in u voorbereiding op die operasie en vir wat om te verwag na die operasie?*
- 1.3 What emotional reaction(s) did you experience and for what reason(s) were these reactions experienced after the patient had been diagnosed and informed of the proposed operation? / *Watter emosionele reaksie(s) is ondervind en om watter rede is hierdie reaksies ondervind nadat die pasiënt diagnoseer is en ingelig is oor die beplande operasie?*

2. PHYSICAL RE-ADJUSTMENT / FISIESE HERAANPASSING

- 2.1 Which permanent physical changes of the patient were the most difficult to cope with for you as family member? / *Watter permanente liggaams veranderinge van die pasiënt was die moeilikste om by aan te pas vir u as familielid?*

2.2 When you discovered the inevitable permanent physical changes in the life of the patient caused by this operation (stoma, smell, taste, breathing, speech), describe your personal experience as family member. / *Toe u uitgevind het van die permanente fisiese veranderinge in die lewe van die pasiënt wat nie weer gaan wees soos voor die operasie nie (stoma, reuk, smaak, asemhaling, spraak), beskryf u persoonlike belewenis as familielid.*

3. COPING AND STRENGTHS

3.1 What, post-operatively, was your own most difficult adjustment to normal life after your family member's operation? / *Wat was na afloop van u familielid se operasie u moeilikste aanpassing om te maak?*

3.2 Did you know what the hospital team expected from you as a family member after the patient's medical treatment had finished and you had to cope with the patient on your own at home? / *Het u geweet wat die hospitaalpersoneel van u as familielid verwag toe die pasiënt se mediese behandeling klaar was en u op u eie by die huis moes aangaan met die lewe?*

3.3 Identify the most important sources of social support that you received following the patient's operation. / *Identifiseer die vernaamste bronne van maatskaplike ondersteuning wat u ná die pasiënt se operasie ontvang het.*

4. PSYCHOSOCIAL EFFECTS / RE-ENTRY INTO SOCIETY

PSIGO-MAATSKAPLIKE GEVOLGE / HERINSKAKELING IN GEMEENSAP

4.1 Describe the influence of the operation on your family relations and how you adjust to it. / *Beskryf die invloed van die operasie op die gesinsverhoudinge en hoe u daarby aangepas het.*

4.2 How did you experience die loss of the patient's natural voice after the operation / *Hoe het u die verlies van die pasiënt se natuurlike stem na die operasie ervaar?*

4.3 After completion of the patient's treatment, how did you experience your adjustment to society as family? / *Na afloop van die pasiënt se mediese behandeling, hoe het u as familie u aanpassing by die gewone lewe gevind?*

- 4.4 What helped you to make your re-entry into society easier? / *Wat het u gehelp om u aanpassing by die gewone lewe makliker te maak?*
- 4.5 For a laryngectomy patient it is not unusual to experience fear and uncertainty. Describe whether you as family member experienced fear and uncertainty. / *Vir 'n laringektomie pasiënt is dit nie ongewoon om bang en onseker te voel nie. Beskryf u as familielid se ervaring van bangheid en onsekerheid.*
- 4.6 What did you learn from / *Wat het u geleer uit:*
- 4.6.1 Your family member's cancer experience in general? / *U familielid se belewenis van kanker in die algemeen?*
- 4.6.2 Your family member's laryngectomy experience? / *U familielid se laringektomie-ervaring?*
- 4.6.3 To what extent did previous strengths you had discovered within yourself or lessons you have learned help you to cope with your family member's laryngectomy experience? / *Watter krag wat u binne uself ontdek het, of lesse wat u vantevore in u lewe geleer het, het u gehelp om u aanpassing by u familielid se operasie makliker te maak?*

5. COMMENT / KOMMENTAAR

THANK YOU VERY MUCH FOR YOUR CO-OPERATION /

BAIE DANKIE VIR U SAMEWERKING

ANNEXURE D – Participant information leaflet and consent form for patients (Afrikaans)



UNIVERSITEIT•STELLENBOSCH•UNIVERSITY
jou kennisvenoot • your knowledge partner

UNIVERSITEIT VAN STELLENBOSCH DEELNEMINGINLICHTINGSBLAD EN -TOESTEMMINGSVORM (PASIËNTE)

Oorlewing van 'n laringektomie: Die ervaring van post-operatiewe kanker pasiënte en hul families.

U word genooi om deel te neem aan 'n navorsingsprojek wat uitgevoer sal word deur Mej Beatrix Hendrina Steyn (M SW), Departement Maatskaplike Werk, Universiteit van Stellenbosch. Dit is baie belangrik dat u ten volle moet verstaan wat die navorsingsprojek behels en hoe u daarby betrokke kan wees. Die resultate van hierdie navorsingsprojek sal deel vorm van 'n proefskrif. U is geïdentifiseer as 'n moontlike kandidaat om deel te neem aan hierdie studie aangesien u eerstehandse ervaring van 'n laringektomie het in u behandeling van larinkskanker.

Kontakbesonderhede van die navorser en haar promotor is soos volg:

Navorser: Beatrix Hendrina Steyn
Telefoonnommer: (021) 938 5092
E-pos adres: Beatrix.Steyn@westerncape.gov.za
Promotor: Prof S Green, Universiteit van Stellenbosch
Telefoonnommer: (021) 808 2069
E-pos adres: sgreen@sun.ac.za

1. DOEL VAN DIE STUDIE

Die doel van hierdie studie is om 'n beter begrip van pasiënte en families se oorlewing van hul laringektomie-ervaring te bekom. Weinig inligting vanuit 'n maatskaplikewerk-perspektief is tans oor die onderwerp beskikbaar.

2. PROSEDURE

Die navorsingsprojek sal by die Afdeling Stralingsonkologie uitgevoer word. Die volgende prosedure sal op hierdie navorsingsprojek van toepassing wees:

- Die navorser sal 'n eenmalige persoonlike onderhoud aan die hand van 'n semi-gestruktureerde vraelys met u voer. Met u toestemming, sal hierdie onderhoud op 'n bandopnemer opgeneem word. Gedurende 'n tuisbesoek sal u die geleentheid gebied word om deur die getranskribeerde weergawe van die navorser se opname te lees ten einde te verseker dat dit 'n ware weerspieëling van die inhoud van die onderhoud bevat.
- Hierdie onderhoud sal in die privaatheid van die kantoor van die maatskaplike werker verbonde aan die afdeling Stralingsonkologie gevoer word.
- Na afloop van onderhoudvoering met al die deelnemers aan hierdie navorsingsprojek, sal inligting wat ingewin is, verwerk word. 'n Navorsingsverslag sal beskikbaar gestel word. Aangesien die navorser hierdie studie gebruik vir voorlegging vir haar doktorsgraad in Maatskaplike Werk, sal resultate aan die opleidingsinstansie, naamlik die Universiteit van Stellenbosch, beskikbaar gestel word. Hierdie inligting sal bekend gemaak en gepubliseer word sonder dat vertroulikheid geskend word. Hierdie navorsingsverslag kan ook gebruik word vir verdere publikasies, byvoorbeeld in akademiese tydskrifte of vir opleidingsdoeleindes, naamlik vir lesings of voordrag tydens 'n kongres. U kan die navorser na afloop van die projek nader rakende die bevindinge van die projek.

3. POTENSIËLE RISIKO'S EN ONGEMAK

Die enigste moontlike risiko wat in die studie voorsien word, is die moontlikheid dat u moegheid mag ondervind indien u blootgestel word aan 'n onderhoud met 'n lang tydsduur. Ten einde vir hierdie beperking te kompenseer, word die lengte van die onderhoud tot 45 tot 60 minute beperk. Indien u fisieke ongemak sou ondervind, soos probleme met u spraak as gevolg van hoes, moegheid of u spraakleppie wat geblokkeer is en wat op sy beurt weer die kwaliteit van u stem mag beïnvloed, of indien u emosionele ongemak sou ondervind terwyl u aan die onderhoud deelneem, sal u toegelaat word om die onderhoud te beëindig, indien u so sou verkies. Beëindiging van die onderhoud sal geen negatiewe implikasies vir u inhou nie. Die navorser, 'n geregistreerde maatskaplike werker, sal beskikbaar wees om ná afloop van die onderhoud berading aan u te bied, indien sodanige behoefte gedurende die verloop van die onderhoud geïdentifiseer sou word.

4. POTENSIËLE VOORDELE VIR DEELNEMERS EN/OF DIE SAMELEWING

U antwoorde sal binne die studie saam met al die ander deelnemers s'n tot gevolgtrekkings verwerk word, ten einde 'n beter begrip vanuit 'n maatskaplikewerkperspektief vir laringektomiepatiënte en hul familieleden se post-operatiewe aanpassing, wat op hul eie perspektief van hul aanpassings en oorlewingsvermoë gebaseer is, te bied. Aangesien daar weinig inligting oor hierdie onderwerp vanuit 'n maatskaplikewerkverwysingsraamwerk beskikbaar is, sal u bydrae tot voordeel van dienslewering aan hierdie pasiënte en hul families strek, sowel as aan gesondheidsorgwerkers (maatskaplike werkers).

5. BETALING VIR DEELNAME

U sal nie betaal word vir deelname aan die navorsingsprojek nie. Daar sal geen koste vir u verbonde wees aan deelname aan die navorsingstudie nie. Onderhoude sal geskeduleer word vir die datum waarop u u mediese behandeling ontvang, sodat geen addisionele vervoerkoste vereis sal word nie. Indien dit sou gebeur dat onderhoude nie op dieselfde dag as u mediese afspraak gevoer kan word nie, en u addisionele vervoerkoste moet aangaan vir u deelname aan die navorsingstudie, sal die navorser u vir u vervoerkoste vergoed.

6. VERTROULIKHEID

Die navorser, as geregistreerde maatskaplike werker, sal die kwessie van vertroulikheid met die nodige respek en verantwoordelikheid hanteer. Dit sal verseker word deur by die volgende reëls te hou: alle inligting sal as vertroulik hanteer word; inligting sal nie bekend gemaak word nie; die gebruik van demografiese inligting wat nodig is vir die studie en alle ander inligting sal in 'n veilige plek geberg word. Slegs die navorser sal toegang tot die kabinet hê waarin inligting geberg word. Rekords sal volgens die protokol van die hospitaal vir 'n tydperk van vyf jaar in veilige bewaring gehou word. Reëlins vir die vernietiging van inligting sal in lyn met die hospitaalprotokol gedoen word.

Inligting wat deur hierdie navorsingsprojek bekom word, sal bekend gemaak word aan die Universiteit van Stellenbosch, aan die US biblioteek in 'n elektroniese formaat, en aan die Departement Maatskaplike Werk, van die hospitaal waar die studie uitgevoer word. Inligting wat ingewin is, sal as vertroulik hanteer word en sal beskerm word. Indien dit vir publikasiedoeleindes gebruik word, vir 'n tesis of 'n lesing, sal u identiteit geheim gehou word.

7. DEELNAME EN ONTTREKING

U deelname aan die studie is volkome vrywillig en u is welkom om te eniger tyd aan die studie te onttrek. Indien u sou toestem om aan die studie deel te neem, sal van u verwag word om antwoorde op die vrae in die vraelys so eerlik as moontlik te verskaf ten einde die waarde van die studie te verhoog. U deelname sal slegs 'n eenmalige onderhoud behels. U sal geen verdere verpligtinge teenoor die navorsingstudie hê nie.

Indien u nie instem om aan die studie deel te neem nie, sal dit u geensins benadeel nie. U is ook welkom om te eniger tyd aan die studie te onttrek, selfs al het u aanvanklik tot deelname ingestem. U mag ook weier om antwoorde op sekere vrae te verskaf indien u verkies om nie daarop te antwoord nie en u kan steeds as deel van die studie beskou word. Die navorser mag u ook te eniger tyd aan die studie onttrek, indien 'n behoefte daartoe sou ontstaan.

8. IDENTIFIKASIE VAN NAVORSER

Indien u enige vrae of navrae oor die studie het, kan u gerus met Professor S Green van die Universiteit van Stellenbosch, Departement Maatskaplike Werk skakel by telefoonnommer (021) 808 2069 of e-pos adres sgreen@sun.ac.za.

9. REGTE VAN RESPONDENTE

U mag te eniger tyd van die studie onttrek en sal nie benadeel word nie. U doen nie afstand van enige geregtelike eise, regte of regsmittele deur u deelname aan hierdie studie nie. Indien u vrae aangaande u regte as navorsingsrespondent sou hê, kontak asseblief Me Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] verbonde aan die Afdeling vir Navorsingsontwikkeling.

HANDTEKENING VAN NAVORSINGSDEELNEMER OF REGSVERTENWOORDIGER

Bostaande inligting is aan [my/die proefpersoon/deelnemer] beskryf deur [naam van betrokke persoon] in [Afrikaans/English/Xhosa/Ander] en [ek/die proefpersoon/die deelnemer] is bedrewe in hierdie taal of dit is bevredigend aan [my/hom/haar] getolk. [Ek/die proefpersoon/die deelnemer] is geleentheid gebied om vrae te vra, wat tot [my/sy/haar] bevrediging beantwoord is.

[Ek verleen hiermee gewillig my toestemming om aan hierdie studie deel te neem/Ek verleen hiermee toestemming dat die proefpersoon/deelnemer aan hierdie studie mag deelneem.] Ek het 'n kopie van hierdie vorm ontvang.

Naam van Proefpersoon/Deelnemer

Naam van Regsverteenwoordiger (indien van toepassing)

Handtekening van Proefpersoon/Deelnemer of Regsverteenwoordiger **Datum**

HANDTEKENING VAN NAVORSER

Ek verklaar dat ek die inligting in hierdie dokument aan _____ [naam van proefpersoon/deelnemer] en/of [sy/haar] verteenwoordiger _____ [naam van verteenwoordiger] verduidelik het. [Hy/sy] is aangemoedig en is genoeg tyd gegee om enige vrae te rig. Hierdie gesprek is in [Afrikaans/Engels/Xhosa/Ander] gevoer en [geen tolk is gebruik nie/hierdie gesprek is getolk in _____ deur _____].

Handtekening van Navorsers

Datum

ANNEXURE E – Participant information leaflet and consent form for patients (English)



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STELLENBOSCH UNIVERSITY CONSENT TO PARTICIPATE IN RESEARCH (PATIENTS)

Surviving a laryngectomy: The experience of post-operative cancer patients and their families

You are being invited to take part in a research project conducted by Miss Beatrix Hendrina Steyn (M SW) of the Department of Social Work at the University of Stellenbosch. It is important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. The results of this research project will form part of a dissertation. You have been identified as a possible participant in this study as you have first-hand experience of a laryngectomy as surgical treatment for a diagnosis of larynx cancer.

Contact details of the researcher and her promoter are as follows:

Researcher: Miss Beatrix Hendrina Steyn

Telephone number: (021) 938 5092

E-mail address: Beatrix.Steyn@westerncape.gov.za

Promoter Prof. S Green, University of Stellenbosch

Telephone number: (021) 808 2069

E-mail address: sgreen@sun.ac.za

1. PURPOSE OF THE STUDY

The goal of the study will be to contribute to a better understanding of the survivorship experience for both the laryngectomy patient and the family in order to deal with the laryngectomy experience. At present, little information from a social work perspective is available in this regard.

2. PROCEDURES

The research project will be conducted at the Department of Radiation Oncology. The following procedures will be applicable to this research project:

- A single face-to-face interview will be conducted by the researcher with the aid of a semi-structured questionnaire. With your consent, this interview will be audio-taped. During a home visit, you will have the opportunity to read through the transcribed version of the researcher's recording in order to ensure that it is a true reflection of the contents of the interview.
- Interviews will take place in the privacy of the researcher's office at the hospital.
- The responses of all participants in the study will be processed, after which a research report will be made available. As the researcher is conducting this study to meet the requirements of a Doctoral Degree in Social Work, the results of the research will be made available to the training institute, the University of Stellenbosch. This information will be made public and can be published without compromising confidentiality. The research report may be used for publications, for example in academic journals or for training purposes like conferences or lectures. You may obtain information of the results of the study from the researcher after the project has been concluded.

3. POTENTIAL RISKS AND DISCOMFORTS

The only potential risks foreseen in this study is the possibility that you may experience fatigue by participating in an interview of long duration. In order to compensate for this limitation, the duration of the interview will be limited to 45 to 60 minutes. Should you experience physical discomfort like difficulty to produce voice due to coughing, tiredness or a blocked speech valve which may, in turn, influence the quality of your voice, or emotional discomfort while participating in the interview, you will be allowed to terminate the interview if you choose to do so. Termination of the interview will have no negative implications for you. The researcher, as a registered social worker, will be able to offer counselling should the need for counselling arise during the course of the interview.

4. POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

Your response will be processed together with those of all the participants in the research study in order to contribute to a better understanding of the post-operative survivorship of laryngectomy patients and their families on the basis of their own perspectives of their coping strategies and survivorship. As there is little available information in this regard from a social work perspective, your contribution will benefit future laryngectomy patients and their relatives, as well as health care professionals (social workers).

5. PAYMENT FOR PARTICIPATION

No, you will not be paid to take part in the study. There will be no costs involved for you, if you do take part. Interviews will be conducted at the Department of Radiation Oncology and will as far as possible be scheduled for the day of your medical appointment. If it should happen that you have to travel to hospital especially for the

purpose of the research study, the researcher will accept responsibility for your transport fees.

6. CONFIDENTIALITY

The researcher, who is a qualified social worker, will approach the matter of confidentiality with the necessary respect and responsibility. This would be possible by adhering to the following rules: keep all information confidential; information will not be made public; obtain and use only demographic information necessary for the study and store the information in a safe place. Only the researcher will have access to the cabinet where records will be kept. According to the protocol of the hospital, these records will be in safekeeping for a period of five years. Arrangements to destroy information will be in line with hospital protocol.

Information gained by this research project will be released to the University of Stellenbosch, the US library in electronic format, and to the Department of Health of the hospital. Information collected will be treated as confidential and will be protected. If it is used in a publication, thesis or lecture, your contribution will remain anonymous.

7. PARTICIPATION AND WITHDRAWAL

Your participation in the study is entirely voluntary and you are free to decline to participate. If you do agree to participate in the study, you will be expected to answer the questions in the questionnaire as honestly as possible to contribute towards the value of the study. This will only involve a single interview. You will have no further obligations towards the research study.

If you do not agree to participate in the study, it will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part. You may also refuse to answer any questions you do not want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so.

8. IDENTIFICATION OF INVESTIGATORS

If you have any questions or concerns about the research, please feel free to contact Professor S Green of the Department of Social Work at the University of Stellenbosch at telephone number (021) 808 2069 or e-mail address: sgreen@sun.ac.za.

9. RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact Ms Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development.

SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE
--

The information above was described to [*me/the subject/the participant*] by [*name of relevant person*] in [*Afrikaans/English/Xhosa/other*] and [*I am/the subject is/the participant is*] in command of this language or it was satisfactorily translated to [*me/him/her*]. [*I/the participant/the subject*] was given the opportunity to ask questions and these questions were answered to [*my/his/her*] satisfaction.

[*I hereby consent voluntarily to participate in this study/I hereby consent that the subject/participant may participate in this study.*] I have been given a copy of this form.

Name of Subject/Participant

Name of Legal Representative (if applicable)

1 Signature of Subject/Participant or Legal Representative

Date

SIGNATURE OF INVESTIGATOR

I declare that I explained the information given in this document to _____ [*name of the subject/participant*] and/or [*his/her*] representative _____ [*name of the representative*]. [*He/she*] was encouraged and given ample time to ask me any questions. This conversation was conducted in [*Afrikaans/*English/*Xhosa/*Other*] and [*no translator was used/this conversation was translated into _____ by _____*].

Signature of Investigator

Date

ANNEXURE F – Participant information leaflet and consent form for family members (Afrikaans)



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DEELNEMINGINLIGTINGSBLAD EN -TOESTEMMINGSVORM (FAMILIELEDE)

Oorlewing na 'n laringektomie: Die ervaring van post-operatiewe kanker pasiënte en hul families.

U word genooi om deel te neem aan 'n navorsingsprojek wat uitgevoer sal word deur Mej Beatrix Hendrina Steyn (M SW), Departement Maatskaplike Werk, Universiteit van Stellenbosch. Dit is baie belangrik dat u ten volle moet verstaan wat die navorsingsprojek behels en hoe u daarby betrokke kan wees. Die resultate van hierdie navorsingsprojek sal deel vorm van 'n proefskrif. U is geïdentifiseer as 'n moontlike kandidaat om deel te neem aan hierdie studie aangesien u familielid 'n laringektomie ondergaan het vir die behandeling van larinkskanker.

Kontakbesonderhede van die navorser en haar promotor is soos volg:

Navorser: Beatrix Hendrina Steyn
Telefoonnommer: (021) 938 5092
E-pos adres: Beatrix.Steyn@westerncape.gov.za

Promotor: Prof S Green, Universiteit van Stellenbosch
Telefoonnommer: (021) 808 2069
E-posadres: sgreen@sun.ac.za

1. DOEL VAN DIE STUDIE

Die doel van hierdie studie is om 'n beter begrip van pasiënte en hul families se oorlewing van hul laringektomie-ervaring te bekom. Weinig inligting vanuit 'n maatskaplikewerk perspektief is tans oor die onderwerp beskikbaar.

2. PROSEDURE

Die navorsingsprojek sal by die Afdeling Stralingsonkologie van die geïdentifiseerde hospitaal uitgevoer word. Die volgende prosedure sal op hierdie navorsingsprojek van toepassing wees:

- Die navorser sal 'n eenmalige persoonlike onderhoud aan die hand van 'n semi-gestruktureerde vraelys met u voer. Met u toestemming, sal hierdie onderhoud op 'n bandopnemer opgeneem word. U sal die geleentheid gebied word om deur die getranskribeerde weergawe van die navorser se opname te lees, ten einde te verseker dat dit 'n ware weerspieëling van die inhoud van die onderhoud is.
- Hierdie onderhoud sal in die privaatheid van die kantoor van die maatskaplike werker verbonde aan die afdeling Stralingsonkologie gevoer word.
- Na afloop van onderhoudvoering met al die deelnemers aan hierdie navorsingsprojek, sal inligting wat ingewin is, verwerk word. 'n Navorsingsverslag sal beskikbaar gestel word. Aangesien die navorser hierdie studie gebruik vir voorlegging vir haar doktorsgraad in Maatskaplike Werk, sal resultate aan die opleidingsinstansie, naamlik die Universiteit van Stellenbosch, beskikbaar gestel word. Hierdie inligting sal bekend gemaak en gepubliseer word sonder dat vertroulikheid geskend word. Hierdie navorsingsverslag kan ook gebruik word vir verdere publikasies, byvoorbeeld in akademiese tydskrifte of vir opleidingsdoeleindes, naamlik vir lesings of voordrag tydens 'n kongres. U kan die navorser na afloop van die projek nader rakende die bevindinge van die projek.

3. POTENSIËLE RISIKO'S EN ONGEMAK

Die onderhoud sal tussen 45 en 60 minute duur. Indien u fisieke of emosionele ongemak ondervind terwyl u aan die onderhoud deelneem, sal u toegelaat word om die onderhoud te beëindig, indien u so verkies. Beëindiging van die onderhoud sal geen negatiewe implikasies vir u of die pasiënt inhou nie. Die navorser, 'n geregistreerde maatskaplike werker, sal beskikbaar wees om na afloop van die onderhoud berading aan u te bied, indien sodanige behoefte gedurende die verloop van die onderhoud geïdentifiseer sou word.

4. POTENSIËLE VOORDELE VIR DEELNEMERS EN/OF DIE SAMELEWING

U antwoorde sal binne die studie saam met al die ander deelnemers s'n tot gevolgtrekkings verwerk word, ten einde 'n beter begrip vanuit 'n maatskaplikewerk perspektief vir laringektomiepatiënte en hul familieleden se post-operatiewe aanpassing te verkry, wat op hul eie perspektief van hul aanpassings en oorlewingsvermoë gebaseer is. Aangesien weinig inligting oor hierdie onderwerp vanuit 'n maatskaplikewerk verwysingsraamwerk beskikbaar is, sal u bydrae tot voordeel van dienslewering aan hierdie pasiënte en hul families strek, sowel as aan gesondheidsorgwerkers (maatskaplike werkers).

5. BETALING VIR DEELNAME

U sal nie betaal word vir deelname aan die navorsingsprojek nie. Geen koste sal egter vir u aan deelname aan die navorsingstudie verbonde wees nie. Onderhoude sal geskeduleer word vir die datum waarop die pasiënt mediese behandeling ontvang, sodat geen addisionele vervoerkoste vereis sal word nie. Indien dit sou gebeur dat onderhoude nie op dieselfde dag as mediese afspraak gevoer kan word nie, en u

addisionele vervoerkoste moet aangaan vir u deelname aan die navorsingstudie, sal die navorser u vir u vervoerkoste vergoed.

6. VERTROULIKHEID

Die navorser, as geregistreerde maatskaplike werker, sal die kwessie van vertroulikheid met die nodige respek en verantwoordelikheid hanteer. Dit sal verseker word deur die volgende reëls te handhaaf: alle inligting sal as vertroulik hanteer word; inligting sal nie bekend gemaak word nie; die gebruik van demografiese inligting wat nodig is vir die studie en alle ander inligting sal in 'n veilige plek geberg word. Slegs die navorser sal toegang hê tot die kabinet waarin inligting geberg word. Rekords sal volgens die protokol van die hospitaal vir 'n tydperk van vyf jaar in veilige bewaring gehou word. Reëlins vir die vernietiging van inligting sal in lyn met die hospitaalprotokol gedoen word.

Inligting wat deur hierdie navorsingsprojek bekom word, sal bekend gemaak word aan die Universiteit van Stellenbosch, aan die US biblioteek in elektroniese formaat, en aan die Departement Maatskaplike Werk van die akademiese hospitaal waar die studie uitgevoer word. Inligting wat ingewin is, sal as vertroulik hanteer word en sal beskerm word. Indien dit vir publikasiedoeleindes gebruik word, vir 'n tesis of 'n lesing, sal u identiteit geheim gehou word.

7. DEELNAME EN ONTTREKING

U deelname aan die studie is volkome vrywillig en u is welkom om te eniger tyd aan die studie te onttrek. Indien u sou toestem om aan die studie deel te neem, sal van u verwag word om antwoorde op die vrae in die vraelys so eerlik as moontlik te verskaf, ten einde die waarde van die studie te verhoog. U deelname sal slegs 'n eenmalige onderhoud behels. U sal geen verdere verpligtinge teenoor die navorsingstudie hê nie.

Indien u nie instem om aan die studie deel te neem nie, sal dit u of die pasiënt geensins benadeel nie. U is ook welkom om te eniger tyd aan die studie te onttrek, selfs al het u aanvanklik tot deelname ingestem. U mag ook weier om antwoorde op sekere vrae te verskaf, indien u verkies om nie daarop te antwoord nie, en u sal steeds as deel van die studie beskou kan word. Die navorser mag u ook te eniger tyd aan die studie onttrek indien 'n behoefte daartoe sou ontstaan.

8. IDENTIFIKASIE VAN NAVORSER

Indien u enige vrae of navrae oor die studie het, kan u gerus met Professor S Green van die Universiteit van Stellenbosch, Departement Maatskaplike Werk, by telefoonnommer (021) 808 2069 of e-pos adres sgreen@sun.ac.za in verbinding tree.

9. REGTE VAN RESPONDENTE

U mag te eniger tyd van die studie onttrek en sal nie benadeel word nie. U doen nie afstand van enige geregtelike eise, regte of regsmiddele deur u deelname aan hierdie studie nie. Indien u vrae aangaande u regte as navorsingsrespondent sou hê, kontak asseblief Me Maléne Fouché [mfouche@sun.ac.za; 021 808 4622]. Sy is verbonde aan die Afdeling vir Navorsingsontwikkeling.

HANDTEKENING VAN NAVORSINGSDEELNEMER OF REGSVERTENWOORDIGER
--

Bostaande inligting is aan [my/die proefpersoon/deelnemer] beskryf deur _____
[naam van betrokke persoon] in [Afrikaans/English/Xhosa/Ander]. [ek/die proefpersoon/die
deelnemer] is bedrewe in hierdie taal of dit is bevredigend aan [my/hom/haar] getolk. [Ek/die
proefpersoon/die deelnemer] is geleentheid gebied om vrae te vra, wat tot [my/sy/haar]
bevrediging beantwoord is.

[Ek verleen hiermee gewillig my toestemming om aan hierdie studie deel te neem/Ek verleen
hiermee toestemming dat die proefpersoon/deelnemer aan hierdie studie mag deelneem.] Ek
het 'n kopie van hierdie vorm ontvang.

Naam van Proefpersoon/Deelnemer

Naam van Regsverteenwoordiger (indien van toepassing)

_____ Datum
Handtekening van Proefpersoon/Deelnemer of Regsverteenwoordiger

HANDTEKENING VAN NAVORSER

Ek verklaar dat ek die inligting in hierdie dokument aan _____ [naam van
proefpersoon/deelnemer] en/of [sy/haar] verteenwoordiger _____ [naam van
vertteenwoordiger] verduidelik het. [Hy/sy] is aangemoedig en is genoeg tyd gegee om enige
vrae te rig. Hierdie gesprek is in [Afrikaans/Engels/Xhosa/Ander] gevoer en [geen tolk is gebruik
nie/hierdie gesprek is getolk in _____ deur _____].

Handtekening van Navorser

Datum

ANNEXURE G – Participant information leaflet and consent form for family members (English)



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CONSENT TO PARTICIPATE IN RESEARCH (FAMILY MEMBERS)

Surviving a laryngectomy: The experience of post-operative cancer patients and their families

You are being invited to take part in a research project conducted by Miss Beatrix Hendrina Steyn (M SW) of the Department of Social Work at the University of Stellenbosch. It is important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. The results of this research project will form part of a research thesis. You have been identified as a possible participant in this study because of your experience with a family member who has undergone a laryngectomy as surgical treatment following a diagnosis of larynx cancer.

Contact details of the researcher and her promoter are as follows:

Researcher: Miss Beatrix Hendrina Steyn
Telephone number: (021) 938 5092
E-mail address: Beatrix.Steyn@westerncape.gov.za

Promotor Prof S Green, University of Stellenbosch
Telephone number: (021) 808 2069
E-mail address: sgreen@sun.ac.za

1. PURPOSE OF THE STUDY

The goal of the study is to contribute to a better understanding of the survivorship experience for both the laryngectomy patient and the family, in order to deal with the laryngectomy experience. At present, little information from a social work perspective is available in this regard.

2. PROCEDURES

The research project will be conducted at the Department of Radiation Oncology of the hospital where the study will be conducted. The following procedures will be applicable to this research project:

- A single face-to-face interview will be conducted by the researcher with the aid of an interview schedule. With your consent, this interview will be audio-taped. You will have the opportunity to read through the transcribed version of the researcher's recording in order to ensure that it is a true reflection of the contents of the interview.
- Interviews will take place in the privacy of the researcher's office at the hospital where the study will be conducted.
- The responses of all participants in the study will be processed, after which a research report will be made available. As the researcher is conducting this study to meet the requirements for a Doctoral Degree in Social Work, the results of the research will be made available to the training institute, the University of Stellenbosch. This information will be made public and can be published without compromising confidentiality. The research report may be used for publications, for example in academic journals or for training purposes, as in conferences or lectures. You may obtain information of the results of the study from the researcher after the project has been concluded.

3. POTENTIAL RISKS AND DISCOMFORTS

The duration of the interview will be between 45 and 60 minutes. Should you experience physical discomfort, like tiredness, or emotional discomfort while participating in the discussion, you will be allowed to terminate your participation in the discussion, if you choose to do so, with no negative implications for you or the patient. The researcher, as a registered social worker, will be able to offer counselling should the need for counselling arise during the course of the interview.

4. POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

Your response will be processed together with those of the other participants in the research study in order to contribute to a better understanding of the post-operative survivorship of laryngectomy patients and their families on the basis of their own perspectives of their coping strategies and survivorship. As there is little available information in this regard from a social work perspective, your contribution will benefit future laryngectomy patients and their relatives, as well as health care professionals (social workers).

5. PAYMENT FOR PARTICIPATION

You will not be paid to take part in the study. No costs will be involved for you, however, if you do take part. Interviews will be conducted at the Department of Radiation Oncology of the hospital, and will, as far as possible, be scheduled for the day of the patient's medical appointment. If it should happen that you have to travel to hospital especially for the purpose of the research study, the researcher will accept responsibility for your transport fees.

6. CONFIDENTIALITY

The researcher, who is a qualified social worker, will approach the matter of your confidentiality with the necessary respect and responsibility. This will be ensured by adhering to the following rules: keep all information confidential; information will not be made public; obtain and use only demographic information necessary for the study and store the information in a safe place. Only the researcher will have access to the cabinet where records will be kept. According to the protocol of the hospital, these records will be in safekeeping for a period of five years. Arrangements to destroy information will be in line with hospital protocol.

Information gained through this research project will be released to the University of Stellenbosch; the US library, in electronic format; and to the Department of Health of the academic hospital involved. Information that is collected will be treated as confidential and will be protected. If it is used in a publication, thesis or lecture, your contribution will remain anonymous.

7. PARTICIPATION AND WITHDRAWAL

Your participation in the study is entirely voluntary and you are free to decline to participate. If you do agree to participate in the study, you will be expected to answer questions put to you during the interview as honestly as possible to contribute towards the value of the study. This will only involve a single interview. You will have no further obligation towards the research study.

If you do not agree to participate in the study, it will not affect you or the patient negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part. You may also refuse to answer any questions you do not want to answer while still remaining in the study. The investigator may withdraw you from this research, however, if circumstances arise which warrant doing so.

8. IDENTIFICATION OF INVESTIGATORS

If you have any questions or concerns about the research, please feel free to contact Professor S Green of the Department of Social Work at the University of Stellenbosch at telephone number (021) 808 2069 or e-mail address: sgreen@sun.ac.za.

9. RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact Ms Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development.

SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE
--

The information presented above was provided to [me/the subject/the participant] by [name of relevant person] _____ in [Afrikaans/English/Xhosa/other] and [I am/the subject is/the participant is] in command of this language or it was satisfactorily translated to [me/him/her]. [I/the participant/the subject] was given the opportunity to ask questions and these questions were answered to [my/his/her] satisfaction.

[I hereby consent voluntarily to participate in this study/I hereby consent that the subject/participant may participate in this study] I have been given a copy of this form.

Name of Subject/Participant

Name of Legal Representative (if applicable)

Signature of Subject/Participant or Legal Representative

Date

SIGNATURE OF INVESTIGATOR

I declare that I explained the information given in this document to _____ [name of the subject/participant] and/or [his/her representative] _____ [name of the representative]. [He/she] was encouraged and given ample time to ask me any questions. This conversation was conducted in [Afrikaans/*English/*Xhosa/*Other] and [no translator was used/this conversation was translated into _____ by _____].

Signature of Investigator

Date

ANNEXURE H – Letter of conditional ethics approval from Research Ethics Committee: Human Research from University of Stellenbosch (25.08.2011)



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY
jou kennisvenoot • your knowledge partner

25 August 2011

Tel.: 021 - 808-9183
Enquiries: Sidney Engelbrecht
Email: sidney@sun.ac.za

Reference No. 476/2010

Ms H Steyn
Department of Social Work
University of Stellenbosch
STELLENBOSCH
7602

Ms H Steyn

LETTER OF CONDITIONAL ETHICS APPROVAL

With regard to your application, I would like to inform you that the project, *Surviving a laryngectomy: The experience of post-operative cancer patients and their families*, has been approved on condition that:

1. The researcher will remain within the procedures and protocols indicated in the proposal, particularly in terms of any undertakings made in terms of the confidentiality of the information gathered.
2. The research will again be submitted for ethical clearance if there is any substantial departure from the existing proposal.
3. The researcher will remain within the parameters of any applicable national legislation, institutional guidelines and scientific standards relevant to the specific field of research.
4. The researcher will consider and implement the foregoing suggestions to lower the ethical risk associated with the research.
5. The researcher will submit the relevant letters of permission from Department of Social Work at Tygerberg Hospital and the Department of Radiation Oncology at Tygerberg Hospital to Mr. Sidney Engelbrecht [sidney@sun.ac.za / 021 808 4622] of the Division for Research Development, Stellenbosch University.

Best regards



MR SF ENGELBRECHT

Secretary: Research Ethics Committee: Human Research (Humaniora)
Registered with the National Health Research Ethics Council (NHREC): REC-050411-032



ANNEXURE I – Consent from Research Ethics Committee: Human Research from University of Stellenbosch (11.10.2011 - 10.10.2012)



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY
jou kennisvenoot • your knowledge partner

11 October 2011

Tel.: 021 - 808-9183
Enquiries: Sidney Engelbrecht
Email: sidney@sun.ac.za

Reference No. 476/2010

Ms BH Steyn
Department of Social Work
University of Stellenbosch
STELLENBOSCH
7602

Ms BH Steyn

LETTER OF ETHICS CLEARANCE

With regard to your application, I would like to inform you that the project, *Surviving a laryngectomy: The experience of post-operative cancer patients and their families*, has been approved on condition that:

1. The researcher will remain within the procedures and protocols indicated in the proposal, particularly in terms of any undertakings made in terms of the confidentiality of the information gathered.
2. The research will again be submitted for ethical clearance if there is any substantial departure from the existing proposal.
3. The researcher will remain within the parameters of any applicable national legislation, institutional guidelines and scientific standards relevant to the specific field of research.
4. The researcher will consider and implement the foregoing suggestions to lower the ethical risk associated with the research.
5. This ethics clearance is valid for one year from 11 October 2011 to 10 October 2012.

We wish you success with your research activities.

Best regards




MR SF ENGELBRECHT

REC Coordinator: Research Ethics Committee: Human Research (Humaniora)
Registered with the National Health Research Ethics Council (NHREC): REC-050411-032



ANNEXURE J – Consent from Research Ethics Committee: Human Research from University of Stellenbosch (11.09.2012 -10.09.2013)



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY 11 September 2012
Jou kennisvenoot • your knowledge partner

Tel.: 021 - 808-9003
Enquiries: Mr. Winston A Beukes
Email: wabeukes@sun.ac.za

Reference No. HS476/2010P

Ms BH Steyn
Department of Social Work, Stellenbosch University

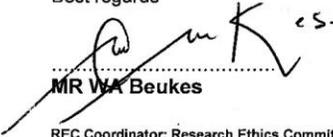
Ms Steyn

LETTER OF ETHICS CLEARANCE: Renewal of ethics Protocol

With regard to your application for ethics renewal, I would like to inform you that the progress report on study with title, *Surviving a laryngectomy: The experiences of post-operative cancer patients and their families*", was approved with the following proviso's:

1. The researcher will remain within the procedures and protocols indicated in the proposal, particularly in terms of any undertakings made in terms of the confidentiality of the information gathered.
2. The research will again be submitted for ethical clearance if there is any substantial departure from the existing proposal.
3. The researcher will remain within the parameters of any applicable national legislation, institutional guidelines and scientific standards relevant to the specific field of research.
4. The researcher will consider and implement the foregoing suggestions to lower the ethical risk associated with the research.
5. This ethics clearance is valid for one year from 11/09/2012 until 10/09/2013.

Best regards


MR W.A. Beukes



REC Coordinator: Research Ethics Committee: Human Research (Humanforsa)
Registered with the National Health Research Ethics Council (NHREC): REC-050411-032



Afdeling Navorsingsontwikkeling • Division for Research Development

Privaatsak/Private Bag XI • Matieland 7602 • Suid-Afrika/South Africa
Tel: +27 21 808 9184 • Faks/Fax: +27 21 808 4537
www.sun.ac.za/research

ANNEXURE K – Consent from the Division of Research Development and support from Faculty of Health Sciences (14.10.2011)



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14 October 2011

Ms BH Steyn
Department of Social Work
University of Stellenbosch

Dear Ms Steyn

This is to confirm that the ethics clearance granted by the Stellenbosch University Human Research Ethics Committee is recognised by us and that resubmission of your project to the Health Research Ethics Committee is not required.

Please note that research that will be conducted at any tertiary academic institution also requires approval from the relevant hospital manager.

Yours sincerely

Franklin Weber
Division of Research Development and Support
Faculty of Health Sciences



Fakulteit Gesondheidswetenskappe • Faculty of Health Sciences



Verbind tot Optimale Gesondheid • Committed to Optimal Health

Afdeling Navorsingsontwikkeling en -Steun • Research Development and Support Division

Posbus/PO Box 19063 • Tygerberg 7505 • Suid-Afrika/South Africa

Tel: +27 21 938 9820 • Faks/Fax: +27 21 931 3352

E-pos/E-mail: rdsinfo@sun.ac.za

ANNEXURE L – Consent from Hospital (06.02.2012)



Tygerberg Hospital and
Mitchells Plain & Tygerberg Oral Health Centres

REFERENCE: Research Projects
ENQUIRIES: Dr M A Mukosi

STUDENT NO: 10996885

Surviving a laryngectomy: The experience of post-operative cancer patients and their families.

Dear Ms B H Steyn

PERMISSION TO CONDUCT YOUR RESEARCH AT TYGERBERG HOSPITAL

In accordance with the Provincial Research Policy and Tygerberg Hospital Notice No 40/2009, permission is hereby granted for you to conduct the above-mentioned research here at Tygerberg Hospital.

A handwritten signature in black ink, appearing to be 'D Erasmus', written over a horizontal line.

DR D ERASMUS
CHIEF DIRECTOR: TYGERBERG HOSPITAL

6 February 2012