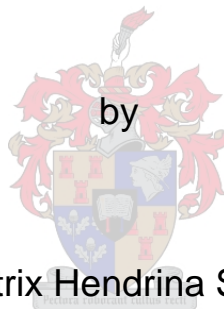


THE LARYNGECTOMY PATIENT'S NEED FOR SUPPORT GROUPS IN A HOSPITAL SETTING: A SOCIAL WORK PERSPECTIVE



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Thesis presented in partial fulfilment of the requirements for the degree
of Master of Social Work at the
University of Stellenbosch

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DECLARATION

By submitting this thesis electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the owner of the copyright thereof (unless to the extent explicitly otherwise stated) and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

Date: 13 February 2009

Dedicated to all laryngectomy patients
from whom I have learned so much of life

“There is life after laryngectomy and one of the most rewarding aspects of this new life with a new voice is the personal satisfaction one finds learning to speak, overcoming any handicaps and helping those who follow ...

Please encourage new laryngectomees as they come to your attention ... they are not alone and with proper guidance, emotional support and teaching, they will find a bright new world of adventure theirs for the taking”.

(Ulbricht, 1986:136)

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SUMMARY

A laryngectomy is mostly indicated as treatment for an advanced stage of cancer of the larynx, during which the patient's voice box is removed. This operation can hold major **psycho-social implications** for the **patient** and **family**. To cope with the challenges in daily life, patients **need social support**. A lack of available literature and research regarding the role of the social worker in facilitating support groups for these patients and families was identified and **motivated** this research study.

The **goal** of the study was to gain a better understanding of the laryngectomy patient's need for support groups in a hospital setting when attending the follow-up clinic at the hospital. A combination of both the exploratory and descriptive **research designs** together with a combination of mainly a qualitative and to a certain extent the quantitative **research approaches**, was used. From this, knowledge, insight and an understanding of the need for support groups in a hospital setting from a social work perspective were obtained. **Permission** to conduct the proposed study was granted by the Committee for Human Research at the University of Stellenbosch.

The **literature study** first focused on medical aspects of a laryngectomy and social work intervention services within a hospital setting as part of the multi-disciplinary approach. Second, psycho-social effects of a laryngectomy from an ecological perspective were discussed, referring to the physical, social and psychological effects of surgery upon the patient and family. Third, support and aftercare were discussed with specific reference to the role of the social worker in offering social support to the patient and family.

For the **empirical study**, twenty laryngectomy patients from the service area of Tygerberg Hospital were involved from January 2008 to May 2008. **Criteria for inclusion** in the study referred to patients who had their operation not less than three months previously, attended the support group during follow-up visits at the hospital and who had successfully acquired trachea-oesophageal speech. Based on the literature review, a semi-structured questionnaire and face-to-face interview were used as **research instruments** to overcome the limitation of illiteracy.

The **results** of the investigation mainly confirmed the findings of the literature study namely that laryngectomy patients can benefit from support groups in order to address their **need for social support** in dealing with daily life challenges. Patients indicated that they mainly needed information regarding post-operative adaptation as this was where problems were mostly experienced. The majority of patients suggested the use of support groups in this regard. Focus was placed on an exploration and description of patients' needs for such support groups. Benefits of support groups were found to be totally compatible with the role of the social worker. The results therefore gave an indication of **social work intervention services** and referred to: provision of information, problem-solving, offer of social and emotional support, and promotion of rehabilitation opportunities, thereby improving the patient's quality of life.

Recommendations were aimed at social work intervention services relating to support and aftercare offered to laryngectomy patients and relatives. **Future research** to develop social work programmes for health care professionals in order to effectively support these patients and their families was proposed. From practical experience of support groups a study regarding the role of pre- and primary schoolchildren or grandchildren in the rehabilitation of laryngectomy patients was also suggested.

OPSOMMING

‘n Laringektomie word meestal uitgevoer vir die behandeling van gevorderde stembandkanker, waartydens die pasiënt se stembande verwyder word. Hierdie operasie hou potensieel grootskaalse **psigo-maatskaplike implikasies** vir die pasiënt en familie in. Ten einde die uitdagings in die daaglikse lewe te kan hanteer, ondervind hulle ‘n **behoefte aan ondersteuning**. ‘n Gebrek aan beskikbare literatuur en navorsing wat die rol van die maatskaplike werker in die fasilitering van ondersteuningsgroepe identifiseer, het hierdie navorsingstudie **motiveer**. ‘n Kombinasie van sowel die verkennende as beskrywende **navorsingsontwerpe** is gebruik, asook ‘n kombinasie van hoofsaaklik ‘n kwalitatiewe en in ‘n sekere mate die kwantitatiewe **navorsingsbenaderings**. Sodoende is kennis, insig en begrip van die laringektomie-pasiënt se behoefte aan ondersteuningsgroepe in ‘n hospitaalopset vanuit ‘n maatskaplikewerk-perspektief bekom. **Toestemming** vir die uitvoer van hierdie studie is van die Komitee vir Mensnavorsing van die Universiteit van Stellenbosch verkry.

Die **literatuurstudie** het eerstens gefokus op mediese aspekte van ‘n laringektomie en maatskaplikewerk-intervensie binne die hospitaalopset as deel van die multi-dissiplinêre span. Tweedens is die psigo-maatskaplike effek van ‘n laringektomie vanuit ‘n ekologiese perspektief bespreek, met verwysing na die fisiese, maatskaplike en psigiese uitwerking van die operasie op die pasiënt en familie. Derdens is ondersteuning en nasorg bespreek met spesifieke verwysing na die rol van die maatskaplike werker in die lewering van maatskaplike ondersteuning aan die pasiënt en familie.

Die **empiriese studie** het vanaf Januarie 2008 tot Mei 2008 geduur waarby twintig laringektomie-pasiënte vanuit die bedieningsgebied van Tygerberg Hospitaal betrek is. **Kriteria vir deelname** aan die studie sluit in: pasiënte wie se operasie nie minder nie as drie maande gelede gedoen is, die ondersteuningsgroep tydens hul opvolgbesoek aan die hospitaal bygewoon het, en wat suksesvol trachea-oesofageale spraak aangeleer het. Gebaseer op die literatuurstudie, is ‘n semi-

gestruktureerde vraelys en 'n onderhoud as **navorsingsinstrumente** gebruik om die probleem van ongeletterdheid te oorkom.

Die **resultate** van die studie het grotendeels die bevindinge van die literatuurstudie bevestig, naamlik dat laringektomie-pasiënte kan baat by ondersteuningsgroepe. Sodoende kan hul behoefte aan sosiale ondersteuning aangespreek word wat hulle in staat sal stel om die eise van die daaglikse lewe te hanteer. Pasiënte het aangedui dat hulle meestal inligting oor aanpassing na die operasie benodig aangesien dit hoofsaaklik die area is waar hulle probleme ervaar. Die meeste pasiënte het die gebruik van ondersteuningsgroepe voorgestel om in hul behoefte aan ondersteuning te voldoen. Die fokus is geplaas op 'n verkenning en beskrywing van die pasiënte se behoefte aan sulke ondersteuningsgroepe. Voordele van ondersteuningsgroepe is versoenbaar met die rol van die maatskaplike werker. Die resultate het dus 'n aanduiding van **maatskaplikewerk-intervensie** ten opsigte van laringektomie-pasiënte en families gebied, naamlik: probleemoplossing, inligtingverskaffing, maatskaplike en emosionele ondersteuning, en bevordering van rehabilitasie-geleenthede waardeur die pasiënte se lewenskwaliteit bevorder kan word.

Aanbevelings is gerig op maatskaplikewerk-intervensie met verwysing na ondersteuning en nasorgdienste. Onderwerpe vir **toekomstige navorsing** behels die ontwikkeling van maatskaplikewerk-programme vir gesondheidswerkers om hierdie pasiënte en hul families te ondersteun. Uit praktiese ervaring van die fasilitering van ondersteuningsgroepe is 'n verdere aanbeveling vir 'n voorgestelde studie die rol wat voorskoolse en laerskoolkinders of kleinkinders in die rehabilitasie van laringektomie-pasiënte, speel.

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CHAPTER 1

INTRODUCTION

1.1 MOTIVATION FOR STUDY

Although a laryngectomy is considered as a life-saving operation, the **physical, functional, emotional** and **social** well-being of a patient is being affected by such a medical procedure (Graham, 2004:134; Kleinsasser, 1988:190-191; Zeine & Larson, 1999:52). Kleinsasser (1988:190-191) referred to a laryngectomy as having the potential to result in severe psychological and physical mutilation or as Renner (1995:215) described it, “entering the unknown without a map or travel plan”.

Most laryngectomy patients will experience some degree of **depression** following a laryngectomy, although it may occur at various stages and in different degrees (Casper & Colton, 1998:5; Graham, 2004:128; Renner, 1995:217). Depression can follow as a result of loss of voice and the quality of domestic support (Stell, 1991:222), with a negative effect on the patient’s recovery, ability to learn speech, lack of energy or social isolation (Birkhaug, Aarstad, Aarstad & Olofsson, 2002:203; Casper & Colton, 1998:5).

The patient’s experience of anxiety and fear about the future may be caused by lack of knowledge regarding the operation and its accompanying effects, physical changes and functioning following surgery (Renner, 1995:215). **Family members** may experience similar reactions, although it may be from a different perspective because of their close relationship with the patient (Casper & Colton, 1998:3-4).

Renner (1995:215) pointed out that a laryngectomy has an impact on the patient and family’s psycho-social needs. The expertise of various members of the **inter-disciplinary team** is therefore required to adequately address these special needs, as emphasised by Casper and Colton (1998:35). Both Casper and Colton (1998:50) and Dhooper (1985:220, 225) stated that the **social worker** should form part of this inter-disciplinary team as he or she is equipped with interpersonal skills to assist in the care, treatment and rehabilitation of the laryngectomy patient.

It is the responsibility of team members within the **hospital setting** to offer aftercare to the patient and his family after his discharge from hospital (Zeine & Larson, 1999:60), because the unique context of the hospital setting offers an excellent opportunity to provide aftercare and support to these patients, while attending the follow-up clinic on a regular basis.

Rehabilitation of laryngectomy patients is described as a complex process (Casper & Colton, 1998:52) and should ideally include an understanding of the patient as a “total person” within the context of the patient’s family system (Renner, 1995:219). This process requires the implementation of the **ecological perspective** by identifying and describing the various systems within which the patient functions (Meyer & Mattaini, 1995:16-27; Sheafor, Horejsi & Horejsi, 2000:91-93).

In a study conducted by Llatas, Ramírez, Ferriol, Doménech, Suárez-Varela and Martínez (2003:816), it was found that the factors determining laryngectomy patients’ post-operative adjustment were the social and medical **support** they received from family members and not their experience of the permanent stoma or loss of voice. Lack of support was the most negative and constant complaint from these patients.

The **benefits** of **social support** are well defined by various authors. Llatas *et al.* (2003:816) referred to possible improvement of the patient’s self-confidence and satisfaction; promotion of speech rehabilitation; improvement of physical and psychological adjustment and improvement of general quality of life. Support can also reduce distress and limit the incidence of depression (Richardson, Graham & Shelton, 1989:284).

Richardson *et al.* (1989:284, 291) distinguished between different **types** of **support**, each with its unique qualities and benefits. Support may come from the spouse and family or providers (professionals) and peers, and can play a role in the limitation of physical and psycho-social dysfunction. Development of new skills to overcome limitations after surgery is also promoted.

Graham (2004:134-135) stressed that a comprehensive rehabilitation plan cannot be achieved without using **support groups**. The value of support groups is widely acknowledged in literature and may include various benefits: to solve problems; to serve as a source of educational information; to develop social skills and coping strategies; to promote emotional adjustment; to reduce a patient's sense of isolation; to provide a protected and supportive atmosphere for learning communication; to encourage and motivate rehabilitation and to improve the patient's quality of life and prognosis (Birkhaug *et al.*, 2002:203; Graham, 2004:135; Herranz & Gavilán, 1999:996; Llatas *et al.*, 2003:816; Renner, 1995:219; Ruiz & Crevier-Buchman, 2000a:173). Although support offered from the family is of the utmost importance, the support offered within the context of support groups has a different focus (Richardson *et al.*, 1989:284).

At Tygerberg Hospital where this research study is conducted, all laryngectomy patients are referred to the social worker for pre-operative counselling. According to available statistics, respectively twenty and thirteen patients who presented with larynx cancer at Tygerberg Hospital, were surgically treated with a total laryngectomy during 2006 and 2007 (until July). This procedure refers to the total removal of the larynx (Casper & Colton, 1998:1). Treatment of patients is followed up at the Radiation Oncology Department of Tygerberg Hospital on a regular basis. The researcher has twenty-one years of **experience** as a social worker in the oncology unit at Tygerberg Hospital. The clinical field includes services to patients of the Ear, Nose and Throat Clinic.

During March 2006 the researcher (a social worker) and a speech-language therapist initiated **support groups** for laryngectomy patients and their accompanying relatives who attended the follow-up clinic. The frequency of follow-up visits varied according to the patient's medical condition. Visits were scheduled on a six-weekly, two-monthly, three-monthly, four-monthly or six-monthly and later on an annual basis. Groups were facilitated by the social worker and co-facilitated by the speech-language therapist. Group discussions were followed up with an individual speech therapy session if it was shown that patients had not successfully mastered speech post-operatively. These group sessions clearly demonstrated a need for a social

work aftercare programme for the laryngectomy patient and family members in a hospital setting.

Although the importance of support groups for laryngectomy patients was described earlier, it was found from the literature review that **no clear social work framework** for a social work aftercare programme for laryngectomy patient support groups in a hospital setting was available. Existing literature mainly expressed the viewpoint of other members of the inter-disciplinary team (for example speech-language therapists) or self-help groups. Dhooper (1985:217, 225) found that little information was available from a social work perspective and that few studies in the cure and rehabilitation of these patients included social workers in their investigations. The current situation is much the same. Zeine and Larson (1999:60) stated that it is important to improve or increase the knowledge and degree of experience of future clinicians working with laryngectomy patients. Social work with laryngectomy patients and their family members requires intense involvement and specialised skills and a Masters Degree is recommended, especially to deal with the complexity of these patients' needs with compassion and insight (Dhooper, 1985:225).

From the above it is clear that **social workers** have an **important role** to play in offering support to the laryngectomy patient and family members, taking in account the numerous psycho-social implications arising from this surgical procedure. However, there is little information from a social work perspective on dealing with laryngectomy patients within the context of support groups. The need for the proposed study was discussed with the Head of the Department of Radiation Oncology, the Head of the Ear, Nose and Throat Department and speech-language therapist at Tygerberg Hospital. It was also presented to the staff of the Department of Radiation Oncology during a research forum. Following a thorough literature study of local and international literature, it was found that no other similar research projects regarding this topic have been conducted from a social work perspective. The current research project is therefore **relevant**.

1.2 PROBLEM STATEMENT

Loss of voice is a traumatic event (Zeine & Larson, 1999:59) as it not only affects verbal communication, but also psycho-social aspects of life for the patient and his family (Ruiz & Crevier-Buchman, 2000a:171). This traumatic event may result in a significant decrease in social acceptance; the inability to communicate adequately; economic implications; cosmetic and functional disability; a tendency to be dependent on others to perform tasks in daily life or withdrawal from social activities (Deshmane, Parikh, Pinni, Parikh & Rao, 1995:128-129; Ruiz & Crevier-Buchman, 2000a:173). This can threaten the family system because family roles may change and serious breakdowns in family communication may result in a crisis for the patient and relatives (Blood, Simpson, Dineen, Kauffman & Raimondi, 1994:19; Renner, 1995:216). The need for support for these patients was acknowledged in literature (Llatas *et al.*, 2003:816; Renner, 1995:215; Richardson *et al.*, 1989:283-284). Renner (1995:219) mentioned that anxiety levels of patients and family members tend to rise after the patient has been discharged from hospital. Blanchard (1982:240) emphasised the need for a specialised aftercare support programme within the hospital setting as families are not always in a position to offer the required support. The above-mentioned serves as a motivation for this study.

1.3 GOAL AND OBJECTIVES

The **goal** of the research study is to gain a better understanding of the laryngectomy patient's need for specialised aftercare and support in order to present a contextual framework for support groups within a hospital setting from a social work perspective. In order to achieve this goal, the research study includes the following **objectives**:

- To *describe* the unique context of the **hospital setting** wherein the social worker functions as part of the **inter-disciplinary team** in rendering services to laryngectomy patients.
- To *describe* the **psycho-social implications** of a laryngectomy for patients and families from an ecological and to a certain extent from the strengths perspective.
- To *describe* the need for **support** and how support for laryngectomy patients can be utilised as part of an aftercare programme when attending the **follow-up clinic** at hospital.

- To *explore* the laryngectomy patients' **existing support systems** and need for a specialised social work aftercare support programme in the hospital.
- To *present* a **contextual framework** for a social work aftercare programme for laryngectomy patients in a hospital setting.

1.4 DEFINITIONS

For the aim of this study the following definitions will be applicable:

1.4.1 Aftercare

"The continuing treatment, **physical** maintenance, and **social** support of formerly hospitalised" patients when trying to ensure "their social transition back to the community" (Dictionary for Social Work, 1999:12). The SA Concise Oxford Dictionary (2007:19) also referred to the element of care to be involved in the process of aftercare being offered to such a person. For the purpose of this study, the ideal of aftercare being offered to the laryngectomy patient would be to support the patient. Through this, his ability to attain his former role functioning within various social systems, will be promoted.

1.4.2 Laryngectomy

A laryngectomy is a surgical procedure to remove the entire larynx when an advanced stage or recurrence of cancer of the larynx or hypopharynx is diagnosed (Casper & Colton, 1998:1; Silver & Ferlito, 1996:179; Stell, 1991:212; Ulbricht, 1986:131). In this context, Casper and Colton (1998:1) and Ulbricht (1986:131) described the person who has had a laryngectomy as "a laryngectomised person or a laryngectomee". As literature (Ross, 2000:13) pointed out that 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.

1.4.3 Rehabilitation

"Restoring to a healthy condition or useful capacity to the extent possible" which is used mainly by social workers in the context of "helping people who have been impaired through injury, disease, or dysfunction". This process can take place in

hospitals as one of many other possible settings, and may include psycho-therapy or lifestyle changes (Dictionary for Social Work, 1999:454). Ideally, the aim of this process should be to reach “health or normal life” after illness, or to “return to a former condition” by using training or therapy, as described by the SA Concise Oxford Dictionary (2007:985). The aim of rehabilitation being offered to the laryngectomy patient would ideally be to promote successful adjustment towards former or nearly former levels of functioning despite his health disability.

1.4.4 Social support

“Formal and informal activities and relationships that provide for the needs of humans in their efforts to live in society. These needs include education, income security, health care, and especially a network of other individuals and groups who offer encouragement, access, empathy, role models, and social identity” (Dictionary for Social Work, 1999:454). Within the context of this study, social support will be required by the laryngectomy patient in his effort to successfully return to society. During this process group members will be in a position to act as role models for one another, whereby the patient will be encouraged to return to his previous level of functioning.

1.4.5 Support groups

“A structured ongoing series of meetings between people who share a common problem and who give advice, encouragement, information and emotional sustenance. The group may be led by a professional social worker but more often consists of only the members themselves, and the degree of structure varies considerably” (Dictionary for Social Work, 1999:474). The one factor common to laryngectomy patients is their similar medical condition and treatment, namely a laryngectomy. However, the laryngectomy experience has the potential to affect each patient and his family’s psycho-social functioning in a different way. Within this context, advice, encouragement, information and emotional support can be offered by fellow group members.

1.5 RESEARCH DESIGN AND METHODS

1.5.1 Research approach

A **combination** of mainly the **qualitative** and to a certain extent also the **quantitative approach** will be used to conduct the study and obtain the goal of the research project. Within the context of a social science, it is not unusual to use a combination of these two approaches as the choice will be determined by the project (Fouché & Delport in De Vos, Strydom, Fouché & Delport, 2005:73). The aim of the **qualitative approach** is “to understand social life and the meaning that people attach to everyday life, by using the respondent’s own words, beliefs and values” (Fouché & Delport in De Vos *et al.*, 2005:74). The focus will be to study human behaviour from the “perspective of the actors themselves”, viewing the world “through their eyes”, in order to understand them better (Babbie & Mouton, 1998:271). For the purpose of this study, the qualitative approach will focus on the laryngectomy patient’s world from the perspective of the patient.

Following a **quantitative approach**, a profile of the respondents’ demographic background will also be presented within which context the study will be interpreted. In view of the above-mentioned description of both research approaches, it was concluded that a combination of the qualitative and quantitative approaches would be applicable to reach the goal of the study, namely to gain a better understanding of the laryngectomy patient’s need for specialised aftercare and support in order to present a contextual framework for support groups within a hospital setting from a social work perspective.

1.5.2 Research design

As indicated by Garbers (1996:287) a research project usually includes elements of more than one research design. For the purpose of this study the focus will be on a **combination** of the **exploratory** and **descriptive designs**. While the exploratory design refers to the “what” question, the descriptive design refers to the “how” and “why” question (Fouché & De Vos in De Vos *et al.*, 2005:106; Mouton, 2006:53-54).

An **exploratory design** is used to explore a relatively unknown or new area of interest to obtain new insight into this field of study of people who have had practical

experience of a similar problem (Babbie & Mouton, 1998:79-80; Garbers, 1996:287; Mouton & Marais, 1992:45). This research design can help to obtain basic information in a new area of interest and can try to provide a basic familiarity with the topic or satisfy the researcher's curiosity and desire for a better understanding (Babbie & Mouton, 1998:80; Fouché & De Vos in De Vos *et al.*, 2005:106).

In a **descriptive** research **design** the researcher observes the situation or event after which the details of the situation are documented (Babbie & Mouton, 1998:80), presenting a picture of the special details of the situation (Fouché & De Vos in De Vos *et al.*, 2005:106).

A combined research design will be chosen to best achieve the goal of the study, namely to describe the need for a social work aftercare programme using support groups for laryngectomy patients in a hospital setting. **Motivation** for implementing a combined research design is:

- To *gain* new insight into the special aftercare and support needs of the laryngectomy patient in accordance with the psycho-social implications of the diagnosis and treatment (exploratory design).
- To *study* available literature, followed by a survey of people who have had a practical experience (laryngectomy) of a similar problem (exploratory design).
- To *present* the findings mainly from the ecological and to a certain extent also from the strengths perspective wherein these patients function (descriptive design).

1.5.3 Research method

The research method was conducted to include a thorough literature study, followed by the selection of the research population and sample. The research method was preceded by collection, analysis and finally, verification of data which were collected.

1.5.3.1 Literature study

A review of the literature can be seen as a contribution towards a clearer understanding of the nature and meaning of the problem that has been identified and therefore providing a logical framework for research placed within a scientific context

of related studies (Babbie & Mouton, 1998:565; Fouché & Delport in De Vos *et al.*, 2005:123-124; Marshall & Rossman, 1995:28).

Both local and international literature will be reviewed to create a better understanding of the laryngectomy patient's psycho-social experiences and need for specialised support and aftercare. The literature will be selected from the social, medical and speech therapy sciences. Sources such as books, journals and articles will be studied and utilised. Study material will be obtained from the following sources: the JS Gericke Library and the Health Science Library (at Tygerberg Hospital) of the University of Stellenbosch, both of which request literature from other educational institutions when indicated, and the Erica Theron Reading Room in the Social Work Department at the University of Stellenbosch.

The questionnaire was designed in a deductive manner, moving from the general to the specific, with reference to the literature study which was used as a basis to develop the semi-structured questionnaire (Grinnell, 1988:327-328). The semi-structured questionnaire (Annexure A) was used as research instrument for data collection.

1.5.3.2 Population and sampling

Arkava and Lane (1983:27, 157) defined the universe as "all potential subjects who possess the attributes in which the researcher is interested". The population "sets boundaries on the study units and refers to individuals in the universe who possess specific characteristics". The sample is "the element of the population considered for actual inclusion in the study" and it is seen as a "small representation of a whole".

Within the context of this research study the following definitions are applicable: The **universe** will include all patients who present with a diagnosis of cancer of the larynx or hypopharynx. The **population** will refer to those patients who received a total laryngectomy as surgical treatment for this condition at Tygerberg Hospital. During January until December 2006 and January until July 2007, respectively twenty and thirteen patients who presented with larynx cancer at Tygerberg Hospital, were surgically treated with a total laryngectomy. The **sample** will include a selection of laryngectomy patients attending the follow-up clinic on a Wednesday at the

Department of Radiation Oncology during a specific period (9 January 2008 until 28 May 2008); patients who had their operation not less than three months before this period; patients who will be involved in support groups presented by the social worker (researcher) and speech-language therapist, and patients who successfully acquired trachea-oesophageal voice. Twenty-five patients met the criteria for inclusion in the study during this period. Four patients were involved in the pilot study (Delpont in De Vos *et al.*, 2005:170-171) and the other twenty patients in the empirical study. One patient was not involved due to employment obligations.

Strydom and Delpont (in De Vos *et al.*, 2005:328-329) stressed that **sample selection** should be chosen after careful consideration of the parameters of the population. In exploratory research the researcher identifies individuals, groups and settings where the specific process being studied is most likely to occur (Strydom & Delpont in De Vos *et al.*, 2005:328). The **sample size** will be determined by factors such as what the researcher wants to study; purpose of the study; usefulness and credibility of the study and available time and resources (Strydom & Delpont in De Vos *et al.*, 2005:328). After consultation with a statistician as recommended by the Committee for Human Research at Tygerberg Hospital, the following guidelines were determined:

- Although a combination of the quantitative and qualitative research approach will be followed in this study, the focus will fall mainly on a qualitative approach. In view of this approach and the number of cancer patients who received a total laryngectomy at Tygerberg Hospital as described earlier, a sample size of twenty patients will be adequate.
- After the target of twenty patients has been reached, the researcher, in co-operation with her supervisor, may decide to increase the sample size if it is found that the information is insufficient for the study.

Purposive sampling as a type of a non-probability sampling technique in qualitative research is described as where the researcher uses his own knowledge and judgement about the population to select a sample (Arkava & Lane, 1983:159; Babbie & Mouton, 1998:166; Grinnell, 1993:162-163), taking into account the purpose of the study. It should thus be representative of a good source of information which is specially sought out and selected.

The importance of clear identification and formulation of criteria for the selection of respondents is stressed by Strydom and Delport (in De Vos *et al.*, 2005:329). The **criteria for inclusion** in the sample will be based on the following conditions:

- Patients' medical treatment namely a **total laryngectomy** as surgical treatment of cancer of the larynx or hypopharynx at Tygerberg Hospital.
- Patients from the service area of **Tygerberg Hospital**.
- Patients' attendance at the laryngectomy **support group** (Wednesdays) after their visit to the follow-up clinic or while receiving treatment at hospital.
- Patients' ability to participate in the study on the grounds of acquiring sufficient **tracheo-oesophageal voice** needed for a face to face interview.
- Patients should only be involved in the research study after a certain period of time following their surgery. The researcher decided on a **three month** post-operative period. This will give them enough time to adjust to the psycho-social implications, without getting too used to the changed situation. Graham (2004:130) remarked that with time, patients adjust to the experience of cancer, giving rise to the need for a holistic treatment approach by the rehabilitation team and therefore their need for support.

Selection of the study population will be fair, as no potential participant will be excluded on grounds of language preference, culture, age, gender or location. The only potential **risk** foreseen in this study is that patients may possibly experience fatigue and the study population therefore could find it difficult to participate in a long interview. In order to compensate for this limitation, the length of the semi-structured questionnaire will be limited. **Practical problems** such as transport will not put an additional financial burden on these patients, as they have to attend the follow-up clinic. Interviews will be scheduled for the same date as the patients' follow-up appointments at the hospital. If patients specifically have to visit the hospital for the purpose of the research interview, the researcher will pay their transport fee.

Criteria for exclusion from the sample will be laryngectomy patients with post-operative speech inability as they will not be able to participate in the face to face interview; patients who had their operation less than three months previously and

patients who do not attend the support group during their follow-up appointment at hospital. Patients who prefer not to attend support groups, already demonstrate their lack of interest in this type of support being offered at the hospital. The aim of the present research study will exactly be to identify the laryngectomy patient's need for this type of support when he shows interest to attend these groups.

1.5.3.3 Method of data collection

As part of the process of data collection, preparation for data to be collected will be important in order to meet the aim of the study. This will include a decision regarding the research instruments to be used within the research process.

Research instruments will include the use of a **face to face interview** to obtain research data. The researcher will collect data by using a **semi-structured questionnaire** (Annexure A). Both the use of the questionnaire and the face to face interview are seen as the most basic and common method of collecting data (Babbie & Mouton, 1998:249; Delport in De Vos *et al.*, 2005:166; Grinnell, 1993:268). Literature based on similar studies will set the foundation for the formulation of the questionnaire. The researcher (social worker) will use professional interview techniques with the respondents of the questionnaire, as described by Greeff (in De Vos *et al.*, 2005:288-290).

Within the semi-structured interview a combination of open-ended and closed-ended questions will be used. Interviews will be conducted in the home language (Afrikaans, English or Xhosa) of the participant and permission to audiotape interviews will be requested (Greeff in De Vos *et al.*, 2005:298).

Both Babbie and Mouton (1998:249) and Grinnell (1993:268) referred to the limitation of illiteracy of respondents while conducting a research study. This may also be a possible limitation when conducting this research. Face to face interviews for completion of questionnaires, will allow respondents with reading and writing inability or physical impairment to be included in the research study (Grinnell, 1993:268). Laryngectomy patients presenting with speech inability post-operatively will be excluded from the study and will be discussed under the limitations of the study.

1.5.3.4 *Method of data analysis*

Data analysis is described as “a process of bringing order, structure and meaning to the mass of collected data” (De Vos in De Vos *et al.*, 2005:333; Marshall & Rossman, 1995:111). This process means to break collected data into discrete parts, according to De Vos (in De Vos *et al.*, 2005:341). Data collection and analyses are described as a systematic procedure which is tightly interwoven and which occurs continuously (De Vos *et al.*, 2005:270, 341, 403). The researcher will focus on the data analysis model described by Marshall and Rossman (1995:113-119) when conducting the study:

- Information obtained during interviews with the respondents, using a semi-structured questionnaire, needs to be **organised**. This will only be possible after reading the data repeatedly, to become familiar with the contents.
- This process will be followed by identifying and creating **categories, themes and patterns**.
- Alternative explanations will be looked for by challenging the patterns that seem to be apparent and **formulating linkages** among these patterns.
- Information obtained during this study will be presented in a scientific manner (**research report**) with descriptions and illustrations. In presenting **quantitative data** the researcher will make use of visual statistics such as tables and figures (Arkava & Lane, 1983:28; De Vos in De Vos *et al.*, 2005:339), and in presenting **qualitative data** the researcher will use themes and sub-themes when analysing participants’ verbatim responses (De Vos *et al.*, 2005:74, 351).
- These findings **need to be communicated** to others in order to be of scientific value.

1.5.3.5 *Discussion of data verification*

Criteria for data verification were adopted into the following framework to guarantee the validity of qualitative research (Babbie & Mouton, 1998:276-278; De Vos in De Vos *et al.*, 2005:345-347; Marshall & Rossman, 1995:143-145):

- **Credibility:** The goal will be to demonstrate that the research study was conducted in such a manner that will ensure that the research topic was accurately identified and described. The scientific selection of a sample will be

essential. Within the context of this study, criteria for inclusion in the sample were already discussed under “*population and sampling*” (1.5.3.2).

- **Transferability:** This guideline refers to the extent to which findings of the study can be applied in other contexts or with other respondents. The sample has to be representative of the entire population of laryngectomy patients in a South African setting. Within the context of this study, generalisation of the results of the study to the entire population is not possible due to the size of the sample.
- **Dependability:** If the study is repeated with the same or similar respondents in the same or 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, wherein a different set of results may be obtained with a different set of respondents.
- **Confirmability:** The concept of objectivity described in 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 will be guided by a scientific process during this research. Objectivity will be a basic criterion.

1.6 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” ... “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 in De Vos *et al.*, 2005:57).

The **professional code of ethics** is an essential prescription of what is considered acceptable and unacceptable professional behaviour as ethical issues in social research are important and yet often ambiguous (Babbie & Mouton, 1998:528). Although social work research in South Africa has no specific ethical code, the general Ethical Code of the South African Council for Social Service Professions

(1986) can be seen as binding for social work research as well (Strydom in De Vos *et al.*, 2005:68).

Tygerberg Hospital has a **committee for human research** (Babbie & Mouton, 1998:528; Strydom in De Vos *et al.*, 2005:68) who reviews all research proposals involving human subjects to ensure that the rights and interest of the participant will be protected. The researcher received final approval to conduct this proposed research project from the Committee for Human Research during September 2007 (Annexure B), which will be valid until September 2008. The following applicable ethical considerations as viewed in the literature will be taken into account when conducting the research study:

- **Avoidance of harm:** Strydom (in De Vos *et al.*, 2005:58-59) referred to the obligation of the researcher to protect the respondents from any form of physical or emotional harm or discomfort, while Grinnell (1993:85) also included mental discomfort. It is the responsibility of the researcher to inform the respondents beforehand regarding the potential impact of the investigation. Within the context of this study, avoidance of harm can also refer to preventing participants becoming exhausted during interviews.
- **Informed consent:** The community will not be involved in the informed consent process in any way. The informed consent process will be discussed with potential participants prior to their participation in the research study. Information applicable to the study will be disclosed in a culturally and linguistically sensitive manner. Participation in the research project will be voluntary (Strydom in De Vos *et al.*, 2005:59-60) and therefore informed consent should result in voluntary participation. The aim of the study, the procedures which will be followed, advantages, disadvantages and dangers to which respondents may be exposed, will be discussed. After explaining these guidelines to participants, the researcher will issue participants with a written consent form to be signed before taking part in the study in which they will declare their voluntary participation. The possibility of withdrawal from the study at any time will also be discussed. Afrikaans, English and Xhosa versions of the consent form are attached (Annexures C, D & E). The Xhosa translation was set as a condition by the Committee for Human Research for final approval of the proposed research study (Annexure F). The Language

Centre at the University of Stellenbosch issued a certificate as confirmation of their translation of the consent form from English to Xhosa (Annexure G).

- **Confidentiality:** Strydom (in De Vos *et al.*, 2005:61-63) described this criterion as “handling of information in a confidential manner.” Also included under confidentiality is privacy, implying the personal privacy of the patient. The importance of this prescription is widely emphasised (Arkava & Lane, 1983:5-6; Grinnell, 1993:86-87). The researcher will approach the matter of the respondent’s confidentiality with the necessary respect and responsibility. This is possible by adhering to the following rules: Keep all information confidential unless respondents have given written consent; obtain and use only demographic information that is necessary for the study and store the information in a safe place.
- **Debriefing of respondents:** It is recommended that the respondents are given the opportunity to work through their experience after participating in the study (Strydom in De Vos *et al.*, 2005:66-67). Time will be set aside to rectify any misconceptions and to terminate the session. This will be done in a professional manner by the researcher, who is a qualified social worker.

1.7 LIMITATIONS OF THE STUDY

Limitations that were experienced include the following:

- **Literature** regarding the facilitating of support groups for laryngectomy patients from a social work perspective was limited.
- Some laryngectomy patients do not rehabilitate post-operatively to such an extent that they have successfully acquired **trachea-oesophageal voice**. This will handicap their ability to take part in the research process, as an interview will be conducted to complete a semi-structured questionnaire. For this reason they were excluded from participating in the study.
- Due to the **size of the sample**, generalisation of the results of the study to the entire population is not possible.

The researcher implemented the following steps to **compensate** for these limitations:

- An extensive **literature search** was done regarding support groups for laryngectomy patients, even from the perspective of other members of the inter-disciplinary team, specialising in this field.

- When setting the **criteria** for inclusion in the **sample**, laryngectomy patients who have not mastered tracheo-oesophageal speech ability and who are illiterate were excluded from the study. The speech-language therapist assessed the patient's communication ability.
- Selection of the **sample** was performed in a scientific manner within a specific timeframe (9 January 2008 until 28 May 2008) with no control over the size of the sample during that period of time.

1.8 PRESENTATION OF THE STUDY

The research report will be presented in six chapters, set out as follows:

Chapter 1 gives some background on the motivation for the study; problem statement; goal and objectives; definitions; demarcation of research area; research design and methods, ethical considerations and limitations of the study.

The **second chapter** supplies medical information regarding this surgery including the unique context of the hospital setting wherein the social worker functions as part of the inter-disciplinary team rendering services to laryngectomy patients.

In **chapter 3** the psycho-social implications of a laryngectomy for the patient and his family will be described from an ecological perspective.

Chapter 4 will describe the patient's need for support in order to cope with the psycho-social aspects of surgery. The use and value of support groups for patients will be described from a social work perspective.

In **chapter 5** the data of the empirical investigation will be brought into relation with the literature review to gain a better understanding of the laryngectomy patient's need for specialised aftercare and support at the hospital with specific reference to the use of support groups.

Based on these findings, **chapter 6** will provide a contextual framework, conclusions and recommendations for support and aftercare for the laryngectomy patient within the context of support groups in a hospital setting.

CHAPTER 2

MEDICAL ASPECTS OF A LARYNGECTOMY AND SOCIAL WORK INTERVENTION WITHIN A HOSPITAL SETTING

2.1 INTRODUCTION

This chapter will describe the unique context of the hospital setting wherein the social worker functions as part of the multi-disciplinary team rendering services to laryngectomy patients. Knowledge of the medical aspects of a laryngectomy is essential as it will contribute to a better understanding of the social worker's role towards laryngectomy patients and their relatives. This description is the first objective of this study.

The focus of this chapter will first be on a description of the **hospital setting** from the ecological perspective. Follow-up visits at the clinic after laryngectomy form part of these patients' prescribed medical treatment. It is during this phase of treatment that the social worker can contribute to a valuable aftercare support service for these patients. Discussion of the hospital setting will be from the viewpoint of patients and their relatives, and will include the social worker as a professional team member.

Second, a description of the **functioning** of the **social worker** as a member of the multi-disciplinary team within this hospital setting will follow. Emphasis will be on the role of the social worker as a team member and the aim of the team approach in rendering support services to laryngectomy patients.

Third, **medical aspects** of larynx cancer and total laryngectomy as treatment for this medical diagnosis will be described, as the social worker needs to be equipped with this knowledge in order to render services effectively to these patients.

2.2 HOSPITAL SETTING

Ross (1995:1367) described the hospital setting from the **ecological perspective** as being a process of interaction between a person and his environment. When a person is first diagnosed, he is introduced to an external support system. The patient

and his family will then interact with this new support system from their individual frame of reference. In other words, both the patient who has been diagnosed with larynx cancer and his family will be introduced to the hospital system as an additional external system. For both the patient and family this will be a new experience which they will enter from their individual backgrounds.

The primary function of the hospital setting as a system is to admit patients, provide them with efficient care and to discharge them after treatment (Ross, 1995:1367). For the purpose of this study, emphasis will be on offering **aftercare and support**, therefore the discharge and follow-up of patients will be described. Ross (1995:1371) defined **discharge planning** as “a broad range of activities directed towards returning the patient home or transferring to another facility”. Within the context of the ecological perspective, **social work activities** involved in discharge planning can be summarised as follows:

- **Coordination** of services after an assessment of patients’ **expectations** and pre- and post-operative **needs** (Belch & Beamish, 1992:61; Ross, 1995:1371-1372). This coordination function of the social worker is to meet the aim of the strengths perspective because focus will be on building people’s strengths by trying to eliminate problems or deficiencies they may experience (Sheafor, Horejsi & Horejsi, 2000:93).
- **Referral** of patients to **community resources** as social workers can offer various services that can possibly benefit patients (Dhooper, 1985:220, 223; Ross, 1995:1372). Ross (1995:1367) emphasised that the social worker promotes interaction between different systems (family, significant others, hospital, community) and therefore bridges the boundaries between these various systems. This function of the social worker will also contribute to building on the strengths perspective, as the assumption is that the environment in which the person lives and functions, is filled with resources (Sheafor *et al.*, 2000:93). The role of the social worker is therefore to bring together available resources to meet the needs of patients. From an ecological perspective, the social worker will focus on ways to promote growth, development and people’s adaptive ability by making use of available resources (Ross, 1995:1372; Sheafor *et al.*, 2000:92).

- **Emotional and educational counselling** of patients and families (Dhooper, 1985:225; Ross, 1995:1371). From an ecological perspective, the patient and his family may be in need of help to adapt to a changing environment in order to cope, survive and compete for essential resources (Sheafor *et al.*, 2000:91).
- **Practical service delivery** may be required such as financial assistance or arrangements for medical equipment at home (Ross, 1995:1371).

Discharge planning should ideally include discussions between the patient, family and team members (Dhooper, 1985:223). Although **various team members** have some responsibility towards discharge planning, the **social worker** is particularly skilled in planning how to take care of the patient's social needs. The social worker has a primary role during the patient's discharge planning by referring the patient to community resources in order to resolve his needs. Qualities of the social work profession acknowledged to fulfil this task of discharge planning will be discussed under "the role of the social worker as team member".

The **success** of discharge planning is mainly dependent on the patient's psychological preparation for discharge, taking into account the availability of required resources within the community (Dhooper, 1985:223). The care and counselling of the laryngectomy patient should not be terminated when the patient leaves the hospital (Zeine & Larson, 1999:60), because the patient could find that friends and family "may not or cannot" be in the position to meet his special need for support, as described by Blanchard (1982:240).

According to Belch and Beamish (1992:61), the patient's post-operative follow-up services as part of their rehabilitation programme are often neglected. The frequency of these follow-up visits should be scheduled on a regular, indefinite and life-long basis (Depondt & Gehanno, 1995:35; Kleinsasser, 1988:258). The importance for the patient of attending post-operative **follow-up visits** after being discharged from hospital is well described by Blanchard (1982:240) and Ruiz and Crevier-Buchman (2000b:169). Regular contact with team members may therefore lead to a beneficial post-operative **outcome** for the patient such as the promotion of quality of life aspects (Schuster, Lohscheller, Kummer, Hoppe, Eysholdt & Rosanowski,

2003:212). The patient's **motivation** for frequent follow-up visits can be enhanced by professionals from the following perspectives:

- From a **medical** point of view, examination of the patient is important to diagnose possible relapse of disease, metastases or a second cancer; to assess the patient's general condition, including nutritional status, pulmonary infection or aspiration (Depondt & Gehanno, 1995:33, 35; Kleinsasser, 1988:258; Ruiz & Crevier-Buchman, 2000b:169).
- From a **social** point of view, the patient can be motivated to cultivate a sober lifestyle, by trying to eliminate risk factors such as **alcohol** or **tobacco** use and to bring the patient and family in contact with **social support** (Blanchard, 1982:240; Depondt & Gehanno, 1995:33, 35).
- **Rehabilitation** of the patient and family can be promoted with specific reference to assessment of the patient's speech ability and to promote speech rehabilitation (Belch & Beamish, 1992:62; Depondt & Gehanno, 1995:33, 35).
- Follow-up visits of the patient ensure that the patient **stays** in the medical setting (Ross, 1995:1372).

Aftercare by professionals during follow-up visits at the hospital plays an important role in the patient's post-operative rehabilitation. The expertise, knowledge and skills of the social work profession can contribute to successful discharge planning and aftercare being offered to the patient and family during follow-up visits at the hospital.

2.3 TEAMWORK WITHIN THE HOSPITAL SETTING

In the following section, teamwork within the hospital setting will be discussed. Focus will be on the purpose of teamwork; benefits of teamwork; requirements for effective teamwork and potential obstacles team members may confront when rendering services to patients. An awareness of these aspects of teamwork will result in a better understanding of the dynamics of teamwork within a hospital setting and as a result may improve services to the patient and family. This section will first describe teamwork within the hospital setting in general, before discussing teamwork with the laryngectomy patient specifically from a social work perspective.

2.3.1 A general overview of teamwork

It is important to take into account that at Tygerberg Hospital where the research study is conducted, the team rendering comprehensive care services to the laryngectomy patient, will include the following team members: surgeon, oncologist, nursing staff, speech-language therapist, dietician, physiotherapist, social worker and radiographer (if radiotherapy is applicable). When indicated, the psychologist may also be involved. It is most important that the patient and family members also have to be seen as part of this team. Figure 2.1 illustrates some of the team members involved in rendering services to the laryngectomy patient and his family.

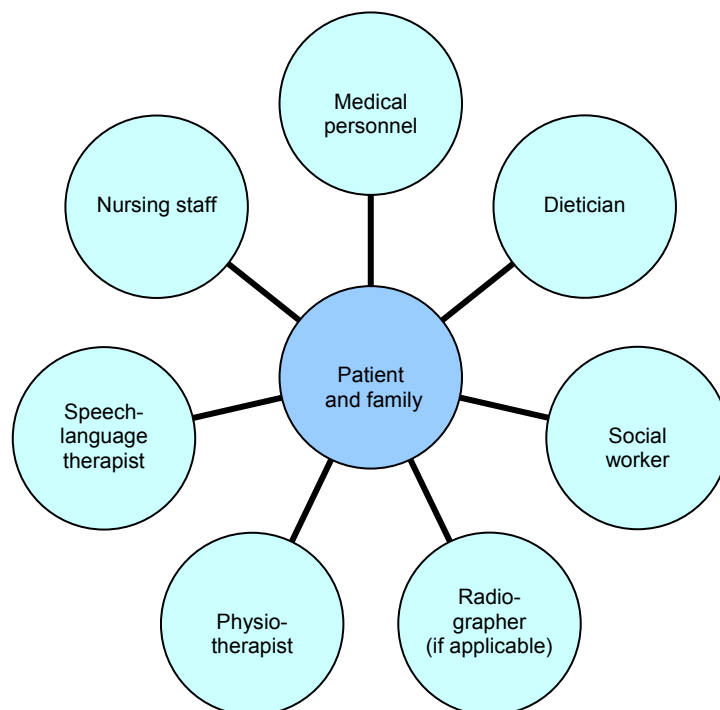


Figure 2.1: Schematic illustration of some of the team members

2.3.1.1 General purpose of teamwork

In order to gain a better understanding of the purpose of teamwork, it is important to first present an overview of theoretical literature viewpoints in this regard.

Within the hospital setting, the patient is cared for by professionals from various disciplines. Ross (1995:1373) stipulated the purpose of teamwork as “optimal, coordinated, efficient and realistic health decision making and care delivery”. Team members aim to **work together** for the greatest benefit of the patient, each with their **own unique** and **significant role**. The social worker’s collaboration with

professionals of the multi-disciplinary team mainly involves discussions with team members regarding the patient's psycho-social background and its effect on medical treatment. From an **ecological perspective**, the social worker will share with team members an assessment of the patient's interaction with the various systems wherein he may function (Sheafor *et al.*, 2000:91). This assessment and exchange of information will be to the benefit of the patient's medical treatment.

Knowledge of the purpose of teamwork will aid the social worker's understanding of the potential benefits of teamwork to the patient and family.

2.3.1.2 General benefits of teamwork

Ross (1995:1373) referred to the benefits of social work involvement in teamwork within the context of the hospital setting as follows:

- Various team members can **contribute** towards the implementation of decisions regarding the patient's suggested treatment regime, each from his or her own frame of reference.
- **Consultation** with or for team members is possible and can be provided on a continuous basis.
- Armed with knowledge of human behaviour and available resources, the social worker will be in a position to **advise** or **counsel** other team members.
- The social worker can assume the role of **advocate** with team members for the needs and concerns of the patient and family by interacting with community resources on behalf of and for the greatest benefit of the patient.
- As a result of collaboration with team members, **follow-up plans** can be adjusted according to the patient's unique circumstances. With the social worker's knowledge of the patient's functioning from the ecological perspective, this assessment can be of great help to the rest of the team.

The various benefits of teamwork also set obligations for the team members to work together effectively.

2.3.1.3 General requirements for teamwork

Ross (1995:1373) referred to the requirements for effective teamwork by emphasising the following factors:

- First, a thorough **knowledge** of the patient's **medical condition** and the **implications** of this medical diagnosis for patients and their families will be necessary. This is in line with the aim of this chapter, as the medical aspects of this diagnosis and treatment of cancer of the larynx will be presented in the next section of this chapter. The psycho-social aspects of this medical condition will be described in chapter three.
- Second, each team member needs to have **appreciation** and **respect** for the skills and viewpoints of other team members, as they act from their specific frame of reference. Third, each team member should be aware of his or her own **skills** and **limitations**.

Knowledge of the requirements of effective teamwork will also result in an awareness of potential obstacles in effective teamwork.

2.3.1.4 Potential obstacles in teamwork

Ross (1995:1373) mentioned potential problems encountered by team members due to role blurring between team members; role rigidity; extension of roles beyond disciplinary boundaries; unrealistic expectations of colleagues or inability of team members to find common ground. An awareness of the potential obstacles in teamwork will empower the social worker with knowledge to enhance service-delivery to the patient and his relatives.

2.3.1.5 Integration of social work into health care

The role of the social worker as part of the multi-disciplinary team rendering health care services to the patient within a hospital setting will now be described.

Ross (1995:1366) mentioned the interaction and interwoven process between **health problems** and **social factors** where the one can be identified as a causal factor to the other. However, aspects of the illness, diagnosis, treatment (excision of the cancer lesion) and cure of the patient and improvement of his prognosis will always remain the main focus of care (Ross, 1995:1367; Zeine & Larson, 1999:51). In the

past there was a tendency to underemphasise the patient's experience of the effect of the illness on daily life and the necessary adjustments that needed to be made during the illness and prescribed medical treatment.

This tendency has changed since the integration of social work into medical care (Ross, 1995:1367). The medical viewpoint in medical care is integrated within a psycho-social model. Zeine and Larson (1999:52) acknowledged that awareness of the patient's psycho-social adjustments after surgery and rehabilitation was increasing. This implies that besides having a medical history, the patient was now being viewed as also having a personal history. Strengths and limitations of the patient were being assessed and taken into account. This agrees with the strengths perspective, which acknowledges the strengths of every person (Sheafor *et al.*, 2000:93).

Psychological, environmental and social circumstances of people were regarded by Ross (1995:1366) as being equally important as medical issues in determining the patient's and his family members' overall rehabilitation. The circumstances referred to, will determine the patient's reactions towards illness and medical treatment; ability to adjust to chronic or disabling health conditions; return to a former level of functioning and the patient's adaptation to limitations caused by the disease and medical treatment.

Against the background of the effective functioning of teamwork within the hospital setting in general, the following section will describe social work intervention to address the needs of the laryngectomy patient and family members.

2.3.2 Social work intervention services to laryngectomy patient from a team approach

In this section the role of the social worker with specific regard to the laryngectomy patient will be described. Focus will be on the need for teamwork; the value of teamwork to address the needs; the role of the social worker in rendering aftercare support services to the laryngectomy patient; the aim of social work intervention services to the laryngectomy patient and future agenda to improve social work

services to these patients. Within the context of this study, the social worker will be referred to in the female form as the researcher herself is female.

2.3.2.1 The need for teamwork

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). The teamwork model ties in well with the **ecological perspective** as described by Ross (1995:1367), acknowledging the various systems in which the patient functions.

Working in this **specialised field** of rendering services to the laryngectomy patient, involves a high level of teamwork. Team members such as medical personnel, nursing staff, speech-language therapists and social workers are being integrated in this multi-disciplinary team model. Dhooper (1985:225) advocated a **close working relationship** among multi-disciplinary team members and various community resources to best meet the needs of the laryngectomy patient.

Within the context of the multi-disciplinary team approach it can be concluded that the social worker can play a key role to add to the value of the team approach.

2.3.2.2 The value of the team approach

Dhooper (1985:225) referred to the value of the multi-disciplinary team approach as "the key to good care and treatment" to render services to the laryngectomy patient by involving various team members. For Ross (2000:22) the value of teamwork can be seen as the best possible way of dealing with the pre- and post-operative **counselling needs** of the patient. Each team member emphasises a **different aspect** of the patient's functioning from his or her individual and specialist frame of reference. Ultimately, the value of teamwork with people with an acquired communication disorder can be seen to determine a person's **rehabilitation**, according to Code, Müller, Hogan and Herrmann (1999:205).

The value of teamwork is important, taking into account the patient's need for rehabilitation which continues even after his discharge from hospital.

2.3.2.3 The role of the social worker as a team member

Kaplan and Hurley (1979:57) were of the opinion that the laryngectomy patient needs to be assisted in dealing with “planned and unplanned events” which may arise during his illness and even after the patient **has left** the hospital system. Although literature referred to the participation of various disciplines working together towards the patient’s care and rehabilitation, Dhooper (1985:225) remarked that only a few included the role of the social worker in their frame of reference.

The role of the social worker as team member can be seen as constituting a valuable contribution towards the laryngectomy patient’s **rehabilitation needs**, as the social worker serves the needs of the patient and family members (Casper & Colton, 1998:50). Ideally, this role of the social worker should start with the patient’s **first visit** to the hospital. According to Dhooper (1985:220), time can then be spent to address **issues** otherwise being ignored (Casper & Colton, 1998:50), such as psychological, social and economic help in order to cope with the medical diagnosis and treatment. The applicable information and assurance of continuing assistance can also be offered at that time (Casper & Colton, 1998:50-51). Dhooper’s (1985:220-225) view of the role of the social worker as team member is to enable the patient and family to cope with the effects during the different stages of the disease, namely after diagnosis, during treatment (before surgery, after surgery, discharge planning), remission and recurrence of the disease and death.

The value of social work intervention to the laryngectomy patient is based on the **capacities** of the social worker as professional team member (Casper & Colton, 1998:50-51; Dhooper, 1985:225; Kaplan & Hurley, 1979:53; Kleinsasser, 1988:258; Ross, 1995:1371-1372). These capacities of the social worker will be based on the following characteristics of the social work profession:

- The social worker is in contact with both the **patient** and his **family** during the process of treatment and even after discharge from hospital. Besides this, the social worker also has the ability to **mediate** between the patient and family members when they experience differences in needs and expectations.
- The social worker has the expertise and is well positioned to assist the patient and his family to cope with the **psycho-social implications** following a

laryngectomy (which will be discussed in chapter 3). This is possible due to the capacity of the social worker to assist the patient and family to form an understanding of the psycho-social implications of the operation and to serve the needs of the patient and his relatives. The social worker also empowers them to cope with feelings and reactions by using available **sources**. The social worker has **expert specialised skills** to address problem situations the patient or his relatives may experience.

- Within the context of the ecological perspective, the social worker is in an ideal position to fulfil her role as coordinator of services, bringing together patients' needs and available resources. The social worker has **expert knowledge** of available **community resources** from which the patient may benefit. Ross (1995:1371-1372) referred to this coordination function as "to bring people, services and resources together on behalf of the patient", to form a link between the patient and available resources. This is in line with the ecological perspective as described by Ross (1995:1367), as the boundaries between various systems are bridged during the social worker's outreach to community resources.
- The social worker has the ability to provide the necessary **support** for family and friends of the patient, as will be discussed in chapter 4.

From the above information it is clear that social workers as professionals, operating within the context of a team approach in the hospital setting, are well equipped with specialised knowledge and interpersonal skills. Social workers are extremely well positioned to adequately address the needs of the laryngectomy patient and his family. However, intense involvement in the field of oncology will be required by social workers to effectively meet the laryngectomy patient's needs.

2.3.2.4 Aim of service delivery by the team approach

The aim of service delivery towards the laryngectomy patient from a multi-disciplinary approach is to prevent or reduce the physical (cosmetic or functional) disability and emotional effect (Casper & Colton, 1998:52) of the disease and its treatment and to enable the patient to return to his "former life style and routine with a means of communication that satisfactorily fulfils social, emotional and vocational needs". In other words, the laryngectomy patient and his family can benefit from this team

approach that attempts to reduce the physical and psycho-social impact of the disease and its treatment.

2.3.2.5 *Future agenda for social work services*

Dhooper (1985:225-226) recommended that social workers in future widen their spectrum of work in order to change society's attitudes and behaviour towards the laryngectomy patient. This change in attitude is needed as statistics indicate an increasing number of younger patients diagnosed with larynx cancer. By increasing the public's knowledge and sensitivity, it may have a positive impact on the social and employment handicaps the laryngectomy patient presently experiences.

Taking into account the value of teamwork within a hospital setting from a general viewpoint and also with specific reference to the needs of the laryngectomy patient, it is of the utmost importance for the social worker to have a thorough knowledge of the medical aspects of this operation.

2.4 MEDICAL ASPECTS OF LARYNGECTOMY

This section will describe the medical aspects of laryngeal cancer where a laryngectomy as medical treatment for these patients is indicated.

2.4.1 Medical background

The first total laryngectomy was performed by Theodore Billroth in 1873 (Kleinsasser, 1988:190; Ross, 2000:14; Silver & Ferlito, 1996:159; Stell, 1991:212; Wei & Sham, 2000:26). Due to improvement of surgical and anaesthetic techniques (Wei & Sham, 2000:26), this operation became more common. Total laryngectomy, as surgical treatment, was not widely performed for many decades (Silver & Ferlito, 1996:159). In addition, radiotherapy was frequently used in the first half of the twentieth century to achieve beneficial results. For thirty years (1920 to 1950) radiotherapy was the preferred treatment option for an advanced or recurrent cancer (Stell, 1991:212).

With the recognition of the potential limitations of radiotherapy, surgical treatment of patients who present with diagnoses of larynx cancer continues to play an important role (Wei & Sham, 2000:26). It was during the 1950s that surgery became essential

treatment for patients who present with an advanced stage or recurrence of larynx cancer (Stell, 1991:212).

Trends in the treatment of larynx cancer can be classified into different time periods at forty-year intervals (Doyle, 1994:2-3). These changes in the treatment of patients who present with larynx cancer, are based on the following motivations:

- Additional and more selective treatment options were used as the diagnosis and treatment of larynx cancer have been developed and refined.
- A better understanding of the induction, spread and management of the malignancy was developed.
- Recognition of additional factors other than medical factors began to stimulate the underlying perspectives of treatment, such as the multi-disciplinary team approach.

The period 1950 to 1980 was described as one of “rapid development in medical science”, which is according to Doyle (1994:2), still developing.

Taking into account the medical history leading to a total laryngectomy as surgical treatment for a diagnosis of larynx cancer, it is obvious that this procedure developed rapidly during the past five to six decades. A discussion of the etiological factors and incidence of this diagnosis will now be presented in order to add to the social worker’s understanding of the implications of this medical diagnosis.

2.4.2 Etiology

A **combination** of **severe smoking** and **alcohol use** are contributing factors to cancer of the head and neck area, including larynx cancer (Byrne, Walsh, Farrelly & O’Driscoll, 1993:174; Depondt & Gehanno, 1995:33; Doyle, 1994:17; Stam, Koopmans & Mathieson, 1991:44; Terrell, Ronis, Fowler, Bradford, Chepeha, Prince, Teknos, Wolf & Duffy, 2004:402). These factors can be seen as the major risk factors of head and neck cancer (Depondt & Gehanno, 1995:33; Terrell *et al.*, 2004:402). Casper and Colton (1998:6) found that the amount and duration of one’s smoking habit (cigarettes, pipes, and cigars) are directly related to the etiology of larynx cancer. Terrell, Fisher and Wolf (1998:970) pointed out that these can be regarded as independent risk factors because “combined it has a synergistic or multiplicative

effect rather than an additive effect". Continued smoking and drinking, following the initial diagnosis of head and neck cancer, may increase the likelihood of developing a second malignancy, with a negative effect on the patient's **survival** (Jay, Ruddy & Cullen, 1991:937; Terrell *et al.*, 1998:970).

Occupational exposure to various environmental factors such as asbestos and chemical air pollution (Casper & Colton, 1998:7; Dhooper, 1985:218; Doyle, 1994:17; Ross, 2000:13), which may interact with a person's biological structure, can increase the incidence of cancer. This process is not yet well understood. Causal factors often act **in combination** with each other; therefore it is difficult to identify a single etiological factor as causing a particular cancer (Doyle, 1994:17).

Of relevance to the social worker, is that etiological factors of larynx cancer can mostly be linked with social factors, such as substance abuse (heavy smoking and drinking) and in some cases, occupational exposure. The presence of these factors can easily be linked with the role of the social worker in preventative care.

2.4.3 Incidence of cancer of the larynx

Groups at the greatest risk of getting larynx cancer appear to be **male smokers** between the age of 45 and 75 years (Casper & Colton, 1998:7; Dhooper, 1985:217; Ross, 2000:13). The disease usually occurs in **late middle age** (retirement) and can therefore be seen as a disease of the elderly (Belch & Beamish, 1992:61; Deshmane *et al.*, 1995:121; Frith, Buffalo & Montague, 1985:476; Renner, 1995:216; Ross, 2000:14). Doyle (1994:14) held the same view but indicated that adult men are not the only group at risk. This pattern is undergoing a change as an increasing number of **women** and **younger** persons are presently being diagnosed with cancer of the larynx (Depondt & Gehanno, 1995:33; Eadie & Doyle, 2005:122; Renner, 1995:216; Ross, 2000:13; Smithwick, Davis, Dancer, Hicks & Montague, 2002:206). Increased **tobacco consumption** by these target groups of patients is seen as the reason for this pattern change (Depondt & Gehanno, 1995:33; Dhooper, 1985:217; Smithwick *et al.*, 2002:206). In addition to tobacco consumption, a change in **smoking and drinking** behaviour of women can also be regarded as a cause of this changing pattern (Dhooper, 1985:217; Doyle, 1994:16).

Cancer of the larynx is the most prevalent malignancy of head and neck cancer diagnoses (Hammerlid, Mercke, Sullivan & Westin, 1998:747; Müller, Paneff, Köllner & Koch, 2001:276). During 1998 to 1999 cancer of the larynx was described as the tenth most common cancer diagnosis among South African males (NCR, 2004:14). The age group most at risk was between 55 and 64 years (NCR, 2004:16).

Information regarding the etiology and incidence of cancer of the larynx creates a clear understanding of the group most at risk for being diagnosed with cancer of the larynx. From the above-mentioned information it can be concluded that elderly males are most at risk. However, social factors such as substance abuse have resulted in a changed tendency. Females and younger persons are now at greater risk for being diagnosed with larynx cancer. In the past, the social worker had to take into account the needs of elderly patients and their relatives when rendering services to laryngectomy patients. In future, it is obvious that the patient and relatives of a younger age group will be targeted for inclusion during social work intervention.

2.4.4 Demographic trends

According to the latest statistics collated by the SA National Cancer Registry (NCR) for the time period 1998 to 1999:

- South African **males** have a lifetime risk of one in four of developing cancer, whilst the **females'** risk is one in six (NCR, 2004:v).
- The numbers of **new cases** of larynx cancer observed were respectively 622 (NCR, 2004:88) and 124 (NCR, 2004:87) for male and female patients during 1999. The majority of these cases were from the **Black population** for both male and female patients (NCR, 2004:91-92). This was followed by White (NCR, 2004:95-96), Coloured (NCR, 2004:93-94) and Asian (2004:89-90) population groups.

The NCR statistics for 1998 to 1999 confirmed the previously mentioned assumption that males are at greater risk for being diagnosed with cancer in general and also specifically with cancer of the larynx, than females.

2.4.5 Social trends

Besides substance abuse, other social characteristics such as low **socio-economic status**, low levels of **education** and a generally **poor social network** are prevalent among patients presenting with cancer of the head and neck area (Eadie & Doyle, 2005:120).

Taking into account the statements in literature that the majority of patients who present with a diagnosis of cancer of the head and neck region have a poor social network, the need for a **team approach** to expand available aftercare and support offered to these patients and their families is clear. It is within this context that the social worker can plan for appropriate aftercare and support services.

As discussed earlier, a person's social habits, in combination with his level of social functioning, can be causal factors to the diagnosis of larynx cancer. In the subsequent section, medical management of the patient will be outlined and discussed. It is essential for the social worker to have a good understanding and knowledge of the patient's medical treatment. A brief description of the medical management of the patient is subsequently given.

2.4.6 Indication for total laryngectomy

Laryngectomy is a surgical procedure in which the total or partial larynx is removed (Devins, Stam & Koopmans, 1994:608; Killarney & Lass, 1979:34; Ross, 2000:14; Smithwick *et al.*, 2002:204; Stam *et al.*, 1991:38). This procedure is usually indicated in the presence of a **cancer diagnosis** of the **larynx** or **hypopharynx** (oesophageal) (Depondt & Gehanno, 1995:34; Karamzadeh & Armstrong, 2001:528; Schuster *et al.*, 2003:212; Lennie, Christman & Jadack, 2001:668; Relic, Mazemda, Arens, Koller & Glanz, 2001:514). On rare occasions, severe laryngeal **trauma**, without the presence of a malignant tumour, may require a laryngectomy as medical treatment (Casper & Colton, 1998:2).

A total laryngectomy is described in literature as a primary, traditional or definitive form of treatment indicated in the following situations (Eadie & Doyle, 2004:753; Karamzadeh & Armstrong, 2001:528; Stewart, Chen & Stach, 1998:143):

- 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, Sherman, Cash, Adams, Vural, Fan & Suen, 2004:875; Kleinsasser, 1988:191; Lotempio, Wang, Sadeghi, Delacure, Juillard & Wang, 2005:948; Relic *et al.*, 2001:515; Schuster *et al.*, 2003:212; Silver & Ferlito, 1996:179).
- **Recurrent** diagnosis of cancer (Finizia, Hammerlid, Westin & Lindström, 1998:1567; Kleinsasser, 1988:191; Maas, 1991:1373; Stell, 1991:212). Jay *et al.* (1991:937) and Kleinsasser (1988:191) specifically referred to recurrence of the disease after previous radiotherapy treatment or partial resection.

Within the context of this research study, a total laryngectomy as treatment for an advanced stage of cancer or recurrence of the disease will be described. Knowledge of the symptoms preceding diagnoses of cancer of the larynx or hypopharynx will be required to successfully diagnose and treat the patient. The psychological effect of the diagnosis of cancer upon the patient and his family will be discussed briefly in the following chapter.

2.4.7 Presenting symptoms of larynx cancer

Persistent hoarseness is described as the most frequent presenting symptom of laryngeal cancer (Dhooper, 1985:218; Hammerlid *et al.*, 1998:747; Wei & Sham, 2000:56). Changes in either the **voice** or **breathing** can also be symptoms of laryngeal tumours (Doyle, 1994:18).

As hoarseness is a presenting symptom even with a small tumour, it is possible to diagnose a laryngeal cancer at an early stage (Hammerlid *et al.*, 1998:747). Symptoms of larynx cancer (like hoarseness) may relate to a variety of other upper respiratory abnormalities, for example: having a cold, flu or respiratory difficulties due to seasonal changes or allergies (Dhooper, 1985:218; Doyle, 1994:18). Treatment of these symptoms with home remedies may result in patients not being prepared for a possible diagnosis of cancer (Dhooper, 1985:218). Other presenting symptoms of larynx cancer are **pain**, **swallowing** problems, **swelling** in the neck or **haemoptysis** (Dhooper, 1985:218).

From a preventative perspective, the patient and his relatives need to be aware of these presenting symptoms in order to receive medical treatment in time, as timeous treatment has the potential to affect the patient's prognosis. In turn, the patient's prognosis will affect his social functioning within the family system.

A clear understanding of the indications for a total laryngectomy is necessary in order to understand the various treatment modalities. The social worker who renders services to the laryngectomy patient needs to be equipped with applicable medical information regarding this medical diagnosis. This will contribute to a better understanding of the psycho-social implications of this operation which will be discussed in the following chapter.

2.4.8 Treatment modalities

A **variety of factors** determine the selection of treatment options whereas the **size** and **stage** of the tumour mostly determine the preferable treatment option (Dhooper, 1985:217; Maas, 1991:1373). In addition to the size and stage of the tumour, Keith and Darley (1986:293) recommended that the selection of a treatment option should be **individualised**. Additional factors should be taken into account such as the **type and location** of the tumour, presence or absence of regional **nodes** and the patient's **general health condition** (Casper & Colton, 1998:1-2; Lennie *et al.*, 2001:668; Wei & Sham, 2000:31). Social and emotional factors, together with medical factors of patients should be considered when deciding on treatment (Silver & Ferlito, 1996:161).

Keith and Darley (1986:293) also referred to **social factors** as determining the choice of a treatment option, for example: the distance between treatment facilities and the patient's home, the likelihood of attending follow-up visits, and the patient's occupation. **Personal factors** such as the patient's preference for a specific treatment option may also influence the selection of treatment. Keith and Darley (1986:293) concluded that any form of conventional treatment may be used, based on an estimation of the probability of success and by taking the above-mentioned factors into consideration.

Treatment for advanced laryngeal cancer usually involves surgery, radiotherapy or chemotherapy (Kaplan & Hurley, 1979:51; Kleinsasser, 1988:259; Lennie *et al.*, 2001:667-668; Lotempio *et al.*, 2005:948; Stewart *et al.*, 1998:143) or a combination of these treatment options. The choice of treatment can be motivated as follows:

2.4.8.1 Surgery

Surgery alone or in combination with radiotherapy or chemotherapy is the most common treatment option for tumours that cannot be cured by radiotherapy alone. The extent of surgery is determined by both the **stage and location** of the lesion (Lennie *et al.*, 2001:668). Casper and Colton (1998:1-2) stated that the invasiveness and spread of the tumour will determine the extent of surgery.

Except for a total laryngectomy, other forms of surgery for patients with a diagnosis of larynx cancer may include laser surgery or a partial laryngectomy (Lennie *et al.*, 2001:668). In these cases, the patient will have normal or hoarsened speech without the presence of a stoma (Maas, 1991:1373). As the focus of the study will be upon the laryngectomy patient's need for social support, a description of a total laryngectomy will follow.

(a) Total laryngectomy

A total laryngectomy is indicated when an advanced or recurrent stage of cancer of the larynx or hypopharynx has been diagnosed and the larynx must be totally excised. The trachea is externalised at the base of the neck via a permanent stoma through which the patient will breathe and cough. This results in complete disconnection of the trachea and oro- and nasopharynx. Breathing is therefore exclusively through the stoma and not through the nose and mouth as prior to surgery (Lennie *et al.*, 2001:668). This is illustrated in figure 2.2 which shows the surgical removal of the larynx before and after surgery.

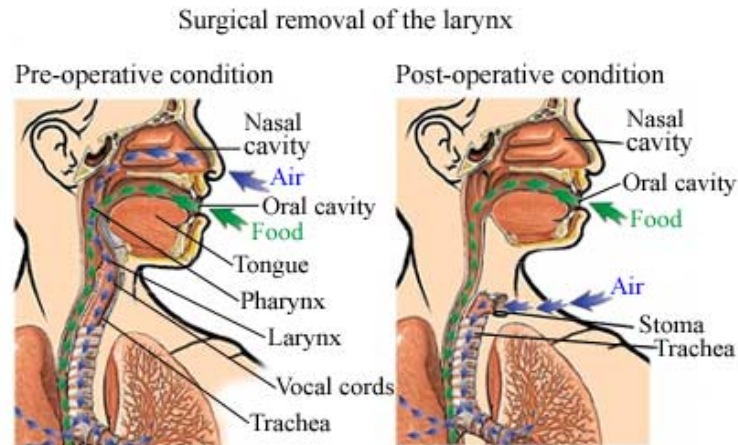


Figure 2.2: Surgical removal of the larynx (pre- and post-surgery)

[Source: "Laryngectomy" 2005. [http://catalog.nucleusinc.com/images/matl/thumbs; 94\(9445.jpg\)](http://catalog.nucleusinc.com/images/matl/thumbs; 94(9445.jpg))]

(b) Radical neck dissection

In cases of more advanced cancer diagnoses, a radical neck dissection may also be required. It may be necessary to remove adjacent structures if also infiltrated by cancer (Lennie *et al.*, 2001:668). As a result of a radical neck dissection, the patient may experience pain and limitation of movement of the shoulder due to the fact that the nerve that controls the shoulder is removed during surgery (Dhooper, 1985:218). This will have an effect on the patient's future working ability which will affect the social worker's service delivery.

2.4.8.2 Radiotherapy

Radiotherapy is indicated as primary treatment when the tumour is **small** and minimally invasive or **restricted** to the vocal cords (Lennie *et al.*, 2001:667; Maas, 1991:1373). Radiotherapy can also be used in combination with surgery. Long-term consequences of radiotherapy treatment may include dryness of the mouth and a decreased sense of taste as the salivary glands and taste buds will be affected (Lennie *et al.*, 2001:667). With radiotherapy, the patient will retain his normal voice.

In conclusion to the discussion of selection of the treatment option for patients with larynx cancer, Lotempio *et al.* (2005:948) remarked that treatment modalities for a diagnosis of advanced larynx cancer had changed significantly over the past ten years. Current treatment protocols usually involve either chemotherapy with radiation or total laryngectomy with post-operative radiotherapy.

The previous discussion of the various treatment options of the patient presenting with laryngeal cancer contributes to the social worker's knowledge and understanding of these patients. Knowledge about the prognosis of treatment is necessary in order to plan adequately for services to the laryngectomy patient.

The social worker needs to have an understanding of the implications of the various treatment modalities for patients and families, as each treatment modality will affect the patient's social functioning. These implications will be described in the next chapter.

2.4.9 Outcome of laryngectomy

Treatment of larynx cancer is widely described in the literature as having a **favourable** outcome and as a **highly curable** disease (Desanto, Olsen, Perry, Rohe & Keith, 1995:763; Dhooper, 1985:217; Frith *et al.*, 1985:475; Mathieson, Stam & Scott, 1991:153; Wei & Sham, 2000:31). Silver and Ferlito (1996:179) described this procedure as the best chance for cure for a specific stage of the disease. A total laryngectomy is an effective and often optimal treatment and is the only option for an advanced stage of laryngeal or hypopharyngeal cancer with a **life-saving** effect (Relic *et al.*, 2001:514; Silver & Ferlito, 1996:179).

Factors determining an optimistic prognosis for diagnoses of cancer of the larynx are:

- Treatment at an **early stage** of the disease (Dhooper, 1985:217; Mathieson *et al.*, 1991:153; Stam *et al.*, 1991:38).
- **No** nodal or distant **metastases** are present (DeSanto *et al.*, 1995:763).
- **Advances in treatment modalities** such as progress in surgery and radiotherapy including advances in medical, surgical and associated medical health care services (Belch & Beamish, 1992:60; Depondt & Gehanno, 1995:33; Richardson & Bourque, 1985:84).
- The presence of **close cooperation** between the patient and team members (Wei & Sham, 2000:31).

The main objective of cancer treatment is to **cure** the patient of disease (Relic *et al.*, 2001:514). Preservation of function is considered secondary to the cure of the patient

(Wei & Sham, 2000:31). Schuster *et al.* (2003:212) pointed out that total laryngectomy is the **only adequate form of curative treatment** in many cases of advanced laryngeal and hypopharynx cancer. In some cases, surgery alone will be sufficient for optimal treatment of larynx cancer patients. However, in cases of advanced larynx cancer diagnosis, a combination of surgery and radiotherapy will be necessary to offer the best possible cure rate (Dhooper, 1985:217).

Although this operation is mostly indicated for patients who present with an advanced stage of disease, a favourable prognosis is expected. It is for this reason that team members need to turn their focus towards comprehensive and effective rehabilitation efforts.

2.5 CONCLUSION

This chapter described aspects concerning the medical setting as a system wherein these patients function and thus meets the first objective of this study, describing the unique context of the hospital setting wherein the social worker functions as part of the multi-disciplinary team rendering services to laryngectomy patients.

First, the unique context of the **hospital setting** which places unique demands on professionals dealing with the special needs of these patients was described. Specialised knowledge and skills are required. Care and support must be continued even after patients are discharged from hospital. This can be achieved by regular attendance at the hospital **follow-up clinic**.

Second, the **multi-disciplinary team** approach was described as it can best address various needs of the patient. **Social work** intervention with laryngectomy patients from a multi-disciplinary perspective was described, as social workers are equipped with the necessary specialised knowledge and skills.

Finally, the **medical aspects** of larynx cancer were discussed as it is important to gain a better understanding of the medical aspects of the diagnosis and treatment of these patients in order to gain a better understanding of their needs.

In the following chapter the psycho-social implications of a laryngectomy for patients and families will be described from an ecological perspective.

CHAPTER 3

PSYCHO-SOCIAL EFFECTS OF A LARYNGECTOMY FROM AN ECOLOGICAL PERSPECTIVE

3.1 INTRODUCTION

An understanding of the medical aspects of a laryngectomy is essential in order to realise what comprehensive impact this surgical procedure could have on both the patient and his family. A laryngectomy potentially holds major psycho-social implications for the patient and family, as it interrupts some of the most basic and vital human functions, such as breathing, swallowing and speaking. To meet the second objective of the research study, a description from an ecological perspective of the psycho-social implications of a laryngectomy for the patient and his family will follow.

To contextualise the study a description of the ecological perspective within a social work framework will be presented first. In the second part of the chapter the concept of quality of life will be discussed. The last part will give an overview of the comprehensive impact of a laryngectomy, referring to the **physical**, **social** and **psychological** effect of this procedure.

3.2 ECOLOGICAL PERSPECTIVE

This section presents a description of the ecological perspective as theoretical framework in social work practice. It will be followed by a description of the benefits of the implementation of this specific perspective.

Ecology refers to the concept of the person in his environment and in relation to his environment as described by Germain and Gitterman (1996:5), Meyer and Mattaini (1995:16) and Sheafor *et al.* (2000:91), and may include biological and physical aspects (Sheafor *et al.*, 2000:91).

An explanation of the ecological perspective will contribute to a better understanding of the various ways in which the client system may adapt to a changing environment.

Concepts of interdependence, exchange and interrelatedness are of importance. This is especially applicable in the case of the laryngectomy patient who has to adapt to a new and changed lifestyle. The ability to adapt to change is essential in order to cope, survive or compete for needed resources (Sheafor *et al.*, 2000:91). It is also helpful to understand the relationship or interaction between and among people and their physical and social environment as influence among individuals, families, groups, physical or social environments occurs continuously (Germain & Gitterman, 1996:6). People shape their environment and are shaped by their environment, therefore Sheafor *et al.* (2000:92) emphasised that personality or environmental factors cannot be seen as the only factors creating problems in social functioning, but rather people-environment interaction.

The ecological perspective can assist the social worker to focus on the person in his environment (Germain & Gitterman, 1996:5; Meyer & Mattaini, 1995:16; Sheafor *et al.*, 2000:91). This perspective describes the psycho-social aspects of functioning of individuals, families, groups and communities (Meyer & Mattaini, 1995:16). In the current research project, the laryngectomy patient's interaction with the various systems he relates to will be described.

3.3 CONCEPT OF QUALITY OF LIFE

Using as point of departure the ecological perspective in social work practice, the following section will concentrate on a discussion of the concept of quality of life and how this may be affected when a total laryngectomy is performed. Following this discussion, the comprehensive impact of a laryngectomy will be described. This ties in well with the ecological perspective, as it describes the person who is in constant interaction with his environment, trying to adapt to changed situations (Sheafor *et al.*, 2000:91).

3.3.1 Current trends in observing quality of life

In the field of oncology, there is currently an **increasing awareness** of quality of life aspects when measuring results of cancer treatment (Birkhaug *et al.*, 2002:197; Hammerlid *et al.*, 1998:747; Schuster *et al.*, 2003:212; Vigili, Colacci, Magrini, Cerro & Marzetti, 2002:11, 13). This is in contrast with **traditional** medical practice, where medical aspects (survival, cure, complication rate) receive the main focus of

treatment in cancer care (Lee-Preston, Steen, Dear, Kelly, Welch, Meikle, Stafford & Wilson, 2004:432; Otto, Dobie, Lawrence & Sakai, 1997:693). **Recently** and specifically during the past two decades quality of life dimensions have been forming an integral part of assessing the outcome of cancer treatment (Birkhaug *et al.*, 2002:197; Hanna *et al.*, 2004:877; Schuster *et al.*, 2003:212; Schuster, Lohscheller, Hoppe, Kummer, Eysholdt & Rosanowski, 2004:62).

Advances and progress in medical, surgical and health care services improved the patient's prognosis and made **issues other than survival** important (Belch & Beamish, 1992:60; Blanchard, 1982:233; DeSanto *et al.*, 1995:763; Hilgers, Ackerstaff, Aaronson, Schouwenburg & Van Zandwijk, 1990:425; Stam *et al.*, 1991:38). Quality of life issues describe the **multi-dimensional aspects** of medical treatment and its implication for the patient which is seen as being equally important as medical treatment issues (Hammerlid *et al.*, 1998:747; Op de Coul, Ackerstaff, Van As, Van den Hoogen, Meeuwis, Manni & Hilgers, 2005:169). When there is a choice between treatment options with the same curable rate, the choice will be the one that offers the best quality of life outcome (Birkhaug *et al.*, 2002:197; Lee-Preston *et al.*, 2004:432; Terrell *et al.*, 2004:401).

The above shows that there has been a shift from a solely medical model to a model that now includes the multi-dimensional and the patient's subjective interpretation of treatment results.

3.3.2 Definition of quality of life

A definition of the concept of quality of life is needed when describing the multi-dimensional and subjective nature of this term. It is **difficult** to define this concept, as the definition is **broad** and quality of life can be seen as a **dynamic** process (Graham, 2004:128; Jones, Lund, Howard, Greenberg & McCarthy, 1992:238; Lotempio *et al.*, 2005:949).

Graham (2004:128) and Herranz and Gavilán (1999:990) described the two main characteristics of quality of life as multi-dimensional and subjective. **Multi-dimensional** characteristics of the concept of quality of life refer to various levels of

functioning of the person that may be affected (Birkhaug *et al.*, 2002:197; Eadie & Doyle, 2005:115; Graham, 2004:128; Ramírez, Ferriol, Doménech, Llatas, Suárez-Varela & Martínez, 2003:95; Vigili *et al.*, 2002:11). The effect of treatment can best be described by the patient from an individual and **subjective** perspective because of his own experience (Birkhaug *et al.*, 2002:197; Graham, 2004:128; Ramírez *et al.*, 2003:95; Schuster *et al.*, 2004:63; Vilaseca, Chen & Backscheider, 2006:314).

Graham (2004:128) and Morton (1997:244) described the concept of quality of life to be representative of the gap between the patient's current functional and ideal level of functioning. This will be representative of the aspects that have changed since the operation by looking at what the patient has, what he wants and expects compared to what the patient had pre-operatively. Quality of life serves as a description of a patient's experiences of the disease or degree of satisfaction and well-being on a daily basis (Lotempio *et al.*, 2005:949; Schuster *et al.*, 2004:63).

In other words, after surgery the laryngectomy patient will experience a difference between his former and present or future level of functioning. In order to best describe this impairment in functioning, it is necessary to have a close look at the multi-dimensional aspects of the concept of quality of life.

3.3.3 Multi-dimensional aspects of quality of life

A comprehensive definition will include the following multi-dimensional aspects of functioning, namely a **physical, social and psychological** level of functioning (Eadie & Doyle, 2005:115; Graham, 2004:128-129; Hanna *et al.*, 2004:877; Lee-Preston *et al.*, 2004:432; Lotempio *et al.*, 2005:949; Schuster *et al.*, 2004:62). This will be in line with the definition of the comprehensive impact of a laryngectomy upon the patient and his family as will be described in the following section.

3.4 COMPREHENSIVE IMPACT OF A LARYNGECTOMY

Literature (Byrne *et al.*, 1993:173; Eadie & Doyle, 2004:753; Eadie & Doyle, 2005:115-116; Graham, 2004:125-126; Zeine & Larson, 1999:52) referred to a combination of the **physical, social and psychological** effects of a laryngectomy in order to describe the comprehensive impact of surgery on the patient's functioning.

Murrills (1975:514) and Relic *et al.* (2001:514) summarised this impact of a laryngectomy on a patient's life by noting that all aspects of daily life are affected "... and the patient experiences the sum of these impairments".

A laryngectomy is described as an **uncommon operation** which has a great or strong impact on a person's life (Byrne *et al.*, 1993:174; Relic *et al.*, 2001:514; Sewnaik, Van den Brink, Wieringa, Meeuwis & Kerrebijn, 2005:95). This operation is seen as a life-saving procedure in the treatment of larynx cancer where the comprehensive impact of the operation is mainly due to implications which will be experienced as disfiguring and on a permanent basis (Carr, Schmidbauer, Majaess & Smith, 2000:39; Relic *et al.*, 2001:514).

Many adjustments occur after surgery (Meyer, Kuhn, Campbell, Marbella, Myers & Layde, 2004:1981), as it heavily disrupts the patient's **basic** and **crucial** functioning in all aspects of daily life. Patients may experience impairment of their ability to perform normal activities like **breathing**, **swallowing** and **speaking** (Herranz & Gavilán, 1999:993; List, Ritter-Sterr, Baker, Colangelo, Matz, Pauloski & Logemann, 1996:1; Ramírez *et al.*, 2003:95; Relic *et al.*, 2001:514; Sewnaik *et al.*, 2005:95).

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 on quality of life for these patients. They were respectively requested to identify their ratings in sequence of importance for patients' daily functioning. The findings of the study showed a **difference** in the **patients'** and **health care workers' assessments** of the potential impact of a laryngectomy on quality of life, as patients ranked the following sequence: physical consequences; interference with social activities; disturbance with communication; lifestyle changes, followed by a change in functional status. Health care workers rated the potential impact on the patient's functioning in the following sequence: impairment in communication; effect on self-image and self-concept; cancer control; physical consequences; interference with social activities followed by vocational functioning. The effect of a laryngectomy on the patient's quality of life as described by the patient himself, who has personal experience, is real. This differs from the health care worker's perception of the

patient's experience of a laryngectomy, which emphasises the importance of viewing the patient's perception of his experience.

The comprehensive impact of surgery (laryngectomy) referred to, is in accordance with the definition of the concept of quality of life which has a **physical**, **social** and **psychological** impact, where the latter refers to various experiences of change or disturbance the patient has to deal with. Figure 3.1 illustrates the correspondence between the comprehensive effects of surgery and the definition of quality of life.

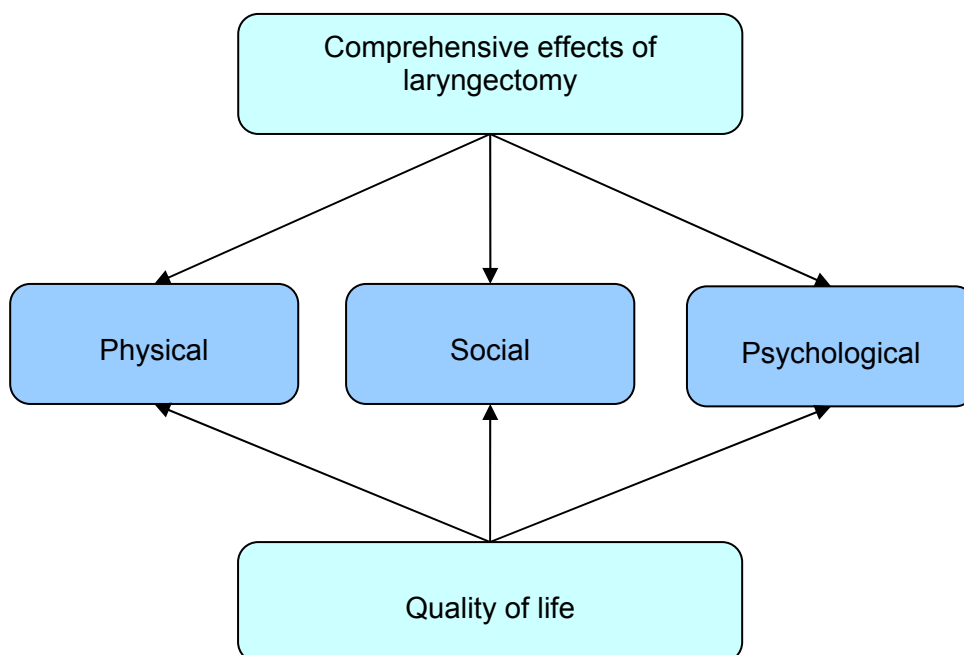


Figure 3.1: The comprehensive effects of a laryngectomy versus multi-dimensional aspects of quality of life

As illustrated in figure 3.1, this study will use Ross's (2000:15) model to describe the effect of a laryngectomy on the patient's and family's most important areas of functioning, namely: **physical**, **familial**, **social**, **occupational**, **economic** and **psychological** functioning. For the purpose of this study familial and social impact of surgery will be combined and will be discussed under the comprehensive term of **social** impact.

3.4.1 Physical impact

In order to gain a better understanding of the comprehensive effect of a laryngectomy on the life of the patient and his family, it is important to first gain a better understanding of the **physical implications** resulting from this operation. Focus will be on problems that the patient may experience regarding his **respiratory**, **swallowing** and **sensory** functions. Impairment of the patient's sphincter function and problems relating to ageing and previous lifestyle will also be looked at. A discussion of the influence of surgery upon the patient's **speech** will follow in the next chapter. As will be outlined, social and psychological issues may arise as a result of physical problems the patient may experience.

3.4.1.1 Respiratory problems

First, a description of respiratory problems a laryngectomy patient experiences will be presented.

After surgery the patient has to breathe through a permanent tracheostoma (Graham, 2004:126; Meyer *et al.*, 2004:1981; Ross, 2000:15; Stam *et al.*, 1991:38). Inhaling is no longer through the nose and pharynx and exhaling is no longer from the lungs to the nose and mouth as the stoma is now the only airway to the lungs (Ross, 2000:15; Ulbricht, 1986:132-133). The cause of respiratory problems can be due to the disconnection between the upper and lower airways, and loss of the function of the nose (Hilgers *et al.*, 1990:424; Hilgers, Aaronson, Ackerstaff, Schouwenburg & Van Zandwijk, 1991:152).

These changes and impact on the patient's basic and crucial functioning are experienced as heavily disrupting, with social and psychological implications for the patient and his relatives. Implications may cause interference with and reduction of social contact, decrease in voice quality, sleep difficulties and fatigue, and psychological reactions like anxiety and depression (Hilgers *et al.*, 1990:424-425; Hilgers *et al.*, 1991:152). Hilgers *et al.* (1990:424) found that almost all patients continue to suffer from these symptoms. However, respiratory problems the patient experiences may improve over time or the patient may adjust better to these implications, especially after the first year.

Respiratory problems clearly have a significant impact on the patient's social and psycho-social functioning and this impact needs to be described in order to gain a better understanding of the laryngectomy patient's post-operative adjustment.

(a) Stoma crusting and narrowing

The patient has to adapt to breathing, coughing and sneezing through the stoma (Belch & Beamish, 1992:60; Graham, 2004:126; Ross, 2000:15-16; Ulbricht, 1986:132). Respiratory problems result from increasing irritation of bronchial mucosa which in turn results in an increase in coughing and sputum production (Hilgers *et al.*, 1990:424; Ross, 2000:15-16). Mucus, which collects in the lungs, exits through the stoma by coughing which makes the mucus visible. This has potential implications for the patient's social and psychological functioning (Renner, 1995:218; Sewnaik *et al.*, 2005:95; Ulbricht, 1986:133-134).

Patients experience loss of the humidifying function of the nose and mouth. Air is no longer warmed, cooled, cleaned and moistened after inhalation (Dhooper, 1985:219; Devins *et al.*, 1994:608; Stam *et al.*, 1991:38). This results in irritation of the bronchial mucosa and an increased flow of mucus contributes towards the forming of crusting of the stoma (Devins *et al.*, 1994:608; Hilgers *et al.*, 1990:424; Jay *et al.*, 1991:936; Ross, 2000:16; Stam *et al.*, 1991:38). Patients may experience or may be afraid of the possible experience of narrowing of the stoma (Deshmane *et al.*, 1995:125; Dhooper, 1985:224).

Care of the stoma includes the following:

- Clearing the mucus from the stoma by wiping it away in order to avoid irritation and odour (Ross, 2000:15; Ulbricht, 1986:133).
- This cleaning process must be done frequently and may cause feelings of discomfort in social situations. Cleaning of the stoma must also be done during the night. This care of the stoma may be bothersome and time consuming (Hilgers *et al.*, 1990:421; Hilgers *et al.*, 1991:155; Op de Coul *et al.*, 2005:173).
- The stoma needs to be protected from the inhalation of foreign objects (Landis, Giger, Lacroix & Dulguerov, 2003:341).

This clearly illustrates that care of the stoma results in extensive social interruptions in the patient's and family's social functioning.

(b) Coughing

The patient has to adapt to coughing mucus through the stoma (Ross, 2000:16). Coughing is more common after a laryngectomy. Due to the lack of the cleaning, warming and moisturising effect of the upper airway on inhaled air, as well as small particles of dust, air pollution or irritants in the air potentially entering the airway to the lungs, it may result in an increase in mucus production which causes coughing, may result (Dhooper, 1985:219; Stam *et al.*, 1991:38; Ulbricht, 1986:133). Another source of increased mucus production which causes coughing is the change in airflow, post-laryngectomy (Ross, 2000:16).

Sputum production and continuous coughing have social implications for patients and their families. The patient may feel uncomfortable in social situations as he finds 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

Hilgers *et al.* (1990:422, 424-425; 1991:152, 155) referred to the correlation between respiratory problems and sleep difficulty which may result in fatigue. Fatigue may have an impact on the quality of the patient's voice, which consequently may reduce social contact and result in psychological problems like anxiety and depression. A decrease in respiratory problems may have a significant effect on daily functioning with reduced fatigue and improved social contact.

(d) Infection

After surgery the patient may experience an increased risk of tracheo-pulmonary infection. This is a result of breathing through the tracheostoma instead of the nose and mouth (Belch & Beamish, 1992:60; Deshmane *et al.*, 1995:125; Dhooper, 1985:219; Hilgers *et al.*, 1990:421; Landis *et al.*, 2003:341).

(e) Nasal discharge

The patient experiences loss of normal nasal function after laryngectomy as earlier described. Air now bypasses the nasal cavity during respiration (Deshmane *et al.*, 1995:123; Jay *et al.*, 1991:935). Loss of normal nasal function results in functional limitation (Schuster *et al.*, 2003:212). This is specifically noticeable when the patient has a cold or flu and cannot blow his nose (Ross, 2000:16).

It is thus clear that a laryngectomy affects one of the most basic aspects of one's functioning, namely respiration. It was illustrated that respiratory problems have the ability to disturb the social functioning of the patient and his relatives.

3.4.1.2 Swallowing problems

Second, swallowing problems as experienced by the laryngectomy patient will be described with the accompanying effect on the patient and his family's social functioning.

The presence of swallowing problems seems to be persistent both before and after surgery although it may differ in severity (Armstrong, Isman, Dooley, Brine, Riley, Dentice, King & Khanbhai, 2001:20; List *et al.*, 1996:2; Radford, Woods, Lowe & Rogers, 2004:376). Armstrong *et al.* (2001:20) and Radford *et al.* (2004:380) referred to a time period of six months after surgery while Hammerlid *et al.* (1998:747) referred to several years wherein patients may experience difficulty with swallowing. Change in the patient's eating and drinking pattern will now be described, with specific reference to its social implications.

(a) Eating and drinking

The patient has to undergo major lifestyle changes regarding his eating habits as cancer of the head and neck region and its treatment can directly affect the patient's eating and drinking processes. Impairment of his ability to tolerate a regular diet will be experienced. Consequently, the patient may experience nutritional problems (Armstrong *et al.*, 2000:16; Depondt & Gehanno, 1995:35; Lennie *et al.*, 2001:668, 673; Lotempio *et al.*, 2005:948; Stewart *et al.*, 1998:143).

Due to a loss of the sense of taste and smell, the patient experiences loss of appetite and loss of weight (Depondt & Gehanno, 1995:35). Flavour is a combination of taste and smell and requires both senses to be effective (Lennie *et al.*, 2001:672). Another consequence may be malnutrition as the patient who presents with cancer of the head and neck region is mostly linked with substance abuse (Depondt & Gehanno, 1995:34). Gastro-intestinal problems, including stomach rumblings, distension or flatulence may be experienced. Gastro-intestinal problems can also be caused by swallowing too much air while eating (Dhooper, 1985:219; Lennie *et al.*, 2001:668).

Alterations in eating habits may result in various social implications, such as:

- It takes longer to finish meals (Lennie *et al.*, 2001:668; Renner, 1995: 219; Ross, 2000:17);
- The need to use liquids during meals to ease swallowing problems (Renner, 1995:219);
- Embarrassment to eat in public due to an inability to tolerate a regular diet (Lotempio *et al.*, 2005:948);
- Decreased enjoyment of meals due to the loss of sense of smell and taste or difficulty in eating and swallowing (Lennie *et al.*, 2001:668, 673; Sewnaik *et al.*, 2005:97);
- Less desire to try new food (Lennie *et al.*, 2001:672);
- Restriction of conversation and socialisation during meals as it is impossible to swallow and talk simultaneously. Social aspects and pleasure while eating are as important as providing the body with adequate nutrients (Lennie *et al.*, 2001:672; Renner, 1995:218, 219; Ross, 2000:17).

Eating and drinking form an essential part of one's social life and the above lists the disturbances the laryngectomy patient will experience these processes. In other words, it can be noted from the above that swallowing difficulty after surgery has the potential to severely affect the patient and his family's social functioning.

3.4.1.3 Sensory impairment

Third, a description of the sensory impairment following a laryngectomy will be presented.

A laryngectomy does not destroy the sense of smell, but does interfere with the olfactory process (Lennie *et al.*, 2001:668). The presence of the permanent tracheostoma prevents air from being in contact with receptors in the nasal passage, which is important for the olfactory process. The patient experiences a loss of the sense of **smell** that 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). Apart from sensory impairment caused by a laryngectomy, the majority of patients may also experience loss of **hearing**, as they are mostly elderly people (Ross, 2000:17).

Loss of smell also affects social aspects of life as it may interfere with the following levels of functioning:

- **Safety** issues due to the inability to smell odours like smoke and natural gas, strong fumes, aerosols or toxic gasses which can be breathed directly into the lungs causing possibly severe danger to the patient (Lennie *et al.*, 2001:673; Ross, 2000:17);
- **Hygiene** issues due to the inability to detect body odour with an effect on the patients' social acceptance (Lennie *et al.*, 2001:673; Ross, 2000:17);
- Limitations upon **pleasurable odours** like food, flowers, fragrances (Lennie *et al.*, 2001:673).

A summary of the social implications of respiratory, swallowing and sensory impairment will be presented in table 3.1.

Table 3.1: Social implications of physical effects of a laryngectomy upon the patient and his family

PHYSICAL EFFECTS		
Respiratory problems	Swallowing problems	Sensory problems
<ul style="list-style-type: none"> • Coughing and frequent cleaning of the stoma which results in discomfort in social situations • Reduction of social contact • Decrease in voice quality • Sleep difficulty and fatigue • Anxiety and depression 	<ul style="list-style-type: none"> • Takes longer to finish meals • The need to use liquids during meals • Embarrassment to eat in public • Decreased enjoyment of meals • Less desire to try new food • Restriction of conversation and socialisation during meals 	<ul style="list-style-type: none"> • Safety issues • Hygiene issues • Loss of smelling pleasurable odours

Following a description of the effect of a laryngectomy on the patient's respiratory, swallowing and sensory functioning, the effect of this operation upon the patient's sphincter function will be looked at. Important to take into account when discussing the physical effect of a laryngectomy, are other age-related medical problems the patient may present.

3.4.1.4 Impairment of sphincter function

Deshmane *et al.* (1995:125) and Jay *et al.* (1991:934) referred to loss of the thoracic fixation or sphincter function of the larynx following a laryngectomy. Jay *et al.* (1991:934) described this loss by referring to the inability of the chest to fixate when the vocal cords adduct. As a result of this action, the patient experiences a rise of pressure in the intra-abdominal area while performing straining tasks, like lifting heavy weights, or bodily functions such as urinating or defecation. Impairment of the patient's sphincter function may result in the necessity for alternative employment and financial arrangements which will be described in section 3.4.3 of this chapter.

3.4.1.5 Ageing and previous lifestyle

Larynx cancer is typically a disease of older people. Many laryngectomees may experience additional age-related medical problems such as cardio-vascular or cerebro-vascular disorders, arthritis, hearing loss or dental problems. A history of heavy smoking over a long period of time may contribute to respiratory problems for these patients (Ross, 2000:17).

The above outline of the physical characteristics of a laryngectomy adds to a better understanding of the **physical impact** of this operation on the functioning of the patient and his family. As described, physical implications of a laryngectomy will result in social problems that the patient and his relatives have to adapt to. Next, the social characteristics of the laryngectomy patient and family will be discussed.

3.4.2 Social impact from an ecological perspective

In this section, the effect of a laryngectomy on the following aspects will be discussed: family relationships, marital and sexual relationships, other social relationships, recreational activities and employment considerations.

3.4.2.1 Impact on family relationships

From an ecological perspective it can be said that a person functions in relation to his environment (Germain & Gitterman, 1996:5-6; Meyer & Mattaini, 1995:16; Sheafor *et al.*, 2000:91). This perspective is defined by various characteristics such as:

- Systems wherein the patient functions, which are interdependent, exchange energy and information and are interrelated (Sheafor *et al.*, 2000:91).
- Although systems have boundaries, they are open and can interact with the environment, with the potential of growth (Meyer & Mattaini, 1995:21).
- As systems preserve their structure and characteristics even if they interact with each other, this is a process of dynamic homeostasis (Meyer & Mattaini, 1995:22).
- Ecosystems are never static as they slowly and constantly adapt to an ever-changing environment (Sheafor *et al.*, 2000:92).
- A species has to be adaptive to be competitive and to cope with a changing environment (Sheafor *et al.*, 2000:92). Elements of the system have the potential to be reciprocal as change in one part of the system will have an impact or change in all parts involved (Meyer & Mattaini, 1995:22).

The laryngectomy patient functions in relation to his family and environment in various ways. This patient will always be challenged by change in his physical, social and psychological status. In his attempts to adapt to these changes, his relation to his family and environment will be affected.

As is done in this study, Deshmane *et al.* (1995:121) referred to major psycho-social implications for the patient and his family due to the diagnosis and treatment of cancer, as it also affects those close to the patient (Finizia *et al.*, 1998:1567). The social impact of a laryngectomy can be widespread. Graham (2004:127) and Ross (2000:19) described different systems to include the spouse, family, friends and community, while Kaplan and Hurley (1979:52) added that the diagnosis of cancer may affect a patient's relationship to his world. This is in accordance with the ecological perspective which describes the patient as interacting with other systems

in the environment (Germain & Gitterman, 1996:5-6; Meyer & Mattaini, 1995:16; Sheafor *et al.*, 2000:91).

Relic *et al.* (2001:516) described the family system as being the closest social environment to the patient and can thus be seen as the most important system for coping with the diagnosis and treatment of cancer. DeSanto (1994:53) realised the importance of this close family relationship by emphasising that following surgery, the patient will go back to his or her previous relationship, whether it was positive or negative.

It is within this context that Renner (1995:215) mentioned that an understanding of the “total person” should ideally include an understanding of how that patient functions within his family system (Renner, 1995:215). Chronic disability has the potential to disrupt established patterns in the patient’s and family’s life (Mathieson *et al.*, 1991:162). Literature refers to possible breakdown, damage or even deterioration in family communication after surgery (Renner, 1995:216; Richardson *et al.*, 1989:283; Ross, 2000:19). Cancer and its treatment have the potential to cause problems in interpersonal relationships or to enforce previously experienced family problems (Kaplan & Hurley, 1979:52; Richardson *et al.*, 1989:283).

(a) Change in family roles

Casper and Colton (1998:3) described the patient’s experience of frustration and difficulties after discharge from hospital. The patient feels that he is no longer in a position to fulfil previous role functioning within the family context. Families assess the patient’s role as diminished. Difficulty in communication may add to the experience of frustration and other difficulties referred to.

Family roles will undergo change or loss with a threat to the integrity of the family system (Dhooper, 1985:222; Graham, 2004:127; Renner, 1995:216; Ross, 2000:18-19). The change will disturb the equilibrium of a longstanding relationship although existing relationships are not easily changed during stressful situations (Dhooper, 1985:223; Renner, 1995:217; Richardson *et al.*, 1989:291). Change in social life can be stressful as adjustments need to be made (Renner, 1995:218).

The patient will become increasingly aware of the loss of his pre-operative status (Graham, 2004:127). Casper and Colton (1998:47-48) referred to feelings of dependence, frustration and irritation for patients who previously fulfilled a dominant role and after surgery realise they are no longer able to do so. Emotional reactions sometimes result in non-productive behaviour and as a result, 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.

Change of roles may mean that spouses assume the most dominant role as they have speech ability and the laryngectomy experience may cause stress and strain in caregivers (Blood *et al.*, 1994:30; Dhooper, 1985:223). Blood *et al.* (1994:31) remarked that caregivers normally adjust to this role within the first year which may result in a positive outcome for the patient.

(b) Emotional reactions of family members

According to the ecological system perspective, change in the one system will affect the other systems. From an ecological perspective (Germain & Gitterman, 1996:10), a wide spectrum of potential emotional reactions that the family may experience in response to the external life stressor of a patient who undergoes a laryngectomy, will be described. This knowledge is necessary in order to enhance adaptation to the negative relation between the patient and his environment. Casper and Colton (1998:3) remarked that families may experience many concerns similar to those of the patient, although from a different perspective.

- *Guilt*

Guilt may be experienced in reaction to a possible cause of cancer, such as smoking, alcohol abuse or diet (Renner, 1995:217; Ross, 2000:18). The family may wish that they had reacted more firmly in the past, or may experience guilt for not seeking medical attention earlier. Other sources of guilt may result from anger or being impatient, being irritated or experiencing feelings of anger.

- *Overprotection*

In an attempt to be supportive, the family can easily overprotect the patient which may result in the patient's withdrawal into the sickness. Families realize that they cannot rely on the patient's ability of self-expression, do not want to leave the patient alone and carefully watch every step of the patient. This in return can contribute towards the patient's inability to function independently (Dhooper, 1985:223; Depondt & Gehanno, 1995:36; Renner, 1995:217; Ross, 2000:18). Spouses easily forget about their own needs as all their time and energy is now focused on satisfying the patient's needs (Renner, 1995:217; Ross, 2000:18).

- *Anger*

Anger may be aimed towards the patient due to a continued smoking habit in spite of previous warnings (Renner, 1995:217). On the other hand, spouses may be the target of the patient's anger and negative feelings (Blood *et al.*, 1994:21).

- *Fears and concerns*

The family may experience fears and concerns about the diagnosis of cancer, the effect of the operation, the possibility that the cancer may return, the patient's ability to adjust to his changed circumstances, concern about finance or permanent disability, or interference with social activities (Belch & Beamish, 1992:61; Blood *et al.*, 1994:22; Casper & Colton, 1998:3).

- *Withdrawal*

The family may withdraw from others after the patient's initial diagnosis of cancer. Renner (1995:216) and Ross (2000:19) referred to this reaction of the family who sometimes regret that they had informed others, as they experience an inability to answer their questions. This may increase their feelings of anxiety.

- *Realization*

The family is aware of physical changes in the patient which cannot be avoided such as the patient's inability to communicate verbally. Family members observe and experience these changes on a continual basis (Casper & Colton, 1998:3). A study by Mathieson *et al.* (1992) found that spouses presented with higher scores for

depression, fatigue and tension than patients. This finding emphasises the comprehensive impact of a laryngectomy on families of patients.

3.4.2.2 Impact on marital and sexual relationships

Focus will now be on the impact of the laryngectomy experience on marital and sexual relationships as the closest form of family relationships.

The patients may experience difficulty in intimate relationships and sexuality as a result of extensive and permanent disfigurement (Hanna *et al.*, 2004:878). The most prominent factor referred to is the presence of the tracheostoma with its stoma odour, noisy stoma breathing, the need to cough mucus through the stoma and the permanent disfigurement it causes (Casper & Colton, 1998:50; DeSanto, 1994:53; Dhooper, 1985:219; 224; Ulbricht, 1986:133). These problems will increase with worsening of the patient's self-image and concern regarding the partner's reaction to these physical changes after surgery (Casper & Colton, 1998:50). Mathieson *et al.* (1991:161) warned that the marital relationship cannot be separated from other post-operative effects on the relationship. It can also not be assumed that the patient is unique in his experience.

Ulbricht (1986:133-134) described the neck area as representative of sensuality and sensitivity. She pointed out that not all husbands are supportive and will be able to overlook physical imperfections. The patient has to deal with various losses, which may have a negative effect on marital and sexual relationships. Loss of voice may be associated with sexual loss, loss of femininity or masculinity, feeling less desirable to the partner or feeling isolated (Dhooper, 1985:222; Renner, 1995:219).

A previously strained marriage may collapse resulting in divorce and therefore more distress for the patient (Ross, 2000:19; Stell, 1991:222-223; Ulbricht, 1986:134). Such an experience also has the potential of bringing couples together (Ross, 2000:19). Long-term adjustment for the spouse may potentially initiate or increase smoking or drinking behaviour (Mathieson *et al.*, 1991:162).

Marital and sexual 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, 129). DeSanto (1994:43) found that there was little available data on this topic. Baker and Cunningham (1980:24) emphasised the need for discussion of this topic during counselling with the family. The aim will be to re-integrate the patient into a normal lifestyle. It is further recommended by Herranz and Gavilán (1999:996) that this sensitive issue be included in the support group sessions.

Except for the effect of surgery upon the patient's family and marital and sexual relationships, other social relationships may also be affected by this operation.

3.4.2.3 Impact on other social relationships

Physical symptoms like the presence of a permanent tracheostoma and loss of normal voice may result in problems in other social relationships (Deshmane *et al.*, 1995:128). The following descriptions will add to a better understanding of this impact of a laryngectomy on a patient's social functioning:

- Respiratory problems like coughing of mucus and regular cleaning of the stoma which have a significant impact on several aspects of **daily life** (Hilgers *et al.*, 1991:155; Lotempio *et al.*, 2005:948).
- Difficulty to tolerate a regular **diet** or **feed** themselves in public (Lotempio *et al.*, 2005:948).
- **Attitudes** of the **patient** or **significant others**: social myths and stigma attached to cancer such as avoidance of cancer patients due to the belief that cancer may be contagious, or that cancer serves as a punishment for previous sins (Dhooper, 1985:221; Kaplan & Hurley, 1979:52).
- Problems with **communication** (Ross, 2000:19).
- **Social withdrawal** and feelings of **isolation** (Clements, Rassekh, Seikaly, Hokanson & Calhoun, 1997:493; Kaplan & Hurley, 1979:52). The patient easily withdraws himself from social activities such as using the telephone, social events where he may not be heard and the work place, and become dependent and reliant on others (Ruiz & Crevier-Buchman, 2000a:173).
- **Embarrassment** due to respiratory problems like coughing and cleaning of the stoma when **eating in public** or **speaking** (Belch & Beamish, 1992:61; Hilgers *et al.*, 1991:155; Lotempio *et al.*, 1995:948; Ross, 2000:20).

- Reduction in **social acceptance** and **social activities** (Deshmane *et al.*, 1995:128; Ross, 2000:20).
- **Change** in **social relations** and normal patterns of social **interaction** (Hilgers *et al.*, 1990:421; Ross, 2000:19-20).
- The patient has to make **various adjustments** when moving into social situations. Some patients require the presence of an accompanying person to help them with communication (Deshmane *et al.*, 1995:128; Ross, 2000:20).
- **Problems** that previously existed may be **reinforced**, for example marital problems, problems with family members, employment or finances (Kaplan & Hurley, 1979:52).

Social implications of a laryngectomy can be experienced as a result of physical problems due to the presence of a permanent tracheostoma and loss of voice. In other words, the physical impact of a laryngectomy will result in an impact on all social relationships of the patient.

Next, the impact of surgery on recreational activities will be described, as they also form part of a person's social functioning.

3.4.2.4 Impact on recreational activities

The physical presence of a tracheostoma results in limitation of certain activities such as water-related activities, such as water sports or swimming, bathing or showering (Baker & Cunningham, 1980:24; Belch & Beamish, 1992:60; Devins *et al.*, 1994:608; Karamzadeh & Armstrong, 2001:528). It is necessary to protect the tracheostoma from dangerous conditions when participating in outdoor activities as patients face the possibility of water aspiration and drowning (Devins *et al.*, 1994:608; Karamzadeh & Armstrong, 2001:528, 531; Landis *et al.*, 2003:341).

This may result in a reduction of participation in social and outdoor activities (Jay *et al.*, 1991:937) and the patient sometimes have to give them up (Deshmane *et al.*, 1995:126). Some patients manage to find creative ways of continuing with previous leisure time activities (Ross, 2000:20) as their desire to return to these activities becomes increasingly strong (Karamzadeh & Armstrong, 2001:528). Karamzadeh and Armstrong (2001:532) encouraged patients to return to alternative pleasurable

activities after surgery, as these have the potential to increase their sense of well-being.

It is clear that in specific cases some patients have to alter their former recreational activities to suit their changed lifestyle. Karamzadeh and Armstrong (2001:531) warned that due to the fact that alcohol consumption and abuse can be associated with a cancer of the head and neck area, these patients need to be warned against the combination of alcohol use and swimming, as it can be life threatening.

3.4.3 Occupational and economic impact

Other levels of the patient's social functioning which need to be described will include the impact on occupation and finance. Knowledge of this aspect is advantageous as the tendency is that an increasing number of younger patients will be diagnosed in future, considering the etiological factors leading to a diagnosis of larynx cancer.

3.4.3.1 *Employment considerations*

The patient may have to consider when or whether he should return to his previous employment (Renner, 1995:216; Ross, 2000:20). Baker and Cunningham (1980:26) found that many laryngectomees do return to work after the recovery period. It is necessary to advise the patient to resume work as soon as possible (Kleinsasser, 1988:258). Dhooper (1985:220) pointed out that some patients do not wish to return to work. Goldberg (1975:7) found that patients who had realistic plans prior to surgery, accepted greater responsibility and had an improved chance of re-employment after surgery.

3.4.3.2 *Occupational restrictions*

After surgery the laryngectomy patient may need to alter his previous employment to exclude certain employment conditions: dusty air; chemical substances which may affect the tracheostoma; airborne irritants like dust, smoke, pollutants, temperature extremes; prolonged exertion with sudden temperature changes; extreme temperatures; exposure to wind and cold air; atmospheric pollution or lifting of weights (Baker & Cunningham, 1980:26; Goldberg, 1975:1-2; Graham, 2004:127; Ross, 2000:20). Some patients may lose their previous employment due to the loss

of natural speech especially when employment is dependent on verbal communication (Dhooper, 1985:219; Graham, 2004:127; Murrills, 1975:56; Ross, 2000:20). Patients who have to use their voice frequently are more affected than others (Relic *et al.*, 2001:514).

3.4.3.3 Changing or losing former employment

Disability may be temporary or permanent as some patients may change or lose their jobs (Ruiz & Crevier-Buchman, 2000a:173). Dhooper (1985:219) referred to potential reasons for disability as being experienced from either a medical perspective (diagnosis of cancer; loss of natural speech; shoulder pain; weakness) or a psychological perspective (worsened self-image).

3.4.3.4 Impact of altered employment arrangements

Financial problems due to loss of previous employment have been extensively described (Blood *et al.*, 1994:22; DeSanto, 1994:50; Deshmane *et al.*, 1995:128-129; Graham, 2004:126; Müller *et al.*, 2001:279). The patient may experience an increase in financial costs such as medical costs, long periods of sick leave or other related expenses such as transport, speech therapy sessions or prosthetic devices (Casper & Colton, 1998:4; Ross, 2000:20-21). Many patients become pensioners due to extensive surgery or already are pensioners at the time of surgery. From a **social perspective**, it can be said that previously existing financial problems may be intensified by current financial problems (Müller *et al.*, 2001:279). Patients may experience a decrease in economic status which in turn reflects a person's socio-economic milieu, social acceptance and awareness of the general population (Deshmane *et al.*, 1995:128; Graham, 2004:127). From a **psychological perspective**, temporary or permanent disability may result in change in the patient's self-worth, identification with society and attitude about the future (Kaplan & Hurley, 1979:53) while the opportunity to resume previous employment may boost the patient's self-esteem (Relic *et al.*, 2001:517).

The above effects of a laryngectomy on a person's occupational and financial position are of great importance for the laryngectomy patient. Previously, this target group of patients consisted mostly of elderly males. However, statistics show that there is now a greater incidence of younger persons being affected by this surgical

management. This changed incidence implies that in future more people who form part of the labour market will be involved.

In this section the social implications of a laryngectomy upon the patient and his family have been outlined and discussed in order to promote a better understanding of the effects of this operation.

3.4.4 Psychological impact

In this section the psychological impact of a laryngectomy on the patient and his relatives will be discussed.

3.4.4.1 *Diagnosis of cancer*

The diagnosis of cancer has a tremendous impact as patients fear the association of a poor prognosis, association with pain, decline in dignity, disfigurement or the loss of a body part (Casper & Colton, 1998:48; Depondt & Gehanno, 1995:34; Graham, 2004:126; Renner, 1995:215; Ross, 2000:14). This experience is intense and personal and can be seen as entering an emotional field (Graham, 2004:125; Ruiz & Crevier-Buchman, 2000b:165). The emotional state of the patient and spouse may affect their ability to hear, accept or recall information (Casper & Colton, 1998:49; Zeine & Larson, 1999:59-60). These feelings need to be expressed before the patient will be able to understand that larynx cancer can be successfully treated (Ross, 2000:14).

The diagnosis of cancer is a new and threatening situation and has the potential to **create a crisis** for the patient and others (Blood *et al.*, 1994:19; Graham, 2004:126; Herranz & Gavilán, 1999:994; Ramírez *et al.*, 2003:97). A period of disorganisation follows while seeking to regain homeostasis. Patients may use a defence mechanism when they are not able to handle the situation and may try to make it go away through wishful thinking (Kaplan & Hurley, 1979:55).

Many myths and misconceptions about cancer are experienced (Renner, 1995:215; Ross, 2000:14). Stigma may be experienced due to the diagnosis and treatment of cancer and may result in the following reactions: difficulties in interpersonal

relationships, blaming themselves or others for causing the illness, low self-esteem or negative reactions (Belch & Beamish, 1992:60; DeSanto, 1994:43; Mehta & Abrol, 1982:107, 111; Richardson *et al.*, 1989:283).

In summary, Kaplan and Hurley (1979:51) mentioned that cancer is much more than a medical diagnosis, as it also has an effect on the physical, social and psychological aspects of living.

3.4.4.2 External life stressors and internal stress

Germain and Gitterman (1996:10) referred to a negative relationship between the person and his environment when an external life stressor causes internal stress. An external life stressor can take the form of harm or loss, or a threat of possible harm or loss. Internal stress may result in physiological or emotional consequences, or both. For the purpose of this study it can be said that the diagnosis of advanced cancer (external life stressor) which requires surgical treatment such as a laryngectomy, has the potential to cause internal stress.

3.4.4.3 Dimensions of external life stressors and internal stress

In this section an ecological perspective as conceptualised by Germain and Gitterman (1996:11) will be used to describe various dimensions of stress in the case of a traumatic life event (laryngectomy as external life stressor) which results in internal stress as experienced by the patient. Practical examples of how an external life stressor may have an effect on internal stress with specific reference to the target group of this study, namely laryngectomy patients, will be supplied:

- **Whether a stressor is chronic or acute affects its impact.** A patient suffering from larynx cancer that requires a laryngectomy as surgical treatment is referred to by the caregiver as having a chronic condition (Blood *et al.*, 1994:31).
- **At times a person may be ambivalent about the stressor and its resolution.** The patient may experience ambivalence between survival (accepting surgery) and mutilation (following surgery). Although surgery is seen as a life-saving operation, Kleinsasser (1988:190-191) referred to psychological and physical mutilation as it affects the patient in various ways.

- **Whether a critical event is anticipated or unexpected can affect the amount of time available for a person to prepare for the life change. Unpredictable life events are more difficult to cope with than predictable ones.** Dhooper (1985:218) stated that most patients were not prepared for their diagnosis and treatment of cancer.
- **Lack of control over a stressor has a profound effect.** Blood, Dineen, Kauffman, Raimondi and Simpson (1993:764) referred to the fact that loss of control may result in a sense of helplessness and dependency and even more so for laryngectomy patients. Renner (1995:216) emphasised that this experience of loss of control will be more intense for patients who present with loss of voice.
- **Timing, the point on the life course at which the stressor strikes, is a significant factor in the degree of stress experienced.** Historically cancer of the larynx is seen as a disease of the elderly (Morton, 1997:249; Renner, 1995:216). Currently there are an increased number of women and younger persons who are diagnosed with larynx cancer.
- **Expected desired events may not take place.** Not all patients reach the same degree of rehabilitation that they may have wished to achieve post-operatively.

From this description of Germain and Gitterman's model of dimensions of stress in traumatic life events, it is clear that the laryngectomy patient experiences a high level of stress.

3.4.4.4 External consequences of internal stress

From an ecological perspective, Germain and Gitterman (1996:11) stated that stressful feelings, caused by the stressor, can potentially be negative and immobilising. With reference to the present study, the experience of stress may result in the patient exhibiting some of the following reactions:

- *Shock*

Shock may be present as the patient experiences a threat to his survival (Dhooper, 1985:221; Kleinsasser, 1988:256). This may result in non-productive behaviour

where little or no emotional reaction is present (Kaplan & Hurley, 1979:53; Renner, 1995:216).

- *Anxiety*

Literature acknowledges feelings of anxiety as a common experience by both the patient and the spouse and this may be increased due to the following reasons (Dhooper, 1985:221; Kaplan & Hurley, 1979:54; Mathieson *et al.*, 1991:161; Mehta & Abrol, 1982:107):

- Lack of information regarding the complications of the diagnosis, treatment and uncertainty to manage it especially during the first month after surgery (Herranz & Gavilán, 1999:995; Ramírez *et al.*, 2003:96);
- Uncertainty regarding the nature of the illness, fear of recurrence of the disease or difficulty with communication (Depondt & Gehanno, 1995:36);
- Uncertainty about the future (Renner, 1995:215; Ross, 2000:13);
- Anxiety about the patient's expected prognosis (Kleinsasser, 1988:256).

- *Withdrawal and isolation*

The patient's tendency to isolate himself is described by Dhooper (1985:219, 223-224), Graham (2004:128), Kaplan and Hurley (1979:52), Maas (1991:1375) and Mehta and Abrol (1982:11). This could possibly be due to the experience of mutism or being unable to deal with the experience of facial disfigurement or the effect of the operation upon speech ability. Another factor contributing to the patient's social withdrawal and isolation is mentioned by Casper and Colton (1998:49) as fear of re-entrance into social life or recognition of families' or friends' discomfort. The physiological impact of surgery and impaired communication ability of the patient contribute to this reaction.

Social withdrawal and isolation ultimately has the potential to result in alcoholism which has been discussed as an etiological factor to the diagnosis of larynx cancer (Dhooper, 1985:224). As this type of surgery is carried out infrequently, patients seldom know anyone else who has experienced such surgery, which may lead to the patient's reactions of withdrawal and isolation (Renner, 1995:215; Ross, 2000:14). Renner (1995:216) and Richardson *et al.* (1989:285) described withdrawal and isolation as non-productive behaviour when facing an unbearable challenge.

Withdrawal and isolation from social activities result in patients' dependency on others (Ruiz & Crevier-Buchman, 2000a:173).

- *Fear*

The potential fears are widely described by various authors: fear associated with the diagnosis and treatment of cancer; fear of recurrence of disease; fear that the diagnosis may be fatal; fear of the future; fear of mutilation and the lack of ability to maintain adequate communication; fear for loss of social acceptance; fear of pain; fear for loss of voice; fear of a possible negative influence on relationships; fear of financial dependency or fear of an altered appearance and self-esteem (Depondt & Gehanno, 1995:34; Dhooper, 1985:220-221; Graham, 2004:128; Mehta & Abrol, 1982:111; Natvig, 1983:155; Renner, 1995:215; Richardson *et al.*, 1989:283; Ross, 2000:13). In other words, the patient may experience different levels of fear for many different reasons following surgery.

- *Helplessness*

Helplessness results from loss of control when the situation seems overwhelming, and has the potential of dependency on others. The patient may find it difficult to extend his affection to people other than family and close friends (Blood *et al.*, 1993:764; Casper & Colton, 1998:49; Dhooper, 1985:221; Kaplan & Hurley, 1979:54).

- *Frustration*

Ulbricht (1986:134) referred to frustration as a response to the limitations experienced following surgery. For example, a patient's difficulty in learning to talk after surgery, can contribute to feelings of frustration (Casper & Colton, 1998:49).

- *Denial*

Denial is mostly a defence reaction when trying to avoid the reality of dealing with an overwhelming problem. The patient may refuse to think about the changes and plan as if nothing has changed (Dhooper, 1985:221; Kaplan & Hurley, 1979:55).

- *Anger*

This may result from an inability to communicate adequately (Dhooper, 1985:218; Kaplan & Hurley, 1979:55).

3.4.4.5 Challenge of coping

Some patients cannot deal with the adjustments following surgery as they feel that life will never be the same. The patient experiences stress in the realisation that one cannot escape reality and denial is no longer effective (Kaplan & Hurley, 1979:55). Using an ecological perspective, Germain and Gitterman (1996:12-14) referred to the fact that a traumatic life issue can possibly be experienced as either a stressor or a challenge. The latter is applicable in circumstances where personal and environmental resources are available to master this traumatic life event. Coping occurs over time and is an expression of the relationship between a person and his environment, as both personal and environmental resources are required to take control of a traumatic life issue.

Kaplan and Hurley (1979:57) explained that cancer may offer the experience for growth if the patient will view his future from a different and new perspective, with a positive effect on the patient's social functioning. This assumption 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.

Knowledge of the laryngectomy experience and of how to use it as an opportunity for growth, must of necessity include a close look at the various loss experiences patients have to deal with.

3.4.4.6 Experiences of loss

Laryngectomees are confronted with various experiences of loss which they have to work through (Renner, 1995:218). Dhooper (1985:218, 221) also referred to grief reactions of patients when they attempt to work through their experience of loss. Literature (Blood *et al.*, 1993:764; DeSanto, 1994:43; Dhooper, 1985:221, 223; Graham, 2004:127; Hilgers *et al.*, 1990:421; Kaplan & Hurley, 1979:56; Renner, 1995:216-217; Ulbricht, 1986:134) referred to the following experiences of loss the patient has to deal with:

- Loss of natural **voice**.
- Loss of **control** may result in a sense of helplessness and dependency.

- Loss of **self-expression** - laughing, crying or shouting out loud.
- Change in **body-image** and reduced **self-esteem** or confidence.
- Impact on **femininity** or **masculinity**.
- Loss of **status** in society.
- Loss of the **pleasure of conversation**, loss of **oral gratification** while on tube feeding, loss of **accustomed activities**, loss of **intact body**.
- Loss of **function** and loss of **self**.
- Loss of **social acceptance** due to fear of death, mutilation, lack of ability to maintain adequate communication.
- Loss of **larynx** which may result in communication problems and as a result may affect the patient's social interaction patterns.

Some of these loss experiences, such as loss of control, loss of communication, voice and identity can be visualised as in figure 3.2 and will be explained further.

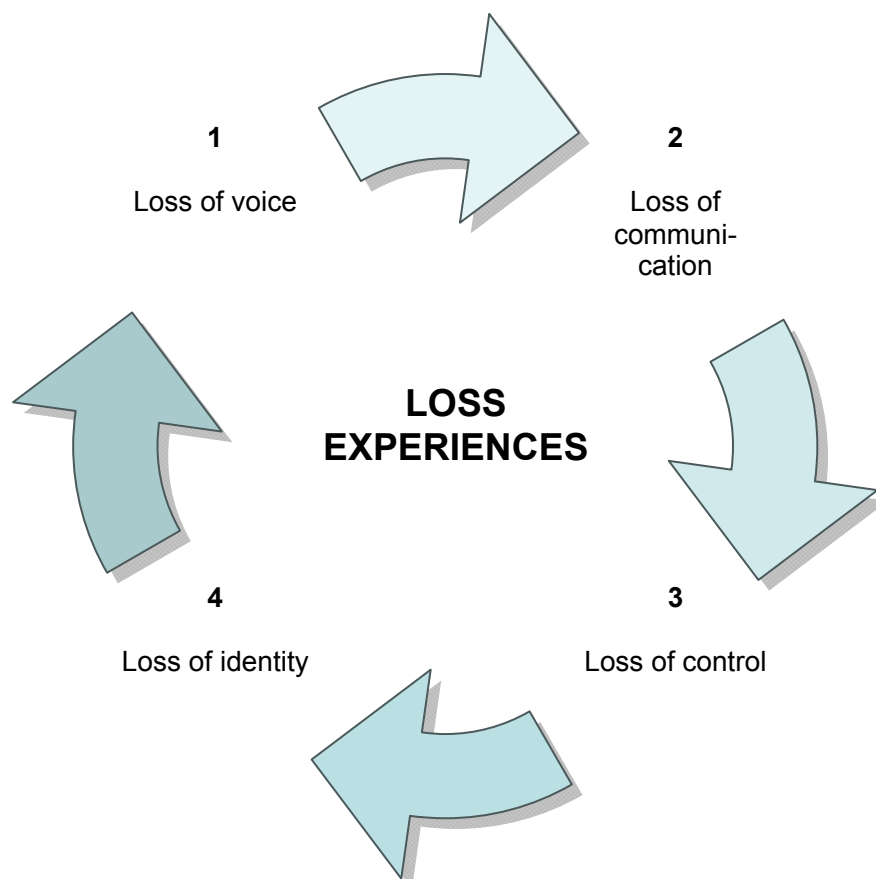


Figure 3.2: Various experiences of loss

(a) Loss of voice

Loss of natural voice is one of the most drastic changes after surgery and results in complete and permanent loss of normal verbal communication (Deshmane *et al.*, 1995:121; Eadie & Doyle, 2005:116; Maas, 1991:1374; Natvig, 1983:155; Ulbricht, 1986:131). Post-operatively, the patients will need to learn alternative methods of communication (Dhooper, 1985:218; Graham, 2004:127). They experience the immediate loss of vocal sound; the ability to laugh, cry, shout, whistle or sing out loud (Belch & Beamish, 1992:60; Ross, 2000:21; Ulbricht, 1986:134). Losing this form of self-expression is a highly emotional experience (Ulbricht, 1986:134).

Literature (Jay *et al.*, 1991:934; Kaplan & Hurley, 1979:51-52; Mathieson *et al.*, 1991:153; Otto *et al.*, 1997:696; Stam *et al.*, 1991:38) describes loss of normal voice as a major disability and that the patient may experience it as a threat. This handicap is disabling and can be traumatic with psycho-social problems for the patient and family (Deshmane *et al.*, 1995:121; Otto *et al.*, 1997:696; Ruiz & Crevier-Buchman, 2000a:171; Zeine & Larson, 1999:59). Loss of voice can be regarded as a crisis event which can result in depression and grief (Dhooper, 1985:222; Graham, 2004:126).

Patients may experience constant difficulty in making themselves understood especially in a noisy environment (Jones *et al.*, 1992:241; Op de Coul *et al.*, 2005:173; Ross, 2000:20). This could possibly be due to an inability to produce sufficient volume necessary to be heard (Carr *et al.*, 2000:43).

Disturbance in speech ability influences the person's sense of himself, as his voice and manner of speaking is a major expression of self and personality (Kaplan & Hurley, 1979:52; Mehta & Abrol, 1982:107). According to Casper and Colton (1998:6), absence of the patient's ability to express himself may increase his experience of isolation and depression. Loss of voice has the potential to result in disturbed negotiation with the world, causing a lack of independence and control (Kaplan & Hurley, 1979:52).

(b) Loss of communication

Communication is described as an integral element of social life (Schuster *et al.*, 2003:212). Communication means to visit, to share experiences with, and to interact

with others (DeSanto, 1994:43). Impairment of speech ability will result in the fact that patients do not experience the “give and take”, “sharing and belonging” of conversation (Kaplan & Hurley, 1979:52). Communication is a dynamic exchange of information through all senses and expresses one’s thoughts, emotions, and attitudes and elicits responses and recognition from others. Communication skills involve a complex creative process in which influence between people occurs (Kahn & Kelly, 1991:581, 588; Kaplan & Hurley, 1979:52).

Loss of the larynx may result in impaired communication which may result in the experience of multiple problems with communication, such as limited ability to communicate or complete loss or distortion of normal verbal communication (Baker & Cunningham, 1980:23; Clements *et al.*, 1997:494; Eadie & Doyle, 2005:116; Hilgers *et al.*, 1990:421; Meyer *et al.*, 2004:1981). The patient has to make permanent alterations in his ability to communicate with others (Meyer *et al.*, 2004:1977). This ties in with the ecological perspective, with Sheafor *et al.* (2000:92) referring to ecosystems that are never static but are slowly and constantly adapting to an ever-changing environment.

Loss of communication may result in difficulty in **interpersonal relationships** and inability to communicate with family and friends, and restriction or even breakdown in family communication, as communication is essential to interact with others in order to form relationships (Clements *et al.*, 1997:493; Kaplan & Hurley, 1979:52). Eadie and Doyle (2005:116) found that the public tend to refer to altered ways of communication as non-normal and less acceptable and intelligible than that of normal speakers. People may also wrongly assume that the patient is deaf (Murrills, 1975:55). This will impact negatively on social acceptance and interaction, communication and adjustment after surgery (Eadie & Doyle, 2005:116). As a result, patients may experience social withdrawal or become socially isolated (Clements *et al.*, 1997:493; Kaplan & Hurley, 1979:52).

(c) Loss of control

Loss of control takes place after receiving the diagnosis of cancer. New situations and environments, over which the patient has no control, as others control what happens, now have to be faced. The patient is left with few choices (Casper &

Colton, 1998:36). Ross (2000:21) emphasised that loss of control may be intensified for patients facing loss of voice.

(d) Loss of identity

Loss of speech and loss of communication are also related to loss of identity. Casper and Colton (1998:47) referred to the role of communication as shaping our environment, establishing our status and positioning and stating ideas, thoughts and approval or lack thereof. The unique sound of a voice is associated with a person's identity and therefore loss of identity will result in a process of mourning and grief.

Viewed from an ecological perspective a person may use a traumatic life issue as either a stressor or a challenge (Germain & Gitterman, 1996:12-14). In the laryngectomy patient's attempt to use his limitation as a growth experience, he has to work through various experiences of loss where after depression may follow.

3.4.4.7 Depression as reaction to experience of loss

The effect of post-laryngectomy depression experienced by the patient and spouse is described in literature by various authors (Casper & Colton, 1998:5; Graham, 2004:128; Mathieson *et al.*, 1999:161; Ramírez *et al.*, 2003:96; Ross, 2000:21).

(a) Incidence of depression

Renner (1995:217) was of the opinion that **most** laryngectomy patients may experience depression at different times and to some degree, as it manifests as a symptom of cancer patients in general (Mehta & Abrol, 1982:111). Kleinsasser (1988:258) agreed with the assumption that almost all laryngectomy patients will experience depression, and Dhooper (1985:222) felt that some may experience it more severely than others.

(b) Symptoms of depression

Casper and Colton (1998:5) referred to the importance of identifying presenting symptoms of depression. These symptoms are identified as refusal to comply with medical instructions, rejection of medical treatment, ignoring follow-up visits, a decrease in decision-making ability, sudden change in behaviour, lack of energy, social isolation, disruption of communication or talking about suicide. Depression

may also have a negative effect on the patient's ability to recover, physical healing and speech rehabilitation (Birkhaug *et al.*, 2002:203; Casper & Colton, 1998:5; Dhooper, 1985:223; Renner, 1995:217; Ross, 2000:21). In extreme cases depression may result in isolation and alcoholism or suicide (Maas, 1991:1375; Stell, 1991:223).

(c) Reasons for depression

Jones *et al.* (1992:241) and Ramírez *et al.* (2003:96) agreed that head and neck cancer patients are at **greater risk** for depression as the incidence of depression is related to the extent of the surgery. Stell (1991:222) described the most obvious reason for post-operative depression as a result of the patient's experience of loss of voice.

Of equal importance is the assumption that the incidence of depression can be seen as a grief reaction towards the experience of loss, including loss of voice, coping with the reality of a permanent tracheostoma and change in breathing pattern (Dhooper, 1985:222; Richardson *et al.*, 1989:285; Ross, 2000:21; Stell, 1991:222). Other reasons may include lack of information experienced by the spouse, fear of recurrence of disease or the handling of major challenges after surgery and quality of domestic support (Herranz & Gavilán, 1999:995; Otto *et al.*, 1997:693). Stell (1991:222) noted that in many cases alcohol use can be related to patients who needing a laryngectomy, resulting in related psychiatric disorders like depression.

Ross (2000:21) summarised the experience of depression as a grief reaction to a loss of voice, smell, taste, ability to laugh out loud or cry out loud, being unable to blow their noses and sneeze, frustration at being unable to give vent to feelings verbally; changes towards femininity or masculinity, and changes in body-image and self-esteem.

Following a description of depression as a reaction towards various loss experiences, additional psychological problems patients have to deal with post-operatively, also need to be discussed. This will add to a better understanding of the psychological effect of surgery upon the patient and his family.

3.4.4.8 Permanent stoma

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 two most dramatic physical changes of the patient post-operatively are the presence of the tracheostoma and the absence of normal laryngeal speech. The tracheostoma is described as a hole in the neck through which the patient has to breathe, cough and sneeze and 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). The visible effect of the stoma increases when mucus is visible (Sewnaik *et al.*, 2005:95). Disappointment and the realisation of the permanent impact of the stoma may leave the patient with feelings of dissatisfaction (DeSanto *et al.*, 1995:768). For female patients it is even worse as it represents unattractiveness and unfeminine-ness (Ulbricht, 1986:133).

3.4.4.9 Self-concept / self-image

Cancer of the head and neck region is visible and very obvious (Deshmane *et al.*, 1995:121; Hanna *et al.*, 2004:878). Treatment of larynx cancer results in severe cosmetic disfigurement and functional disability (Deshmane *et al.*, 1995:121).

Patients may experience an impaired self-image due to possible disfigurement of the face (Belch & Beamish, 1992:60; Dhooper, 1985:222; Kaplan & Hurley, 1979:53; Ross, 2000:21). Obvious changes in the patient's physical appearance will have an effect on the patient's self-image. These may include the presence of the tracheostoma, different look to the contours of the neck, scarring, respiratory sounds, sound of coughing, and the need to clean the stoma after coughing (Casper & Colton, 1998:48). This is especially true for female patients as they may experience the disfigurement as unfeminine, unattractive, embarrassing or unlovable (Belch & Beamish, 1992:60; Ulbricht, 1986:134).

The face can be regarded as representative of a person's physical appearance. Disfigurement in this regard, will have an effect on a person's body-image and eventually self-image. These concepts will now be discussed in greater detail.

(a) Face

The face is closely associated with the patient's personality, physical attractiveness and body-image, and represents the person's individual characteristics (Belch & Beamish, 1992:60; Dhooper, 1985:222; Kaplan & Hurley, 1979:53; Ross, 2000:21). Kaplan and Hurley reminded us that "people know us, remember us and perceive feelings from our face". A change in one's face is easily noticed by others and has a definite impact on one's self-image and self-esteem (Kaplan & Hurley, 1979:53; Ross, 2000:21).

(b) Appearance

A total laryngectomy does affect the patient's external appearance (Herranz & Gavilán, 1999:990). Impairment or change in appearance and an altered body-image may result in psycho-social problems for the patient (List *et al.*, 1996:2; Natvig, 1983:155). Kaplan and Hurley (1979:53) pointed out that the psycho-social impact of this change correlates with the function and symbolic meaning of the affected body part.

(c) Disfigurement

Treatment of cancer is often feared for its potential of pain and disfigurement or mutilation (Kaplan & Hurley, 1979:51-52). The patient's feelings of disfigurement and mutilation may affect his self-concept and self-image (Belch & Beamish, 1992:60; Dhooper, 1985:222; Hanna *et al.*, 2004:878; Kaplan & Hurley, 1979:53). According to Dhooper (1985:222), loss of the larynx may represent the experience of death to the patient.

(d) Body-image

The face can be viewed as a crucial determinant of the patient's body-image (Belch & Beamish, 1992:60). Ross (2000:21) remarked that the face and senses form a special part of the person's personality and body-image. After surgery the patient has to adjust to a disrupted or changed body-image (Byrne *et al.*, 1993:173; Hanna *et al.*, 2004:878).

3.4.4.10 Differences between the sexes in the experience of laryngectomy

Ulbricht (1986:131) noted that although all laryngectomees experience similar problems, women will experience certain additional difficulties and adjustments. On an **emotional level**, male patients will experience loss of independence, especially financial independence, whilst women will experience impairment in personal relationships and responsibilities (Salva & Kallail, 1989:292).

A total laryngectomy will influence the patient's experience of **femininity** or **muscularity** (Ulbricht, 1986:134). Women will be embarrassed by their new voice (Salva & Kallail, 1989:300; Ulbricht, 1986:134) as it may be lower than their natural voice and could easily be mistaken for a male voice. Women may isolate themselves and feel less loveable. Permanent disfigurement will "affect the way they think, feel and act" (Ulbricht, 1986:134). Another practical problem is having to avoid perfume that can irritate the airways and cause coughing, which also contributes towards feeling less feminine (Ulbricht, 1986:134).

A further difference between men and women is in their **need for support**. Men are less supportive and need less support due to the strong support of spouses, whilst women will need help from family and friends outside the home (Salva & Kallail, 1989:300-301).

The above discussion of the **physical**, **social** and **psychological** effects of a laryngectomy on the lives of the patient and family underscores the theoretical definition of the comprehensive impact of this type of surgery on this target group's functioning. From an ecological perspective this clearly illustrates the various aspects of functioning which could possibly be affected by this operation.

3.5 CONCLUSION

This chapter described aspects concerning the psycho-social effects of a laryngectomy on the life of the patient and his family from an ecological perspective, thus meeting the second objective of the research study. First, the term **quality of life** was described, including: current trends in observing quality of life, definition of quality of life, and multi-dimensional aspects of quality of life. Keeping in mind the

multi-dimensional aspects of quality of life, the comprehensive impact of surgery was discussed to include **physical**, **social**, occupational, economic and **psychological** aspects of functioning.

The most obvious **physical** changes caused by a laryngectomy are the presence of a permanent tracheo-stoma and loss of natural voice. Physical characteristics of a laryngectomy were mainly divided into respiratory, swallowing and sensory problems following surgery. These physical effects have potentially severe social implications, not only for the patient, but also for family members.

The various levels on which the laryngectomy experience could affect the patient's **social** functioning were 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 demonstrated that the patient is vulnerable to depression in his attempt to work through various experiences of loss following surgery.

Recognition of the comprehensive impact of a laryngectomy will necessarily lead to an awareness of the need for support and aftercare for these patients within their family system. These needs will be described in the following chapter.

CHAPTER 4

SOCIAL WORK SUPPORT AND AFTERCARE

4.1 INTRODUCTION

The previous chapter presented an overview of the comprehensive impact of a laryngectomy on the lives of patients and those close to the patient, focusing on **medical**, **social** and **emotional** aspects of functioning. It showed that these patients and their relatives are in need of social support and aftercare in order to cope effectively with the impact of this operation when facing the challenges of daily life. Social work involvement is required to offer adequate support and aftercare to these patients within the context of a hospital setting.

To meet the third objective of this research study, this chapter will describe how support for laryngectomy patients can be utilised as part of an aftercare programme when they attend the follow-up clinic at the hospital, with specific reference to the use of **support groups**. Focus will be on the patient's post-operative rehabilitation, describing speech, vocational and psycho-social rehabilitation. The laryngectomy patient's successful re-integration into society will depend on his successful post-operative rehabilitation. **Social work support** and **aftercare** which is essential for the patient's post-operative rehabilitation will therefore be discussed.

4.2 POST-OPERATIVE REHABILITATION

This section describes the laryngectomy patient's post-operative rehabilitation process.

4.2.1 Definition of rehabilitation

In promoting an understanding of the comprehensive impact of and limitations due to a laryngectomy on the life of the patient and his relatives, a definition of rehabilitation is needed to describe and understand the patient's adjustment to his post-operative status.

Goldberg (1975:5) defined the laryngectomy patient's rehabilitation outlook as an indication of optimism or pessimism about the future and his chances of making adequate adjustments to limitations caused by the incidence of larynx cancer. Doyle (1994:262) observed that all laryngectomy patients have to face some degree of change or restriction following surgery. An awareness and understanding of the comprehensive impact of surgery will be helpful in making satisfactory adjustments. Ideally this post-operative adjustment should involve a process of dynamic co-operation between the patient and health care professionals.

Defining the term rehabilitation adds to a better understanding when describing the goal of rehabilitation.

4.2.2 Goal of rehabilitation

Literature (Casper & Colton, 1998:52-53; Deshmane *et al.*, 1995:128-129; Doyle, 1994:262; Keller, 1985:657) described the **goal** of rehabilitation for the patient as the return to a previous level of functioning to be re-integrated into society. By achieving the above-mentioned goal, the ideal would be that the patient will be able to return successfully to a more active and social lifestyle in relation to his family, occupation and community (Keller, 1985:657).

The goal of rehabilitation and Keller's remark link well with the ecological perspective, which holds that although a person is exposed to change (laryngectomy), he has to adapt to those changes (comprehensive impact of laryngectomy) in order to cope, survive or to interact successfully with various systems (family, work, community). The ideal outcome of this process would be the positive growth of the patient (Meyer & Mattaini, 1995:21), in other words, the successful rehabilitation of the patient.

Knowledge of the goal of the laryngectomy patient's rehabilitation process will underscore the need for a rehabilitation programme to best fulfil these patients' individual rehabilitation expectations.

4.2.3 Need for an individualised rehabilitation programme

The need for rehabilitation of the laryngectomy patient will be intensified by the following factors: **first**, physical and psychological mutilation following surgery will require intensive rehabilitation efforts (Kleinsasser, 1988:191); **second**, the high rate

of cure and the patient's improved prognosis will increase the demand for rehabilitation (Frith *et al.*, 1985:475) and **third**, association with previous substance abuse may result in a difficult rehabilitation period (Byrne *et al.*, 1993:174). This is specifically applicable to patients with a diagnosis of larynx cancer as tobacco and alcohol use is directly linked to etiological factors that cause larynx cancer, as described in chapter 2.

Most patients face a difficult rehabilitation process after surgery (Landis *et al.*, 2003:341). Salva and Kallail (1989:300-301) requested counsellors to be prepared to meet the patient's unique needs, by having sufficient knowledge and an understanding of the comprehensive impact of treatment. Skill of team members is required to recognise and address these specific needs of patients (Graham, 2004:125, 134). Landis *et al.* (2003:341) viewed the task of the rehabilitation team as being able to find simple ways to address the patient's identified needs in order to improve his quality of life. By keeping the unique needs of the patient in mind, the counsellor will be in a position to adapt the rehabilitation process according to the individual needs of the patient (Salva & Kallail, 1989:300). In this way, counsellors will be able to meet the need for an individualised programme as patients' coping strategies may vary (Doyle, 1994:261-262; Relic *et al.*, 2001:514).

After an individualised rehabilitation programme has been developed to best meet the needs of these patients, the next question will concern the start of this process of rehabilitation.

4.2.4 When to start rehabilitation

Various authors (Baker & Cunningham, 1980:24; Belch & Beamish, 1992:62; Casper & Colton, 1998:35; Kleinsasser, 1988:256; Natvig, 1983:161) agreed that rehabilitation should be initiated prior to the start of the patient's treatment. Ideally the family and the counselling team should be involved in the rehabilitation process from the time of diagnosis (Belch & Beamish, 1992:62; Relic *et al.*, 2001:517).

Rehabilitation has to start in time in order to achieve the best results in the patient's rehabilitation programme. The role of teamwork in the rehabilitation process will be described subsequently.

4.2.5 The role of teamwork in rehabilitation

To achieve a comprehensive rehabilitation model, the involvement of various team members in the long term and co-ordination of team efforts are necessary (Belch & Beamish, 1992:61; Casper & Colton, 1998:35, 52; Doyle, 1994:262; Graham, 2004:126; Zeine & Larson, 1999:60). Motivation for an inter-disciplinary approach is based on the complexity of the effect of surgery which has an impact on the patient's **medical**, **social** and **psychological** functioning (Casper & Colton, 1998:52). Apart from including team members of various disciplines, it was recommended that the patient, family members, friends and other patients who have experienced this operation form part of the rehabilitation team.

From the above it can be concluded that inter-disciplinary teamwork is essential for a laryngectomy patient's successful comprehensive post-operative rehabilitation plan. Principles in the rehabilitation process will be described next.

4.2.6 Principles of rehabilitation

Of the utmost importance for the professional team member is an awareness of the unique principles which need to be followed when working with the laryngectomy patient.

A major principle to be taken into account when rendering services to the laryngectomy patient, is that the patient should be directly involved in the rehabilitation process (Ruiz & Crevier-Buchman, 2000b:165). However, the expectations of the spouse should also be included in rehabilitation programmes (Mathieson *et al.*, 1991:161). This is extremely important as it takes into account the characteristics of the ecological perspective which describes the person's interaction with various systems, including his family and environment (Sheafor *et al.*, 2000:91; Germain & Gitterman, 1996:5-6; Meyer & Mattaini, 1995:19).

Keith and Darley (1986:131) drew our attention to another principle of rehabilitation of the laryngectomy patient by the warning that rehabilitation should consist of more than only arranging plans for the patient's discharge from hospital. Savary (1977:1521) remarked: "... medical care is not finished after surgery ...

Laryngectomees cannot be left to struggle with their distress alone, and an effort should be made to help them ... it is a way to keep medicine humane”.

Team members’ knowledge of the definition, goal, need for rehabilitation, time frame, role of teamwork as well as various principles in the rehabilitation of laryngectomy patients, will add to their awareness of contributing factors influencing the patient’s post-operative functioning along the road of rehabilitation.

4.2.7 Factors influencing post-operative rehabilitation

Factors influencing the patient’s post-operative rehabilitation process can be divided into **medical**, **social** and **psychological** factors:

4.2.7.1 Medical factors

Pre-operative counselling of the patient and family can include an explanation of the patient’s diagnosis and implications of surgery (DeSanto, 1994:43; Stam *et al.*, 1991:54; Ulbricht, 1986:132).

4.2.7.2 Social factors

The availability of and satisfaction with **social support** systems have the potential to contribute positively towards the patient’s post-operative adjustment and rehabilitation (DeSanto, 1994:43; Natvig, 1983:160; Ramírez *et al.*, 2003:97; Stam *et al.*, 1991:54; Ulbricht, 1986:132).

4.2.7.3 Psychological factors

Psychological factors that can influence the laryngectomy patient’s post-operative adjustment in a positive way may include the patients’ cognitive approach towards dealing with cancer by gaining control over their lives again; coping abilities which can be more important than the severity of surgical treatment; previous psychological state, as well-adjusted patients should adapt reasonably well, and the patients’ ability to maintain their sense of identity (Blood *et al.*, 1993:764; Ely, 1991: 4046; Stam *et al.*, 1991:54; Ulbricht, 1986:132).

These factors which may influence the patient’s post-operative rehabilitation are presented in table 4.1. This will add to a clearer understanding of factors influencing post-operative rehabilitation.

Table 4.1: Factors promoting the patient's post-operative rehabilitation

Medical factors	Social factors	Psychological factors
<ul style="list-style-type: none"> • Explain the diagnosis and implications of surgery 	<ul style="list-style-type: none"> • Availability of and satisfaction with social support 	<ul style="list-style-type: none"> • Cognitive approach towards dealing with the diagnosis • Coping abilities • Previous psychological status. • Ability to maintain sense of identity

Positive **medical**, **social** and **psychological** factors in combination with one another will be of value to promote the laryngectomy patient's post-operative adjustment and therefore rehabilitation. Care has to be taken of factors which may limit the patient's post-operative rehabilitation process.

4.2.8 Factors limiting the rehabilitation process

Limited success of rehabilitation attempts can be ascribed to various possible reasons, for example lack of time, lack of available facilities, doctors who focus solely on medical treatment and cure of the patient, lack of the caregiver's understanding of the positive qualities of the rehabilitation programme, and pre- and post-operative counselling or socio-economic inability of the patient to make use of available rehabilitation resources (Baker & Cunningham, 1980:23; Deshmane *et al.*, 1995:128).

A discussion of the factors influencing the rehabilitation of the laryngectomy patient was necessary in order to add to a better understanding of the process of the patient's rehabilitation. A discussion of the focus points of an ideal rehabilitation model for this target group of patients will now be presented.

4.2.9 Focal points in rehabilitation

Zeine and Larson (1999:51) acknowledged that previously, rehabilitation was focussed on attempts to improve the patient's prognosis or to develop post-operative communication ability (Renner, 1995:215; Richardson & Bourque, 1985:84; Ross, 2000:14). Currently rehabilitation attempts focus on **total rehabilitation** of patients which include overall satisfaction with life and a sense of well-being (Renner, 1995:215; Ross, 2000:14).

For different people rehabilitation will focus on different aspects of aftercare. Many authors (Belch & Beamish, 1992:62; Graham, 2004:130-131; Maas, 1991:1374-1375; Natvig, 1983:155) argued for a rehabilitation model that includes **speech**, **vocational** and **psycho-social** aspects in order to address the comprehensive impact of a laryngectomy. These components of rehabilitation are interrelated and serve as an indicator of the degree of post-operative stress experienced after surgery. In other words, the less one rehabilitates, the more stress will be experienced (Maas, 1991:1375).

Ideally, rehabilitation should go beyond speech rehabilitation and should include a greater understanding of the patient “as a total person” within the context of the family system (Baker & Cunningham, 1980:23; Renner, 1995:219). This supports the ecological perspective in social work practice, as it refers to the person interacting with various systems within his environment (Germain & Gitterman, 1996:5-6; Meyer & Mattaini, 1995:19; Sheafor *et al.*, 2000:91).

Graham (2004:126, 134), Zeine and Larson (1999:51-52) and Baker and Cunningham (1980:23) supported a **comprehensive approach** to achieve **total rehabilitation**. Graham felt that input by various team members should best benefit the comprehensive rehabilitation approach by involving an inter-disciplinary team. Practical aids such as written material, educational videos, support groups, speech therapy sessions and regular family conferences are suggested. In a comprehensive approach, rehabilitation needs to be extensive in order to treat “the whole person” (Baker & Cunningham, 1980:23). A comprehensive rehabilitation programme should preferably include physiological, **psychological**, **social** and **medical** aspects of functioning (Belch & Beamish, 1992:62).

In other words, the suggested model for a comprehensive rehabilitation programme is in accordance with the description of the comprehensive impact of a laryngectomy which was discussed in the previous chapter. The components of this comprehensive rehabilitation model will therefore include **medical**, **social** and **psychological** aspects.

4.2.10 Components of rehabilitation

Graham (2004:130-131) and Maas (1991:1374-1375) supported the comprehensive rehabilitation model described earlier by referring to three forms of rehabilitation of the laryngectomy patient, namely **speech**, **vocational** and **psycho-social** rehabilitation.

4.2.10.1 Speech component in rehabilitation

Maas (1991:1375) pointed out that speech rehabilitation may interact with vocational and psycho-social rehabilitation in a positive way and vice versa as illustrated in figure 4.1.

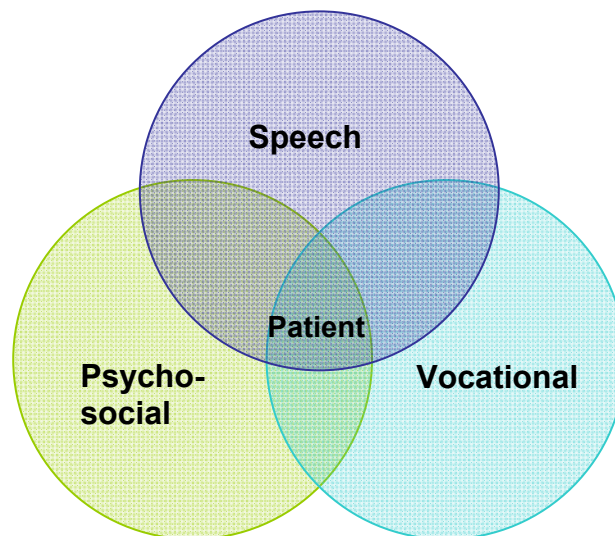


Figure 4.1: Components of rehabilitation

(a) When to start speech rehabilitation

There is general agreement among authors (Baker & Cunningham, 1980:26-27; Depondt & Gehanno, 1995:35; Wei & Sham, 2000:56) that speech therapy training should start as soon as possible after healing of surgical wounds, after radiotherapy treatment, when the patient is medically stable and after normal feeding has started. The process of speech rehabilitation should not be delayed in order to avoid feelings of social isolation (Depondt & Gehanno, 1995:35). Baker and Cunningham (1980:24, 27) stressed that this process ideally should be initiated pre-operatively in the form of information giving and counselling, but acknowledged that there was controversy

about this. They also suggested that the first visit of the rehabilitation team to the patient should include at least a brief description of the new methods of speech production.

(b) Methods of speech with specific reference to trachea-oesophageal speech

The patient has to learn to speak without the use of the vocal folds as normal voice production has been eliminated (La Borwit, 1978:5253; Smithwick *et al.*, 2002:204). Some patients may prefer to stay mute. Various types of post-operative alaryngeal speech are available such as oesophageal speech, speech using an electrolarynx, trachea-oesophageal speech, or non-verbal methods of communication such as writing, gesturing, mouthing words, miming or signing, eye blinks and hand signals (Carr *et al.*, 2000:39; Eadie & Doyle, 2004:753; Schuster *et al.*, 2003:211; Smithwick *et al.*, 2002:204; Stewart *et al.*, 1998:143, 147).

Carr *et al.* (2000:42-43) emphasised the importance of the patient's informed decision regarding post-operative speech, following proper pre-operative counselling including a brief description of the various speech methods (Baker & Cunningham, 1980:24-25). This will result in a feeling of control and independence, as the patient may already experience loss of control after surgery, as described in the previous chapter. It is important however, that the chosen method of speech should be compatible to the patient's lifestyle.

Patients communicating primarily by writing, should be counselled about a more effective and satisfying method of speech, which will promote easier re-integration in society (Clements *et al.*, 1997:496; Depondt & Gehanno, 1995:35). Baker and Cunningham (1980:24) warned that whispering should be avoided as it may hinder the development of oesophageal speech. According to Ward, Koh, Frisby and Hodge (2003:46) the majority of patients maintain the use of the initial method of speech that was offered post-operatively.

At Tygerberg Hospital where the research project is conducted, the **trachea-oesophageal speech method** is taught. Trachea-oesophageal speech is seen as the closest to natural speech, the most acceptable method of alaryngeal speech, and the most pleasant and most intelligible and satisfactory of all speech methods. The quality of speech is higher and the ability to communicate over the phone is better

(Carr *et al.*, 2000:41; Clements *et al.*, 1997:494-496; Eadie & Doyle, 2004:753; Schuster *et al.*, 2004:65; Smithwick *et al.*, 2002:204). Clements *et al.* (1997:496) commented that these benefits should be considered in the procedure of choice for speech rehabilitation.

A further benefit of the trachea-oesophageal speech method is that after a relatively simple surgical procedure speech is learnt rapidly (Clements *et al.*, 1997:496). The surgical procedure involved is described by Doyle (1994:190) as the surgical creation of a fistula between the trachea as primary airway and the oesophagus as vicarious voicing source.

To produce speech, a speech prosthesis (Provox) is inserted during the process of surgery (laryngectomy). During follow-up visits medical personnel will assess the possibility of leakages, in which case the prosthesis has to be replaced. Regular maintenance of the prosthesis is important.

Pulmonary air serves as the power for speech production. The amount of air available and the fact that the pulmonary air source is under greater voluntary control, contributes towards the production of this method of speech (Doyle, 1994:190). This process is demonstrated in figure 4.2.

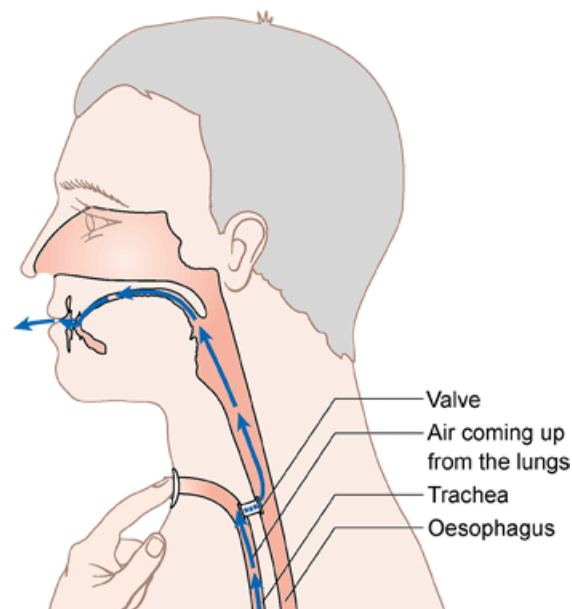


Figure 4.2: An illustration of the process of speech production in a laryngectomy patient

[Source: CancerHelp UK. 2002. www.cancerhelp.org.uk/help/default.asp]

Carr *et al.* (2000:39) mentioned that some patients do not master any of these speech methods, while Dhooper (1985:224) also emphasised that many patients failed to achieve trachea-oesophageal speech. According to Byrne *et al.* (1993:174), failure in satisfactorily achieving alternative speech methods may add to the patient's experience of loss following surgery.

Patients need to meet certain criteria in order to master the trachea-oesophageal speech method. According to Casper and Colton (1998:114-116) these should ideally include medical, emotional and personal stability.

- **Medical criteria** should include healing from previous surgery, recovery from side-effects of radiation therapy, medical stability, adequate size of tracheostoma, and a healthy common wall between the trachea and oesophagus to accommodate the prosthesis.
- **Emotional stability** includes the patient's degree of motivation to follow the speech therapy programme. Patients with substance abuse may not be able to keep their appointments at hospital or maintain the speech device.
- **Personal factors** such as the patient's eyesight; manual dexterity and control; habits of general hygiene and general alertness must also be taken into account.

(c) Benefits of successful speech rehabilitation

Schuster *et al.* (2003:218) described potential benefits of successful speech rehabilitation as the improvement of the patient's emotional well-being, social integration and quality of life. Social isolation will also be reduced and self-esteem improved (Byrne *et al.*, 1993:174). In the words of Depondt and Gehanno (1995:35) "... it will allow the patient to rapidly find his place in society".

From the above it is clear that successful speech rehabilitation will improve the patient's post-operative **social** and **psychological** adjustment and will result in a decrease of the patient's experience of loss.

(d) Prognostic factors that influence success in speech rehabilitation

Knowledge of the various factors contributing towards the patient's successful speech rehabilitation will enable team members to focus better on these factors, which in turn will improve the patient's re-entry into social life.

In a study of 116 laryngectomy patients, Frith *et al.* (1985:475-483) investigated the relationship between oesophageal speech proficiency and surgical, biographical and social factors. The findings of the study showed that apart from medical or biological factors, non-medical factors also play an important role in successful speech rehabilitation of laryngectomy patients. These factors can also be referred to as **social** and **psychological** factors. This agrees with the description of the comprehensive impact of surgery, previously discussed in chapter 2 and it also concurs with the elements to be included in the rehabilitation process, discussed earlier in this chapter. As this study will concentrate on **social support** and **aftercare** for laryngectomy patients, the emphasis will be on a description of the **social** and **psychological** factors which contribute towards the patient's successful rehabilitation.

Social factors affecting rehabilitation may include the age of the patient and availability of social support:

- The **age** of the patient is important, as the older the patient, the less likely he will be to learn speech due to probable depression, loss of physical (hearing ability) or mental abilities, or motivation (Richardson & Bourque, 1985:85). The elderly patient may feel that there is no point in learning speech (Maas, 1991:1374; Stewart *et al.*, 1998:147).
- The greater the degree of **support** from **family** and **friends**, the more likely the patient will be to learn speech as it may increase the need to speak (Dhooper, 1985:224; Maas, 1991:1374; Richardson & Bourque, 1985:85, 95). **Spouses** will be in a position to force the patient to verbalise his thoughts and feelings, provide affection and give positive feedback (Richardson & Bourque, 1985:84). Byrne *et al.* (1993:174) suggested that speech rehabilitation should be combined with available support resources. Patients with limited social contacts may be prevented from learning speech (Frith *et al.*, 1985:476). The patient's involvement with **other laryngectomy patients** is also very

important, providing additional support for learning speech (Richardson & Bourque, 1985:96).

Psychological factors may include the patient's level of motivation, attitude, problem-solving behaviour and hope for the future:

- Depondt and Gehanno (1995:35) agreed that learning of post-operative speech is difficult and therefore may require a lot of effort and **motivation** to succeed. Involvement in support groups is also useful in increasing a patient's motivation to learn speech (Frith *et al.*, 1985:481; Richardson & Bourque, 1985:84).
- The **positive attitude** of the patient is important when learning speech, as the more positive the experience, the more likely the patient will be to learn speech (Richardson & Bourque, 1985:84, 96). Anticipation of failure and evaluating speech as not socially acceptable will result in the patient speaking less and being less intelligible. On the other hand, a positive attitude (Richardson & Bourque, 1985:84, 96) will result in the patient being more likely to learn speech.
- When the patient feels that the family is **uncomfortable** (Richardson & Bourque, 1985:84, 96) with him, it may increase his feelings of rejection, inferiority, depression and social isolation that will result in limited efforts to learn speech (Richardson & Bourque, 1985:84, 95). This will lead to more limited communication efforts and increase social isolation.
- **Problem-solving behaviour** which refers to the patient's ability to cope with the fact that he will no longer have normal speech ability, which in turn will motivate the patient to learn alaryngeal speech (Graham, 2004:130; Maas, 1991:1374).
- **Hope for the future** and desire to **return to previous employment** will improve the patient's motivation to learn speech (Frith *et al.*, 1985:482; Goldberg, 1975:6; Richardson & Bourque, 1985:85), while lack of motivation will have a negative effect on speech rehabilitation attempts (Dhooper, 1985:224).

Other factors which could promote speech rehabilitation may include:

- **Clinical factors** such as voice therapy sessions, involvement in a support group or visits from a previously operated patient (Richardson & Bourque, 1985:85).
- Gender differences can be seen as an **additional factor** determining successful post-operative speech. Richardson and Bourque (1985:85) and Stam *et al.* (1991:52) found that men are more likely to learn speech because the sound of the new voice may lead to self-consciousness or embarrassment in women as it has a lower pitch. Women are often mistaken for men and this could add to their concern about loss of their femininity.

Baker and Cunningham (1980:24) warned that it is important not to give false hope to patients regarding speech rehabilitation. In cases where the patient is not prepared for speech failure, it may cause psychological complications.

From the above discussion it is clear that **social support** plays an important role in the post-operative rehabilitation process of the laryngectomy patient. Successful speech rehabilitation may add to successful vocational and psycho-social rehabilitation as Maas (1991:1375) described earlier.

4.2.10.2 Vocational component in rehabilitation

Maas (1991:1374) defined vocational rehabilitation as job satisfaction, with reference to the patient's former job. Factors determining successful re-employment will include socio-economic status (residence, education, social groups), problem-solving behaviour and age (Graham, 2004:130; Maas, 1991:1374). Socio-economic factors are highly correlated as high socio-economic status will result in a greater potential to be re-employed (Natvig, 1983:370). A good coping ability will also enable the patient to return to work. Age will also determine the patient's re-employment. Older patients may choose to retire after being diagnosed and treated or may already be retired at the time of treatment. As discussed under statistics of larynx cancer in chapter 2, it is mostly elderly male patients who are already pensioners or become pensioners after surgery who are affected.

4.2.10.3 Psycho-social component in rehabilitation

Maas (1991:1375) distinguished between social and psychological rehabilitation, where the first-mentioned refers to the extent to which patients will be able to resume their former level of functioning with specific reference to social contacts. Graham (2004:131) and Maas (1991:1375) defined psycho-social rehabilitation in terms of how successfully the individual resumes pre-operative social life and maintains social relationships.

From the above discussion of speech, vocational and psycho-social rehabilitation, it can be concluded that rehabilitation of the laryngectomy patient is a process by which the patient learns to adapt to the consequences of surgery and learns to return to a previous level of functioning.

Although a combination of **medical**, **social** and **psychological** factors is required to contribute to the patient's post-operative rehabilitation, this study will focus mainly on a discussion of the **social factors** as part of an aftercare programme for laryngectomy patients within a hospital setting. Social support is referred to as the most important social factor promoting the patient's rehabilitation process.

4.3 SOCIAL SUPPORT

Social support as factor promoting the patient's post-operative rehabilitation will be described.

4.3.1 Need for social support

The need to obtain adequate support for the laryngectomy patient and his family is described in literature and may include any of the following motivations (Armstrong *et al.*, 2001:16; Blanchard, 1982:240; Depondt & Gehanno, 1995:36; Herranz & Gavilán, 1999:994; Lee-Preston *et al.*, 2004:437; Richardson *et al.*, 1989:283):

- To deal with anxiety, fear and stress experienced by patients due to the diagnosis and treatment of larynx cancer.
- To deal with the psychological impact of surgery that has the potential to be experienced as mutilating by the patient.
- To adjust to the laryngectomy experience.

- To improve self-confidence and satisfaction.
- To deal with difficulties in interpersonal relationships.
- To face the multiple problems in daily life.
- To serve as a valuable source of supportive and informative help.

The need for social support is intensified due to various reasons such as:

- At the same time that the cancer patient needs social support, the fear, stigma and disfigurement associated with cancer and its treatment frequently result in **difficulties in interpersonal relationships** (Richardson *et al.*, 1989:283). This may also reduce the patient's use of available support systems (Doyle, 1994:262).
- The experience of a laryngectomy has the potential to result in a significant **decrease** in social acceptance, social activity, sexual activity and the ability to communicate adequately (Deshmane *et al.*, 1995:128-129).
- The laryngectomy experience can be seen as a **lonely experience**. This operation is seldom performed and patients seldom know other patients who have had such an operation (Ross, 2000:14).
- The patient's family and friends are **not always capable** of supporting these patients as they are not always equipped to deal with the side-effects of the operation (Blanchard, 1982:240).
- The patient's post-operative inability to talk may **threaten** the **availability** of social support resources. These resources are essential for the patient's post-operative adjustment and rehabilitation (Richardson *et al.*, 1989:284).

The need for social support was described from the viewpoint of **social** and **psychological** benefits patients may gain by utilising social support.

4.3.2 Positive value of social support

Now that it is clear that social support is needed for the laryngectomy patient's post-operative rehabilitation, a description of the positive value of support will follow.

4.3.2.1 Improvement of post-operative adjustment

Literature (Ramírez *et al.*, 2003:96; Herranz & Gavilán, 1999:994; DeSanto, 1994:43; Eadie & Doyle, 2005:122) acknowledged the positive connection between social support and the improvement of post-operative adjustment following laryngectomy. According to Blood *et al.* (1994:20, 22) laryngectomy patients who have experienced social support perceived themselves as being better adjusted to their situation than those who experienced no social support.

Literature refers to various **components** of support contributing to a patient's efforts to successfully make the necessary adjustments after surgery. Stam *et al.* (1991:39) and Richardson *et al.* (1989:290) referred to the **crucial** role of support in patients' post-operative adjustment and rehabilitation; Blood *et al.* (1994:20) included the factor of **stability** for effective long-term adjustment while DeSanto (1994:43) emphasised patients' **satisfaction** with their social support systems.

Social support has the potential to improve the laryngectomy patient's post-operative adjustment to the comprehensive impact of surgery, as has previously been described. A description of improvement of the patient's quality of life will subsequently be presented.

4.3.2.2 Improvement of quality of life

The definition of the concept of quality of life described in the previous chapter indicates that quality of life can be regarded as multi-dimensional and subjective as it describes the patient's degree of satisfaction with his or her post-operative status. It includes the **physical**, **social** and **psychological** aspects of the patient's functioning.

Birkhaug *et al.* (2002:198) and Stam *et al.* (1991:54) referred to the positive relationship between social support from health care professionals and an improved experience of quality of life for these patients. An extended network of support as well as the patient's satisfaction with available social support systems will contribute to better post-operative adjustment (Birkhaug *et al.*, 2002:198; Stam *et al.*, 1991:54).

With reference to the definition of quality of life, it can now be concluded that social support has the ability to contribute to the patient's physical, social and psychological post-operative functioning. A description of the benefits of social support on the patient's overall functioning, including **physical**, **social** and **psychological** functioning will follow.

4.3.2.3 Minimising the effect of surgery

Richardson *et al.* (1989:291) pointed out that social support can be helpful in minimising **physical** and **psycho-social** effects of surgery and in experiencing less distress. Limitation of physical and psycho-social effects of surgery is extremely important for the laryngectomy patient, as this surgical procedure has the potential to cause major disability. Blood *et al.* (1994:19-20) agreed with this viewpoint and referred to the importance of social support systems to enable the patients to master difficulties and crises regarding their medical condition. The quality and quantity of such support will also be important in reaching this aim to minimise the effects of surgery.

(a) Medical benefits

Social support may improve the patients' adjustment to difficult medical regimes and improve their compliance with requirements of the health care team (Blood *et al.*, 1994:20).

(b) Social benefits

Devins *et al.* (1994:614) referred to the value of social support which encourages and supports patients to maintain involvement in valued relationships, activities and interests.

(c) Psychological benefits

Literature (Belch & Beamish, 1992:61; Depondt & Gehanno, 1995:35; Doyle, 1994:262; Herranz & Gavilán, 1999:994; Ramírez *et al.*, 2003:96) described the psychological value of social support, such as: improvement of self-confidence and satisfaction, ability to adapt in times of crisis and significant change, avoidance of reactions such as regression and depression, and assistance for patients diagnosed with larynx cancer.

Social support can potentially contribute to an improvement of the laryngectomy patient's quality of life. This will benefit the patient's **medical**, **social** and **psychological** functioning. This description ties in with the concepts of the comprehensive impact of surgery and aspects of quality of life.

4.3.2.4 Promoting speech and rehabilitation efforts

Richardson and Bourque (1985:95) and Ulbricht (1986:131) referred to the positive relationship between social support and the patient's motivation to acquire post-operative speech. Positive exposure to social support will increase the patient's motivation to learn speech.

Social support is of great value in promoting the laryngectomy patient's post-operative rehabilitation process, as it has the potential to improve the patient's post-operative adjustment, improve the patient's overall quality of life, minimise the effect of surgery, improve the patient's quality of life (**physical**, **social** and **psychological**) and to promote speech and rehabilitation efforts of team members.

4.3.3 Target groups to benefit from social support

The following categories of laryngectomy patients have been found to be specifically in need of social support:

- **Young patients** as they have poorer emotional well-being and increased anxiety (Lee-Preston *et al.*, 2004:437). This may be due to the possibility of having more to lose with specific reference to employment and financial income, due to the diagnosis and treatment of cancer. Statistics of the incidence of larynx cancer indicate that there is an increase in the number of younger patients.
- **Spouses of patients** as they often neglect their own need to cope with personal fears and anxieties and fail to understand their role in the patient's return to emotional and physical health (Blanchard, 1982:240).
- **All laryngectomy patients** but especially those in frail psychological condition. The latter may include patients with tobacco and alcohol habits or who are from a low cultural and socio-economic environment (Herranz &

Gavilán, 1999:994). Substance abuse was described as a contributory etiological factor to the incidence of larynx cancer.

The above-mentioned target groups who can potentially benefit from social support are identified in terms of the ecological perspective, as it refers to the person in relation to his support system on a *situational* (laryngectomy experience); *micro* (family system); *meso* (other laryngectomy patients) and *macro* level (hospital), as described by Compton, Galaway and Cournoyer (2005:52-53).

The above discussion shows that all laryngectomy patients and their relatives are in need of social support in order to adapt to the comprehensive impact of surgery. It is also necessary to consider several difficulties that may arise in maintaining the required social support.

4.3.4 Difficulties in maintaining support

Richardson *et al.* (1989:284) referred to contributing factors when reporting on the difficulties that laryngectomy patients may experience in maintaining social support. **First**, physical implications of surgery may cause the support person to become impatient and in reaction to this, the patient may experience embarrassment. **Second**, people who are potential sources of support may provide negative feedback to the patient, which has the potential to emphasise the disability. **Third**, patients may also find it difficult to maintain social support once they have acquired it. After surgery, patients experience an initial phase of inability to communicate verbally due to loss of voice. Communication problems may have a negative influence on the availability of the patient's social resources as other people may be threatened by the patient's inability to talk.

Knowledge of the importance and dependability of social support for the laryngectomy patient and his family's post-operative rehabilitation was discussed. It was clearly stated that the physical effect of the operation has the potential to contribute to the patient's need for support. It is not always easy for role players who provide this support, to maintain it. A discussion of the difficulties in maintaining social support was presented.

A description of the various sources of social support is necessary in order to utilise these support systems with knowledge and insight, to best meet the needs of patients and their relatives.

4.3.5 Sources of social support

Social support refers to the many different ways in which people can possibly assist one another and may include emotional encouragement, advice, information, guidance, tangible aid, or concrete assistance (Tracy & Whittaker, 1990:462). Social support can be provided spontaneously through the natural helping networks of family and friends or through professional intervention. Tracy and Whittaker (1990:461) remarked that clinical practitioners increasingly recognise the importance of informal social support resources and can use it as a focal point in service delivery. These support sources may support, weaken, substitute for, or can be complementary to, the help offered by professionals.

A social support network therefore refers to a set of relationships that provide nurturance and reinforcement for coping with life on a daily basis (Tracy & Whittaker, 1990:462). This is especially applicable in the case of laryngectomy patients who are in need of support as described earlier.

4.3.5.1 Ecological perspective on sources of support

According to Compton *et al.* (2005:352), Meyer and Mattaini (1995:19, 26) and Tracey and Whittaker (1990:467), the ecological perspective enables social workers to focus on a person's psycho-social functioning by means of a **systematic approach** with the use of the ecomap. Therapists will be able to gather information about social and environmental resources in a more systematic manner. It is also emphasised that a person operates **in interaction** with his or her **environment** as one is not separated from the environment. The social worker will therefore be in a position to **organise** the complexity of relationships and interaction in that person's world by using the ecological perspective.

4.3.5.2 The use of the ecomap from an ecological perspective in social work practice

As no person can be understood apart from his social context, the ecomap represents a graphic, visual, concrete and holistic picture or diagram of social interaction between a person and various systems in his environment (Compton *et al.*, 2005:352; Meyer & Mattaini, 1995:18-19; Tracey & Whittaker, 1990:463).

The ecomap not only clearly illustrates the major **systems** to be included in a person's family life, but can also indicate the **quality** of interaction or relation between systems. The flow of energy is clearly illustrated, namely whether there is a strong, tenuous, stressful or conflicting relationship. By this, it is possible to visually present an overview of the patient and family in their specific situation. Conflict or deficiencies can easily be identified and it will help to identify where to mediate and mobilise resources (Compton *et al.*, 2005:352-353; Tracey & Whittaker, 1990:463). In the words of Compton and Galaway (1979:301), "... it maps in a dynamic way the ecological system".

Literature (Compton *et al.*, 2005:358; Meyer & Mattaini, 1995:25-26; Tracey & Whittaker, 1990:463,467,469) described a wide spectrum of uses of the ecomap in social work practice. As the intention of this study is to describe and explore laryngectomy patients' need for support, the use of the ecomap will be explained within this context.

Tracey and Whittaker (1990:463) indicated the use of the ecomap in a wide variety of practice settings. As an example, Compton and Galaway (1979:305) referred to the creative use of the ecomap by social workers in a rehabilitation programme in a medical setting as it can help patients and families to objectively assess changes to be made in their lives following hospitalisation. On the one hand, patients will be in a position to mourn interests and activities which may be lost, and on the other hand they will be able to identify available and new sources of support. This can be a very helpful aid for laryngectomy patients who have to deal with various experiences of loss. It can also assist laryngectomy patients to plan for appropriate compensation for lost activities and to identify possible new resources which could expand the patient's social world.

Although the social network map is currently being developed as an assessment tool and practice technique, it can also help to link formal and informal sources of support. Consistent with the characteristics of the ecological perspectives, it will help patients to become more competent in dealing with their environment and to make the environment more supportive. Other benefits of the use of the ecomap in social work practice may include (Tracey & Whittaker, 1990:467, 469):

- To obtain information about other potentially useful resources as well as the client's perception of these resources;
- To form a better idea of the types of support available to clients, the gaps that exist in support availability, and the resources available or potentially available to fill these gaps; and
- To gather specific, clearly defined, and individualised social support assessment information which will be essential when planning social support interventions.

For the social worker who renders services to laryngectomy patients, the ecomap will be useful to better understand the patient's social environment, and the interaction between the environment and the patient, and will equip the social worker with skills to help create a more supportive environment for them.

4.3.5.3 Identifying possible social support systems

The availability of sources of support is **limited**, due to the physical results of the operation and restriction of the ability to communicate. A study was performed by Richardson *et al.* (1989:283-292) with sixty laryngectomy patients. The purpose of the study was to determine which social environmental factors could possibly minimise the effect of a laryngectomy, as the operation has the potential to result in major disability. The findings of the study confirmed that **different sources** and **types** of social support contribute towards a reduction of **physical** and **psycho-social** dysfunction, and contribute to the learning of new skills to overcome limitations of surgery. Different types of support may result in different outcomes and are valuable and appropriate for the laryngectomy patient's post-operative adjustment. It was also found that each of the different sources of support has its own unique qualities.

Richardson *et al.* (1989:283-292) used a model describing the various categories of support, namely family and friends and such sources of support that are disease-specific, including members of the multi-disciplinary team and peers (patients who had a similar operation). In this research project, the model of Richardson *et al.* will be used to best describe these different sources of support. This model will refer to support from family (including the spouse), other rehabilitated laryngectomy patients and from team members at the hospital, as will be illustrated in figure 4.3.

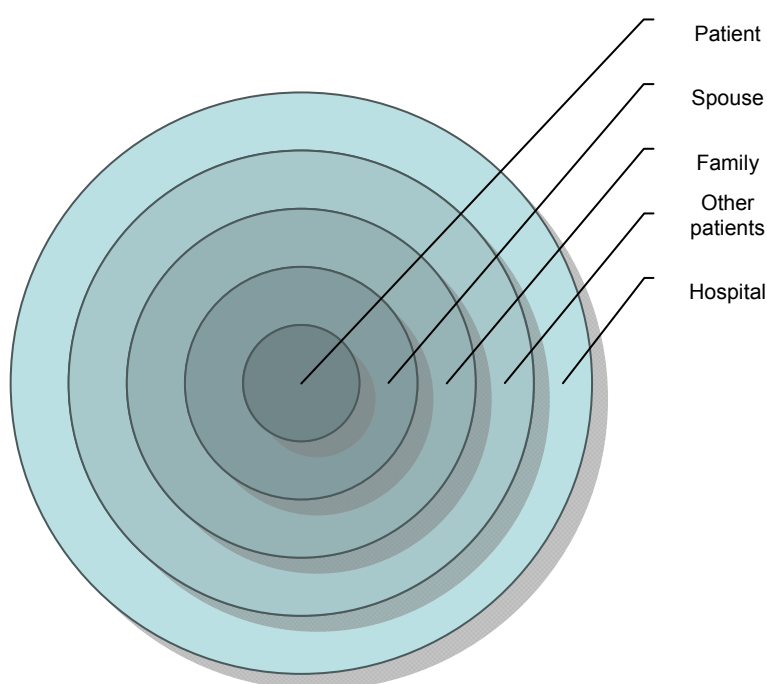


Figure 4.3: Various sources of support within the context of the ecological perspective

The sources of support illustrated in figure 4.3 tie in with the characteristics of the ecological perspective which states that people function in relation to their environment (Sheafor *et al.*, 2000:91). Again, the ecological perspective refers to the person who receives social support in relation to his family system (micro level), all other laryngectomy patients (meso level), and the hospital (macro level). Compton and Galaway (1979:10) described the micro level as the person as an individual or as

part of a family or small group, while the macro level refers to the community or larger social systems.

(a) Support from spouse

Spousal support forms a core element of family support. As statistics show that currently the majority of laryngectomy patients are elderly male patients, the pressure will be on their wives to provide the required social support. On the other hand, etiological factors indicate that an increasing number of females and patients of a younger age are nowadays target groups for a laryngectomy. The spouses of these younger laryngectomy patients may need to offer a different kind of spousal support.

The **importance** of spousal support in the rehabilitation of the patient is described by Mathieson *et al.* (1991:154) and Salva and Kallail (1989:299). The first-mentioned authors stressed inclusion of the spouse as an integral part of the rehabilitation process, whilst the latter found that the attitudes of the spouse and families “can make or break the patient”.

The **benefits** of spousal support are emphasised by Mathieson *et al.* (1991:153-154) and Richardson and Bourque (1985:89) as playing an important role in encouraging the patient to return to his former levels of functioning. Spousal support will contribute to positive rehabilitation of the patient, including acquisition of alaryngeal speech methods, reduction in depression and anxiety levels and an increase in social functioning.

It is clear that spousal support has a great impact upon the laryngectomy patient’s post-operative rehabilitation process.

(b) Support from family

Relic *et al.* (2001:517) stressed the importance of including the family in the treatment and rehabilitation of the patient to potentially improve the patient’s situation. Ideally, this process should start at the stage the patient is diagnosed. Information provided to the family at this stage should include notification of the diagnosis, discussion of treatment options, preparation for possible problems and the importance of cooperation in the rehabilitation process. A study performed by

Herranz and Gavilán (1999:994-997) stresses that patients rated lack of help from family members as the most negative and constant complaint following surgery. Blood *et al.* (1994:20) acknowledge the fact that the request for the caregiver's **social, physical** and **psychological** support can at times be demanding.

Literature (Eadie & Doyle, 2004:753-754; Graham, 2004:134; Mathieson *et al.*, 1991:153; Richardson *et al.*, 1989:283-292) referred to several aspects regarding the **importance** of family support in the rehabilitation of patients. Family support can serve as a critical motivating factor which can promote successful post-operative adjustment. It has the potential to help determine the outcome of the laryngectomy experience and the patient's post-operative quality of life.

Benefits of family support are widely described in literature (Frith *et al.*, 1985:476; Mathieson *et al.*, 1991:153; Relic *et al.*, 2001:516; Richardson *et al.*, 1989:290; Richardson & Bourque, 1985:95; Ulbricht, 1986:131) and may include any of the following: help for the patient to cope with the cancer diagnosis during and after treatment (surgery); adjustment in communication skills as the supportive environment at home may increase the patient's motivation to acquire speech; positive influence on the level of the patient's physical-psycho-social dysfunction; assistance in leading a full and productive life; help in mastering the often extreme demands of chronic illness; and critical factors in the successful adjustment of the patient.

It is clear that family support has the potential to contribute towards improvement of the laryngectomy patient's quality of life. Improvement of the patient's **medical, social** and **psychological** functioning can be a positive outcome of this support.

(c) Support from rehabilitated laryngectomy patients

The benefits of support from rehabilitated laryngectomy patients may include the following:

- Patients with similar experience have **more influence** on other patients' attitudes and emotions (Graham, 2004:131);
- They have the potential to provide **useful information** regarding the appropriateness of feelings, solutions to problems, comments on

communication methods and responses and choices based on personal experience (Richardson *et al.*, 1989:284);

- They **best understand** the needs of the patients and their relatives as they share the same experience (Renner, 1995:219; Ross, 2000:20);
- They serve as a **role model** (Beverly-Ducker, 1991:60) and demonstrate (Gardner, 1971:189) a positive adjustment and rehabilitation as they prove in an enthusiastic and encouraging way that they have mastered their own limitations; and
- Long surviving laryngectomy patients **demonstrate** their current way of living: "... they give little appearance of being handicapped, disfigured, depressed or anxious; rather, they appear to be well adjusted and successful in business and in social activities" (Gardner, 1971:189).

Support from the peer group (other rehabilitated laryngectomy patients) can serve various functions, such as being a source of information, problem-solving and motivating the patient to positive post-operative adjustment.

(d) Support from the hospital during follow-up visits

The patients and their families are in need of support when attending follow-up visits at the hospital, as they may experience a lack of support after leaving the hospital, due to various reasons. The hospital setting has a protective and supportive atmosphere, and is a warm and safe environment (Blanchard, 1982:240; Dhooper, 1985:223; Ulbricht, 1986:133). When leaving the hospital, feelings of fearfulness and isolation may arise (Dhooper, 1985:223; Ulbricht, 1986:133). The patient is confronted with the reality of his situation when entering the outside world (Ulbricht, 1986:133). Leaving the hospital environment may also mean the loss of the support and counselling of the inter-disciplinary team. Support and counselling are essential for the patient's rehabilitation (Blanchard, 1982:240). The patient's feelings of isolation may increase when it is realised that friends and family members may not or cannot offer the required supportive help (Blanchard, 1982:240).

Spouses report difficulties in handling the patient's self-centred demands when at home. This is caused by the change from having received attention as an in-patient in the hospital. Having to cope at home can be frightening and disorientating for the

patient (Evans, 1996:85). Doyle (1994:251) confirmed that patients may have to confront a variety of obstacles after being discharged. In order to promote the patient's recovery and rehabilitation, it is important to eliminate or minimise potential problems which may occur during this post-discharge period. Belch and Beamish (1992:61) also recommended more intensive post-operative follow-up visits to be part of an extended rehabilitation programme.

The need for social support being offered by the hospital as part of an aftercare programme for laryngectomy patients during follow-up visits has been clearly illustrated. The possibility of using support groups as a forum where patients and families who share a similar experience can support one another by discussing problems of daily life after discharge from the hospital is described by Keith and Darley (1986:131). A description of a specific and unique form of support, namely support groups for laryngectomy patients and their families, will now be presented. Support groups can be useful in the reduction of anxiety experienced by patients, as anxiety levels of patients may increase after discharge from hospital (Renner, 1995:219).

4.4 SUPPORT GROUPS

Support being offered by other rehabilitated laryngectomy patients and the hospital as part of an aftercare programme at the follow-up clinic at the hospital, is valuable for these patients' post-operative rehabilitation. As discussed, each source of support has unique qualities and outcomes.

A description of support groups offered to these patients will be presented in the following sections.

4.4.1 Definition of support groups

A definition of support groups will promote understanding of the dynamic aspects of such groups. Support groups are defined by Keller (1985:658) as "patients and/or families meeting under leadership of a professional: a psychologist, nurse, social worker, other professional counsellor, or physician ... these meetings for cancer patients and/or their families to assist them in coping with cancer".

4.4.2 Homogeneous group experience

Graham (2004:132) viewed a homogeneous group in terms of having a **common purpose**, such as to learn post-operative speech skills. However, members of the group are **diverse**. This refers specifically to their gender, age, ethnicity, marital status, occupation, educational background, social status, religion, medical history and time since surgery. For the purpose of this study, a homogeneous group consists of patients who experienced a similar medical condition namely a laryngectomy due to a diagnosis of larynx cancer (Richardson *et al.*, 1989:284).

Inherent to the dynamics of a homogeneous group is the characteristic of “**sharing**” among group members. Sharing refers to a discussion of experienced problems, emotional problems following surgery, and personal experiences (Beverly-Ducker, 1991:60; Jay *et al.*, 1991:937; Mehta & Abrol, 1982:111; Relic *et al.*, 2001:516). Renner (1995:219) and Murrills (1975:55) agreed that the emotional trauma after an operation can best be understood by those who share a similar experience.

Interaction among members of a homogeneous group can be of positive **value** and can be described as follows:

- Patients can **solve problems** by referring to others’ personal experiences of problem-solving, as health care professionals cannot prepare patients for all possible problems that could possibly occur in daily life (Keith & Darley, 1986:131; Lennie *et al.*, 2001:673).
- An opportunity for **emotional support** is provided by meeting others who have been through the same experience and have reached some level of adjustment (Belch & Beamish, 1992:61; Lennie *et al.*, 2001:673; Murrills, 1975:55). Emotional support experienced, include the following:
 - The patient will experience encouragement in the belief that he will improve (Ruiz & Crevier-Buchman, 2000a:173);
 - An opportunity for social comparison and feedback for improvement is provided (Richardson *et al.*, 1989:290);
 - The patient’s positive feeling of well-being is increased by being able to talk to fellow laryngectomy patients (Salva & Kallail, 1989:299);

- A reduction of anxiety levels can be achieved by having the opportunity to meet others “who are in the same boat” (Ross, 2000:20);
- Information provided is trustworthy, as it has the value of being viewed “through a patient’s eyes” (Doyle, 1994:250).

The element of “sharing” among members of this homogeneous group of laryngectomy patients has the potential of supporting laryngectomy patients. Social support is necessary for patients’ adjustment and rehabilitation following surgery, as discussed earlier. With reference to laryngectomy patients, this “sharing” element within support groups is essential and needs to be encouraged, as the most basic human function, the use of natural voice, has been taken away by this operation.

The goal and format of support groups for laryngectomy patients will now be discussed before focusing on the contents of such an aftercare program.

4.4.3 Goal of support groups

Doyle (1994:250) described the goal of support groups as to provide a knowledgeable resource to the patient and his family. Doyle (1994:251) emphasised that support groups need to be encouraged to develop their own objectives for the group. Although contact with hospitals or health care facilities has to be encouraged, group members have to decide upon this co-operation. Graham (2004:132) stressed that the goal of group therapy is, except for learning alaryngeal speech, to increase the patient’s ability to identify and cope with personal stress.

4.4.4 Format of support groups

Casper and Colton (1998:46) acknowledged the fact that support groups may vary in their programmes, to best serve a variety of purposes. Doyle (1994:250) referred to various forms of support groups being applicable in order to achieve the above-mentioned goals of such a group.

While in larger metropolitan areas support groups may be conducted through local cancer care agencies, clinics, community resources or universities, they are mostly offered in smaller centres via the speech therapy facilities. It is preferable that

centres, where a significant number of such operations are performed, should develop their own support groups. This may occur in co-operation with community agencies that share a common interest (Doyle, 1994:251).

The support programme should ideally provide the following (Doyle, 1994:250-251; Casper & Colton, 1998:46):

- Continued **speech therapy** sessions and opportunity to practice the newly acquired speech;
- Informational or **educational** types of **programmes** providing information or information that may not be formally provided by health care professionals regarding cancer in general and the specific diagnosis of larynx cancer;
- Opportunity to **socialise** which is extremely important in the case of laryngectomy patients who may experience a sense of isolation as their opportunity to form relationships is limited;
- Support for patients in order to deal with their **concerns, worries** and **complaints**;
- Support for **family members** of the patient;
- A visitor training programme of well rehabilitated laryngectomy patients, and which could organise sponsorship for a **visitation programme**;
- A resource list of **contact numbers** of people who are available to offer help when needed, including members of **other cancer support groups** that are not specifically for patients with cancer of the larynx.

The discussion of the goal and format of support groups for laryngectomy patients, demonstrates that support groups offer an important component of social interaction among group members. This is extremely important as laryngectomy patients experience loss of natural voice, which may contribute to their feelings of social isolation, withdrawal and depression as described in the previous chapter. Various themes for discussion will now be examined, all to promote the goal of social support given within support groups to benefit these patients.

4.4.5 Themes for discussion in support groups

A variety of themes can be used and are desirable in promoting the process of learning, communication and adjustment (Graham, 2004:132). These themes will deal with quality of life issues which include aspects of physical well-being, functional abilities, emotional and social well-being, and will thus cover the comprehensive impact of a laryngectomy.

4.4.5.1 Educational theme

The purpose of education is to promote a better understanding of various aspects of alaryngeal speech rehabilitation. Topics to be discussed will concentrate on the needs of patients and will include information regarding: medical changes resulting from the operation; medical conditions and procedures; introduction to the various methods of communication; alaryngeal speech products and services; diet; care of the stoma; assessing visual and hearing ability; and the motivation for alaryngeal speech goals. Practical or visual aids such as videos, literature and product samples could be useful to convey this information. Former laryngectomy patients can add to this by sharing their personal experiences with the newly diagnosed patient (Graham, 2004:132).

4.4.5.2 Speech activities theme

The most important goal of speech activities will be to achieve functional and intelligible speech in order for laryngectomy patients to successfully adapt to their home and employment environment (Graham, 2004:132-133). After patients have been instructed regarding a specific method of speech, they will have the opportunity to practice their newly acquired speech with other group members. Graham (2004:133) also emphasised the importance of taking the needs of individual group members into account. A rehabilitated laryngectomy patient can also demonstrate certain aspects of positive achievements to the group, which will benefit other group members as it will strengthen their self-confidence.

4.4.5.3 Social interaction theme

The desire for learning post-operative speech is based on the desire to communicate with others and to experience the positive results of social interaction (Graham,

2004:133). Whilst experiencing possible failure, frustration and negative reactions from others, patients can experience a feeling of safety within the group setting by being “among friends”. It will also teach other laryngectomy patients to be patient, as communication embraces a two-way process, with a good listener and a good speaker. Graham (2004:133) suggested the practical idea of using topics to stimulate interaction, and referred to the possible use of role-play, question-answer games, and interesting current events. Following this, group members and the group facilitator can provide constructive feedback and suggestions for possible improvement.

4.4.5.4 Support counselling theme

Within the context of the group setting, patients and families learn to cope with daily situations and problems. Group members can address, share and learn effective coping strategies to **return** to their **previous level of functioning** (Graham, 2004:133). This is possible due to the protective and supportive environment of the group, where they will experience the opportunity to release feelings of anger, fear, guilt and depression. Feelings of uncertainty regarding employment, economic status and rejection from former friends can be discussed spontaneously. Graham (2004:133) emphasised that group sessions create the opportunity to teach patients the process of cognitive restructuring, to view obstacles as challenges, to reduce negative feelings and to take all aspects into account before making a decision. In this way, group members will be empowered to take part in a creative problem-solving process. Practical suggestions could be to offer group members the opportunity to share their stories of personal strengths and resources. In the words of Graham (2004:133) “Those more recently laryngectomised may find reassurance in the optimistic words of those who have survived laryngeal cancer for a longer period of time and have reached a level of acceptance.”

Table 4.2 illustrates the various themes for discussion within laryngectomy support groups. The purpose or goal, topics for discussion, and practical or visual aids to be used during discussion of the various themes will also be presented.

Table 4.2: Themes for discussion within laryngectomy support groups

	Educational	Speech activity	Social interaction	Support counselling
Purpose or goal	<ul style="list-style-type: none"> Promote better understanding of alaryngeal speech rehabilitation 	<ul style="list-style-type: none"> Achieve functional and intelligible speech to adapt to home and employment environment 	<ul style="list-style-type: none"> Communicate with others Experience positive results of social interaction Experience a feeling of safety 	<ul style="list-style-type: none"> Address, share or learn effective coping strategies to return to previous level of functioning
Topics for discussion	<ul style="list-style-type: none"> Offers information regarding: <ul style="list-style-type: none"> - Medical changes after surgery - Medical conditions and procedures - Communication methods - Speech products and services - Diet - Stoma care Assessing visual and hearing ability Motivation for alaryngeal speech goals 	<ul style="list-style-type: none"> Opportunity to practice new speech Taking needs of individual group members into account Experienced patients can demonstrate positive achievements Strengthen new patients' self-confidence 	<ul style="list-style-type: none"> Teach patience Teach communication skills Provide constructive feedback Suggestions for improvement 	<ul style="list-style-type: none"> Offers protection and support Release feelings (anger, fear, depression, guilt) Discuss uncertainties (employment, economic status, rejection) Teach cognitive restructuring Participate in creative problem-solving process
Practical or visual aids	<ul style="list-style-type: none"> Videos Literature Product samples 		<ul style="list-style-type: none"> Role play Question-answer games Discuss interesting events 	<ul style="list-style-type: none"> Offers opportunity to share stories of personal strength and resources

(Based on the model presented by Graham, 2004:132-133)

Knowledge of the various themes for discussion as presented in table 4.2 will be helpful when facilitating support groups for laryngectomy patients, to best realise the potential value of these support groups. Suggested themes for discussion embraced a wide spectrum, including education, speech therapy, social interaction and support counselling.

4.4.6 Benefits of support groups

Benefits of support groups are numerous, and participation in support groups following laryngectomy, benefits the patient and his relatives in **various ways**. Birkhaugh *et al.* (2002:198) described this type of support as an attractive form of rehabilitation as it fulfils a need for help beyond the professional health care system, which often has to cope with limited resources. A discussion of the potential value of support groups for laryngectomy patients includes a number of aspects, as mentioned below.

4.4.6.1 Benefits of problem-solving

Problems experienced by patients and their families are described as various, severe (Murrills, 1975:55), and multiple (Depondt & Gehanno, 1995:36) and arise on a daily basis (Graham, 2004:133). In group sessions, patients are taught to face and cope with problems in daily life (Depondt & Gehanno, 1995:36; Graham, 2004:133). This is possible by providing them with the help they need to cope with problems and fears and to solve them (Herranz & Gavilán, 1999:996; Ramirez *et al.*, 2003:97). Group sessions offer an excellent opportunity to meet, share and discuss identified problems they have experienced (Jay *et al.*, 1991:937; Murrills, 1975:55). Group dynamics such as comprehensive advice, intelligence and compassion amongst group members, family, friends, and clinicians will help to promote problem-solving behaviour of patients (Graham, 2004:132).

Information about the appropriateness of solutions to problems can be provided by group members (Doyle, 1994:251; Richardson *et al.*, 1989:284). Hints and ideas for improvement by using new skills and coping with physical difficulties can be discussed (Murrills, 1975:55). The experience of a common problem, namely a laryngectomy, can promote the problem-solving process by group members as they have the same problems and have already reached some level of adjustment (Lennie *et al.*, 2001:673; Murrills, 1975:55).

To sum up, the dynamics of support groups help patients and families to adjust to their problems in daily life by offering knowledge and support (Keith & Darley, 1986:133). Support groups can be seen as an important aid in overcoming problems,

forming a vital link between speech therapy sessions and the outside world (Murrills, 1975:55; Relic *et al.*, 2001:516).

4.4.6.2 Benefit of information source

Literature (Beverly-Ducker, 1991:60; Graham, 2004:131; Herranz & Gavilán, 1999:995) viewed support groups for laryngectomy patients as a valuable forum for exchanging information, as patients share a similar situation.

Support groups have the potential to offer excellent access to information for laryngectomy patients and their relatives, as it is easy to do on a regular basis. The value of such information is that patients will be exposed to information which may not be formally provided by health care professionals (Doyle, 1994:250-251). Help provided to patients and their relatives can be considered as supportive and informative (Blanchard, 1982:240) or educational (Graham, 2004:135; Ross, 2000:20). Ulbricht (1986:135) stressed that support groups can be regarded as the most important source of sharing information with patients and their relatives.

4.4.6.3 Benefits of promoting rehabilitation opportunities

There is an agreement in literature on the potential of support groups to promote the rehabilitation of patients, as rehabilitation is found to be strongly influenced by support from other patients (Renner, 1995:219; Stam *et al.*, 1991:39). For Birkhaugh *et al.* (2002:198) this characteristic of support groups is applicable “because it offers help beyond the professional health care system, which often has limited resources”.

Acquiring **speech ability** and **communication** when patients participate in support groups, forms an essential part of these patients’ rehabilitation process (Beverly-Ducker, 1991:60; Graham, 2004:132; Richardson *et al.*, 1989:284, 290; Stam *et al.*, 1991:39). Important information on new communication skills can be provided.

From a **psychological** viewpoint and within the context of support groups, patients are being motivated in a positive way to learn new communication skills (Frith *et al.*, 1985:481; Richardson & Bourque, 1985:85). By having the opportunity to practice their speech within the milieu of the group, patients gain confidence in using their newly acquired communication skills (Murrills, 1975:55). **Socially**, support groups

establish an interpersonal forum where motivation and re-enforcement of communication methods are possible (Graham, 2004:131).

Support groups are a practical and valuable learning school wherein the teaching and acquiring of speech can occur. Speech is demonstrated by some patients while other patients have the opportunity to observe, practice and learn (Frith *et al.*, 1985:481; Gardner, 1971:189; Graham, 2004:132). Patients have the opportunity to listen when other patients are talking, and will be in a position to ask questions (Baker & Cunningham, 1980:26). Fellow group members are also in a position to provide feedback (Graham, 2004:133).

4.4.6.4 Benefits of social support

The **beneficial value** of support groups for laryngectomy patients and their relatives has been described in literature (Belch & Beamish, 1992:61; Beverly-Ducker, 1991:60; Blanchard, 1982:240; Graham, 2004:132). Ideally, support offered within the context of support groups will result in a reduction of anxiety levels especially for laryngectomy patients who often suffer from anxiety and depression, as has been described in the previous chapter (Renner, 1995:219). Various characteristics of support groups offer benefits to group members:

- Group discussions contain an element of “sharing” as patients will **share experiences** with those who potentially face similar problems. This feeling of unity will motivate the patient to improve relationships with other group members and will ideally encourage patients to improve their level of adjustment, to cope better with this experience (Beverly-Ducker, 1991:60; Keith & Darley, 1986:131; Ruiz & Crevier-Buchman, 2000a:173; Murrills, 1975:55).
- In group sessions, **knowledge is offered** during this difficult period and patients are given encouragement and suggestions on how to resume normal life (Beverly-Ducker, 1991:60; Keith & Darley, 1986:133).
- Support groups lend themselves to and are in an ideal position to offer this support, as group discussions take place in a **protective and supportive environment**. Together with a milieu of **understanding** offered within the context of the group, communication and social skills, coping strategies and dealing with problems in daily life will be addressed (Graham, 2004:132-133).

- Participation in support groups **offers the opportunity** for comparison on a social level with other patients, who in turn, can provide feedback on the patient's improvement which will result in improved social adjustment of the patient (Doyle, 1994:251; Eadie & Doyle, 2005:122; Graham, 2004:132; Richardson *et al.*, 1989:290). Gardner (1971:190) viewed support groups as an aid to the easiest and quickest re-adjustment of patients post-operatively.

The social value of support groups for laryngectomy patients can be summarised as promoting their social adjustment and re-integration into social life following surgery (Doyle, 1994:251; Kleinsasser, 1988:258). Re-integration into social life is necessary in the case of laryngectomy patients, as the patient's social life can be reduced after surgery (Depondt & Gehanno, 1995:36).

4.4.6.5 Benefits of psychological support

Various benefits observed from a psychological perspective have been documented in the literature (Eadie & Doyle, 2005:122; Gardner, 1971:189; Graham, 2004:131; Renner, 1995:219; Ross, 2000:20). These benefits may include reduction of the patient's sense of isolation, and decreasing of the patient's levels of anxiety, depression and pain caused by the laryngectomy. Underlying these psychological benefits, are improvement in speech ability and a desire to have a social life like other patients (Gardner, 1971:189).

A further psychological benefit of attending support groups will be to increase the patient's self-esteem and decrease feelings of isolation (Graham, 2004:131). This is possible due to the process of the patient expressing himself and the feedback given by fellow group members. Patients with similar experiences have more influence on these patients' attitudes and emotions. Another psychological benefit of support groups is that patients are assisted in dealing with reactions from the public, as they are sometimes mistaken as being deaf (Murrills, 1975:55).

Furthermore, the patients' sense of well-being may be improved by sharing their inner feelings with other patients (Graham, 2004:133; Mehta & Abrol, 1982:111; Salva & Kallail, 1989:299). This is accomplished through various forms of interaction among patients:

- **Reassurance** from patients who had their operation long ago (Graham, 2004:133).
- **Sharing a feeling of understanding** of emotional shock with those who had a similar experience (Renner, 1995:219).
- Group members who demonstrate **enthusiasm** and **encouragement**, are proof of mastering a disability (Gardner, 1971:189).
- **Appropriateness** of feelings, responses and choices can be discussed and enforced, based on personal experiences (Richardson *et al.*, 1989:284).
- Laryngectomy patients who attend support groups gain **confidence** especially when using a new method of communication (Mehta & Abrol, 1982:111; Murrills, 1975:55). The patient will have an opportunity to share his or her experiences of problems, with other patients (Mehta & Abrol, 1982:111).
- Patients may experience feelings of **relief** and **anticipation**. While the first-mentioned refers to the process where anxiety will diminish and inner assurance that he will rehabilitate as other patients have, will be enforced, the latter refers to a level where the patient is confident about getting back to former employment and earning a living again (Gardner, 1971:189).

4.4.6.6 Benefits of improvement of quality of life

Several studies have found a positive correlation between laryngectomy patients' participation in support groups and improved quality of life (Birkhaugh *et al.*, 2002:203). Amongst the spectrum of potential benefits of support groups for laryngectomy patients, social support was discussed. The laryngectomy patient's participation in support groups emphasises the goal of rehabilitation, namely to be re-integrated into society and to attain the former level of functioning, taking into account the comprehensive impact of surgery upon the patient and family members and various experiences of loss they have to deal with. Quality of life may potentially be improved as a result of the patient's participation in support groups, as **medical**, **social** and **psychological** aspects of the patient's functioning are addressed during these group sessions.

4.4.7 Support groups for caregivers

Evans (1996:85) emphasised that not only the patient, but also the caregiver has to face great adjustment after surgery. Spouses can be expected willy-nilly to fulfil the role of the health care professional's team when the patient is at home.

Caregivers may possibly benefit from support groups in the following ways: caregivers will have the opportunity to gain practical knowledge; share experiences of daily living and concerns with other caregivers; help to deal with the psychological aspects of rehabilitation; help to avoid burnout and increased stress, anxiety and strain; the idea that they are not alone is reinforced and groups act as a "stress buffer" upon caregivers (Baker & Cunningham, 1980:26; Blood *et al.*, 1994:30, 32; Evans, 1996:85).

Blood *et al.* (1994:32) found that the majority of caregivers successfully deal with stress and strain resulting from a spouse who has been diagnosed with larynx cancer. This information may be helpful and encouraging to new caregivers. However, Evans (1996:85) reported that spouses sometimes experience difficulty in coping with the patient after his discharge from hospital due to the fact that patients are used to intensive attention while in hospital, which may result in self-centred or demanding behaviour when at home, as a result of feelings of freight and disorientation.

The support groups will not only benefit the patient, but also the caregivers, as caregivers play an indispensable role in the patient's post-operative adjustment. Caregivers are regarded as making a necessary contribution to these patients' overall post-operative rehabilitation programme.

4.5 CONCLUSION

This chapter presented a description of the laryngectomy patient's **rehabilitation** following surgery. A comprehensive rehabilitation programme will ideally include aspects of speech, and vocational and psycho-social functioning of the laryngectomy patient.

The positive factors promoting the patient's post-operative adjustment in society have been described. **Social support** is seen as an essential element for successful re-integration into society. A description of the possible **sources of support** was presented in accordance with the characteristics of the ecological perspective. These sources of support include support from family members, friends, other laryngectomy patients and the hospital during follow-up visits. These systems referred to micro and macro levels of functioning.

Finally the **role of support groups** was described with specific reference to the homogeneous group experience where laryngectomy patients have the opportunity to share their experiences.

Following the above discussion, it can be concluded that laryngectomy patients and families need social support in order to promote their post-operative rehabilitation. This can be utilised effectively within the context of support groups as part of an aftercare programme when attending the follow-up clinic at the hospital. The third objective of the study has thus been addressed.

The **next chapter** explores the laryngectomy patients' existing support systems and their need for a social work aftercare support programme at the hospital, followed by an outline of the results of the current research study.

CHAPTER 5

A PROFILE OF LARYNGECTOMY PATIENTS' NEEDS AND THE ROLE OF THE SOCIAL WORKER

5.1 INTRODUCTION

A laryngectomy potentially affects not only verbal communication of the patient, but also **psycho-social aspects** of functioning (Ruiz & Crevier-Buchman, 2000a:171). These effects are not only applicable to the **patient**, but also to **those close** to the patient (DeSanto *et al.*, 1995:764). The literature study showed that underlying this need for support was the comprehensive impact of a laryngectomy which has the potential to affect the patient's physical, social and emotional functioning. After surgery, patients and their families **are in need of support**.

Renner (1995:215) remarked that even before surgery, patients need to know that there will be assistance and resources available to ensure their post-operative recovery and therefore their quality of life. In a study performed by Llatas *et al.* (2003:816) it was found that social and medical support were the most important factors determining the laryngectomy patient's post-operative adjustment, and not the patient's experience of the permanent tracheostoma or loss of voice as one would have expected. On the one hand, Blanchard (1982:240) found that families are not always capable of offering the needed support as they are not always equipped to deal with the side-effects of the operation. On the other hand, Dhooper (1985:224) remarked that laryngectomy patients may experience difficulty in retaining support once they have acquired it, as they often remove themselves from the very people who could possibly offer that needed support. Depondt and Gehanno (1995:33) were of the opinion that in sickness, the personality of the patient can often constitute a major handicap. In this regard they referred to the incidence of substance abuse among these patients which may contribute to the patient's experience of rejection, which further demonstrates the patient's need for support.

The exploration of the laryngectomy patients' need for support as part of an aftercare programme in a hospital setting was based on the above. The methods and results of

the study will now be discussed in the context of the theoretical data and existing literature.

5.2 DELIMITATION OF THE INVESTIGATION

The researcher recognised laryngectomy patients' need for support, and became increasingly aware of the potentially positive value of such support being offered to these patients. Support offered to laryngectomy patients in a hospital setting, became an area of interest to the researcher, who initiated **support groups** for laryngectomy patients in co-operation with the speech-language therapist.

Little information in this area of research was available within the context of the social work profession. This was confirmed by a **literature study**. The need for this research project was **discussed** with the head of the Department of Radiation Oncology, as well as the head of the Ear, Nose and Throat (ENT) Department at Tygerberg Hospital. The researcher also presented her intention of conducting the proposed study at a research forum at the Department of Radiation Oncology, Tygerberg Hospital. Permission to perform this study was granted by the **Committee of Ethics**, Medical School of the University of Stellenbosch at Tygerberg Hospital (Annexure B).

A combination of the qualitative and quantitative research **approaches** and a combination of the exploratory and descriptive **designs** were used to best determine the aim of the study, namely to gain a better understanding of the laryngectomy patient's need for specialised aftercare and support in order to present a contextual framework for support groups within a hospital setting from a social work perspective.

Twenty-five patients met the criteria for inclusion in the study during the period 9 January 2008 until 28 May 2008. The first four patients were involved in the pilot study and the other twenty patients in the empirical study. One patient was not involved due to employment obligations. No patient who successfully met the criteria of inclusion in the study, refused to participate in the study. Exclusion from participation was due mainly to patients' lack of successfully acquiring tracheo-oesophageal speech and/or refusal to be included in the support group.

The **population** of the study consisted of all patients diagnosed with cancer of the larynx who subsequently underwent a laryngectomy at Tygerberg Hospital. The **sample** consisted of twenty laryngectomy patients who attended the follow-up clinic at the Department of Radiation Oncology, as well as the support group between January 2008 and May 2008 and who successfully acquired tracheo-oesophageal speech, enabling them to participate in a semi-structured interview of 45 minutes. A **pilot study** was performed with the first four patients who attended the clinic during January, after which the research study started on 23 January 2008. Participants were selected by means of the **purposive sampling method** as described by Strydom and Delport (in De Vos *et al.*, 2005:328-329).

5.3 GATHERING AND ANALYSING DATA

The researcher was dependent on the **close co-operation** of **team members** in order to successfully identify possible participants for the study. On the day preceding the follow-up clinic at the hospital, which is conducted on Wednesdays, the clerk at the clinic by prior arrangements provided the list of names of the Ear, Nose and Throat Clinic's follow-up patients. On Tuesday afternoons the researcher had the opportunity to go through patient folders in order to identify laryngectomy patients. The help of the doctor and speech-language therapist was at times requested to identify potential candidates for the study. Social work records and records of previous support group attendances were also used in order to check whether patients had the required speech abilities. However, it was not always possible or advisable to rely on previous notes in the medical, speech-language therapist or social worker's notes, as patients' speech ability can vary at times due to medical complications. In a few cases where the researcher was confident that the patient would meet the criteria of the study, that patient was phoned prior to his medical appointment at the hospital to enable him to allow time for the interview and to make transport arrangements accordingly.

Only patients who had **fluent speech** prior to joining the group were included and patients who learnt speech during the group sessions were not included. The reason for this arrangement was that patients who only started using their voice during the

sessions, found it difficult to maintain voice for the duration of the interview and easily became tired. One interview had to be discontinued for this reason.

Data collection started by making **contact** with potential participants while they were waiting for their follow-up appointments with the doctor. The researcher, as a **social worker** in the department, had already been working with and interviewing these patients on a routine basis prior to surgery. After assessing which patients would meet the criteria of the study, they were asked if they would be willing to join the support group. The researcher then explained the research project to them, including the purpose and procedures of the research study. After the patients had attended the support group and visited the doctor, the researcher took them to her **office** to ensure privacy during the interview.

First the consent form was discussed and signed, whereafter their **permission** was asked to audiotape the interview, as suggested by Greeff (in De Vos *et al.*, 2005:298). Participants were assured of the **confidentiality** of the tape recordings and transcripts of the interview. Tape recordings were extremely important during this study, as it was at times difficult to properly understand the patient's speech. Due to their limited speech ability, it was recommended not to interrupt participants in order to properly hear and write down all the information. During the interview the researcher frequently used the technique of repeating the responses of participants to make transcription of the audio recording easier.

It is important to take into account that participants often have to draw breath in the middle of a sentence. For that reason, phrasing of sentences was **not always fluent** or logically structured, and the researcher had to listen carefully to the recordings in order to capture the correct information. The alternation of **open-ended** and **close-ended questions** worked well during interviews. This method enabled participants to rest between responses.

The researcher proceeded with the **interview** once she was convinced that the patients met the criteria for inclusion in the sample and were willing to take part. All patients who were asked, immediately agreed to be part of the study. In cases where too many potential patients were booked for the same day, the researcher

rescheduled their **appointments** for research interviews, in which case she paid their transport fee. Data were selected by means of a **semi-structured interview**, using a **questionnaire**. All interviews were conducted in the home language of the participants, which was Afrikaans. Interview **techniques** as described by Greeff (in De Vos *et al.*, 2005:288-289) were used.

The researcher **explored** the participants' **experience** of being interviewed after the interview. It was clear that all the participants had felt honoured to be part of the study as they described their involvement as a positive experience. One of the participant's wives passed away soon after his laryngectomy. Another participant experienced anger at himself for not having paid attention to previous warnings of the doctor to stop smoking in order to avoid the operation. These were emotional experiences but as a registered social worker, the researcher was able to understand their feelings and to offer emotional support.

When the target of twenty interviews was reached, the process of **data analysis** followed. De Vos (in De Vos *et al.*, 2005:335) warned that in a qualitative study the process of data collection and analysis cannot be separated as these two components go hand in hand during the research process. According to Fouché (in De Vos *et al.*, 2005:270) the process of data analysis requires a systematic approach. The researcher conducted this process in different phases. The *first phase* was to transcribe tape-recorded interviews on the same day of the interview. A great demand was placed on the researcher to properly transcribe all the information. At times it required a high level of concentration to carefully listen to and understand the responses during the interview. After the interview had been typed, the tape was played back to confirm accuracy of transcriptions.

The *second phase* of data analysis was to summarise answers to **open-ended questions**. During the *third phase* answers were analysed by sorting them into themes, sub-themes and categories (Marshall & Rossman, 1995:114-115). As it was a qualitative study, central themes had to be identified. Data analysis was conducted by using open coding where categories were deduced from participants' narrative responses. The main ideas of what had been said were identified and presented into various themes (De Vos in De Vos *et al.*, 2005:340-341). An innovative approach

was followed during the *fourth phase* of the analysing process by creating a practical aid such as a “colour-coded chart” (Annexure H) where certain themes were marked with certain colours (De Vos in De Vos *et al.*, 2005:338). The literature review was also “colour-coded” to correspond with the colours in the questionnaire. Markers of the same colour were then inserted in the literature study manual to form linkages between literature review and data from the empirical study. Answers to **close-ended questions** were analysed according to numeric codes. In the *fifth phase*, theoretical data were marked and inserted in the draft of the chapter. During the *sixth* and final *phase*, linkages were formed between theoretical and empirical data.

Data obtained from the **empirical study** will now be presented and interpreted against the background of data obtained from the **literature review**.

5.4 RESULTS OF THE INVESTIGATION

Results of the study will be presented and discussed in the following sections:

- Identifying details.
- Medical information of a laryngectomy and the role of the social worker.
- Comprehensive effects of a laryngectomy (physical, social, psychological).
- Support and aftercare.

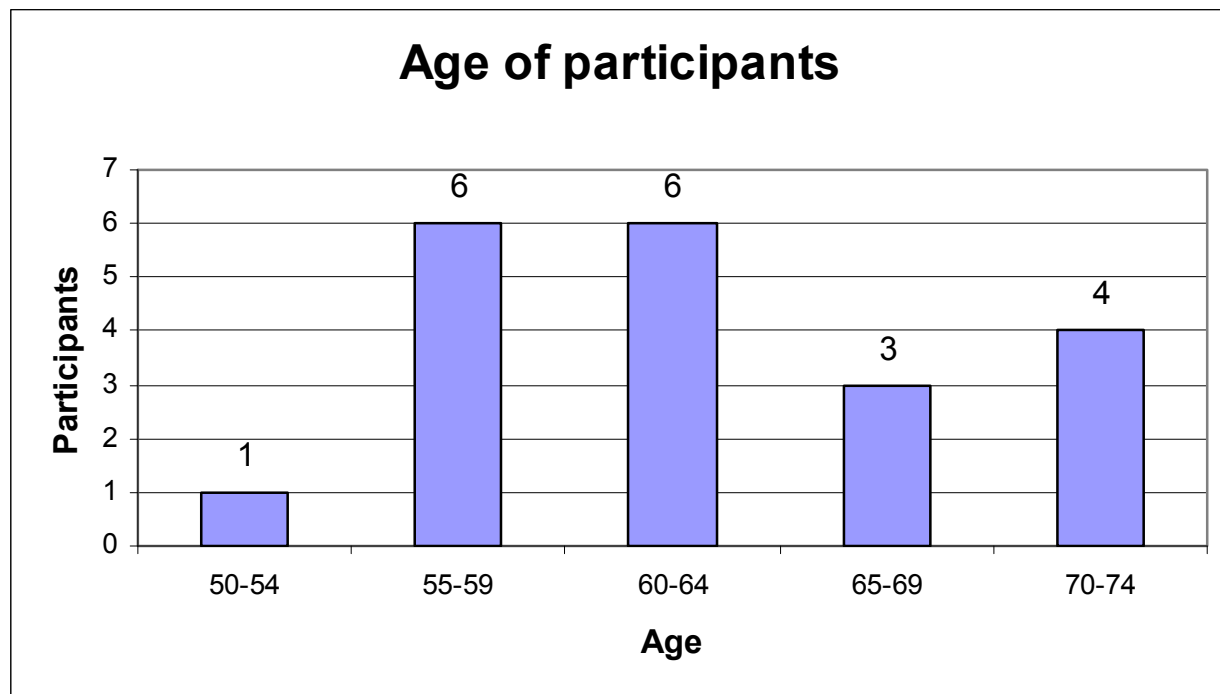
Due to the amount of information gained during the empirical study, results of the study will be presented in two chapters. Chapter 5 will focus on the first two sections, namely a presentation and discussion of identifying details and medical information together with an exploration of participants’ opinion on the role of the social worker in rendering services to these patients and their relatives. Chapter 6 will focus on an exploration of the last two sections, namely participants’ opinion on the comprehensive effects of a laryngectomy (physical, social, psychological), followed by a discussion of the support and aftercare being offered to these patients.

5.4.1 Identifying details of participants

Identifying details of participants will be presented according to: age, marital status, race, gender, education and training, occupation (pre- and post-operative) and total monthly income.

5.4.1.1 Age

The first area of investigation pertained to the age of participants. The findings are presented in figure 5.1.



n=20

Figure 5.1: Age of participants

All twenty participants (100%) in the study were older than 51 years. As shown in figure 5.1, the participants' ages ranged between 51 and 74 years with an average of 62 years. Nine (45%) participants were in their sixties, seven (35%) in their fifties and four (20%) participants were older than 70 years. This is in accordance with recent NCR statistics for 1998 to 1999 (2004:16) which showed that the age group most at risk for a diagnosis of cancer of the larynx is between 55 and 64 years. Twelve (60%) of the participants in the study represented the high risk group. However, age was not a criterion for inclusion in the study.

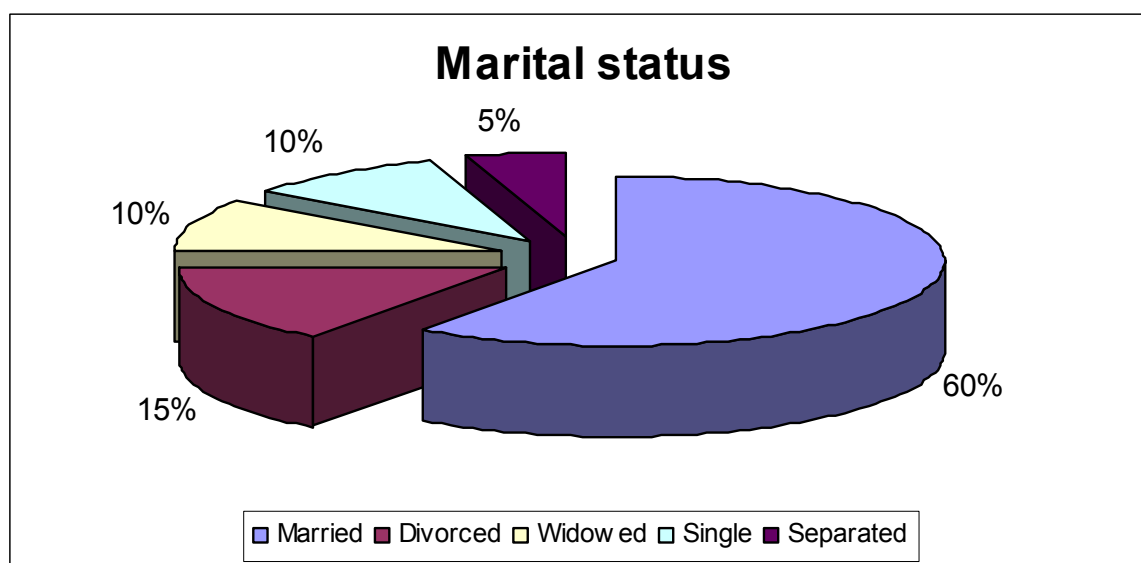
Cancer of the larynx is predominantly a disease of the elderly (late middle age or retirement) and therefore many laryngectomees may experience additional age-related medical problems like respiratory problems due to a history of heavy smoking over a long period of time (Renner, 1995:216; Ross, 2000:14). A change in this pattern of older persons being diagnosed with larynx cancer is occurring, as an

increasing number of women and younger people are being diagnosed mainly due to change in smoking and drinking behaviour (Dhooper, 1985:217; Doyle, 1994:16; Renner, 1995:216). Lee-Preston *et al.* (2004:437) mentioned that younger people potentially have more to lose after a laryngectomy in terms of their coping ability, degree of anxiety and possible influence on their employment and finance. These factors therefore may intensify younger persons' **need for support** following surgery.

Besides areas of employment and finance, literature (Maas, 1991:1374; Stewart *et al.*, 1998:147) related the age of patients with their post-operative speech rehabilitation. Older persons may feel that there is no necessity for learning speech or may be less likely to learn speech due to depression, loss of hearing ability, mental ability or motivation (Richardson & Bourque, 1985:85).

5.4.1.2 Marital status

In the second place, enquiries were made about the marital status of participants, and this information is presented in figure 5.2.



n=20

Figure 5.2: Marital status of participants

In this study, twelve (60%) participants were **married** as shown in figure 5.2. Literature (Mathieson *et al.*, 1991:153-154, 161; Salva & Kallail, 1989:299) viewed spousal support as a contributing factor in the patient's rehabilitation, wherein spouses' attitudes towards the patient's recovery play an important role. A possible

benefit of spousal support is to promote speech rehabilitation as it increases the need for patients to use speech (Dhooper, 1985:224; Maas, 1991:1374).

Spouses of patients are a **target group to benefit** from **support** as they often neglect their own needs in order to adapt to the patient's emotional and physical post-operative situation (Blanchard, 1982:240). Spouses also have to deal with great adjustments after surgery as it can easily be expected of them to fulfil the role of the professional health care team when the patient is at home (Evans, 1996:85).

Three (15%) participants were **divorced** and one (5%) participant was **separated** from her husband. Ross (2000:19) remarked that a previously strained marriage has the potential to result in divorce after a laryngectomy but conversely, it also has the potential of bringing couples together. In this study, divorce and separation of participants did not occur as a result of participants' diagnosis and treatment, as they were already divorced or separated prior to their diagnosis and surgery. Two (10%) participants were **widowed** (10%) and two (10%) had **never** been **married**. One of the widowed participants lost his wife shortly after his surgery. One can expect that participants who are single (8 or 40%) (divorced, separated, widowed or never married) will experience an increased **need for support** as they lack spousal support.

5.4.1.3 Race

In the third place, the race of those patients who participated in the study will be presented in table 5.1.

Table 5.1: Race of participants

Race	Number	Percentage
Black	0	0%
Coloured	19	95%
White	1	5%
Asian	0	0%
TOTAL	20	100%

n=20

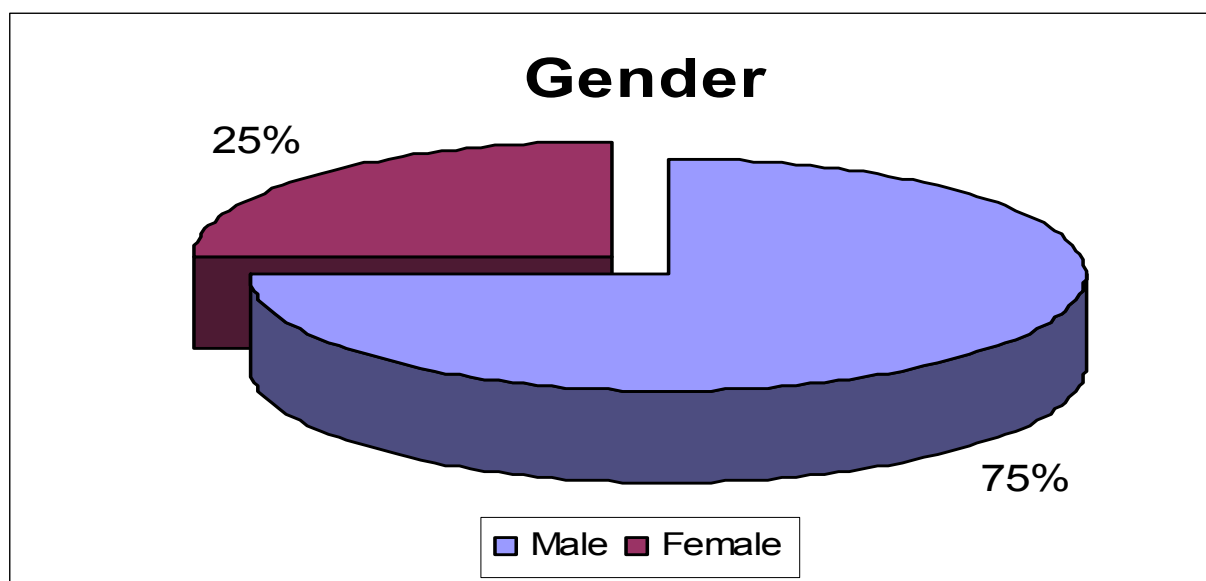
According to the census of 2001 (<http://www.statssa/gpv/za/census>), the largest population group in South Africa is the Black (79,02%) group. The second largest group is White (9,58%) followed by Coloured persons (8,91%). The smallest population group in South Africa is the Indian or Asian (2,49%) group. It is within this context that the latest available NCR can be interpreted. NCR statistics for 1988 to 1989 (2004:89-96) showed that the majority of newly diagnosed patients in South Africa with cancer of the larynx were from the Black population for both male and female patients. This was followed by White, Coloured and Asian population groups. This accords with 2001 census information reflecting the population proportion of the various race groups.

The census results of 2001 also indicated that in the Western Cape, which is the catchment area for patients who are treated at Tygerberg Hospital, Black persons represent 26,69% of the total population, followed by Coloured (53,91%), White (18,41%) and Indian or Asian (0,99%). At Tygerberg Hospital during the period January 2006 to August 2007 for which statistics were obtained (thirty-three laryngectomy patients in total), one (3%) Black person, twenty-five (75,8%) Coloured, seven (21,2%) White and no Asian persons had a laryngectomy as treatment for a diagnosis of cancer of the larynx. Only patients who successfully met all the criteria for inclusion in the sample were asked to participate in the study.

Although Tygerberg Hospital renders services to all population groups, it was only Coloured (19 or 95%) and White (1 or 5%) participants who took part in the study as illustrated in table 5.1. 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 (95%) of participants form part of this group.

5.4.1.4 Gender

Fourth, when indicating the gender of patients who participated in the study, figure 5.3 shows that a majority of male patients (15 or 75%) took part in the study, and five (25%) female patients.



n=20

Figure 5.3: Gender of participants

Although male smokers have the highest risk of getting larynx cancer, this pattern will change in future, due to change in social behaviour of women and younger persons (Lee-Preston *et al.*, 2004:437). The ratio between male and female patients studied also agrees with the statistics of the SA National Cancer Registry (NCR, 2004:v), which indicated that males have a greater **lifetime risk** than females of developing cancer. Statistics also showed that it is mostly males (NCR, 2004:87-88) who are affected by larynx cancer.

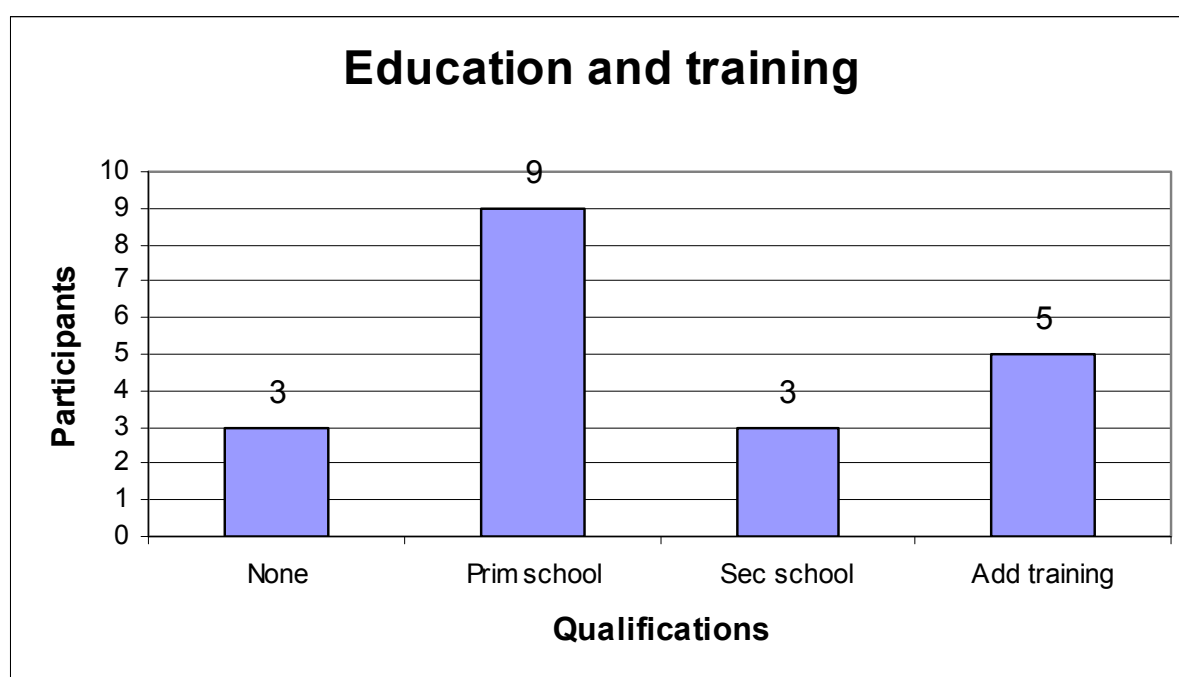
Although all laryngectomy patients experience similar problems, literature (Salva & Kallail, 1989:292, 300-301; Ulbricht, 1986:131) confirmed that women will experience certain additional difficulties and adjustments which will place extra demands on their experience of their femininity. Richardson and Bourque (1985:85) and Stam *et al.* (1991:52) stressed that male patients are more likely to learn speech as women may feel self-conscious or embarrassed by the deep, throaty character of their new voice. Women are therefore often mistaken for men and this could add to their concern about loss of their femininity.

Salva and Kallail (1989:300-301) summarised the major difference between male and female's laryngectomy experience as being on an emotional level and their **need for support**. Men are seen as less supportive and need less support due to the

strong support of spouses, whilst women patients will need help from family and friends outside the home in order to cope.

5.4.1.5 Education and training

In the fifth place, participants were asked about their level of education and training. A graphic illustration of participants' education and training (scholastic or additional training) is presented in figure 5.4.



n=20

Figure 5.4: Education and training

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

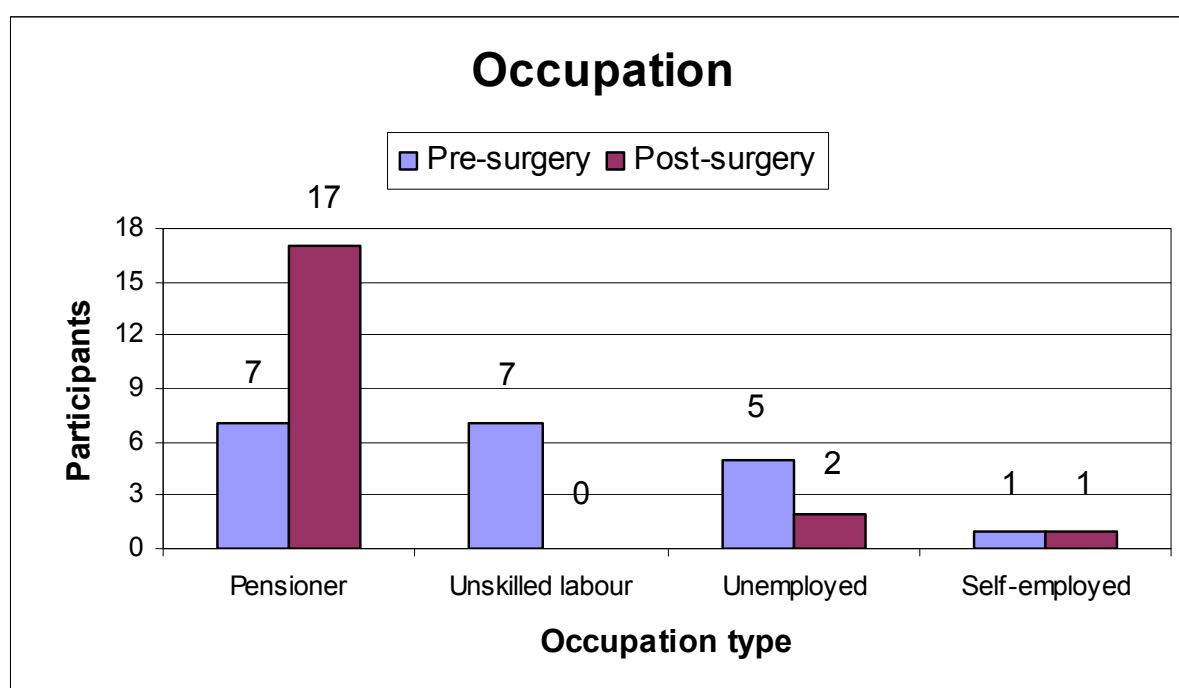
Three (15%) participants had **no** scholastic training. Nine (45%) participants had **primary school** training. These can be divided into one (5%) who had passed Grade 3; three (15%) Grade 5; three (15%) Grade 6 and two (10%) who completed Grade 7. Only eight (40%) participants had **secondary** school training which included three (15%) who had passed Grade 8, two (10%) Grade 10 and three (15%) Grade 12. Five (25%) of these participants also had **additional training** after school. These included training as a housing manager after passing Grade 12; scale fitter after passing Grade 12; teaching after passing Grade 12 and two who trained as

carpenters after passing Grade 8. Qualifications were achieved at a technicon or college.

Besides substance abuse, social characteristics such as low socio-economic status, low levels of education and a generally poor social network are common among patients who present with cancer of the head and neck area (Eadie & Doyle, 2005:120). Findings of the study confirmed literature findings as the majority of participants had no or low levels of educational training.

5.4.1.6 Occupation (before and after surgery)

Previous and current occupation of participants was investigated in the sixth place. Figure 5.5 illustrates changes in participants' occupation after surgery.



n=20

Figure 5.5: Pre- and post-operative occupation of participants

Legend: Pensioner includes both social and civil pensioners

Five (25%) participants were **unemployed** prior to surgery and applied for a social pension thereafter. One (5%) participant who was unemployed before surgery did not qualify for a social pension due to the amount of his wife's monthly income. Seven (35%) participants were already **pensioners**, including six (30%) social pensioners of whom four (20%) were old-age pensioners and two (10%) received a disability grant,

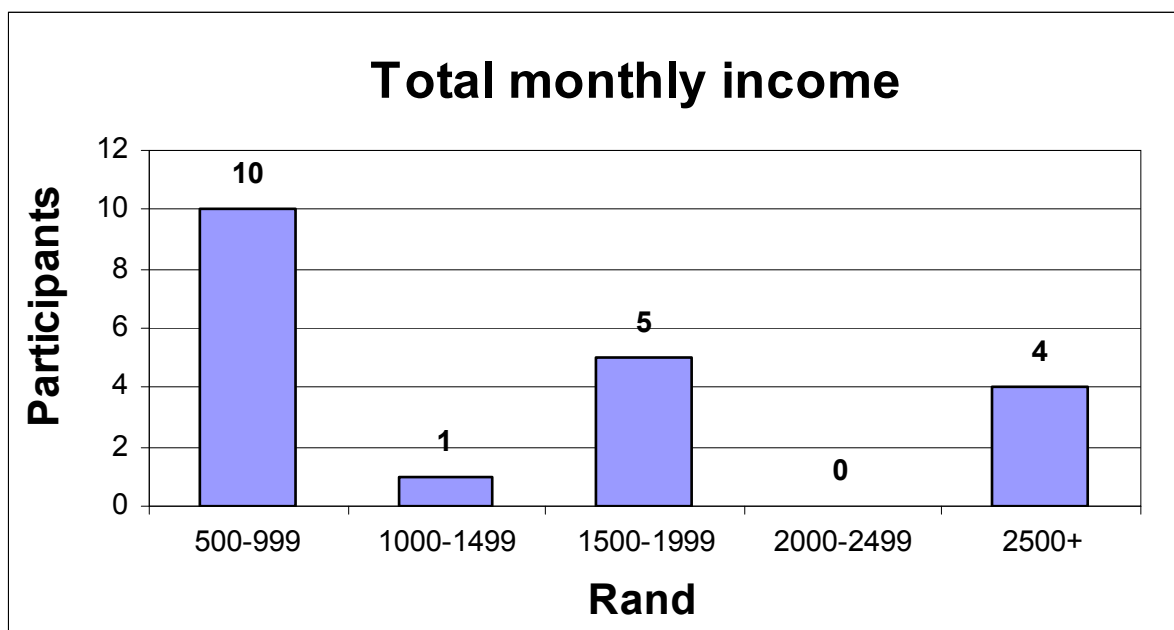
and one (5%) civil pensioner. As it is mostly elderly patients who are affected by a laryngectomy, patients of this age are generally already social pensioners or become pensioners after their surgery (Silver, 1991:222)

Patients may have to change or lose their former employment due to various reasons, including conditions in their workplace, limitation of speech, worsened self-image, impairment in sphincter function, or shoulder pain (Baker & Cunningham, 1980:26; Dhooper, 1985:218-219; Graham, 2004:127; Ross, 2000:20). Seven (35%) participants terminated their former employment (**unskilled labour**) after surgery. They were employed as a heavy vehicle driver, mechanic, labourer, domestic servant or in casual jobs. None (0%) of the participants were **professionals**.

An increasing number of younger persons are affected by a laryngectomy (Dhooper, 1985:217, 226; Renner, 1995:216). Younger persons may be afraid of **having more to lose** than older persons (Lee-Preston *et al.*, 2004:437), with specific reference to occupation and income. In this regard it is also important to mention that one of the participants who was 55 years old, applied for a social grant after his surgery, but was motivated to start working again as a driver, although for another company and on a casual basis. Only one (5%) participant continued with his **business** following surgery and did not apply for a social pension although he was 60 years old. Part of the ideal of rehabilitation would be for the patient to successfully return to his previous occupation (Keller, 1985:657). This may help the patient to function as normal or near normal his capacity as possible.

5.4.1.7 Total monthly income

Lastly, monthly income of participants was investigated in order to complete the profile of participants' identifying details. Figure 5.6 illustrates the total of the participants' and their spouses' current monthly income.



n=20

Figure 5.6: Total monthly income

Half (10 or 50%) of the participants were in the income group of R500-R999 per month. Six of these participants did not have a spouse, as two (10%) were divorced, one (5%) was separated, one (5%) was widowed and two (10%) were single. In the other four (20%) cases participants were married, but three (15%) of their spouses were unemployed and in one (5%) case the participant was in the process of applying for a disability grant. His wife did domestic service on a casual basis. One (5%) participant had a total monthly income of R1000-R1500, as a social pensioner, with his wife doing casual domestic service. Five (25%) of the participants had a total monthly income of R1500-R1999. This was mostly (4 or 20%) due to the fact that both the patient and his/her spouse received a monthly social pension. In the remaining case (1 or 5%) the patient's civil pension was supplemented with a reduced social grant. Only four (20%) had an income of more than R2500 per month. Of these, one (5%) participant had his own business, two (10%) received a civil pension and one (5%) participant's wife received a civil pension.

As it is mostly the elderly who are affected by a laryngectomy, these patients are usually already social pensioners or become pensioners after their surgery (Silver, 1991:222). This is especially applicable in this study, as with the exception of one (5%) participant who still had his own business, all the other (95%) participants were

currently pensioners (social or civil) or were in the process of becoming pensioners by applying for a disability grant.

Literature (Casper & Colton, 1998:4; Natvig, 1983:155; Ross, 2000:20-21) referred to laryngectomy patients' fear of financial dependency as patients face increasing financial costs in order to afford medical expenses; transport fees; speech therapy sessions and prosthetic devices; and at times need long periods of sick leave. Problems that previously existed may be reinforced after a laryngectomy, including employment or financial problems (Kaplan & Hurley, 1979:52). Deshmane *et al.* (1995:128) mentioned that low socio-economic status may have a limiting effect on rehabilitation attempts. As Tygerberg Hospital 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. Arrangement for payment of medical bills can be made. No patient is excluded from medical treatment due to financial reasons.

Low socio-economic status is one of the characteristics of patients who present with head and neck cancer (Eadie & Doyle, 2005:120). Herranz and Gavilán (1999:994) were of the opinion that although all laryngectomy patients will benefit from social support, those from a low cultural and socio-economic environment are the **target group** to especially benefit from **social support**.

5.4.2 Medical aspects of a laryngectomy and functioning of the social worker as member of the multi-disciplinary team

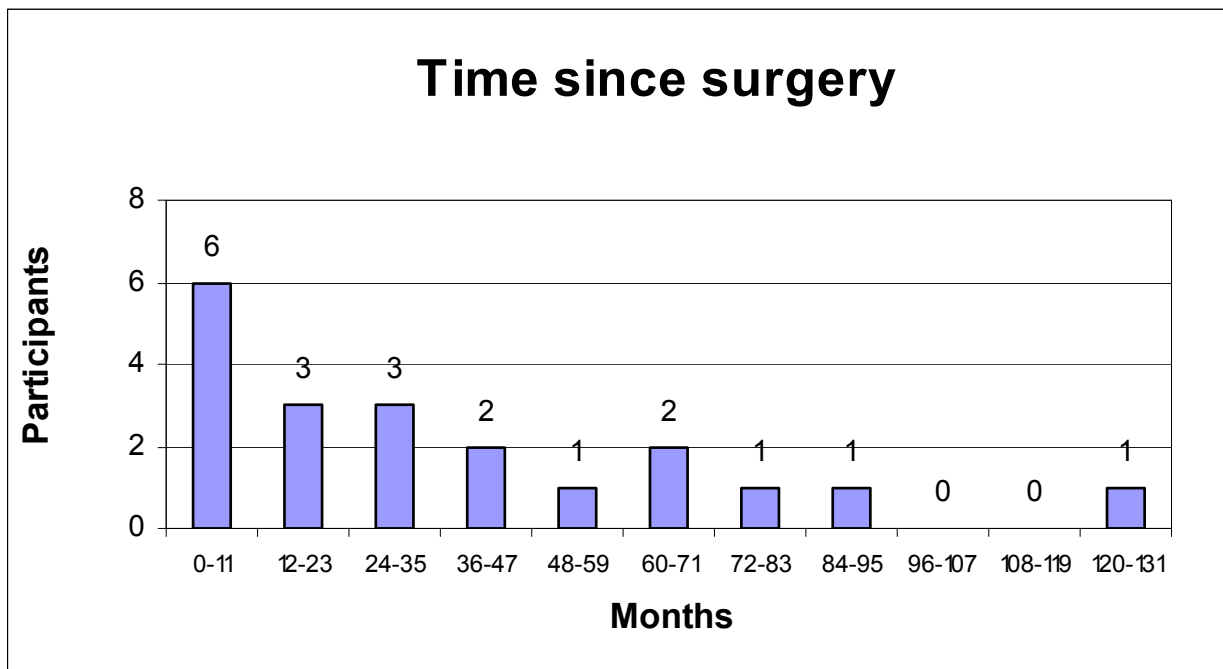
5.4.2.1 Medical aspects of a laryngectomy

Participants' medical information related to date, type of treatment and frequency of follow-up visits at the hospital.

(a) Date of surgery

Problems that patients face may underscore the need for a holistic team approach and therefore their **need for support** shortly after their operation (Graham, 2004:130). From the experience of the researcher, it was clear that patients need

time to deal with the “outside world” before they will realise their own need for support. At this stage patients are confronted with the reality of their situation (Ulbricht, 1986:133). Patients have to adjust to the psycho-social implications of the operation, before getting too used to the changed situation. It was for this reason that a minimum of three months after surgery was determined as criterion for inclusion in the sample group. The post-operative period varied among study participants (figure 5.7) as time elapsed after surgery will have an effect on the lived experiences of participants.



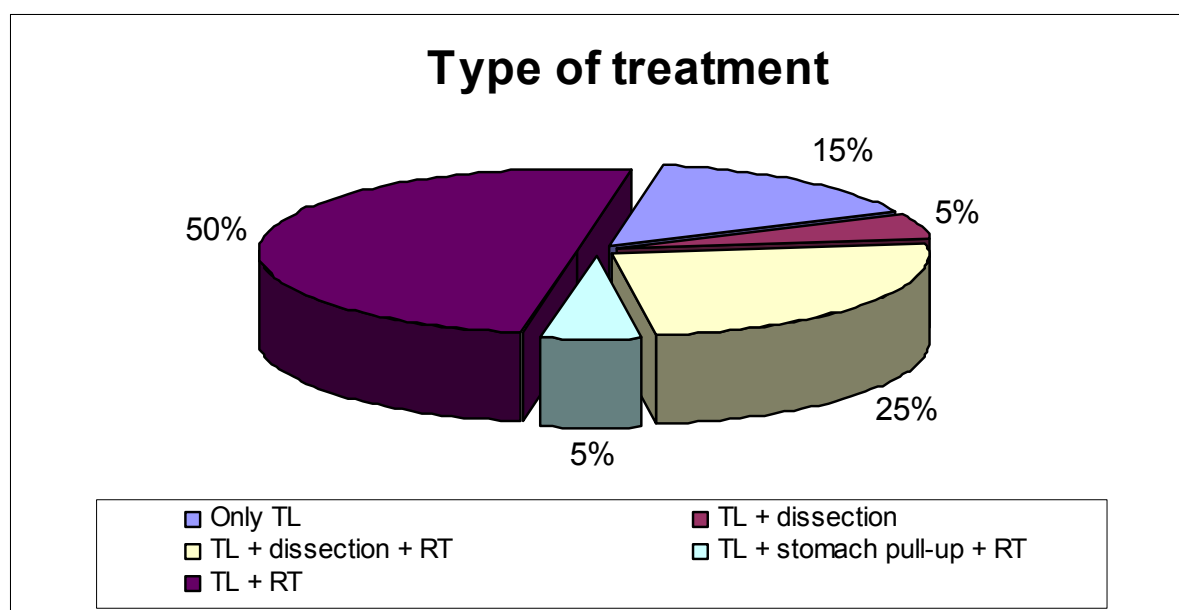
n=20

Figure 5.7: Time since surgery

Six (30%) participants had surgery less than a year ago; six (30%) between one and three years ago; three (15%) between three and five years ago; and four (20%) between five and eight years ago. One (5%) participant had his operation between ten and eleven years ago. Because participants represented a wide spectrum of post-operative time periods, the results of the study will give a true reflection of their **need for support**. The average post-operative period was three years and two months.

(b) Type of treatment

All the patients (100%) who participated in the study received a total laryngectomy as treatment after a diagnosis of advanced cancer of the larynx. This was set as a primary condition for inclusion in the study and formed part of a clear identification and formulation of criteria for the selection of respondents (Strydom & Delport in De Vos *et al.*, 2005:329). Figure 5.8 illustrates participants' types of treatment options.



n=20

Figure 5.8: Type of treatment

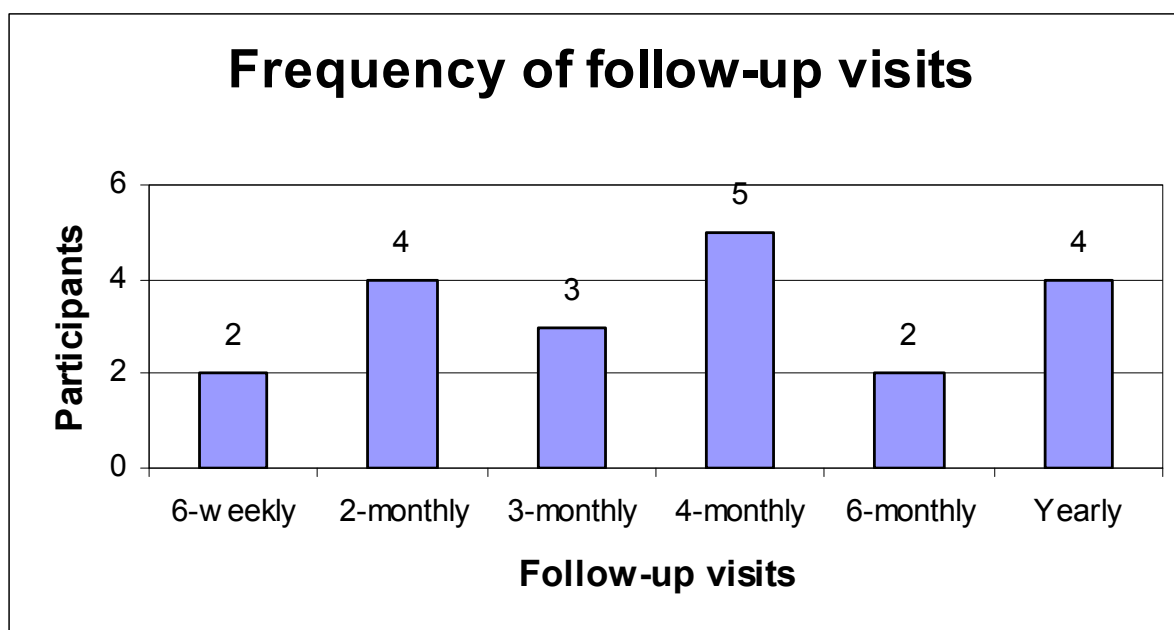
Legend: TL = total laryngectomy; RT = radiotherapy

Three (15%) participants received only a total laryngectomy as primary treatment for their diagnosis of larynx cancer. Fifteen (75%) participants also received post-operative radiotherapy treatment as part of their treatment regime and one (5%) participant would soon start with radiotherapy treatment. Seven (35%) participants received additional surgery which included block or neck dissections. Impairment of the patient's sphincter function may occur during surgery (Deshmane *et al.*, 1995:125). This may result in alternative employment and special financial arrangements. One (5%) participant underwent excision of nodes and one (5%) participant a stomach pull-up.

A laryngectomy has the potential to affect the patient's physical, social and psychological functioning (Zeine & Larson, 1999:52) but **social support** can be helpful in limiting these effects (Richardson *et al.*, 1989:291).

(c) Frequency of follow-up visits at the clinic

Follow-up visits should be scheduled on a regular, indefinite and life-long basis as suggested by Kleinsasser (1988:258) and Depondt and Gehanno (1995:35). At Tygerberg Hospital, 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. Distribution of participants' follow-up visits can be viewed in figure 5.9 and varied between a six-weekly (2 or 10%), two-monthly (4 or 20%), three-monthly (3 or 15%), four-monthly (5 or 25%), six-monthly (2 or 10%) and yearly (4 or 20%) basis.



n=20

Figure 5.9: Frequency of participants' follow-up visits to the clinic

Follow-up visits will allow patients to have contact with **support groups** at the clinic, available at the hospital.

(d) Purpose of follow-up visits at the clinic

Literature (Depondt & Gehanno, 1995:33, 35; Ross, 1995:1372) stressed the purpose of follow-up visits to include medical control; eliminating risk factors such as alcohol and smoking, by motivation to maintain a sober lifestyle; assessment of nutritional status; promotion of post-operative speech; contact with social support; promotion of rehabilitation of the patient and family; and ensuring that the patient stays in the medical setting. Table 5.2 illustrates the participants' opinions on the purpose of attending the follow-up clinic at the hospital.

Table 5.2: Participants' opinion on the purpose of follow-up visits to the clinic at the hospital

Purpose	Definite		Probable		Not at all	
	Number	%	Number	%	Number	%
Medical assessment	19	95%	1	5%	0	0%
Identification and treatment of medical problems	19	95%	1	5%	0	0%
Motivation to stop alcohol / tobacco use	19	95%	1	5%	0	0%
Assess nutritional condition	20	100%	0	0%	0	0%
Assess speech ability and promote speech rehabilitation	18	90%	2	10%	0	0%
Contact with hospital team members	19	95%	1	5%	0	0%
Act as a source of support	19	95%	1	5%	0	0%
Contact with other laryngectomy patients	19	95%	1	5%	0	0%

n=20

From table 5.2 it was clear that all (100%) participants agreed on the above-mentioned purposes of attending the follow-up clinic at the hospital. However, three (15%) participants were not sure whether certain elements should be included as “*definite purposes*” when attending the follow-up clinic and marked these options as “*probable purposes*”. The one participant (5%) who viewed “*medical assessment*” and “*identification and treatment of medical problems*” as a “*probable purpose*” of attending the follow-up clinic felt it was a demand from the hospital that had to be obeyed.

When asked about **other benefits** of attending the follow-up clinic at the hospital, two (10%) participants confirmed that they saw it as a valuable opportunity to meet other patients as they could communicate and share their problems with one another, and one (5%) of those two added that it was supportive to meet team members at the hospital. This is in accordance with literature (Blanchard, 1982:240; Dhooper, 1985:223) which emphasised the importance of the hospital as an important source of support as patients may feel isolated when leaving its protective and supportive atmosphere. After leaving the hospital, patients may experience a greater **need for support**. It is regarded as the responsibility of health care team members within the hospital setting to offer aftercare to the patient and family after discharge from hospital (Zeine & Larson, 1999:60).

No participant mentioned **any other** purposes for their attendance at the follow-up clinic at the hospital other than those listed in the literature (Depondt & Gehanno, 1995:33, 35; Ross, 1995:1372). This can possibly be due to the fact that the list already included all the main reasons for attending the follow-up clinic. All (100%) participants remarked that all the listed items should not be included.

5.4.2.2 Role of the social worker

It is important to note that at Tygerberg Hospital, all laryngectomy patients are referred to the social worker prior to surgery. The social worker is responsible for rendering support services to these patients and their relatives throughout the period of treatment and recovery. In this section, participants were asked to give their opinion regarding the role of the social worker in rendering services to the laryngectomy patient within specific areas of service delivery, taking into account the functions of the social work profession. Casper and Colton (1998:50) referred to the role of the social worker in rendering services to laryngectomy patients, as **to serve the needs** of the **patient** and **family** members. These needs may include enabling them to cope with the effect of surgery during the different stages and treatment of the disease, as social workers are equipped with interpersonal skills to assist in the care, treatment and rehabilitation of these patients (Dhooper, 1985:220, 225). Areas of service delivery included:

- to *provide information*;
- to *deal* with **problems** patients may experience;
- to *contact community resources*;
- to *support* the **patient** and **family members** of the patient; and
- to *promote rehabilitation*.

Responses to these questions are reflected in tables 5.3 to 5.7 according to one central theme, namely social work intervention in serving the needs of the laryngectomy patient and his family, sub-themes (serving as a source of information, problem-solving, contact with community resources, support to the patient and family, promotion of rehabilitation) and various categories. Verbatim responses by participants will illustrate participants' opinions.

(a) *Providing information*

In the first place, participants were asked to describe the role of the social worker in the capacity of providing information to laryngectomy patients. Taking into account the sub-theme of the social worker's role to provide information, table 5.3 will summarise answers to this question according to two categories, namely lack of information about medical issues and post-operative adaptation, and the need for support groups.

Table 5.3: Participants' opinions on the role of the social worker in providing information

Theme: Social work intervention to serve the needs of the laryngectomy patient and family members		
Sub-theme	Categories	Narrative responses of participants
Source of information	Lack of information about medical issues and post-operative adaptation	<ul style="list-style-type: none"> Information you are looking for, will be <u>how</u> it will be, <u>what</u> will happen, <u>how long</u> will it take and what the <u>consequences</u> will be. (<i>Inligting wat jy soek is <u>hoe</u> gaan dit wees, <u>wat</u> gaan gebeur, <u>hoe lank</u> gaan dit vat en wat gaan die <u>nagevolge</u> wees.</i>) I did not know whether I would be able to have speech again when the doctor told me that they had to remove my vocal cords. I would like to know whether I <u>would have speech again</u>. (<i>Ek het nie geweet of ek weer sal kan praat nie want ek hoor die dokter sê my stembande moet verwyder raak. Ek sou wou geweet het of ek <u>weer sal kan praat</u>.</i>) I wanted to know <u>how long</u> I will live, because it is a big operation. (<i>Jy wil verseker wees vir <u>hoe lank</u> jy gaan lewe want dit is 'n groot operasie.</i>)
	Need for support groups	<ul style="list-style-type: none"> The best way is <u>to get us together and to listen to us</u> who have had the operation because we managed with it ... then we can <u>share</u> with one another. (<i>Die beste "way" is <u>om vir ons bymekaar te kry en te luister van ons af wat klaar die operasie gehad het, want ons het deur dit gegaan ... om te deel met mekaar.</u></i>) To have a group to communicate about our <u>disease</u> and our <u>future</u>. (<i>Om met ons 'n groepie te hou en met ons te gesels oor ons <u>siekte</u> en te gesels oor ons <u>toekoms</u>.</i>) You experience a lack of information and want to know what to expect ... then we <u>can learn from one another</u>. (<i>Jy is onkundig, en jy wil graag meer geweet het wat wag op 'n mens ... <u>dan leer ons bymekaar.</u></i>)

n=20

- *Lack of information about medical issues and post-operative adaptation*

The first category that was identified in the role of the social worker in offering information was participants' need for information regarding medical issues and their post-operative adaptation. Participants' description of the role of the social worker in providing information correlates with literature (Casper & Colton, 1988:50-51) which indicated that the social worker has expertise to help patients form an understanding of the psycho-social implications of the operation. Participants indicated that they were mainly in need of more information regarding the operation, implications of the operation, post-operative adjustment, recovery period, prognosis and information on post-operative speech. The hospital setting offers an excellent opportunity for access to the speech-language therapist who will be the responsible team member to provide information on post-operative speech rehabilitation. It is thus important for the social worker to work in close co-operation with the specific team member.

Zeine and Larson (1999:59) emphasised the importance of thorough pre-operative counselling of the patient and family in order to promote their successful post-operative adjustment. They were also of the opinion that adequate preparation before the operation to deal with the various effects of the operation would promote successful social and speech rehabilitation following surgery.

- *Need for support groups*

The second category for providing information was identified by five (25%) participants who recommended **support groups** as a practical way to provide information to laryngectomy patients, as they share a similar situation (Graham, 2004:131). Among group members they would therefore be exposed to information which might not be formally provided by health care professionals (Doyle, 1994:251). In this regard participants described the use of support groups as a practical forum to discuss problems commonly experienced, medical information, health issues, consequences of the operation in daily life, post-operative adaptation, or uncertainties about the future. Participants agreed with the opinion of Beverley-Ducker (1991:60), that within group discussions, group members could experience the positive benefits of communication with others where "sharing" could take place

as they had the opportunity to learn from others who had a similar experience (Renner, 1995:219).

- *Additional findings*

Half (10 or 50%) of the participants acknowledged that the social worker has a role to play in providing information to patients regarding their illness and directing them where to find help if needed. Four of these participants had their operations less than six months ago while the others had their operations between one and eleven years ago. Their follow-up visits were mostly scheduled on a yearly, three-monthly and two-monthly basis.

Taking into account participants (10 or 50%) who commented positively on the role of the social worker to provide information and those who suggested the use of support groups (5 or 25%) as a practical way of doing it, it was clear that the majority (15 or 75%) of participants positively correlated the role of the social worker with providing information. Suggestions made by participants support available literature in this regard. Casper and Colton (1998:50-51) emphasised that the social worker should offer applicable information and assurances of continuing assistance to patients and their families.

(b) Dealing with problems

In the second place, participants were asked their opinion on the role of the social worker in dealing with problems that laryngectomy patients might experience. The sub-theme of problem-solving will be divided into the various categories as reported by participants. These categories are reflected in table 5.4 and include participants' opinions on the need for assistance with post-operative communication and their need for support groups.

Table 5.4: Participants' opinions on the role of the social worker in solving problems

Theme: Social work intervention to serve the needs of the laryngectomy patient and family members		
Sub-theme	Categories	Narrative responses of participants
Problem-solving	Need for assistance with post-operative communication	<ul style="list-style-type: none"> It is mostly about your <u>adaptation in society</u> now that you have a <u>speech limitation</u>. (<i>Dit gaan meerendeels oor <u>aanpassing in die samelewing</u> nou dat jy 'n <u>spraakgebrek</u> het.</i>) You (social worker) will be there to help and to encourage us. To tell us that <u>you will have speech and be able to communicate with others again</u>. (<i>Julle (maatskaplike werker) is daar om vir ons te kan help en vir ons moed in te praat. Om te kan sê kyk, jy gaan <u>weer praat</u> en jy sal weer kan <u>kommunikeer met ander mense</u>.</i>) Then they <u>talk to me as if I cannot hear</u>, then I tell them that there is nothing wrong with my ears. (<i>Dan <u>praat hulle saam met my soos ene wat nie kan hoor nie</u>, dan sê ek maar my ore makeer niks nie man, ek kan hoor wat jy praat.</i>)
	Need for support groups	<ul style="list-style-type: none"> To hear that the other one has <u>the same problem</u> then we can <u>support one another</u>. (<i>Om te hoor die ander het <u>dieselfde probleem</u> en dan <u>versterk ons mekaar</u>.</i>) All of us share the <u>same problem</u> and <u>we all understand one another</u>, it is a new and a pleasant experience. (<i>"Because" ons almal sit met <u>dieselfde "problem"</u> en ons almal <u>verstaan mekaar</u>, dit is vir my lekker, 'n nuwe ondervinding.</i>) To hear from the patients who had their <u>operation longer ago</u>, to explain to those who had their operation a <u>shorter while ago</u>. (<i>Om vir die wat <u>langer die operasie gehad het</u> om vir die wat <u>nou kort gehad het</u>, om te verduidelik.</i>)

n=20

- Need for assistance with post-operative communication*

The first category of problems mostly experienced by participants related to those associated with their post-operative speech and communication. Participants therefore indicated this as the most important area where they needed assistance from the social worker. A practical example was that they were sometimes mistaken by the public as being deaf (Murrills, 1975:55). Assurance from team members that there will be post-operative speech was deemed necessary in order to overcome fear of their potential inability to communicate after the operation. Again, within the hospital setting the speech-language therapist will play an important role in assisting the social worker with this role of problem-solving.

- *Need for support groups*

Participants suggested that **support groups** could be used to enhance the social worker's role of solving problems of laryngectomy patients. This will be presented as a second category as illustrated in table 5.4. In group sessions, patients are taught to face and cope with problems in daily life (Depondt & Gehanno, 1995:36; Graham, 2004:133). Aspects mentioned by participants relating to the use of support groups in solving their problems, included comparing themselves with others as they could share and discuss problems commonly experienced. Group discussions offer an opportunity to meet, share and discuss specific problems they have experienced (Jay *et al.*, 1991:937; Murrills, 1975:55). In this regard, participants mentioned the benefits of experiencing communication and support and learning from other patients who had their operation a longer time ago. This links up with Beverly-Ducker's (1991:60) opinion that patients can serve as a role model to one another where they can practically exhibit their own adjustment to post-operative limitations.

- *Additional findings*

Although some participants referred to concrete help being offered by the social worker, this was not the major need they identified for assistance at this stage. Eadie and Doyle (2005:120) remarked that patients, who present with a cancer diagnosis of the head and neck area, are mainly representative of low socio-economic status, low levels of education and a generally poor social network. Concrete help in terms of financial arrangements is therefore the most important requirement. This may refer to practical service delivery such as meeting financial needs, or arrangements for medical equipment needed at home.

To the contrary and unlike literature, the majority of participants in this study considered the social worker's role in dealing with problems regarding their post-operative speech and communication as the most important. The reason for this can possibly relate to the fact that they were already familiar with social work services even before their surgery and that their problems had been addressed at the time of the interview. The average time between surgery and the interview was three years and two months. Except for one participant who awaited payment, following his application, of a social grant, financial problems were not identified as a major

problem. During the discussion of their finances and employment experiences, only five (25%) participants reported that their financial position was now worse than before surgery. Of these, three (15%) had to terminate their previous employment, one (5%) still had his own business but was experiencing increased financial strain and the other (5%) participant was unable to continue earning an additional income by diving for abalone (*perlemoen*).

The majority of participants acknowledged the role of the social worker in dealing with problems they might experience. Whether this could be seen as a joint attempt by the patient and the social worker (7 or 35%) or as solely the role either of the social worker or the patient (5 or 25%), it was positively linked with the social worker. Again, as was the case with the role of the social worker in providing information, a quarter (5 or 25%) of participants suggested the use of support groups as a practical way of solving problems. In total, seventeen (85%) participants linked the role of the social worker with problem-solving.

(c) Contacting community resources

Participants were asked to describe the role of the social worker, regarding her ability to contact community resources, as a third possible role. Table 5.5 presents an overview of the sub-theme of having contact with community resources, and categories of participants' opinions on the benefits of contact with community resources (problem-solving, providing information, offering emotional and social support).

Table 5.5: Participants' opinions on the role of the social worker in contacting community resources

Theme: Social work intervention to serve the needs of the laryngectomy patient and family members		
Sub-theme	Categories	Narrative responses of participants
Contact with community resources	Benefit of problem-solving	<ul style="list-style-type: none"> Because you are interested therefore you will phone and <u>explain how to deal with the problem.</u> (<i>Omdat u belangstel sal u kontak maak en probeer om te "phone" en vir my te kan verduidelik hoe moet ek maak met die probleem.</i>) Phone the hospital and ask to talk to me, or rather, phone the hospital and ask: <u>Can you assist this man</u> on this or that because he lives far? (<i>Lui na ons hospitaal toe of vra eers vir my, dan die hospitaal, en vra: Kan jy die man help met dit en dit want hy is ver?</i>) You can phone my sister, <u>they are concerned</u> about me. (<i>U kan skakel na my suster toe, hulle is bekommerd oor my.</i>)
	Benefit of providing information	<ul style="list-style-type: none"> When I have a problem at home then I can make a plan to contact my social worker to contact my wife to talk to her and to <u>advise her how to try to deal with me.</u> (<i>As ek daar met 'n probleem sit by die huis dan kan ek plan maak om my maatskaplike werker te vra om my vrou te bel en met haar te praat en haar raadgee om my te probeer hanteer.</i>) I will welcome any one who can assist me and who <u>can tell me what to do.</u> (<i>Ek sal enige ene verwelkom wat vir my kan iets doen, vir my kan sê wat om te doen.</i>) The support services in the community are not that much aware of the disease. <u>They know very little.</u> It is her (social worker's) task <u>to inform them.</u> (<i>Want jy kry die ondersteuningsdienste in die gemeenskap is nog nie ingestel op die siekte nie. Hulle weet maar baie min. Dit is haar (maatskaplike werker) taak om dit oor te dra aan hulle.</i>)
	Benefit of offering emotional and social support	<ul style="list-style-type: none"> There are so many organisations, to contact them in order to contact me. They can <u>motivate</u> me and they can <u>talk</u> to me because it can let me <u>keep a good heart.</u> (<i>Daar is so baie organisasies, deur daai organisasies kan u met my skakel. Hulle kan my motiveer en hulle kan gesels met my want dit kan vir my laat moedhou.</i>)

n=20

Participants' responses mainly described the **benefits** of contact with community resources. Literature (Dhooper, 1985:223) points out that referral to community resources can offer various services to benefit the patient. These benefits can be divided into various categories, such as solving problems, providing information or offering emotional or social support, and are illustrated in table 5.5. Sheafor *et al.* (2000:93) mentioned that the environment in which a person lives and functions, is filled with resources. Social workers with expert knowledge of available community

resources will be in a position to bring patients into contact with these resources according to their needs (Ross, 1995:1371-1372).

- *Benefit of problem-solving*

The first category mentioned by participants, referred to their opinion on the social worker dealing with physical problems they might experience following surgery, with problems in general (did not specify) or problems that families might experience. The latter is in agreement with literature (Renner, 1995:216) which stated that a laryngectomy has the potential to affect the integrity of the family system.

- *Benefit of providing information*

Second, another category in the social worker's role, that of contacting community resources, was regarded by participants as to offer information in general or to advise families in order to equip them to take care of the patient at home. Renner (1995:215) emphasised the importance of assuring the patient in the pre-operative stage of assistance and resources that will be available after surgery, in order to assist the patient and family with their post-operative adaptation. One participant was of the opinion that the community was not well informed about the disease and on how to take care of the needs of these patients. This could possibly be due to the fact that this operation is described as a "lonely experience" as patients seldom know other patients who have had such an operation (Renner, 1995:215; Ross, 2000:14).

- *Benefit of offering emotional and social support*

Participants mostly referred to the benefit of emotional and social support as a third category in their opinion of the role of the social worker in dealing with community resources. They referred to general support when having to cope with their medical condition or taking care of problems they might experience at home. Patients might fear discharge from hospital and confrontation with "the outside world", as they might have experienced the hospital setting as a safe environment (Dhooper, 1985:223; Ulbricht, 1986:133).

- *Additional findings*

Participants' responses regarding the potential **benefits** of contact with community resources were in accordance with the viewpoints of Ross (1995:1372) and Belch and Beamish (1992:61) who referred to this co-ordination function as "to bring people, services and resources together on behalf of the patient" and as forming a link between the patient and available resources. From an ecological perspective, boundaries between various systems are bridged during the social worker's outreach to community resources (Ross, 1995:1367). Using available resources can contribute to the patient's growth, development and adaptation ability (Sheafor *et al.*, 2000:92).

It was difficult for participants to describe the role of the social worker in contacting community resources. It is important to take into account that twelve (60%) of the participants were from rural and eight (40%) from urban areas. This might have influenced their thinking in this regard, as people who stay in urban areas are more exposed to available community resources than those in rural areas.

In summary it can be mentioned that the majority (13 or 65%) of participants emphatically linked the role of the social worker with contact with community resources, although they did not clearly specify the process of obtaining these community resources. Participants rather focused on personal benefits as a result of the social worker's utilisation of community resources.

(d) Supporting the patient and his family

In the fourth place, participants were asked to describe the role of the social worker in offering support to the patient and his family. Table 5.6 summarises their responses, referring to the categories of participants' opinions on their need for emotional and social support, need for information and need for support groups.

Table 5.6: Participants' opinions on the role of the social worker in supporting the patient and his family

Theme: Social work intervention to serve the needs of the laryngectomy patient and family members		
Sub-theme	Categories	Narrative responses of participants
Support to the patient and family	Need for emotional and social support	<ul style="list-style-type: none"> In such a situation a person is <u>looking for support</u>. The social worker can be of great assistance. (<i>In so 'n situasie, 'n mens soek net ondersteuning. In 'n groot mate kan die maatskaplike werker help.</i>) When the patient hears that he has cancer for the first time, he will feel devastated. That is where the social worker <u>can be of assistance</u> with a sympathetic ear and supportive shoulder so that the patient can find out that that person cares about him, the sooner he starts talking about it, the better. (<i>Wanneer die pasiënt die eerste keer hoor dat hy miskien kanker het sal hy mos nou teen die planke wees. Dit is waar u dan moet intree met u simpatieke oor of ondersteunende skouer.</i>) Support of the family must include the family member <u>closest to the patient</u>. This is the only way because a person in such circumstances always chooses someone to whom he can talk, the one whom he trusts. In this way you will be able to reach the patient better. (<i>Die ondersteuning aan die familie is die een wat die naaste aan hom is, om saam met daai een te praat ... omdat 'n persoon so in ons omstandighede maar altyd net, hy "pick" ene, dat hy nou sy hart mee kan uitpraat, die een met wie hy nou vertrouwe in het. Dan sal u beter deur kan kom na hom toe.</i>)
	Need for providing information	<ul style="list-style-type: none"> You can use suggestions from other patients <u>to convey to me</u>. (<i>U trek miskien nou uit 'n ander pasiënt iets uit wat u kan oordra na my toe.</i>) To talk to them and <u>to tell them about the situation</u> of the patient and how to take care of the patient. (<i>Om met hulle te praat, om vir hulle te kan vertel van die situasie wat die pasiënt het en hoe die pasiënt moet behandel word.</i>)
	Need for support groups	<ul style="list-style-type: none"> To provide them with <u>knowledge</u> because as the patient is provided with information regarding his condition, the family must also be aware of how to support the patient. (<i>Om die familie toe te lig met kennis want soos die pasiënt inligting kry omtrent sy eie toestand so moet die families ook bewus wees daarvan sodat hulle kan weet hoe om die daardie pasiënt te ondersteun.</i>) When we are in a group we can <u>talk together about our problems</u>. (<i>As ons nou in 'n groepie is en ons praat saam met hulle oor ons probleme.</i>) The other people who can talk, are not much interested in us who have the stomas. When we are together <u>we can talk to one another</u>. (<i>Die ander mense wat nou kan praat hulle is mos nie veel geïnteresseerd in ons mense wat die gaatjies het nie. As ons klompie bymekaar is dan kan ons lekker met mekaar kommunikeer.</i>)

n=20

- *Need for emotional and social support*

With reference to the first category as identified by participants, a need for emotional and social support in both the patient and family members was identified. The importance of identifying and supporting the person closest to the patient was mentioned by a participant, as this will be the person to support the patient. This was also an observational finding of group discussions at hospital. Multiple overlapping of information was found when describing the social worker's role in supporting the patient and family, and this can be seen as an interwoven process. It links well with the ecological perspective where the family system forms part of the various systems wherein the patient functions.

Participants' responses underlined literature viewpoints which described the role of the social worker in assisting or enabling patients and families to cope with the different stages of the disease (Dhooper, 1985:220-225). The social worker has specialist skills in taking care of problem situations and can assist the patient and family to cope with the psycho-social implications of the operation (Dhooper, 1985:225; Kaplan & Hurley, 1979:53).

- *Need for providing information*

The need for providing information was mentioned and will be discussed as a second category of rendering services to the patient and family members. Participants emphasised the importance of offering support to the family in order to equip them with knowledge of the disease and the effect of the operation so that they can develop insight into how to take care of the patient at home. Evans (1996:85) was of the opinion that spouses of patients can easily be expected to fulfil the role of the health care professional once the patient is at home. This will increase their need for information on how to take care of the patient.

- *Need for support groups*

The third category referred to the need for support groups. Participants mostly referred to potential benefits of support groups, such as offering the opportunity to identify, discuss and share problems and finding possible solutions, offering the opportunity to share or to empower families to cope with the needs of patients at home. Literature (Eadie & Doyle, 2005:122; Gardner, 1971:189; Graham, 2004:131;

Renner, 1995:219; Ross, 2000:20) confirmed that support groups can offer social or psychological support by reducing the sense of isolation, decreasing levels of anxiety and depression and increasing a person's self-esteem. A participant also mentioned the relevance of experiencing pleasure from taking part in conversation when they are together, as within group discussions they are in a protective and supportive environment (Graham, 2004:132-133).

- *Additional findings*

To summarise, the majority (17 or 85%) of participants easily related the role of the social worker with support to laryngectomy **patients** and **families**. The use of support groups was suggested by four (20%) participants for support of the patient and family. Support to families is especially necessary as family members may need to adapt to a changing environment (laryngectomy experience of the patient) in order to cope, survive and compete for needed resources (Sheafor *et al.*, 2000:91).

(e) Rehabilitation

In the fifth place, participants were asked to describe their viewpoint of the role of the social worker in their rehabilitation process. Participants' opinions on this question can be viewed in table 5.7, referring to the sub-theme of promoting rehabilitation and categories of participants' opinion on the patient taking responsibility for his own rehabilitation, and his need for support groups.

Table 5.7: Participants' opinions on the role of the social worker in promoting rehabilitation

Theme: Social work intervention to serve the needs of the laryngectomy patient and family members		
Sub-theme	Categories	Narrative responses of participants
Post-operative rehabilitation	Need for the patient to realise own responsibility	<ul style="list-style-type: none"> I do not think that she can make it easier, because <u>I have to learn to adapt</u> to my circumstances. She cannot take my hand and tell me what to do. (<i>Ek glo nie sy kan dit so maklik maak nie, ek moet maar self probeer aanpas. Want sy kan nie my hand vat en my sê maak so of jy moet so maak nie.</i>) The patient must set an <u>aim</u> for himself. It is very important otherwise you will deteriorate ... I can do something with my life and so on. I can change my life, it will not be wasted. (<i>Die pasiënt moet 'n doelwit het. Dit is baie belangrik anders gaan jy net agteruit ... ek kan darem iets met my lewe maak en so aan, ek kan my lewe verander, dit sal nie nutteloos wees nie.</i>) I do not think there are a lot that you can do, you have to <u>look after yourself</u>. (<i>Ek glo nie daar is baie wat u hulle kan doen nie. Jy moet na jousef kyk.</i>)
	Need for support groups to solve problems	<ul style="list-style-type: none"> Because the social worker did not personally experience this trauma, it is important to use <u>other patients</u> who have gone through it, <u>as an example</u>. (<i>Omdat die maatskaplike werker nie persoonlik deur daai trauma gegaan het nie is dit maar net belangrik dat sy of hy ook so aan ander pasiënte wat daardeur is as 'n voorbeeld gebruik ... die wat die trauma verwerk het.</i>) It is to bring us together in a group to talk, yes, to <u>be able to tell your own story</u> encourages you. I have my own <u>problems</u> and when I hear that other patients have also experienced problems, it gives me courage. (<i>Dis om vir ons te bring so in die kringetjie en te praat, ja, en om self te kan vertel gee vir ons moed ... ek het my probleem en nou hoor ek by ander pasiënte dan skep dit weer vir my moed want ek hoor nou hulle s'n.</i>) With communication, to acquire speech <u>so that other people can understand you</u>. (<i>Met die gesels-besigheid, jou stem probeer regkry dat mense jou kan verstaan.</i>)

n=20

- Need for the patient to realise own responsibility*

The first category was identified by participants who felt that it could not be regarded as the primary role of the social worker, but of the patient, to promote his own post-operative adjustment. Patients who participated in the study, all attended the support group as this was set as a criterion for inclusion. According to Salva and Kallail (1989:299), those who are actively involved in support groups, by implication indicated their motivation to adjust to the surgery and its consequences.

- *Need for support groups to solve problems*

The majority of participants saw **support groups** as a way of assisting the patient to adjust to life after surgery, which was classified as a second category when describing their opinion on the role of the social worker in promoting rehabilitation. This is in agreement with literature (Renner, 1995:219) which pointed out that rehabilitation is strongly influenced by support from other patients. Participants mainly linked the use of support groups with the process of problem-solving. Participants referred to their experience of problems in general and did not mention specific problems they might experience. A general area where problems could be expected would be their difficulty with post-operative communication, as was indicated in their responses to the questions regarding the role of the social worker in providing information or in dealing with problems. Participation in support groups can serve as an opportunity to acquire speech, which forms an essential part of patients' rehabilitation process (Beverly-Ducker, 1991:60).

- *Additional findings*

The majority (13 or 65%) of participants positively linked the role of the social worker with offering rehabilitation to the laryngectomy patient. These included the suggestion for the use of support groups (8 or 40%), four (20%) participants who mainly referred to the role of the social worker in promoting rehabilitation, and one (5%) participant who saw the process of rehabilitation as a joint responsibility between the patient and the social worker. The social worker can be valuable in promoting patients' rehabilitation, together with efforts by other team members, as the social worker serves the needs of patients and their family members (Casper & Colton, 1998:50).

(f) Summary

With reference to the various roles of the social worker (as gained from sub-themes in section 5.4.2.2) in rendering services to laryngectomy patients and their families, participants positively linked these roles with responsibilities of the social work profession. Results of responses to questions asked in this section of the questionnaire can be summarised as in table 5.8.

Table 5.8: Summary of participants' opinions on the various roles of the social worker in service delivery to laryngectomy patients

Level of social work service delivery	Number	Percentage
To provide information	15	75%
To solve problems	17	85%
To contact community resources	13	65%
To offer support to the patient and family	17	85%
To promote rehabilitation	13	65%

n=20

From table 5.8 it can be deduced that participants rated the role of the social worker in rendering services to laryngectomy patients in the following sequence of importance: to offer **support** to the **patient** and **family**, to solve **problems**, and to **provide information**. Contact with **community resources** and promotion of patients' post-operative **rehabilitation** received the same score. These were more abstract terms and therefore participants found it difficult to give their opinion in this regard. The majority of participants had no or only primary school training as reflected in figure 5.4. It was obvious that participants mostly referred to direct service delivery towards themselves or their families.

The average time since surgery of participants was three years and two months. All participants had successfully acquired post-operative speech and attended the support group with their follow-up visits to the clinic, as these were set as criteria for inclusion in the study. Most of these participants therefore had already adapted to their post-operative status without referring to the role of the social worker in this regard. This could explain their responses as reflected in table 5.8.

In defining the role of the social worker, thirteen participants suggested the use of **support groups** during social work intervention to laryngectomy patients and their relatives (some participants gave more than one answer so that the total will exceed a hundred percent). A summary of these responses is presented in table 5.9. Some of the identifying and medical details of participants as described in the first section of this chapter could now be related to their responses.

Table 5.9: Summary of participants' reasons for needing support groups during social work intervention with reference to theoretical benefits of support groups

Areas of social work services according to literature	Participants' reasons for needing support groups	Benefits of support groups according to literature
Providing information (5 or 25%)	<ul style="list-style-type: none"> • To provide information regarding the operation and consequences in daily life • To discuss post-operative adaptation • To talk about uncertainties about the future • To listen to others who had a similar experience 	Providing information
Problem-solving (5 or 25%)	<ul style="list-style-type: none"> • To compare oneself with others by sharing and discussing problems commonly experienced, including physical problems • To communicate with others • To experience support • To learn from patients who had their operation a longer time ago 	Problem-solving
Contact with community resources (0 or 0%)	<ul style="list-style-type: none"> • None 	Not applicable
Support to the patient and family (4 or 20%)	<ul style="list-style-type: none"> • To offer opportunity to identify and share problems and feelings and to find possible solutions • To offer support when experiencing emotional problems • To share knowledge and empower families to cope with patients at home • To get patients together to talk and "share" a similar experience 	Social and psychological support
Promote rehabilitation (8 or 40%)	<ul style="list-style-type: none"> • To identify and discuss problems including post-operative adaptation • To give advice • To share the feeling of having the same experience • To think about what had been discussed in order to face challenges in daily life • To experience acceptance from others • To experience interest shown by hospital 	Promote rehabilitation
Social work intervention in the above areas will improve quality of life		Improvement of quality of life

n=13

First, it was remarkable that the participants who suggested the use of support groups in rendering services to laryngectomy patients and their relatives, were those who attended the follow-up clinic on a regular basis. During follow-up appointments,

patients are invited to attend the support group. Patients who regularly visit the follow-up clinic, are therefore more exposed to the possible benefits of these support groups. With the exception of two (10%) participants who attend the clinic annually, all the other participants who initiated the use of support groups, have their follow-up visits scheduled on a six-weekly (1), two-monthly (3), three-monthly (2), four-monthly (3) or six-monthly (2) basis.

Second, four (30,7%) of these participants who suggested the use of support groups, had their surgery less than a year ago. Six (46,2%) participants' surgery was between one and five years ago and three (23,1%) participants had their surgery between five and eleven years ago. Graham (2004:130) stated that with time, patients may become used to their laryngectomy experience and underestimate their post-operative needs. On the other hand, one can expect newly-operated patients to be more aware of their **need for support**.

Third, five (38,5%) of these participants were female participants, in contrast with eight (61,5%) male patients. All the females (100%) suggested the necessity of support groups as part of social work intervention for this target group of patients and their relatives. Salva and Kallail (1989:300-301) found that male and female patients differ in their laryngectomy experience on the grounds of emotional and informational needs and lifestyle changes. Female patients will find help from family members and friends effective. They may also go outside the home for support more often than males, because they might not find their male spouses as supportive as hoped for.

Fourth, four female participants were married, while the fifth one had separated from her husband prior to her diagnosis and treatment. Taking into account the marital status of both male and female participants who recommended the use of support groups in social work intervention, eight (61,5%) participants were married while five (38,5%) were single (divorced, separated, never been married). One would expect single patients to experience an increased **need for support**. However, when the four married female participants described the effect of the operation on their marital and sexual relationship (as presented in the next section of the questionnaire), two indicated that their marital relationship had improved since the operation; one

acknowledged initial problems but did mention improvement, while the other one mentioned that her marital relationship had not changed.

From a theoretical viewpoint, strong similarities between the role of the social worker and the benefits of support groups were found in literature. This is clearly illustrated in table 5.9 where participants were asked to give their opinion on the social worker's role during intervention to laryngectomy patients and relatives. The social worker's role is therefore seen as to be completely compatible with the benefits of support groups.

Although all participants have been exposed to social work services, it was observed that participants did not always respond easily to questions regarding their opinion on the role of the social worker in rendering services to the laryngectomy patient and family, and in most cases needed time to think before responding. In the opinion of the researcher this was the most difficult part of the questionnaire. One explanation could be that in the majority (14 or 70%) of cases, surgery was performed more than a year ago and patients had become used to their social circumstances. Presently, they were not necessarily exposed to social work services except for attending the support group during follow-up visits to the clinic. The follow-up visits may be scheduled on a six-monthly or yearly basis, whilst the other six (30%) participants had their operation less than a year ago and were therefore still actively involved in social work services. Another possible explanation could be that it was difficult for participants to distinguish between the different levels of social work services. Assistance from the social worker was experienced as social work intervention, no matter what area of service delivery it represented.

5.5 CONCLUSION

The aim of the study was to explore the laryngectomy patients' need for support groups in a hospital setting from a social work perspective. This chapter outlined some of the results of the study, including a presentation and description of the first two sections of the results: identifying details of participants and participants' medical information regarding their laryngectomy, and their opinion on the role of the social worker in rendering services to laryngectomy patients and relatives.

First the **identifying details** of participants were described in order to present a general profile of respondents. The average age of participants was sixty-two years old. Furthermore, those patients who participated in the study were mostly married (12 or 60%); were representative of the Coloured population group (19 or 95%); mostly males participated (15 or 75%); the majority had either no or only primary school education (12 or 60%) and half (10 or 50%) of the participants earned a total monthly income less than R 999. The findings of the study cannot be applied to the entire population due to the size of the sample.

Second, **medical information** and the **role** of the **social worker** in rendering services to laryngectomy patients in the hospital setting were described. Medical information referred to the date and type of surgery, and frequency and purpose of follow-up visits at the clinic. The average time since surgery was three years and two months. All participants received a total laryngectomy as treatment for a diagnosis of advanced cancer of the larynx. The majority of participants' follow-up visits were scheduled on a four-monthly basis (5 or 25%).

In defining the **role** of the **social worker**, the following roles of the social worker were described in sequence of importance: participants mostly related the role of the social worker with offering support to the patient and family (17 or 85%) and to solve problems (17 or 85%), followed by the social worker's role to provide information (15 or 75%). Lastly, the social worker's ability to contact community resources (13 or 65%) or to promote rehabilitation (13 or 65%) received the same score and was rated lower by participants. Unlike in literature, participants associated the role of the social worker with offering assistance with their post-operative adaptation and not with financial assistance.

The majority (13 or 65%) of participants suggested the use of **support groups** to meet these roles of the social worker. Strong similarities between the role of the social worker and the benefits of support groups were found. The social worker's role is therefore regarded as completely compatible with the benefits of support groups.

In the following chapter the psycho-social effects of a laryngectomy and aftercare and support to these patients will be presented.

CHAPTER 6

EXPLORATION OF THE PSYCHO-SOCIAL EFFECTS OF A LARYNGECTOMY AND AFTERCARE SERVICES

6.1 INTRODUCTION

Following a presentation and description of participants' identifying details, medical information regarding their laryngectomy and participants' opinion on the role of the social worker in rendering services to these patients and their relatives, this chapter will focus on the last two sections of the results of the study. The laryngectomy patient's need for support groups in a hospital setting will further be explored with specific reference to the psycho-social effects of a laryngectomy for the patient and his relatives, and support and aftercare being offered to these target groups.

6.2 RESULTS OF THE INVESTIGATION

From an ecological perspective, the participant's opinion on the **psycho-social effects** of a laryngectomy upon the patient and his family as well as **support** and **aftercare** being offered to these patients, will be presented and described.

6.2.1 Psycho-social effects of a laryngectomy

In order to explore the psycho-social implications of a laryngectomy, the following effects of this surgical procedure were investigated, namely the **physical**, **social** and **psychological** effects. On all these levels, some participants gave more than one response to certain questions in which case the total of one hundred percent will be exceeded.

6.2.1.1 *Physical effects*

On the *first level* of the psycho-social effects of a laryngectomy, participants were asked to indicate whether they were currently experiencing medical problems, as many adjustments follow surgery (Meyer *et al.*, 2004:1981). Table 6.1 illustrates the physical difficulties experienced at the time. Indicators for medical problems were set according to guidelines as provided in literature. These guidelines referred to

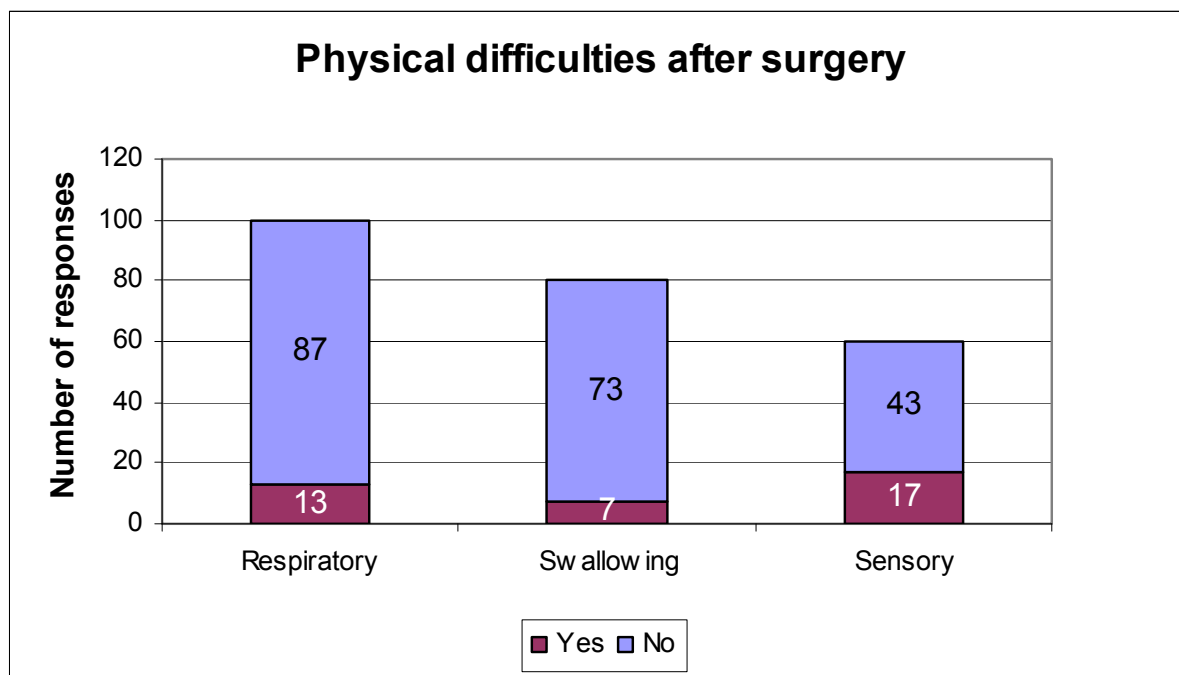
impairment of basic and crucial functioning in daily life, like **breathing**, **swallowing** and **speaking** (Sewnaik *et al.*, 2005:95). The effect of the operation on the participant's speech ability will be described under "psychological effects" in this chapter. From the literature review it was found that impairment of the laryngectomy patient's **sensory functioning** was also applicable and this will be included in questions regarding participants' currently experienced physical difficulties.

Table 6.1: Physical difficulties currently experienced

Physical problems	Yes		No	
Respiratory problems	Number	Percentage	Number	Percentage
Care and cleaning of stoma	1	5%	19	95%
Coughing	5	25%	15	75%
Sleep	2	10%	18	90%
Fatigue	3	15%	17	85%
Infection	1	5%	18	90%
Swallowing problems	Number	Percentage	Number	Percentage
Chewing	4	20%	16	80%
Eating	0	0%	20	100%
Swallowing	3	15%	17	85%
Drinking	0	0%	20	100%
Sensory impairment	Number	Percentage	Number	Percentage
Smell	14	70%	6	30%
Taste	2	10%	18	90%
Hearing	1	5%	19	95%

n=20

Figure 6.1 presents a graphic illustration of the contents of table 6.1 where comparison between respiratory, swallowing and sensory impairment currently experienced by participants can be observed.



n=20

Figure 6.1: Comparison of various physical difficulties experienced by participants

Three (15%) participants identified **no problems** in any of the above-mentioned categories of their physical functioning. The other seventeen (85%) participants experienced physical **problems** in the following domains:

- The majority (17 or 85%) of problems were experienced on the level of their post-operative **sensory functioning**.
- This was followed by **respiratory problems** (13 or 65%).
- **Swallowing problems** (7 or 35%) were experienced the least.

All of these problems in participants' physical functioning have the potential to result in problems on their level of social functioning as was indicated in chapter 3 (table 3.1).

- *Discussion*

Six (30%) participants who identified current physical symptoms in table 6.1, had their **operation** less than a year ago while the other eleven (55%) participants had their operation between one and eleven years ago. The three (15%) participants, who identified **no current physical symptoms**, had their operation between two and eight years ago. With specific reference to breathing problems, Hilgers *et al.*

(1990:424) mentioned that a decrease in breathing problems may possibly be due to improvement of symptoms over time or better adjustment of the patient, especially after the first two years.

When asked about the **quality of support** currently received from various sources as listed in question 4.1 of the questionnaire, two of the three participants who identified no physical complaints, listed all their applicable sources of support currently received, as “*strong*”. This is in accordance with Blood *et al.*’s (1994:19-20) viewpoint that patients will be in **need of support** in order to cope with the physical effects of surgery.

6.2.1.2 Social effects

When asked how the laryngectomy experience affected their social functioning, the following levels were mentioned: relationships with **friends and family**, **marital and sexual** relations, social relationships **outside** the family, **daily activities** and **employment and financial** position. This was the *second level* of the psycho-social effects of a laryngectomy. Responses to this question will be discussed according to one central theme, namely the influence of surgery on **social aspects** of participants’ lives. Verbatim responses of participants illustrate their responses.

(a) Relationships with friends and/or family members

First, the effects of a laryngectomy on participants’ relationships with friends and family members will be looked at. A summary of answers to this question is presented in table 6.2 according to the sub-theme of the effects of a laryngectomy on their relationships with friends and family members and categories (difficulty with post-operative speech and communication method and also loss of friends due to maintaining a sober lifestyle).

Table 6.2: Effects of surgery on relationships with friends and/or family members

Theme: Effects of surgery on social aspects of life		
Sub-theme	Categories	Narrative responses of participants
Friends and family members	Difficulty with post-operative speech and communication method	<ul style="list-style-type: none"> With my friends and family it was a bit difficult because you have to <u>learn to talk like a child</u> again. (<i>Met my vriende en familie het dit maar bietjie swaar gegaan want 'n mens <u>leer weer van kleins af om te praat.</u></i>) You do not feel good when you <u>talk</u> to other people and you <u>have to cough</u> ... they stare at you and are shocked. (<i>Mens voel nie so lekker as jy tussen mense is en jy <u>hoes as jy praat nie</u> ... hulle kyk so na jou toe so verskrik en verbaas.</i>) When I talk to people I cannot talk like before. Before I can say anything further, then they already respond. They <u>do not give me a chance</u> to finish my talking. (<i>Ek kan nou nie meer praat soos wat ek voorheen gepraat het nie, dan voor ek nog iets wil verder sê dan praat hulle al klaar weer terug. Hulle <u>gee my nie kans om verder klaar te praat nie.</u></i>)
	Loss of friends due to maintaining a sober lifestyle	<ul style="list-style-type: none"> Now I cannot do the things I previously did - drinking or smoking. I still see them but <u>we do not visit each other</u>. (<i>Nou kan ek mos nie meer die dinge doen wat ek altyd saam gedoen het nie, die gedrinkery en die gerokery. Ek sien hulle nog maar <u>ons kuier nie meer saam nie.</u></i>) Then I heavily drank and smoke. Now they know when they visit me, they will get nothing, and then <u>they stay away</u>. (<i>Daai tyd het ek mos nou baie gedrink en gerook. Nou kan ek mos nie drink en rook nie. Nou weet hulle as hulle na my toe kom dan gaan hulle niks kry by my nie, <u>dan bly hulle weg.</u></i>)

n=20

- Difficulty with post-operative speech and communication method*

Difficulty with post-operative speech and communication method was established as first category when describing the effects of the operation on their relationship with friends and family. To **learn speech** after surgery was seen by the majority of these participants as the most difficult adaptation in relation to families and friends. Casper and Colton (1998:49) referred to the process of learning speech as to have the experience of being a child, which may add to the patient's frustration. Another area of difficulty with post-operative speech mentioned by a participant was the problem of coughing when talking. This may lead to feelings of discomfort in social situations (Renner, 1995:218; Ross, 2000:16). In addition, patients also have to adapt to a different method of speech and communication, affecting their relations with family and friends. Whenever they manage to adapt successfully in this regard, they

experience social acceptance. Successfully acquiring post-operative speech will improve the patients' emotional well-being, reduce social isolation and promote their re-integration into society (Byrne *et al.*, 1993:174; Schuster *et al.*, 2003:218).

- *Loss of friends due to maintaining a sober lifestyle*

As substance abuse such as a combination of severe smoking and alcohol use is seen as an etiological factor to larynx cancer (Doyle, 1994:17; Eadie & Doyle, 2005:120), the second category refers to some patients who may **lose** their erstwhile **friends** when maintaining a sober lifestyle after surgery. The patients' **need for support** will intensify when they realise their friends had forsaken them.

- *Discussion*

Nine (45%) participants remarked that their medical diagnosis and treatment had **no effect** on their relations with family or friends. Four of these participants had their surgery less than a year ago. The other five participants had their surgery between one and six years ago. Patients need time to adjust to the psycho-social implications of the operation. Soon after the laryngectomy they may not realise the full impact of surgery yet. It was in this context that Graham (2004:130) stated that with time, patients adjust to the experience of cancer, and underscored the need for a holistic treatment approach, including support, by the rehabilitation team.

The majority (7 or 35%) of participants whose **contact** with friends and family members **decreased** after surgery, had their operation between two and eleven years ago, while the operation of two (10%) were less than six months ago. They were therefore more exposed to social contact with family and friends and could give a better evaluation. This decrease was mainly caused by difficulties in their post-operative speech and communication or their decision to maintain a sober lifestyle. These participants rated their current **support** from these two sources as "*strong*" when responding to question 4.1 in the questionnaire about the quality of support then being received from various sources.

From an ecological perspective, the family system provides the closest social environment to the patient and can thus be seen as the most important support system for coping with the diagnosis and treatment of cancer (Relic *et al.*, 2001:516).

The laryngectomy experience as a traumatic event (Zeine & Larson, 1999:59) has the potential to affect psycho-social aspects of life for the patient and his family (Ruiz & Crevier-Buchman, 2000a:171).

Only two (10%) participants indicated that their laryngectomy experience had a **positive effect** on their relationship with friends or family members. This mainly referred to one who mentioned initial confusion before his diagnosis was made and the other patient, who was now staying indoors more after his laryngectomy experience.

To summarise, the majority of participants identified either no (9 or 45%) or a negative change (9 or 45%) in their relations with family and friends since surgery. To a large extent, successfully acquiring post-operative speech and adapting to a different method of speech contributed towards a positive change in these relationships. Also, participants who had their operation more than two years ago were more open regarding problems they experienced as they had been more exposed to social contact with family and friends and could provide a better evaluation. Soon after a laryngectomy experience patients may not realise the full impact of surgery yet. A minority of two (10%) participants mentioned that their relations with family or friends benefited from their laryngectomy experience.

(b) Marital and sexual relationships

Second, participants were asked to describe the effects of their laryngectomy experience on their marital and sexual relationships, identified as sub-theme describing the effects of the operation on social aspects of life (theme). Table 6.3 shows various categories (difficulty in communication, initial uncertainty on how to take care of the patient, awareness of own mortality, improvement in relationship) of responses gained from empirical data.

Table 6.3: Effects of surgery on marital and sexual relationships

Theme: Effects of surgery on social aspects of life		
Sub-theme	Categories	Narrative responses of participants
Marital and sexual relationships	Improvement of relationship	<ul style="list-style-type: none"> We are still the same; no, it even <u>improved</u> because he supports me. (<i>Ons is nog dieselfde, nee, dit het <u>meer beter geword</u> "because" hy staan by my.</i>) He is very good to me, <u>even more</u> than he was before. He is more involved now, more than he was before. (<i>Hy is baie goed vir my, hy is nog <u>meer goeier</u> as wat hy gewees het. Hy het nou nader gekom, baie nader wat hy gewees het.</i>)
	Difficulty in communication	<ul style="list-style-type: none"> My wife and I talk <u>less</u>, we do not talk like before. (<i>Ek en my vrou ons <u>gesels nou minder</u>, ons gesels nou <u>nie soos gewoonlik nie</u>.</i>)
	Initial uncertainty in taking care of the patient	<ul style="list-style-type: none"> My husband did not know how to take care of me. We lived <u>separated</u> from each other. But then we found one another again. I always was a independent person and did not want to thrust myself forward. (<i>My man het <u>nie geweet hoe om my te hanteer nie</u>. Ons het <u>op 'n afstand</u> van mekaar geleef. Naderhand het ons maar nou weer begin en by mekaar uitgekóm. Ek het gevoel ek wil my nie opdring aan iemand nie. Ek was voor my siekte 'n baie "independent" mens gewees.</i>)
	Awareness of own mortality	<ul style="list-style-type: none"> I do not want to become too involved ... if that person may die and you became dependent on that person, what are you going to do then? (<i>Ek wil <u>nie te geheg word</u> aan mense nie ... die dag as daai persoon gaan sterwe en jy het so geheg geword dat jy sê ek kan nie sonder daai persoon lewe nie, hoe dan?</i>)

n=20

Although literature (Ross, 2000:19; Silver, 1991:223; Ulbricht, 1986:134) referred to the possibility that an already strained marriage may collapse resulting in divorce and therefore more distress for the patient, none of the participants indicated that their divorce was as a result of the surgery, as they were already divorced by the time of the operation. For eight (40%) participants this question was **not applicable** as they were not involved in a marital relationship at the time of the interview. Seven (35%) participants confirmed that there was **no change** in their marital relationship.

Only five (25%) participants mentioned **change** in their marital relationship as a result of their operation. Extensive and permanent disfigurement (stoma) may lead to problems in the patient's marital and sexual relationships (Hanna *et al.*, 2004:878). These changes will be presented according to the following categories: improvement

of relationship, difficulty in communication ability, initial uncertainty on how to take care of the patient, and awareness of own mortality.

- *Improvement of relationship*

Improvement in marital relationship since the operation was mentioned as first category when describing the effects of surgery on participants' marital and sexual relationships. This was in agreement with literature (Ross, 2000:19) which stated that the laryngectomy experience has the potential of bringing couples together.

- *Difficulty in communication*

The second category links with literature (Sewnaik *et al.*, 2005:95) which acknowledged that a laryngectomy has the potential to disrupt some of the most basic and crucial functions in daily life, including speech.

- *Initial uncertainty in taking care of the patient*

The third category confirms Ross's opinion (2000:14) that this operation is seldom performed. It can therefore be expected that most people will be unaware of the unique needs of these patients and also of how to take care of these patients' needs.

- *Awareness of own mortality*

The fourth category refers to patients' fear of recurrence of the disease, associated with a poor prognosis (Belch & Beamish, 1992:61). Due to this fear, patients may become increasingly aware of their own mortality. In an attempt to protect themselves and their spouse, they may try to function more independently.

- *Discussion*

It was noticed that in both cases where **improvement** in marital and sexual relationships was mentioned, it was by female participants. It was mostly male participants who indicated that this relationship stayed **the same**, while **problems** were mentioned by both a male and a female participant. Literature (Salva & Kallail, 1989:292, 301) pointed out that female patients' unique emotional needs have to be taken into account when rendering services to laryngectomy patients as females are more concerned with the effects of the disability on their personal relationships and

responsibilities. It can thus be said that the patients' gender plays a role in their evaluation of the quality of their marital and sexual relationships after a laryngectomy.

None of the participants identified **sexual problems** due to the laryngectomy. The two (10%) participants, who did mention problems in their sexual relationship, related it to other medical problems and not to their laryngectomy. This is in agreement with literature (Casper & Colton, 1998:50; Deshmane *et al.*, 1995:127) which stated that patients will not be eager to report problems in this regard.

When comparing results of this open-ended question with the results of question 4.1 of the questionnaire where respondents were asked about **support** currently received from their spouse (where applicable), all participants, with the exception of one who referred to a "*stressful* relationship", mentioned "*strong*" support from spouses. As already mentioned, all participants were known to the social worker and privacy was ensured by taking participants to the researcher's office for interviews. The presence of the audio-tape recorder could have influenced their honesty regarding this sensitive subject.

- *Additional findings*

In general, the majority (7 or 35%) of participants to whom this question was applicable, (8 or 40% of participants were not married at the time of the interview), reported no change in their marital or sexual relationships. The other five (25%) participants reported either a negative (2 or 10%) or a positive (3 or 15%) change.

(c) Social relationships outside the family

In the third place, the sub-theme relating to participants' experience of the effects of the operation on their relationship with others outside the family, was asked. Table 6.4 gives an overview of the various categories of responses gained to this question, such as problems associated with post-operative speech limitation and social rejection.

Table 6.4: Effects of surgery on social relationships outside the family

Theme: Effects of surgery on social aspects of life		
Sub-theme	Categories	Narrative responses of participants
Other social relationships outside the family	Problems associated with post-operative speech limitation	<ul style="list-style-type: none"> When I talk <u>loudly</u> they cannot understand me, but when I talk <u>softly</u> then they come nearer and they ask me what I said. (<i>Want as ek nou miskien <u>hard praat</u> dan verstaan hulle my nie, maar as ek mooi nou <u>sag praat</u> dan kom hulle nader en dan vra hulle weer vir my die vraag.</i>) In the first place I could not talk and that <u>complicated</u> it a bit I would say. (<i>In die eerste plek toe kon ek nie gepraat het nie, toe is dit 'n bietjie "<u>complicated</u>" sal ek sê.</i>) Now that I cannot talk, I <u>walk less</u> and <u>visit less</u>, I <u>do not walk alone</u> since I had the operation. (<i>Noudat ek nie kan gesels nie, nou <u>loop ek baie min</u>, <u>kuier ek baie min</u>, veral ek <u>loop nie alleen</u> van die operasie af nie.</i>)
	Social rejection	<ul style="list-style-type: none"> When we are with people, he would say: He <u>cannot talk</u>, I will <u>talk on his behalf</u> ... then I look at him and say no, I can talk with the people, what is it? I <u>turn around and walk away</u>. (<i>As ons nou by mense kom en ons praat, dan sê hy somer: <u>Hy kan nie met julle praat nie</u>, ek sal maar <u>namens hom praat</u> ... dan sê ek: Nee, ek kan met die mense praat, wat is dit? Ek <u>draai maar net om en dan loop ek maar weg</u>.</i>) People are <u>scared</u> of me. Maybe they thought that they would hurt me, they avoided me. I experienced that <u>they pretend not to see me</u> when they cross the street, because they cannot accept it. (<i>Hulle was <u>skrikkerig</u> vir my. Hulle het seker gedink miskien wil hulle my nou nie seermaak of beledig of so nie. Hulle het my maar vermy. Ek het self gesien as ek sien daar kom iemand aan wat ek goed ken, dan gaan hy oor die pad of <u>maak hy of hy my nie sien nie</u>. Want hulle kan dit nie verwerk nie.</i>) They <u>think that I cannot hear</u> and that I am deaf, then they talk very loudly or demonstrate with their hands, then I say no, I can hear you. (<i>Hulle <u>dink ek kan nie hoor nie</u>, ek is doofstom, nou praat hulle kliphard, of hulle beduie met die hande.</i>)

n=20

- Problems associated with post-operative speech limitation*

The first category of problems relating to social relationships outside the family included problems associated with post-operative speech limitation. As a result, participants now socialised to a lesser extent or stayed indoors more. This has the potential to increase the incidence of depression (Ross, 2000:21; Silver, 1991:222), which may add to the patient's **need for support**.

- *Social rejection*

Second, another category of problems experienced, was identified as social rejection. Various examples were mentioned, including the following:

- **Ignoring** a participant's **ability to talk** and to **form an own opinion**. Eadie and Doyle (2005:116) found that the public tend to refer to altered ways of communication as non-normal and less acceptable and intelligible than normal speakers;
- **Discomfort** and **avoidance** of others as people tend to hold myths and misconceptions about cancer and therefore avoid the patient (Renner, 1995:215; Ross, 2000:14);
- Others who mistake laryngectomy patients as being **deaf**, confirming the opinion of Murrills (1975:55); and
- Difference in **appearance** and **ability to talk**.

- *Discussion*

Seven (35%) participants reported **no problems** in their relations outside the family. Three of them were operated on less than a year ago, whilst surgery of the other four was between two and seven years ago.

When **problems** were identified, improvement of **speech** was reported by four (20%) participants as an important factor limiting initial problems in other social relationships. As a result, they indicated that these problems did decrease as they successfully learned post-operative speech. This helped them to take part in conversation, with the result that others experienced that their disability was diminishing as it was not that obvious anymore. The majority (three) of these four participants had undergone surgery between two and eleven years ago, while the other participant's operation was four months ago.

In another five (25%) cases participants identified **problems** in other social relationships due to **social rejection**. Three of these four participants' operations were done between three and eight years ago, while the other one was only three months before. Participants who had been exposed to the behaviour of other people for a longer time, had been in a better position to comment on their post-operative experience.

Positive experiences with regards to other social relationships were reported by two (10%) participants. They had been operated on between one and eight years ago. It was stated that patients have to make various adjustments when entering social relationships. Two (10%) participants mentioned that they **could not** give an **opinion** on this as they were not in frequent contact with others.

Again, participants who had their operation more than a year ago were more open regarding problems as they had been more exposed to social contact with others and could give a better evaluation. Soon after a laryngectomy experience patients may not realise the full effects of surgery yet.

(d) Daily activities

Participants were asked in the fifth place, to comment on their experience of the effects of a laryngectomy on their daily activities, as a sub-theme, of the effects of surgery on their social life (central theme). A summary is presented in table 6.5, according to various categories mentioned by participants. (Some participants mentioned more than one possible effect on their daily activities, so that the total will exceed a hundred percent).

Table 6.5: Effects of surgery on daily activities

Theme: Effects of surgery on social aspects of life		
Sub-theme	Categories	Narrative responses of participants
Daily activities	Physical implications with a limiting effect on daily activities	<ul style="list-style-type: none"> I have to <u>clean the stoma</u>, I have to <u>take care of my diet</u>, I have to <u>eat slowly</u> and I have to <u>chew my food properly</u>. (<i>Ek moet die gaatjie skoonmaak, ek moet sorg dat ek versigtig eet, dat ek stadig eet, my kos fyn kou.</i>) You cannot talk and eat simultaneously, you have to take a little bit of water to swallow your food and then you can talk. (<i>Jy kan nie praat en eet gelyk nie, dan moet jy bietjie water vat om jou kossies af te sluk en dan kan jy praat.</i>) I find it a bit difficult, I cannot <u>shower</u>, the stoma, it will enter through the stoma. <u>I cannot eat curry</u>. (<i>Ek vind dit net 'n bietjie swaar, ek kan nie lekker "shower" nie, die gaatjie, dit gaan mos by die gaatjie in. Ek kan nie kerriekos eet ook nie.</i>)
	Change in communication	<ul style="list-style-type: none"> In everyday living <u>I do not talk much</u>. (<i>As dit elke dag is dan praat ek nie baie nie.</i>) Since the operation I cannot express myself or cannot talk <u>fluently</u>. (<i>Na die operasie kan ek mos nie so baie uiting gee nie en praat so lekker vlot nie.</i>) When you <u>talk over the telephone</u> ... when someone asks a phone number, then you only have two hands. With the one hand you have to hold the phone, and with the other hand you have to press to talk, now you cannot do it. (<i>Wanneer jy oor 'n foon praat ... miskien wil iemand 'n nommer hê, dan het jy net die twee hande. Met die een hand moet jy die foon vashou en die ander hand moet jy toedruk om te praat, dan kan jy dit nie doen nie.</i>)
	Change in tempo of performing tasks	<ul style="list-style-type: none"> I have to work more according to a <u>certain sequence</u>. It takes a long time before you have all your plans together because you cannot do things quickly. (<i>Ek moet nou baie meer werk volgens 'n agtermekaar orde. Ek moet lank voor die tyd my planne agtermekaar kry want ek kan nie nou sommer haastig dinge doen nie.</i>) When I awake in the mornings, then I know I have to <u>clean the stoma before I can talk</u>. Before I eat, I have to <u>wash my face first</u> ... the moment I bend then the food will exit. (<i>As ek in die oggende opstaan, dan weet ek nou ek moet hierdie plek skoonmaak voor ek kan praat. En voor ek eet, eers my gesig was ... want die oomblik as ek buk dan kom die kos weer uit.</i>)

n=20

A majority of thirteen (65%) participants acknowledged **changes** in their daily life since their operation. These changes can be divided into the following categories:

- *Physical implications with a limiting effect on daily activities*

The first category mentioned by participants, was the physical effect of the operation on their daily activities. These included taking precautions with their diet, stoma care, problems with eating and swallowing at the same time, and showering. Lennie *et al.* (2001:668) referred to lifestyle changes that laryngectomees have to make when adapting their eating habits. Both Renner (1995:218-219) and Ross (2000:17) referred to the restriction on conversation and socialisation during meals, which is experienced as a limiting factor following surgery.

- *Change in communication*

In the second category, participants referred to less talking, loss of self-expression, inability to talk fluently, restrictions on telephone conversations and change in the method of communication. Patients have to make permanent changes in their communication with others (Meyer *et al.*, 2004:1977). These adjustments were also mentioned by Ross (2000:21) as a potential reason for depression, as patients may react with grief reactions to various experiences of loss, including the loss of their natural voice and self-expression, all of which will intensify their **need for support**.

- *Change in tempo of performing tasks*

A third and significant category was identified, relating to a change in the tempo and method of planning and performing tasks, as category which was not found in literature that had been studied. The one participant had his operation nearly four years ago and the other participant had his operation nearly eleven years ago. As they have had practical experience of the effects of the operation on daily activities for a longer time, they were more exposed to these changes and could give a better evaluation.

- *Additional findings*

Thirteen (65%) participants reported **change** in their daily activities as a result of the operation, of which eleven (55%) participants experienced it as a negative change. Four of them had their operation less than six months ago, while the other nine participants' operations were between one and eleven years ago. Three (15%) participants reported **no change** in their experience of daily activities since their operation. With the exception of one participant who had his operation three months ago, the other two participants had their operations between three and eight years

ago. Four (20%) participants did experience change regarding their daily activities but **could not specify** in which regard.

(e) Recreational activities

In the fifth place, participants were asked about their experience of participation in recreational activities after their laryngectomy. This was used as sub-theme in describing the effect of the operation on their social functioning (theme). Table 6.6 summarises the effects of the laryngectomy on participants' leisure time activities. (Some participants mentioned more than one, so the total will exceed a hundred percent.) Various categories of participants' responses will be presented, such as those who experienced no change, dramatic changes, or increased opportunities for outdoor activities.

Table 6.6: Effects of surgery on recreational activities

Theme: Effects of surgery on social aspects of life		
Sub-theme	Categories	Narrative responses of participants
Leisure time activities	No change	<ul style="list-style-type: none"> Not applicable
	Dramatic changes	<ul style="list-style-type: none"> I will say that the adaptation was <u>a bit difficult</u>. But I had managed <u>to overcome it</u> and what I am doing now, I enjoy. (<i>Ek sal sê die aanpassing was 'n bietjie swaar. Maar ek het bo-oor dit gekom en dit wat ek nou doen, ek geniet dit.</i>) When I went there I felt comfortable because they (elderly people) also <u>have pain, walk slowly</u> as I feel I do not belong to the younger children any more. I feel my life is <u>a bit slower</u>, I belong there. (<i>Toe ek daar gaan toe voel ek sommer tuis want hulle (ouer mense) is mense wat pyn het en stadig loop en ek voel ek behoort nie meer by die jongmense en die kinders nie. Ek voel net dat my lewe is bietjie rustiger, ek behoort nou daar.</i>) I <u>walk in the water up to my arms</u>. No, I am not upset because I made a beautiful flower garden in front of my house. (<i>Ek loop maar net daar in die water rond tot hier onder die arms. Nee, ek is nogal nie af nie, want ek maak 'n mooi blomtuin ook daar voor die huis.</i>)
	Increased outdoor activity opportunities	<ul style="list-style-type: none"> I <u>stopped with previous habits</u> and try to only do the good things now. (<i>Ek het al die ou slegte ou goedjies van voorheen het ek gelos en probeer nou net die goeie dinge doen.</i>) Now I do all my work myself, <u>I can do a lot more now</u>. (<i>Nou doen ek al my werk self, ek doen baie meer nou.</i>) I feel important for my family at home <u>as I can do things that they do not want to or cannot do for themselves</u>. (<i>Ek voel "important" vir die huismense, want ek doen vir hulle iets wat hulle nie self wil of nie self kan doen nie.</i>)

n=20

- *No change*

More than a third (7 or 35%) of participants acknowledged that there was **no change** in their recreational activities before and after surgery. This constituted the first category when describing the effect of the operation on participants' recreational activities (sub-theme). These activities mostly included indoor activities where they were not necessarily exposed to other people and were not dependent upon their voice for their activities, such as: walking around, playing pool, watching television, listening to the radio, gardening, reading, cleaning the yard or home, doing needlework, travelling, wood cutting, doing laundry or preparing meals.

- *Dramatic changes*

The second category was identified by a quarter (5 or 25%) of the participants, who had to make **dramatic changes** in their recreational activities following surgery, and replaced them with other activities. One of the five participants had his operation three months ago, whilst the others' operations were between one and six years ago. Dramatic changes included:

- singing and **playing mouth-organ**, but now he loved **listening music**;
- **participated in sport** such as rugby and athletics but now **watched sport**;
- **teaching of younger children** at church, but now attended **activities** of the **senior group**;
- **leader of a choir**, but nowadays he **listened to musical** recordings and advised choir members on their music, and supported community fund-raising projects (dances);
- **diving for abalone** (*perlemoen*), but now did **fabric painting**, which he sold to earn an additional income.

In accordance with the ecological perspective, Compton and Galaway (1979:305) pointed out that the eco-map can be used to objectively assess changes that have to be made following the diagnosis and treatment of a medical condition. Through this, patients will be able to identify available and new sources of support. This is especially applicable in the case of patients' leisure time activities following a laryngectomy, as they sometimes have to give certain activities up (Deshmane *et al.*, 1995:126) and alternatively, have to be encouraged to return to different pleasurable

activities after surgery, as this can increase their sense of well-being (Karamzadeh *et al.*, 2001:532).

- *Increased outdoor activity opportunities*

An increase in outdoor activity opportunities as established by participants as a third category, was described by two male participants as a result of their current sober lifestyle and concentration on more outdoor activities, while two female participants reported that they could now do more things at home due to the fact that they felt healthier.

- *Additional information*

Some patients found creative ways of continuing with previous leisure time activities (Ross, 2000:20). One participant demonstrated this **creativity** by buying a parrot to talk to as his wife died soon after his surgery and he had no one to talk to. In this way he also practiced and improved his own speech:

- Well, I have a few birds and also a parrot which I am teaching to talk. (*Wel ek het weer 'n paar voëltjies en het ek het maar weer daai papegaai wat ek leer praat...*).

- *Additional findings*

Reduction or change in participation in social and outdoor activities (Jay *et al.*, 1991:937) may increase patients' **need for support** to equip them to deal with the impact of surgery and problems which they may experience in daily life (Depondt & Gehanno, 1995:36). It was significant that the majority (14 or 70%) of participants managed to adapt positively to these changes and managed to **replace previous substance abuse** with outdoor activities (2 or 10%) as loss of erstwhile friends could potentially isolate the participant, managed to adapt to **dramatic changes** in outdoor activities (5 or 25%) or **continued** with their **previous activities** (7 or 35%).

Two (10%) participants even mentioned a **positive change** in their recreational activities since their operation as they now experienced more energy to perform tasks at home. The only **two adaptations** mentioned by a minority (2 or 10%) of participants were a change in the tempo of conducting these activities and that they now stayed indoors more. Another two (10%) participants mentioned change in their

recreational activities due to **reasons other** than their laryngectomy experience. Again it can be mentioned that those involved in a support group, had already illustrated their positive post-operative adaptation (Salva & Kallail, 1989:299). It can therefore be said that patients who participated in the study, demonstrated a positive adaptation to their laryngectomy experience.

(f) Employment and financial position

In the sixth place, as last sub-theme to investigate the effects of surgery on social functioning (theme), participants were asked about their experience of the effects of the operation on their employment and financial position. Table 6.7 summarises these responses. The sub-theme of the effects of surgery on participants' employment and financial positions will be presented in the following categories: pensioners, termination of previous employment, unemployed and emotional difficulty.

Table 6.7: Effects of surgery on employment and financial position

Theme: Effects of surgery on social aspects of life		
Sub-theme	Categories	Narrative responses of participants
Employment and financial position	Pensioners	<ul style="list-style-type: none"> Not applicable as this data were obtained from figure 5.5.
	Termination of previous employment	<ul style="list-style-type: none"> Before the operation I already <u>terminated my services</u>. It affected me a bit but as time went by, I accepted it. (<i>Voor die operasie is ek al klaar van werk afgesit. Dit het my 'n bietjie geraak, maar soos die tyd aangegaan het, het ek maar ge-aanvaar.</i>) The doctor <u>booked me off from work</u>, then they paid out my money. I have to be satisfied although it is a smaller amount. (<i>Die dokter het my afgeboek en toe het hulle my geld uitgebetaal. Dit is nou minder maar ek moet maar tevrede wees.</i>) When they <u>booked me off from work</u>, they started to pay me. I earn the same amount I'm earning at the moment. (<i>Toe hulle my afhaal van die werk af toe begin hulle sommer vir my betaal. Ek het dieselfde verdien soos ek nou kry.</i>)
	Unemployed	<ul style="list-style-type: none"> Not applicable as this data were obtained from figure 5.5.
	Emotional difficulty	<ul style="list-style-type: none"> <u>It was a big shock</u>, for me too, but as I have said, let bygones be bygones (<i>Dit was vir almal 'n skok, vir my ook, maar soos ek sê ek het besluit wat verby is is verby.</i>) It was a <u>big adaptation</u>, but as time goes by, you learn not to work. (<i>Dit was 'n groot aanpassing maar soos die tyd aankom, so leer 'n mens maar om nie te werk nie.</i>)

n=20

- *Pensioners*

In the study, the income group most highly represented was **pensioners** (7 or 35%), including six social and one civil pensioner. This was the first category when asked to describe the effects of the operation on the participant's employment and financial position. Taking into account the age group most likely (NCR, 2004:16) to be diagnosed with larynx cancer, many patients become pensioners due to extensive surgery or are already pensioners at the time of surgery (Silver, 1991:222).

- *Termination of previous employment*

The second category referred to five (25%) participants who had to terminate their previous employment. Occupations included the following: labourer, heavy vehicle driver or mechanical work. Two (40%) of these participants mentioned that they still earned the same income, while the other three (60%) acknowledged that they had to become used to a reduced income. Deshmane *et al.* (1995:128) mentioned that socio-economic inability of patients can be seen as a limiting factor in making use of available rehabilitation resources. The situation at Tygerberg Hospital as a government institution is social pensioners are treated free of charge.

- *Unemployed*

Four (20%) participants who were unemployed before surgery, applied for a social pension after their surgery. This was the third category in describing the effect of surgery on patients' employment and financial position. One (5%) participant did not qualify for a social pension due to the size of his wife's income.

- *Emotional difficulty*

The fourth category referred to participants who experienced **emotional difficulty** after having to terminate their jobs although they did not report financial difficulty. These were both female patients. With reference to differences between male and female patients' experience of a laryngectomy, female patients seem to experience difficulties on an emotional level (Salva & Kallail, 1989:292).

- *Discussion*

More women and younger persons will be affected by a laryngectomy, and will be afraid of having more to lose, with specific reference to occupation and income (Lee-

Preston *et al.*, 2004:437). The ages of participants who at the time had to leave their work, varied between 55 and 69 years. Taking into account the date of surgery, one (5%) participant was in his forties when he stopped working, five (25%) were in their fifties, and two (10%) were in their sixties.

Emotional difficulty regarding loss of employment was in both cases reported by female respondents. It was significant that only one quarter of the participants identified **financial** difficulties due to their surgery, as Eadie and Doyle (2005:120) referred to patients who presented with a cancer diagnosis of the head and neck area, as normally being from a low socio-economic status. Even more significant was the response of five (25%) participants who responded positively about their current financial situation by referring to either an increase in their income, or that they now dealt more responsibly with their finances by maintaining a sober lifestyle.

(g) Summary

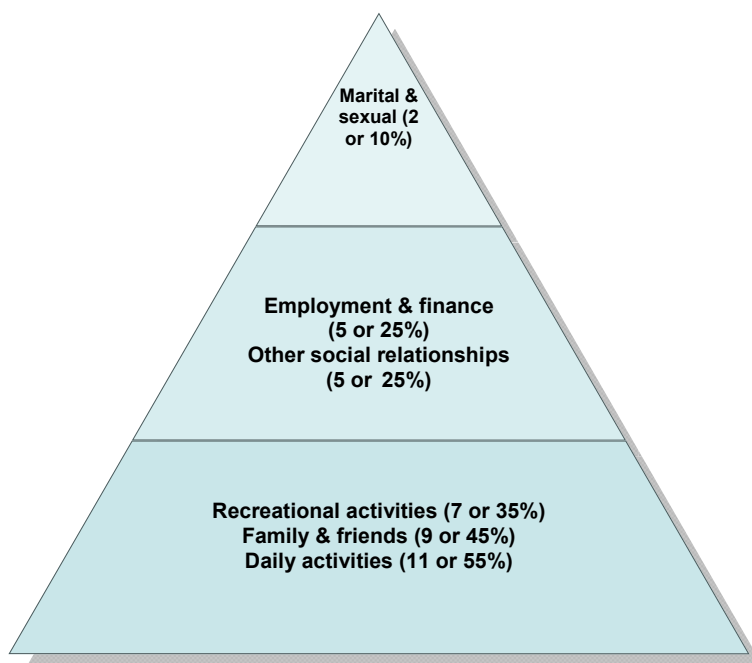
To summarise the effects of a laryngectomy on participants' **social functioning**, the presence of the stoma and loss of voice have the potential to affect the social relationships of the laryngectomy patient and his family (Deshmane *et al.*, 1995:128). These included the effect of the laryngectomy experience on their relationships with **friends and family**, **marital and sexual** relationships, **other** social relationships, **daily** activities, recreational activities, and their **employment and financial** position. This was clearly illustrated by the participants' verbal responses, demonstrating their **need for support** in order to cope with the challenges in daily life.

However, at the same time that the cancer patient is in need of social support, the fear, stigma and disfigurement associated with cancer and its treatment frequently result in difficulties in interpersonal relationships (Richardson *et al.*, 1989:283) which in turn increase the patient's **need for support**. Another factor that may increase laryngectomy patients' **need for support** is that, as it is mostly patients with a history of previous substance abuse (Depondt & Gehanno, 1995:33; Doyle, 1994:17) who are diagnosed with cancer of the head and neck region, they are often separated from their families or relevant others who could have acted as potential sources of support to them. Also, the study showed that when patients decided to maintain a sober lifestyle following their surgery, they may lose their friends. Following these

reasons for separation from others, Dhooper (1985:224) emphasised that patients may feel “ugly” outside their family relationships and therefore withdraw from others. This experience also contributes to their **need for support**.

The area of social functioning mostly influenced by the laryngectomy experience, was that of participants’ **daily activities**, no matter how much time has elapsed since surgery. This could be due to the fact that participants could easily refer to practical and everyday situations. The majority (12 or 60%) of participants had no or primary school education, which could limit their ability to respond to questions of a more abstract nature. Therefore they responded more easily to this question when describing the effects of the operation on their social functioning.

Figure 6.2 provides a **summary** of the severity of social problems on various levels of social functioning as experienced by participants. Daily activities were described by participants as being influenced the most, while marital and sexual relationships were least affected by the laryngectomy experience.



n=20

Figure 6.2: Summary of participants’ opinions on the various areas of their social functioning which were negatively affected by the laryngectomy experience

6.2.1.3 Psychological effects

On the *third level* of the psycho-social effects of a laryngectomy, the psychological impact of surgery upon **patients** and their **relatives** will be described according to the different emotional reactions as outlined in literature. The psychological effects of the operation on the patient will furthermore be described in terms of the patient's description of his **self-image**, **body-image** and various **loss experiences**. The patient's experience of **other people's behaviour** since surgery will also be looked at. Participants were then asked to record their opinion on their **families'** emotional reactions towards their laryngectomy experience.

(a) Reactions and feelings currently experienced by the patient

Table 6.8 provides an overview of participants' current reactions and feelings experienced regarding their diagnosis and treatment.

Table 6.8: Participants' experience of their current reactions and feelings regarding their diagnosis and treatment

Reactions and feelings	Plenty		Few		Not at all	
	Number	%	Number	%	Number	%
Shock	0	0%	2	10%	18	90%
Anxiety	0	0%	4	20%	16	80%
Withdrawal	1	5%	2	10%	17	85%
Isolation	2	10%	2	10%	16	80%
Fear	0	0%	1	5%	19	95%
Helplessness	0	0%	2	10%	18	90%
Frustration	1	5%	6	30%	13	65%
Denial	0	0%	0	0%	20	100%
Anger	0	0%	1	5%	19	95%
Grief	0	0%	5	25%	15	75%
Depression	0	0%	6	30%	14	70%

n=20

The three reactions and feelings mostly indicated by participants (when "*plenty*" and "*few*" are added together) as areas where they were currently experiencing psychological problems, included **frustration**, **depression** and **grief**. Ross (2000:21) described depression as a grief reaction towards various experiences of loss, including loss of voice, smell, taste, ability to laugh out loud or to cry out loud, blow their noses and sneeze, or frustration at being unable to give vent to feelings

verbally. Experiencing these problems will increase the patient's **need for support** in order to effectively cope with these reactions and feelings.

(b) Reactions and feelings currently experienced by the family

Table 6.9 represents the participants' opinion on their families' current emotional reactions and feelings regarding their diagnosis and treatment.

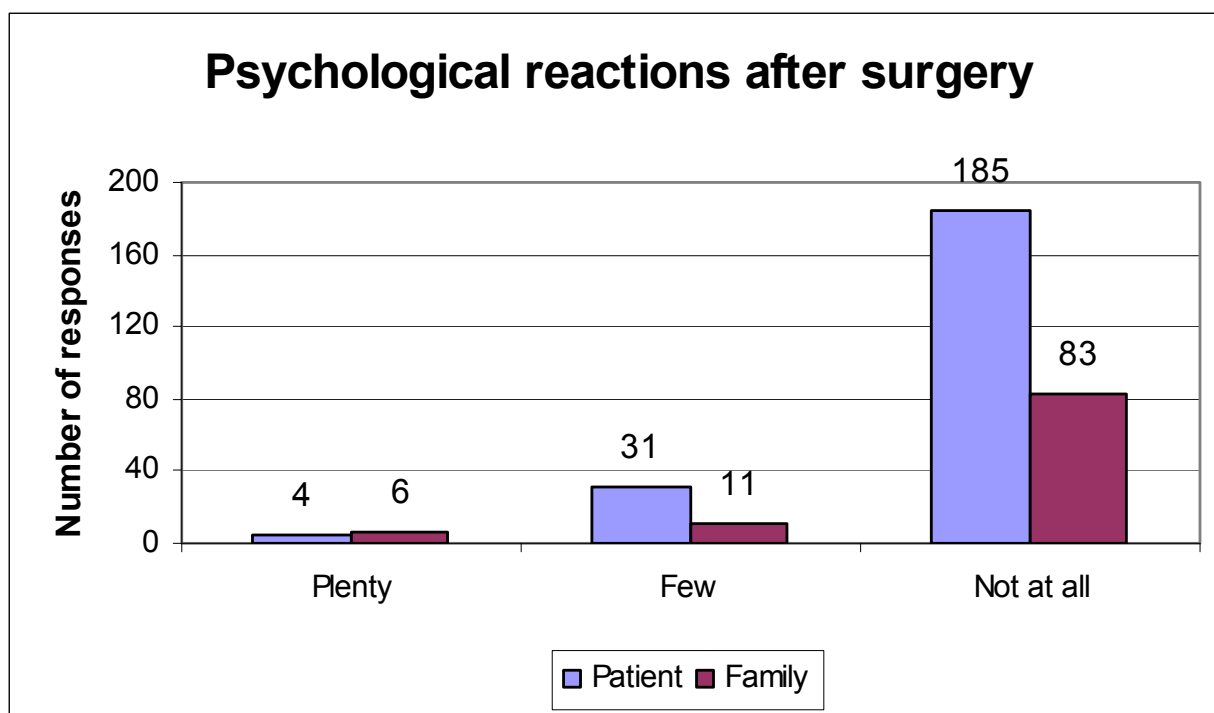
Table 6.9: Participants' opinion of their families' current reactions and feelings regarding their diagnosis and treatment

Reactions and feelings	Plenty		Few		Not at all	
	Number	%	Number	%	Number	%
Guilt	0	0%	1	5%	19	95%
Overprotection	3	15%	3	15%	14	70%
Anger	0	0%	1	5%	19	95%
Fears and concerns	2	10%	6	30%	12	60%
Withdrawal	1	5%	0	0%	19	95%
Acceptance	19	95%	1	5%	0	0%

n=20

When participants were asked to rate their families' current emotional reactions and feelings regarding the participants' laryngectomy, they mainly referred to **fears** and **concerns** families might experience. These may refer to fears and concerns regarding the patient's diagnosis of cancer, effects of the operation and the possibility that the cancer may return, the patient's ability to adjust to his changed circumstances, financial concerns, or interference with social activities (Belch & Beamish, 1992:62; Blood *et al.*, 1994:22; Casper & Colton, 1998:3). In the opinion of the participants, this was followed by **overprotection** as an area where families were currently experiencing psychological difficulties. Families can easily overprotect the patient in an attempt to protect him, as they cannot rely on his ability to express himself and do not want to leave the patient alone, which may contribute towards the patient's feelings of dependency (Depondt & Gehanno, 1995:36; Dhooper, 1985:223; Renner, 1995:217; Ross, 2000:18).

Figure 6.3 presents a summary of the various emotional reactions that patients were currently experiencing versus those of family members (in the opinion of participants).



n=20

Figure 6.3: Summary of emotional reactions and feelings experienced by patients and family

Although different reactions or feelings were used to describe the participants' and their families' emotional reactions and feelings, figure 6.3 showed that families experience even more emotional reactions and feelings than patients. According to these findings it could therefore be said that families are to some extent even more in **need of support** than patients.

- *Discussion*

The majority of participants currently experienced positive reactions towards their laryngectomy experience. With reference to participants' responses regarding their own or their families' psychological experience of their surgery, those who indicated that currently no problems were being experienced, mostly represented those who had their surgery more than a year ago. The following may be possible reasons why nine (45%) and eight (40%) participants respectively reported **no problems** regarding their own or their family's emotional experience after their operation:

- With the exception of one participant who had his operation nine months ago, all the other **participants** who reported in a positive way on their emotional experience of the operation had their operation between one and eight years

ago. Again with the exception of one participant who had his operation nine months ago, all participants who reported positively on their **families'** emotional reactions regarding their surgery had their operation between one and eleven years ago. It was significant that six (30%) participants who reported positively on their own emotional experiences, also indicated a positive response on their families' emotional experiences.

- It could be assumed that these participants and their families had **adapted** in a **successful** way to the side-effects of the operation. One of the criteria for selection of the sample was that patients had to attend the support group when attending the follow-up clinic. According to Salva and Kallail (1989:299) the assumption can be made that these patients who attended the support group by implication had already indicated their motivation to adjust to the surgery and its consequences.
- Participants **might not have been honest** as they thought this would reflect negatively on the study or on their own record.
- Participants really **did not** experience emotional reactions. From the interviews it was clear that in general participants easily accepted challenges in daily life without necessarily questioning them.

(c) Effects of the laryngectomy on self-image

Table 6.10 illustrates participants' opinions regarding the effects of the operation on their self-image, as sub-theme describing the effects of the operation on their psychological functioning, as the central theme. Categories describing those who experienced the same feelings as before about their self-image, felt unable to change anything, and experienced improved health, will be used to describe the above-mentioned sub-theme.

Table 6.10: Effects of surgery on participants' self-image

Theme: Effects of surgery on psychological functioning		
Sub-theme	Categories	Narrative responses of participants
Self-image	Experienced same feelings about self-image	<ul style="list-style-type: none"> The operation did not affect my thoughts, I still feel the same person as before. (<i>Die operasie het glad nie my denke beïnvloed nie, ek voel nog dieselfde as voorheen oor myself.</i>) I feel the same person again ... the only difference is that I cannot talk as I had talked before. (<i>Ek voel maar net dieselfde mens weer ... dit is nou maar net verskil by my is ek kan nie praat meer soos ek gepraat het nie.</i>) I see myself as the same person ... I cannot let the operation change me from the person I previously was. (<i>Ek sien myself as nog altyd dieselfde persoon ... ek kan nie dat die operasie vir my laat "change" nie van wat ek gewees het nie.</i>)
	Acceptance, with the realisation that one could do nothing about it	<ul style="list-style-type: none"> I had the disease and <u>it had to be done</u>, so in other words, I accepted it. (<i>Ek het die siek gekry en dit moet gedoen word, so met ander woorde ek het dit ge-aanvaar.</i>) Nothing did change; it is only my face that is not attractive. I do not feel anything because I cannot help for it; <u>it was the effect of the operation</u>. (<i>Daar het niks verander nie, dis maar net nou my gesig is nie mooi nie. Ek voel niks nie, ek kan mos nie help nie, dis mos die operasie wat dit gemaak het.</i>) I see myself as fine, because I accept everything as <u>I cannot change it</u> and only have to accept it. (<i>Ek sien myself OK "because" ek aanvaar alles en dit is nou so, daar is niks wat ek kan doen nie so ek aanvaar dit.</i>)
	Experience improved conditions of health	<ul style="list-style-type: none"> The operation which I had <u>gave me strength</u>, in other words it had improved my life. (<i>Die operasie wat ek gehad het, hy gee my krag, met ander woorde hy het my lewe verleng.</i>) If I think how I was and I think now after the operation then I have to thank the Lord for my <u>health</u>. (<i>As ek dink hoe ek gewees het en ek dink nou na die operasie dan moet ek vir die Here dankie sê vir my gesondheid.</i>) The operation did not affect me a lot ... now I feel like a different person and I feel <u>healthy</u> because I can still do things for myself. (<i>Die operasie het my nou nie baie beïnvloed nie ... nou voel ek soos 'n ander mens en ek voel gesond en ek kan darem iets doen vir myself.</i>)

n=20

- Experienced same feelings about self-image*

The majority of participants mentioned that in general they still experienced the same feelings as before about their self-image, without providing any reasons for it. This was the first category when describing the effects of the operation on their self-image (sub-theme). This result is in contrast with literature (Belch & Beamish, 1992:60; Dhooper, 1985:222; Hanna *et al.*, 2004:878; Kaplan & Hurley, 1979:53) which referred to physical disfigurement and mutilation as potentially affecting the patient's

self-concept and -image after which depression may follow as a grief reaction towards these changes in body-image and self-esteem (Ross, 2000:21).

- *Acceptance, with the realisation that one could do nothing about it*

The second category referred to those who had known that the operation was necessary in order to improve the participants' health, and which had helped them to adjust to their different self-image. Also, the insight that the various changes they have had to adapt to were caused by the operation and through no fault of their own, had helped them in their experience of their self-image.

- *Experienced improved conditions of health*

In the third category, participants rather focused on how the operation had improved their general health than on their self-image, as that was relevant to them.

- *Discussion*

Participants found it difficult to respond to the question of the effects of their laryngectomy on their self-image. In some cases participants referred to their altered body-image instead of referring to their self-image. It is important to note that the question about their experience of their self-image was asked before the question regarding their body-image.

In an attempt to describe the influence of the operation on their self-image, participants mainly referred to their level of energy that had changed or their altered communication method. Literature (Casper & Colton, 1998:48; Deshmane *et al.*, 1995:121; Hanna *et al.*, 2004:878; Kaplan & Hurley, 1979:53; Ross, 2000:21) described a cancer diagnosis of the head and neck area as being visible and obvious, and that changes in the face were easily noticed by others and had a definite impact on one's self-image and self-esteem. The minority (4 or 20%) reported a negative experience regarding their body-image, which could possibly be related to:

- Participants' **motivation for survival** and that an altered self-image was not that relevant to them at that stage. This is in accordance with the hierarchy of needs distinguished by Maslow (Jordaan, Jordaan & Nieuwoudt, 1977:821) where it was stated that physical needs (food, water) could be regarded as the most basic needs for humans to survive. After total or partial satisfaction of

these needs, people would experience a need of safety. The need to experience love was mentioned in the third place, followed by respect in the fourth place, and lastly, self-fulfilment.

- The majority of participants had none (3 or 15%) or only primary school (9 or 45%) **education**, as showed in figure 5.4. It could therefore have been difficult for them to respond to a question of such an abstract nature.
- The other possible explanation could be that participants **really did not experience** their altered body as problematic.

(d) *Effects of the laryngectomy on body-image*

Table 6.11 presents a summary of participants' experience of their body-image after surgery. Keeping in mind the sub-theme of the effects of the operation on participants' body-image, the following categories were mentioned: acceptance without questioning, experienced improved health, and accepted own responsibility.

Table 6.11: Effects of surgery on participants' body-image

Theme: Effects of surgery on psychological functioning		
Sub-theme	Categories	Narrative responses of participants
Body-image	Acceptance without questioning	<ul style="list-style-type: none"> • I accept it like that as long as I will recover, I cannot fight against it, <u>it just has to be like that</u>. (<i>Ek aanvaar dit maar so sodat ek maar net kan gesondraak, ek kan nie daarteen stry nie, dit moet mos maar nou net so wees.</i>) • I feel satisfied with it. No, <u>nothing</u> bothers me, I can do nothing. (<i>Ek is tevrede daarmee. Nee niks pla my nie, ek kan niks maak nie.</i>) • Actually <u>it did not have an influence</u>, actually it is still the same. (<i>Eintlik het dit nie beïnvloed nie, eintlik is dit maar dieselfde.</i>)
	Experience improved health	<ul style="list-style-type: none"> • After the operation it felt like my body was supposed to feel ... I have <u>energy</u>, I feel <u>better</u>. (<i>Na die operasie ek voel weer soos my liggaam moet wees ... nou het ek krag, ek voel nou beter.</i>) • I feel <u>healthier</u> than before. (<i>Ek voel gesonder as wat ek was voor die tyd.</i>) • I feel satisfied because <u>I feel I improved</u>, my body was like one who deteriorated. (<i>Ek voel tevrede omdat ek voel ek gaan nou vorentoe, my liggaam was soos ene wat agteruitgaan.</i>)
	Accepted own re-sponsibility	<ul style="list-style-type: none"> • I realise that I have to treat my body <u>more healthily</u>. (<i>Ek besef dat ek my liggaam gesonder moet behandel.</i>) • I feel good about my body. I felt that I will <u>look after myself</u> and not frighten others. (<i>Ek voel goed oor my liggaam. Ek het gevoel ek gaan myself versorg, ek gaan nie mense afskrifk nie.</i>) • I adapt to the situation. I just <u>think positively every day</u>. (<i>Ek pas my net aan by die hele situasie. Ek dink net positief elke dag.</i>)

n=20

- *Acceptance without questioning*

The first category identified from participants' responses, was that they accepted their changed body-image in general without questioning it. This is in contrast with literature (Byrne *et al.*, 1993:173; Hanna *et al.*, 2004:878) which reported that after surgery, patients have to adjust to a changed body-image.

- *Experienced improved health*

The second category of responses referred to appreciation of their improved health without letting them down with their altered body-image. Participants realised that the operation had improved physical symptoms and therefore measured their experience of their body-image in terms of these physical symptoms.

- *Accepted own responsibility*

In the third category participants mentioned that they realised they had to take responsibility for their own health. They mentioned their responsibility towards improvement of their own body-image as to be neat.

- *Additional findings*

Participants mostly indicated that change in their body-image was a positive experience (4 or 20%) and also referred to their own responsibility in this regard (7 or 35%). Taking into account that another four (20%) participants indicated that they accepted their changed body-image in general, it was clear that the majority of participants did not have a negative experience of change in their body-image.

- *Discussion*

In the case of participants' opinion on their experience regarding their self-image and body-image, female participants' responses were significant. When referring to **self-image**, female participants described their experience as "*did not change*" (10%) or when it did change, described it as a positive change (15%). When referring to **body-image**, the same pattern was found. One (5%) female participant mentioned that she accepted her changed body-image in general; one (5%) participant described the change in positive terms whilst three (15%) referred to a positive experience but also added the patient's responsibility towards these changes in order to accept them.

None of the **female** participants reported negative feelings regarding their self- or body-image. Unlike literature which indicated that female patients are more vulnerable to change in body-image (Ulbricht, 1986:131, 134), the female participants' opinions in this study were different. On the other hand, Salva and Kallail (1989:301) referred to the difference between male and female patients in their laryngectomy experience by referring to difference to be rather on an emotional and informative level.

Another significant variable was that two (10%) female participants had their surgery less than a year ago, while the other three (15%) had their surgery between three and eight years ago. **Time since surgery** was therefore not responsible for their positive attitudes.

In a discussion of **sources** and **quality of support** in the next section of the questionnaire, it was found that with the exception of one female respondent who described the support she received from the community health centre as "*poor*", all female participants experienced the support currently being received as "*strong*". This finding agreed with a study conducted by Llatas *et al.* (2003:816) who found that medical and social support has the potential to determine the patient's post-operative adjustment.

(e) Effects of the laryngectomy in communication with other people (loss of communication)

Table 6.12 provides an overview of participants' responses on their experience of loss of communication as sub-theme, when describing the central theme of the effect of the operation on participants' psychological functioning. The following categories were derived from these responses: communication as a positive experience, and adaptations to be made in the process of communication with others.

Table 6.12: Participants' experience of loss of communication

Theme: Effects of surgery on psychological functioning		
Sub-theme	Categories	Narrative responses of participants
Loss of communication	Communication as a positive experience	<ul style="list-style-type: none"> I did talk a lot and I still talk a lot. The only thing is that I <u>have to do something to have speech</u>. (<i>Ek het baie gesels en ek gesels baie, so daar is geen verandering nie. Dis nou net dat ek moet iets doen om te kan praat om my stem uit te kry.</i>) I <u>do not have to hide</u>, I can be myself, I do not have to sit there because I can do nothing, I can talk. (<i>Ek hoef nie weg te steek nie, ek kan maar uitkom, ek hoef nie daar te sit omdat ek niks kan doen nie of ek kan nie praat nie, ek praat.</i>) No, I communicate all right, <u>they give me a hearing</u>. (<i>Ek kommunikeer "all right", hulle gee vir my 'n "hearing".</i>)
	Adaptations to be made / limitations	<ul style="list-style-type: none"> I easily become <u>short of breath</u> when I talk too much. (<i>Ek raak gou kort van asem as ek baie met hulle praat.</i>) You <u>cannot talk as loudly as they do</u>, then I keep quiet. Then I give them a chance to finish talking, then I talk. When they see that I am talking, then they keep quiet and listen. (<i>Jy kan nie so hard soos hulle praat nie. As hulle hard praat, dan bly ek stil. Dan gee ek kans dat hulle klaar praat en dan praat ek. Of hulle sien ek praat, dan bly hulle stil en hulle luister.</i>) People talk to you <u>as if you are a deaf person</u>. (<i>Mense praat met jou asof jy 'n dowe mens is.</i>) I talk less. (<i>Ek praat baie minder.</i>) Sometimes there are times that you <u>step backwards</u>, that you write. When we are a lot of people, then I am <u>nervous</u> and then the words will not come out. (<i>Daar is somtyds tye wat ek 'n bietjie terugtree, dan skryf ek, maar as ek en daai persoon alleen is, dan praat ek. As ons 'n klomp mense is, dan is ek baie senuweeagtig en dan sal die woorde nie uitkom nie.</i>)

n=20

- Communication as a positive experience*

The majority of participants' responses were used as the first category when describing the effects of the operation on their experience of loss of communication, namely that they had a positive experience. The time periods passed since the surgery of these participants, represented a wide range. Four of the participants had their surgery less than a year ago, while the other participants' operations were between one and eleven years ago. These participants mostly referred to their degree of acceptance from others and their communication with others, as a pleasant experience.

A positive experience was their realisation that they could still communicate with others, as it was only the technique of speech that had changed. As a result, participants still participated in communication which means visiting, sharing experiences with, and interacting with others (DeSanto, 1994:43). This is of some relevance, as cancer of the head and neck affects some of the most basic human functions, including verbal communication and social interaction (Stewart *et al.*, 1998:143).

- *Adaptations to be made / limitations*

Various adjustments need to be made in the process of communication with others (Meyer *et al.*, 2004:1977) which may have a negative influence on the patient's experience of communication. Restriction or breakdown in family communication may occur after a laryngectomy (Renner, 1995:216). Obstacles in communication with others include: shortness of breath implying a negative ability to communicate, cannot talk loudly, people wrongly assume that they are deaf; talk less now, nervousness when talking in public, and the technique of communication one has to adapt to. As a result, patients may experience social withdrawal or become socially isolated (Clements *et al.*, 1997:493; Kaplan & Hurley, 1979:52), which will increase their **need for support**.

- *Additional findings*

Participants mostly referred to their post-operative communication as a positive experience (12 or 60%). Some (3 or 15%) participants referred to the patient's contribution towards a positive experience.

(f) Effects of the laryngectomy on the ability to talk or express oneself (loss of voice)

Loss of voice is applied as sub-theme to describe the central theme of the effect of the operation on participants' psychological functioning, and in this regard table 6.13 gives an overview of participants' experiences by distinguishing the following categories: the experience of loss of self-expression, general acceptance, and time as healing factor.

Table 6.13: Participants' experience of loss of voice

Theme: Effects of surgery on psychological functioning		
Sub-theme	Categories	Narrative responses of participants
Loss of voice	Experience of loss of self-expression and emotion	<ul style="list-style-type: none"> When my wife passed away, I wanted to cry but I could not. There were tears but I could not cry. (<i>Toe my vrou oorlede was, jy sit, jy wil huil maar jy kan nie. Jy sit maar die trane loop maar jy het nie meer daai huil.</i>) It lets me feel strange, many days I feel heartbroken because I cannot talk or sing. Sunday when I go to church, then I just sit there, then I ask the Lord to help me. (<i>Dit laat my snaaks voel, baie dae dan voel ek so hartseer, omdat ek nie kan praat nie en nie kan sing nie. Sondag gaan ek kerk toe en dan sit en kyk ek net, dan vra ek die Here om my te help.</i>) Sometimes it makes you shiver ... when I want to say something, then I feel like standing up and become angry. But when nothing comes out, then it lets me feel anxious ... then I just feel like keeping quiet. Then I cannot talk ... when I want to talk there is no voice. Then I do not worry, I rather leave it. (<i>Dit laat jou partykeers so, jou lyf so gril. ... of ek wil nou vir haar iets sê, dan smaak dit ek moet opstaan en hard raak. Maar daar kan niks uitkom nie, dit laat my somer so vir 'n ruk swaar en benoud voel ... en dan dink ek ek voel ek bly net stil ... ek kan nie praat nie ... as ek wil probeer praat dan weet ek my stem gaan nie uitkom nie. Dan "worry" ek nie, dan moet ek dit maar los.</i>)
	General acceptance	<ul style="list-style-type: none"> I have to focus on the future. It makes me feel good to experience that <u>when one thing is taken away, then you still have something which can improve</u>. I cannot talk like other people, but anyone can hear and understand me. (<i>Ek moet maar net fokus vorentoe. Dit laat my goed voel om te wys as 'n mens een iets wegvat, dan is daar nog iets wat beter kan wees. Kyk, ek kan nou nie praat soos 'n gewone een nie maar daar is nog altyd 'n manier want enige een kan my hoor en my verstaan.</i>) I just accepted it as there is <u>nothing I can do about it</u>. (<i>Ek het dit nou maar net so aanvaar, ek kan niks daaraan doen nie.</i>) I feel satisfied that it is <u>the work of the Lord</u>. (<i>Ek voel tevrede, dit is die Here se werke.</i>)
	Time as healing factor	<ul style="list-style-type: none"> At the beginning it affects you, but now <u>after three years I am so used to it</u>, it is part of my life now. (<i>Aan die begin affekteer dit jou, maar nou na drie jaar is ek so gewoond daaraan, dit is deel van my lewe nou.</i>) I initially found it strange, <u>but later on</u> I realised that I have to accept it. (<i>Ek het dit eers snaaks gevind, en later van tyd toe besef ek nee wat, ek moet dit maar aanvaar.</i>)

n=20

- *Experience of loss of self-expression and emotion*

Loss of voice also implies loss of self-expression which can at times be a highly emotional experience (Ulbricht, 1986:134) and which may add to patients' experience of isolation and depression (Casper & Colton, 1998:6). This was established as first category for discussion of participants' experience of loss of voice. Examples used illustrated the emotion experienced by participants when they felt heartbroken, wanted to sing and realised that they could not laugh without sound, or when they felt angry.

- *General acceptance*

The second theme which was gained from empirical data was participants' ability to accept their experience of loss of voice in general, without questioning it. Participants easily referred to "the works of the Lord" which helped them to come to terms with their experience of loss.

- *Time as healing factor*

The third theme dealt with participants' experience that feelings associated with their experience of loss of voice improved as time went by. With regards to the experience of respiratory problems, Hilgers *et al.* (1990:424) found that problems patients might experience could possibly be due to improvement of symptoms over time or better adjustment of the patient. This could also be applicable in the case of participants' experience of loss of communication as these participants had their operation between one and six years ago.

- *Additional findings*

This experience was regarded mainly in a positive way (13 or 65%). The majority (5 or 25%) of those who identified problems (7 or 35%) regarding their experience of loss of voice, also made positive suggestions on how to deal with this experience.

- *Discussion*

Although discussion of loss experiences was conducted in terms of abstract concepts, participants managed to respond easily to questions regarding "loss of voice" and "loss of communication" as these were relevant to them. Participants

experienced “loss of voice” as being mostly affected by surgery, and included loss of self-expression. This was followed by “loss of communication”.

It is important to take into account, is **first**, the educational level of participants. The majority of participants had no (3 or 15%) or only primary school (9 or 45%) training. **Second**, time lapsed since surgery was an important factor in their responses. **Third**, loss experiences were present throughout the patients’ recovery period, and not only shortly after being diagnosed and treated. In the **fourth** place, patients easily referred to their religion (which will be indicated as an important source of support in the following section) as being helpful in overcoming their disability, without questioning it.

However, some participants successfully managed to use these loss experiences as a challenge for personal growth, as described by Kaplan and Hurley (1979:57). This is in accordance with the ecological perspective as described by Germain and Gitterman (1996:12-14), namely that a traumatic life issue (external life stressor like the laryngectomy) can be experienced either as a stressor or a challenge. **Social support** can be seen as an important factor contributing towards patients’ successful post-operative adaptation (Llatas *et al.*, 2003:816).

(g) Effects of other people’s behaviour since the laryngectomy

Table 6.14 presents an overview of participants’ experience of other people’s behaviour since their operation, as sub-theme of the central theme of the effects of surgery on participants’ psychological functioning. Categories used to described these influences of other people’s behaviour, included: acceptance of the patient, attitudes which were discouraging, and an experience of the absence of negative responses.

Table 6.14: Participants' experience of other people's behaviour since their operation

Theme: Effects of surgery on psychological functioning		
Sub-theme	Categories	Narrative responses of participants
Other peoples' behaviour	Acceptance of patient	<ul style="list-style-type: none"> No, they are very <u>positive towards me</u>. Actually, they cannot react any other way as they can observe my positiveness and it motivates them to be positive too. (<i>Hulle is baie <u>positief teenoor my</u> ... hulle kan die positiwiteit binne-in my sien en daarom moet hul ook positief wees.</i>) They <u>treat me as if I am part of their family</u> ... love, conversation, invitations to visit them at home and to communicate ... attend meetings ... they accept. (<i>Hul tree op teen my asof dis hul eie familie ... liefde, goeie geselskap, nooi my na hulle huise toe en gesels ... gaan vergaderings toe ... hulle aanvaar.</i>) When we talk, I cannot talk continuously, I have to rest in-between. They wait for me, it is not that they do not want to be in my company, they accept me. (<i>As ons gesels, ek kan nou nie aaneen gesels nie, dis mos nou rus-rus, maar hulle wag vir my en dis nooit dat hulle nie in my geselskap wil wees nie. Hulle <u>aanvaar</u> my.</i>)
	Attitudes which were discouraging	<ul style="list-style-type: none"> When they talk they can talk, I will rather keep quiet. They feel <u>irritated</u> when I talk as they are not familiar with that type of speech. Then I rather keep quiet. (<i>As hulle praat, kan hulle maar praat, ek bly maar stil. Hulle raak 'n bietjie <u>onmanierlik</u> as ek saam met hulle praat, hulle hou nie van die gepraterie nie. Hulle ken nie die soort praat wat ek hier praat nie. Ek moet maar stilbly daai tyd.</i>) Many people will say, shame, <u>they feel sorry for you</u>. (<i>Baie mense wil vir jou sê "haai foei tog", hulle <u>bejammer</u> jou.</i>) They <u>imagine that I am deaf</u>, they they talk loudly as if you cannot hear. (<i>Hulle <u>verbeel</u> vir hulle <u>ek is doof</u>, dan praat hulle kliphard met jou asof jy nie kan hoor nie.</i>)
	Experienced absence of negative responses	<ul style="list-style-type: none"> They do not anger my, they support me. (<i>Hulle <u>maak my nie kwaad nie</u>, hulle staan my by.</i>) They do not react strangely to me, they are still kind to me. (<i>Hulle tree <u>nogal nie snaaks</u> teen my op nie, hulle is nog altyd gaaf.</i>) They are decent and I experience that I am on the same level as they are; it is not that they let me down. (<i>Hulle is heel skaflik en staan met hul op gelyke voet omdat dit is <u>nie</u> by hulle dat die kwaal my <u>agteruit stoot nie</u>.</i>)

n=20

- *Acceptance of patient*

The majority of participants supplied positive examples of their experience of other people's reactions towards them following surgery. Adaptation of others to change in communication technique was an important contributing factor in being accepted by others. This was used as first category in describing other people's behaviour.

Attitudes of significant others may have an impact on the patient's experience of his surgery (Kaplan & Hurley, 1979:52). Half of the participants who experienced the behaviour of other people as positive, had their operation less than a year ago and the other half had their surgery between one and seven years ago. Responses to this question were therefore representative of a wide range of time periods elapsed since surgery.

- *Attitudes which were discouraging*

The second category referred to discouraging attitudes of others, such as feeling sorry for the patient, becoming irritated with participants' method of speech, reacting strangely, or wrongly thinking that the patient was deaf. Difficulty with post-operative speech played a role. A quarter of the participants identified problems in their contact with other people as they had to confront the reality of their situation when entering the outside world (Ulbricht, 1986:133). These participants had their surgery between two and six years ago. They had therefore been more exposed to contact with other people and could do a better evaluation.

- *Experienced absence of negative responses*

Absence of negative responses from others was established as third category when describing the effect of the operation on other people's behaviour towards the patient. These mainly referred to the absence of anger or being treated as inferior, or treated differently than before.

- *Discussion*

A wide variety of responses were reported to this question. Acceptance from others was mainly described as being a positive experience. This was an important finding of the study, as participants were representative of a wide range of time periods elapsed since surgery - the average time since surgery was three years and two months.

(h) Summary

This section of the questionnaire, relating to the **psychological** effects of surgery on the patient, participants sometimes found difficult to answer, as it contained abstract information and they often replied by stating that it had no influence and did not affect

them. It was also difficult for them to distinguish between the different items included under psychological impact of the operation.

Change in the method and technique of participants' speech after surgery, and adaptations to a new form of communication, were found to be an important factor determining the experience of the psychological effects of the operation. Llatas *et al.* (2003:816) found that together with medical support, social support can play an important role in improving the patients' successful psychological adjustment.

6.2.2 Aftercare and support services

In the final section of the questionnaire, participants were asked to identify potential sources of support currently being received and to rate the quality of that support; to identify any other sources of support from which they could potentially benefit and were also asked about their familiarity with other laryngectomy patients.

Attendance of the support group was set as criterion of inclusion in the sample, as the intention of the study was to explore and describe laryngectomy patients' need for support groups as part of an aftercare programme when attending the follow-up clinic at the hospital. Participants were finally asked to give their opinion on the value of these groups and possible themes to be included in support group discussions. Literature (Birkhaug *et al.*, 2002:198; Richardson *et al.*, 1989:290-291) guidelines were used to ask participants about their experience of the value of support groups. These guidelines referred to improvement of post-operative adjustment (medical, social and psychological benefits); improvement of quality of life; minimising the effects of surgery and promoting speech and rehabilitation efforts. When participants described other benefits that support groups might offer, they were also categorised according to these literature guidelines.

6.2.2.1 Sources and quality of support currently being received

Participants were asked to rate the quality of support currently being received according to a list of possible sources of support as illustrated in table 6.15, which demonstrated the items possibly to be included in the laryngectomy patient's eco-map (Compton *et al.*, 2005:352-353; Meyer & Mattaini, 1995:18-19; Tracy & Whittaker, 1990:461-470).

Table 6.15: Sources and quality of support

Sources of support	Strong		Poor		Stressful		Not applicable	
	Number	%	Number	%	Number	%	Number	%
Spouse	11	55%	0	0%	1	5%	8	40%
Life partner	0	0%	0	0%	0	0%	20	100%
Parents	3	15%	0	0%	0	0%	17	85%
Children in home	13	65%	0	0%	0	0%	7	35%
Children out of home	13	65%	1	5%	0	0%	6	30%
Other family	16	80%	2	10%	2	10%	0	0%
Grandchildren	16	80%	1	5%	0	0%	3	15%
Neighbours	18	90%	1	5%	1	5%	0	0%
Friends	19	95%	0	0%	1	5%	0	0%
Church	20	100%	0	0%	0	0%	0	0%
Community health centres	14	70%	4	20%	1	5%	1	5%
Laryngectomy patients (group)	20	100%	0	0%	0	0%	0	0%
Multi-disciplinary team (hospital)	20	100%	0	0%	0	0%	0	0%

n=20

Sources of support were selected from the model proposed by Richardson *et al.* (1989:283-292) and included support from family and friends; support from disease specific peers (other patients who had a similar operation) and professionals (team members at the hospital), as well as from the researcher's personal experience in group sessions. In group sessions it was evident that grandchildren played an important supportive role in the patient's post-operative adjustment. It was for this reason that the researcher identified the need to separate the contribution of grandchildren's support to laryngectomy patients from support by other relatives.

From the findings of the study it was clear that participants mostly rated current or existing support they received, as **strong**. In many cases certain sources of family support were **not applicable**, for example participants who were not married (8 or 40%); did not have a life partner (20 or 100%); whose parents had died (17 or 85%); who did not have children at home (7 or 35%) or out of home (6 or 30%), did not have grandchildren (3 or 15%) or did not attend a community health centre (1 or 5%). Taking into account that seventeen (85%) of the participants did not have parents,

the remaining three (15%) rated parental support as a hundred percent. The same incidence was found regarding support from children in the home – seven (35%) participants mentioned that they did not have children in the home. The remaining thirteen (65%) rated a hundred reported a hundred percent support from children in the home.

Twelve (60%) participants indicated that they received a hundred percent (100%) **strong** support from all the sources of support listed in the questionnaire. Two (10%) of these participants had their surgery less than a year ago, whilst the other ten (50%) participants had their surgery between one and eight years ago, with an average period of three years four months ago. All twenty (100%) participants indicated that they received a hundred percent (100%) support from their **church**, **group members** and **team members** at the **hospital**.

Various sources of support are seen as important contributors to the patient's recovery to meet the different demands of adaptation after surgery. These sources of support should be seen in combination with one another, as different types of support have their own unique qualities and benefits (Richardson *et al.*, 1989:284). Strong support from the **spouse**, **family** and **close friends** in this study can be seen as a positive prognostic factor that would contribute to the success of speech rehabilitation. The greater the degree of support from family and friends and the more positive the patient's experience of social support, the more likely the patient would be to learn speech (Maas, 1991:1374; Richardson & Bourque, 1985:85, 95; Stam *et al.*, 1991:54). It was for that reason that Byrne *et al.* (1993:174) suggested that speech rehabilitation should ideally be combined with available support resources.

Strong support from **patients in the group** as rated by participants, compared well with the opinion of Tracy and Whittaker (1990:461-462) that social support can either be provided informally and spontaneously through the natural helping networks of family and friends or through professional intervention. These support sources could support, weaken, substitute, or could be complementary to the help offered by professionals.

Eight (40%) participants rated **poor** or **stressful** sources of support. Half (20%) of these participants had their operation less than a year ago, and the other half (20%)

had their operation between two and eleven years ago. When summarising the results of **poor** and **stressful** support, it was clear that these sources referred to community health centres (5 or 25%) or other family (4 or 20%). This was followed by support from neighbours (2 or 10%); spouse (1 or 5%); children out of home (1 or 5%); friends (1 or 5%) and grandchildren (1 or 5%).

6.2.2.2 Acquaintance with any other patients who have had the same operation

Participants were asked to comment on their exposure to and experience of possible contact with other people in the area where they stay who have had the same operation, but were not attending the same support group. This was used as a sub-theme for the theme of support and aftercare being offered to these patients. Categories used in table 6.16 included: those who had no contact, those who experienced contact with others as a supportive experience, and those who had a negative experience, of contact with others.

Table 6.16: Acquaintance with other laryngectomy patients in the area

Theme: Support and aftercare				
Sub-theme	Category	Narrative responses of participants	Number	%
Acquaintance with other laryngectomy patients in the area	No contact	<ul style="list-style-type: none"> Not applicable 	15	75%
	Supportive experience	<ul style="list-style-type: none"> It lets me feel good, it encourages me. When we are in contact with each other, then we can talk. (<i>Dit doen my goed, dit bou my op want dan as ons so bymekaarkom en ons sien weer mekaar dan praat ons.</i>) It is good, because then we can communicate about our problems or what to do with the problems. (<i>Dit is goed want dan kan ons met mekaar kommunikeer oor die probleme of wat jy moet doen.</i>) It means a lot to me because we can communicate. (<i>Dit beteken vir my baie omdat ons gesels.</i>) 	3	15%
	Negative experience	<ul style="list-style-type: none"> Because <u>he still smokes</u>, it does not make me feel good ... he has seen what he has been through but he still carries on. (<i>Omdat hy nog rook, laat dit nie vir my so goed voel nie ... hy sien waardeur ons gekom het en hy gaan nog aan.</i>) He is of no help to me ... he continues his life style and I continue with mine, <u>he is a guy who still drinks</u>. (... <i>hy is nie 'n help vir my nie ... hy gaan sy gang en ek gaan my gang, hy is 'n mannetjie wat nog drink.</i>) 	2	10%
TOTAL			20	100%

n=20

- *No contact*

The majority of participants indicated that they had no contact with other people in their area who have had the same operation, which finding was used as first category reflecting responses to this question. This is in agreement with literature (Ross, 2000:14) which stated that a laryngectomy can be regarded as a lonely experience as it is an operation which is seldom performed.

- *Supportive experience*

Renner (1995:219) and Murrills (1975:55) agreed that the emotional trauma after an operation can best be understood by those sharing a similar experience. In the second category, participants described supportive experiences through contact with other laryngectomy patients in their area. The **needs** of laryngectomy patients and their relatives can therefore best be understood by fellow patients (Ross, 2000:20). These listed benefits of contact with fellow patients are in accordance with some of the benefits of support groups for laryngectomy patients, such as problem-solving, or serving as a source of information where they can share practical hints and ideas otherwise not formally provided by the health care professionals (Graham, 2004:131).

- *Negative experience*

The third category referred to participants who had a **negative** experience of contact with other laryngectomy patients in their area, where participants had been maintaining a sober lifestyle since their operation. This was in contrast with others whom they have met who still continued with their smoking and drinking behaviour. This observation agreed with Richardson *et al.*'s (1989:284) warning that support is not always beneficial. However, Richardson *et al.* did not refer to the supportive person's lifestyle, but rather to impatience by the other person or negative feedback, which may emphasise the patient's disability.

- *Additional findings*

The majority (15 or 75%) of participants were **not acquainted** with other laryngectomy patients. This is in line with literature which confirmed that a laryngectomy can be seen as a lonely experience as patients seldom know others who have had such an operation (Renner, 1995:215; Ross, 2000:14). Lack of contact

with other patients may result in not experiencing the above-mentioned benefits of support. Added to patients' loneliness may be reactions of withdrawal or isolation. These reactions intensify their **need for support**.

6.2.2.3 Description of the benefits / value of support groups

Participants were asked to rate their experience of the benefits of their attendance of support groups according to a specific quality value – *great*; *little* or *none*. A summary of participants' responses can be viewed in table 6.17. Guidelines as used in literature (Graham, 2004:131-133) were used to identify possible benefits of support group attendances.

Table 6.17: Participants' responses on the benefits / value of attending support groups

Potential benefit or value	Great		Little		None	
	Number	%	Number	%	Number	%
Problem-solving	20	100%	0	0%	0	0%
Source of information	20	100%	0	0%	0	0%
Promotes adaptation after operation (rehabilitation)	20	100%	0	0%	0	0%
Provides support to cope with feelings (emotional support)	20	100%	0	0%	0	0%
Provides support in relationships with other people (social support)	20	100%	0	0%	0	0%
Improves quality of life	20	100%	0	0%	0	0%

n=20

All (100%) participants evaluated their attendance of support groups as **greatly beneficial** to themselves. When asked to describe any **other benefits** of support groups, four (20%) participants did not record any. Sixteen (80%) participants described positive benefits which related to the above-mentioned literature framework regarding the various potential benefits that support groups can offer.

Table 6.18 can be viewed as a summary of participants' responses to the question of **any other benefits** support groups may offer, whereafter it will be discussed according to literature guidelines already referred to.

Table 6.18: Summary of participants' opinion on other benefits of support groups

Literature benefit of support groups	Responses of participants in study	Number	%
Problem-solving (1 or 5%)	<ul style="list-style-type: none"> Compare own problems with those of others and sort them out together 	1	5%
Source of information (2 or 10%)	<ul style="list-style-type: none"> Learn from others and discuss problems 	1	5%
	<ul style="list-style-type: none"> Discuss practical tips and ideas 	1	5%
Promote rehabilitation opportunities (1 or 5%)	<ul style="list-style-type: none"> Promote post-operative speech 	1	5%
Offer social support (4 or 20%)	<ul style="list-style-type: none"> Decrease level of anxiety regarding possible recurrence of disease by comparing yourself with others 	1	5%
	<ul style="list-style-type: none"> Compare yourself and your problems with others 	1	5%
	<ul style="list-style-type: none"> To be exposed to a pleasant experience of communication by sharing the same attitudes and having time to listen 	1	5%
	<ul style="list-style-type: none"> Experience inspiration as others admire you 	1	5%
Offer psychological support (3 or 15%)	<ul style="list-style-type: none"> Think about what was discussed which reduces feelings of social isolation 	1	5%
	<ul style="list-style-type: none"> Interact with other group members no matter the degree of participation 	1	5%
	<ul style="list-style-type: none"> Reduce feelings of isolation 	1	5%
Improve quality of life (2 or 10%)	<ul style="list-style-type: none"> Learn from others' experiences by discussing and comparing problems and set targets for yourself 	1	5%
	<ul style="list-style-type: none"> Find motivation and strength to continue with life 	1	5%
Additional benefits (3 or 15%)	<ul style="list-style-type: none"> Offer spiritual support 	1	5%
	<ul style="list-style-type: none"> Appreciate interest shown by the hospital 	1	5%
	<ul style="list-style-type: none"> "Many things" 	1	5%

n=16

- Benefit of problem-solving*

Murrills (1975:55) and Jay *et al.* (1991:937) said that group discussions offer an excellent opportunity to meet, share and discuss problems:

- I would say that it is positive to listen to other people's problems in order to compare it with your own. Then we can share ... in general we are like a pool, we pool our problems in one bucket and then we sort it out. (*Ek sal sé dis iets*

goeds om na ander se probleme te luister en jy weeg dit op teen jou eie probleem. Dan kan ons mos nou uitruil ... maar oor die algemeen is ons amper soos 'n "pool", ons "pool" ons probleme in een bak en dan "sort" ons dit uit.)

- *Benefit of gaining information*

This benefit of support groups to offer information is enforced by the fact that patients share a similar situation (Graham, 2004:131). Information being shared is trustworthy, as it has the value of being viewed "through a patient's eyes" (Doyle, 1994:250). Practical hints and ideas can also be discussed:

- To attend something like this is very informative because you can learn a lot from other people ... then you can say again what your problems are ... (*Om so iets by te woon is vir my baie inligting want jy kan baie leer van ander persone ... en dan sê jy weer jou sê wat jou probleme is*)
- You receive many hints and tips which you did not think of and which you can try, then you realise that it makes things easier ... (*Jy kry baie rate daar wat jy nie aan gedink het nie wat jy kan loop toepas, dan sien jy dit maak dit makliker.*)

- *Benefit of promoting rehabilitation opportunities*

Rehabilitation is found to be strongly influenced by support from other patients (Graham, 2004:132; Stam *et al.*, 1991:39):

- ... I don't think that I spoke as well as he did so soon ... you are inspired by others, you feel good. (*... ek dink nie ek het so goed gepraat so gou soos hy nie. ... jy word opgebou deur die een die ander.*)

- *Benefit of social support*

The **first** social benefit of support groups which was mentioned by a participant, was the benefit of comparing yourself with others who had their operation long ago. Patients will receive reassurance from such people (Graham, 2004:132-133), as long-living laryngectomy patients demonstrate their various post-operative adjustments to newly operated patients (Gardner, 1971:189). One of the participants reported:

- It gives me a lot of courage, I told myself I give myself a year, and then it (the cancer) will possibly come back. But when I heard that one person was operated on eleven years ago, it helped me a lot. *(Dit gee vir my baie moed, ek het vir myself gesê ek gee myself 'n jaar, dan die ding sal miskien agter 'n tyd terugkom. Maar toe dat ek hoor daar is een wat elf jaar, dit het my baie gehelp.)*

Second, social support can be offered by members of a homogeneous group as it offers the opportunity for social comparison and feedback. Feedback from fellow patients regarding the patient's improvement, may improve the patient's social adjustment (Richardson *et al.*, 1989:290) as can be viewed from the following example:

- I have listened carefully ..., it went to my head ... because she experienced the disease, but she looks recovered and is healthy and she is still alive. (... *dit het my baie na my kop toe gegaan ... want sy het dit gehad, maar sy lyk genees en sy is gesond en daar is sy nou nog 'n mens.*)

A **third** social benefit of support groups which was mentioned was the idea that communication with fellow patients can be a positive experience. Within support groups, "sharing" between group members takes place, referring to a discussion of experienced problems, emotional problems following surgery, and personal experiences (Beverly-Ducker, 1991:60; Jay *et al.*, 1991:937; Mehta & Abrol, 1982:111). The positive benefit of "sharing" was described as follows:

- It is pleasant to join such a group because other people do not always have time for you, they will not sit and talk to you, those who have natural speech. *(Dis lekker om by so 'n groep uit te kom want die ander mense het mos nie eintlik tyd vir jou nie, hul sal mos nie lekker met jou sit en gesels nie, die wat nou kan reg praat.)*

Finally, a participant (5%) added another social benefit of support groups as his initial feelings of carelessness diminished when he experienced that others were admiring him eleven years after his surgery. Although this participant had inspired a newly operated patient (first example) it was clear that even after eleven years, this

participant also benefited from support group attendance as he was looked up to as a role model. This is in agreement with Gardner's viewpoint (1971:189) that patients can serve as role models (Beverly-Ducker, 1991:60) to one another and demonstrate positive adjustment and rehabilitation as they prove in an enthusiastic and encouraging way that they have mastered their own limitations. A participant mentioned the following:

- It meant a lot to me, because I thought I was down and nobody cares for me. But see how easily the people talk to you, they still have a long way to go before they have achieved eleven years (post-operation), then I can also carry on. *(Dit het vir my baie beteken want ek het gedink ek is nou "down" en niemand gee meer om vir my nie. Maar kyk hoe lekker praat die mense nou, hulle moet nog ver kom voor hulle by die elf jaar kan kom, dan kan ek ook mos weer aangaan.)*

- *Benefit of psychological support*

The second largest group (3 or 15%) of participants referred to the benefits of attending support groups by referring to psychological benefits. Each group member has the opportunity to interact with other group members, no matter what the degree of participation. Support group attendance can also reduce feelings of isolation, as described by Graham (2004:131). Patients can best understand the needs of the patients and their relatives as they share the same experience (Renner, 1995:219; Ross, 2000:20) as can be observed from the following examples:

- When I leave the group I have the idea that I am not alone. It feels as if that person walks with me, alongside me, I feel as if he is continuously walking with me ... in my mind I am still with them, I do not forget them. *(As ek daar uitstap dan loop ek net met die gedagte ek is nie die enigste een wat die siekte het nie. Dan voel dit vir my hy loop nog altyd hier met my, ek voel hy loop nog altyd langs my. ... in my gedagte is ek nog altyd by hulle, ek vergeet hulle nie.)*
- When we are in the group, each of us has a chance to say something. Some talk a lot, others only two words ... it gives you strength. *(As ons so in die groep is het ons elkeen 'n kans om iets te sê. Party praat baie, party praat net twee woorde ... dit gee vir jou baie sterkte.)*

- *Benefit of improved quality of life*

Several studies have found a positive correlation between laryngectomy patients' participation in support groups and improved quality of life (Birkhaugh *et al.*, 2002:203). Participants described this benefit as follows:

- ... in the beginning when I was operated there was not a group. I longed to talk to someone about the operation. Later, when the group started, I could talk to people who have more experience than I have, and it gave me goals. Yes, I can also be like them. If they are better than I am, then I observe that I also can. (*... aan die begin was daar nie so 'n groep toe ek geopereer was nie. Ek het gesmag om met iemand te gesels en om te hoor van wat die operasie beteken. En later, toe die groep kom, toe kan ek praat met mense wat meer ondervinding as ek het, en dit het my weer doelwitte gegee. Ja, ek kan net soos jy word. As jy beter as ek is, dan sien ek ek kan ook.*)
- It meant a lot to me, it gave me something for the future. (*Dit het vir my baie beteken, het my weer iets gegee vorentoe.*)

- *Additional benefits*

Three (15%) participants identified additional benefits of support groups which were not found in literature. These benefits included: the opportunity to support other patients on a spiritual level; to experience appreciation for interest shown by hospital team members or support groups offering "many things to think about" although the participant could not be specific and found it difficult to verbalise his thoughts.

6.2.2.4 Themes for discussion during group sessions

Participants were asked for their opinion on whether themes as suggested in literature (Graham, 2004:132-133) should be included, excluded or whether they were uncertain if it should be included at all within support group discussions. Table 6.19 summarises participants' responses to this question.

Table 6.19: Themes for discussion during group discussions

Themes	Yes		No		Uncertain	
	Number	%	Number	%	Number	%
Learn how to cope with physical aspects of the operation	20	100%	0	0%	0	0%
Learn how to follow a balanced diet	18	90%	0	0%	2	10%
Learn how to take care of the stoma	20	100%	0	0%	0	0%
Learn how to talk again after operation	20	100%	0	0%	0	0%
Learn how to practice newly acquired speech	20	100%	0	0%	0	0%
Learn how to use communication skills	20	100%	0	0%	0	0%
Learn how to cope with daily situations	20	100%	0	0%	0	0%
Learn how to solve problems	20	100%	0	0%	0	0%
Learn how to stop smoking and drinking habits	18	90%	1	5%	1	5%

n=20

The only two themes for discussion about which participants were **not a hundred percent** convinced that they should be discussed within the context of support groups, were “*learn how to follow a balanced diet*” and “*learn to stop smoking and drinking habits*”.

When asked to suggest **any other themes** for discussion within support groups, nine (45%) participants added no additional topics to the list. The other eleven (55%) participants emphasised either themes that were already included in the list or suggested some additional ideas for discussion (some listed more than one).

New suggestions for discussion in groups included: speech prostheses (1 or 5%); radiation treatment (1 or 5%); recreational activities (2 or 10%); an understanding of the patient’s feelings (1 or 5%); relationship with the spouse and family members (2 or 10%); how to maintain oneself in the presence of other people (1 or 5%) and post-operative adaptation to daily life (1 or 5%). Whilst the first two items refer to the educational theme, the third refers to the social interaction theme and the last three to the support counselling theme.

6.2.2.5 *Summary*

Participants easily responded to this section of the questionnaire. This could possibly be due to the fact that all the participants had first-hand knowledge of the functioning and value of support groups. These questions were the more practical part of the questionnaire.

The majority of participants described the quality of support currently being received from various sources of support as **strongly** beneficial. All participants evaluated their attendance of **support groups** also as strongly beneficial to themselves. These were representative of newly operated participants and those who had their operation a longer time ago. Additional **themes** suggested for discussion in support groups were their post-operative adaptation and maintaining social relationships.

6.3 CONCLUSION

As indicated in chapter 5, the aim of the study was to explore the laryngectomy patient's need for support groups in a hospital setting from a social work perspective. Following the previous chapter which outlined the first two sections of the results of the study, this chapter outlined the last two sections of the results of the study.

In the third place, the **psycho-social effect** of the operation was described in terms of physical, social and psychological effects. Social support can be seen as valuable for these patients' and their relatives' post-operative adaptation.

In the fourth place, **support** and **aftercare** were described with specific reference to the value of these groups or suggested themes for discussion. Themes such as post-operative adaptation and maintaining social relationships were mentioned.

Chapters 5 and 6 therefore successfully explored the laryngectomy patient's need for support groups in a hospital setting from a social work perspective. This will help social workers in a health care setting to gain a better understanding of these patients' needs in order to provide guidelines for social work intervention to this target group of patients.

In the following chapter, conclusions and recommendations regarding social work interventions for laryngectomy patients will be presented.

CHAPTER 7

CONCLUSIONS AND RECOMMENDATIONS

7.1 INTRODUCTION

The exploration of laryngectomy patients' need for support groups in a hospital setting was started after this researcher and a speech-language therapist had initiated the use of support groups to benefit laryngectomy patients and their relatives. Little information from a social work perspective was available. The topic of support being offered to these patients became an area of interest to the researcher. The aim of this chapter is to present information gained from the literature study in relation to responses from the empirical data, in order to make recommendations based on these conclusions. These recommendations will indicate general guidelines regarding social work intervention with laryngectomy patients. Through this, the final aim of the study will be met: to present a contextual framework for a social work aftercare programme for laryngectomy patients in a hospital setting. An illustration of this contextual framework can be found in Annexure I.

7.2 CONCLUSIONS AND RECOMMENDATIONS

The following conclusions and recommendations are based on the findings from the empirical investigation.

7.2.1 Identifying details

The **age** of participants who took part in the study varied between 51 and 74 years, with an average of 62 years. Both **male** and **female** participants took part in the study; however, more males than females participated. This is in line with the current tendency as described in literature, namely that mostly elderly male persons are being affected by the diagnosis of cancer of the larynx. This pattern is undergoing change due to changes in substances abuse, as more females and younger persons will be affected in future. The majority of the participants were **married**. With the exception of one White participant, all participants were from the Coloured **population group**. The catchment area of Tygerberg Hospital extends to patients from the Western Cape. The latest available census information showed that the

Western Cape is occupied mostly by Black people, followed by people from the Coloured, White and Asian population groups. Statistics of laryngectomy operations being performed and also of patients who attended the follow-up clinic at the Department of Radiation Oncology, Tygerberg Hospital on Wednesdays, showed that the majority of these patients were from the Coloured population group, followed by the White and Black population groups. Patients who participated in the study were therefore representative of the statistics recorded at Tygerberg Hospital. The majority of participants had primary school or no **education**, were **social pensioners** and previous to their operation did mostly unskilled work or were unemployed and fell into a low **income group**.

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 elderly male persons of low education and socio-economic status (Eadie & Doyle, 2005:120). Findings of the study were in accordance with literature information.

Recommendations

A change in the pattern, to younger patients being diagnosed with larynx cancer, will have implications for **social work intervention** in future:

- Social work intervention will **differ from current practice** which is aimed at the age group of late middle age or retirement, as social workers will have to meet the needs of younger persons.
- Social workers will have to deal with a **different** type of **demand** for social support. Unlike the tendency of elderly female persons being the spouse of elderly male patients, more male persons of a younger age will in future be the spouse of a laryngectomy patient and will therefore be the target group to benefit from social support.

7.2.2 Medical aspects of a laryngectomy and the role of the social worker

7.2.2.1 *Medical aspects*

All participants had undergone a total laryngectomy as treatment for a diagnosis of larynx cancer. The majority also had had additional medical treatment like block or neck dissections and/or radiotherapy. Date since surgery varied between three months and eleven years, with an average time of three years and two months. Three-quarters of the participants' follow-up visits were scheduled on a six-weekly to six-monthly basis, while the appointments of others were scheduled on a yearly basis. Nearly all participants viewed their attendance of the follow-up clinic as a positive contribution towards their medical and rehabilitation progress and their need for support.

The **conclusion** can be drawn that the unique context of the hospital setting offers an excellent opportunity to provide aftercare and support to laryngectomy patients while attending the follow-up clinic on a regular basis. This is an ideal opportunity for the laryngectomy patient to make contact with other laryngectomy patients.

Recommendations

- The social worker should have a thorough knowledge of the **medical aspects** of the etiological factors, diagnosis and treatment of cancer of the larynx, including the laryngectomy as surgical treatment for this procedure.
- The social worker should use her knowledge of the etiological factors of larynx cancer (substance abuse, especially smoking) to initiate community precaution programmes.
- The social worker should work as part of a **multi-disciplinary team** in order to meet laryngectomy patients' medical and rehabilitation requirements and their need for support.
- The social worker should focus on **support services** to be rendered to laryngectomy patients when attending the follow-up clinic at the hospital. From the ecological perspective, the needs of family members should also be taken into account.

7.2.2.2 The role of the social worker

Several **conclusions** with reference to the different roles of the social worker in rendering services to laryngectomy patients and their relatives can be drawn:

First, half of the participants acknowledged that the social worker has a role to fulfil in **providing information**. The majority of participants indicated that they would like to have more information on the operation and post-operative adjustment. A quarter of the participants suggested the use of support groups to provide information. Some participants found it difficult to describe the social worker's role, while one participant did not think that the social worker could be of help in this regard. The majority of participants responded in a positive way, which demonstrates their need to include the social worker in the process of providing information to patients and families. Their preference for obtaining information was recorded as either on an individual basis or within group discussions.

Second, the role of the social worker was positively associated with **problem-solving** by the majority of participants. One participant with good insight referred to the possible connection between medical and social problems which may be present. Types of problems referred to, were mainly those with post-operative adaptation and coping with the effect of loss of voice. Other problems included concrete help, such as with household problems (money and alcohol), problems with children, family problems and physical problems. A quarter of the participants suggested the use of support groups in the process of problem-solving. Two participants were not sure how the social worker could be of help. Participants easily associated the role of the social worker with problem-solving. Surprisingly few referred to concrete problems. The majority rather referred to the role of the social worker in dealing with emotional problems. As the average time since surgery was three years and two months, patients' financial problems had been sorted out by the time of the interview. Again, suggested ways for the social worker to deal with problems were on an individual basis or within group discussions.

Third, the majority of participants were of the opinion that the social worker could link up to **community resources**. These resources mainly included local day hospitals, clinics or hospitals, social workers within the community, a hospice or CANSA

(Cancer Association of South Africa). A quarter of the participants could not specify the role of the social worker in this regard while one participant felt that the social worker could not be of assistance to him from a distance as he lived far from the hospital. One had the insight to mention that the community was not sufficiently prepared to solve problems that patients might experience. Viewed from the ecological perspective, participants easily identified community resources with which the social worker could possibly connect them. However, little effort was made to describe the specific input of the social worker in the process of contact with these community resources.

Fourth, the majority of participants acknowledged that the social worker could render **support** services to **families of patients**. Explanation of the patient's medical condition, implications of the operation and how to take care of the patient after surgery, were mostly mentioned by participants as ways of supporting the family. Practical ways for the social worker to render these services were suggested, such as home visits, family meetings, telephonic contact, contact with local welfare organisations, motivation for families to make contact with the hospital, motivation for families to accompany the patient during follow-up visits, and empowerment of patients to convey information or advice to families or offering concrete help to families. Three participants suggested the use of support groups to families of patients. Two participants were uncertain to what extent the social worker could offer support to families. Participants easily responded to this question as all of them had had personal experience of being part of a family system. Viewed from an ecological perspective, these systems included their relationships with spouses, parents, children or other family members. They could therefore easily relate to the role of the social worker in supporting families. Participants suggested that support to families could either be offered on an individual basis or within a group context.

Sixth, the role of the social worker to **support patients** was described in a positive way by the majority of participants. Mainly referred to, was the social worker's role to encourage the patient. Four participants suggested the use of support groups to support patients. Two participants could not make any suggestions in this regard. Support to patients referred mostly to emotional support which could either be offered

individually or within a group setting. Participants' positive response towards the role of the social worker to support patients, clearly demonstrated their need for support.

Six, the role of the social worker to **promote rehabilitation** was viewed positively by nearly half of the participants, while almost the same number suggested the use of support groups in rendering rehabilitation services to patients. Three participants did not contribute to this answer. Participants easily described the role of the social worker to promote rehabilitation opportunities. The use of support groups was suggested largely to promote rehabilitation, as all participants attended the support group and were familiar with the contents of such group discussions. Items suggested for discussion were: to identify and discuss problems, to give advice, to offer support, to share a feeling of having the same experience - in other words, to experience "sharing".

Seventh, the majority of participants did not comment on **any other** possible **ways** of social work intervention for them or their families. This could possibly be because they had already included all areas of social work intervention and could not add any suggestions. Some participants re-emphasised the importance of the social worker in rendering emotional support services, while others suggested practical ways of social work intervention. In this regard they mainly referred to financial assistance. One participant acknowledged the patient's responsibility towards recovery by referring to his own adaptation and acceptance.

In view of the above-mentioned information, it can be **concluded** that laryngectomy patients and their relatives are in need of social work intervention on the following levels: provision of information, problem-solving, contact with community resources, support to families, support to patients, and promotion of rehabilitation opportunities. On nearly all these levels the use of support groups was suggested to achieve this social work intervention.

Recommendations

- The social worker 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 grade of professional skill.

- The social worker should be equipped with a thorough knowledge of patients' medical diagnosis, treatment and rehabilitation process, including post-operative speech, in order to **provide** appropriate **information**. The following practical aids are suggested:
 - Pamphlets
 - Audio-visual aids.
- The social worker should have the capacity to assess and **solve problems** (practical or emotional) patients and families may experience.
- The social worker should have knowledge of the **ecological perspective** and skills in the implementation of this perspective when rendering services 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 a thorough knowledge of and experience in the availability and mobilisation of **community resources** to best meet the needs of laryngectomy patients and families.
- The social worker should have the potential to offer **support to families** as the family is the closest system wherein patients function and change in one of these systems will also affect the others.
- The social worker should have the ability to **support patients** appropriately, taking into account their physical, social and psychological needs.
- The social worker should have the expertise to participate actively in the patient's post-operative **rehabilitation** process.
- Possible **social work interventions** in order to provide information, to solve problems, to contact community resources, to support families, to support patients or to promote rehabilitation opportunities should include:
 - Individual services
 - Family counselling services
 - The use of support groups.

7.2.3 Psycho-social implications of a laryngectomy

7.2.3.1 *Physical implications*

With the exception of three participants, the majority currently experience **physical difficulties**. Mostly sensory problems were identified, with an impact on safety or hygiene issues and limitation of pleasurable odours. The average time since surgery for all participants varied between three months and eleven years. Physical symptoms might have improved over time or participants might have adjusted better to these symptoms. Participants who did not mention physical complaints, have had their operation an average time of five years and nine months ago and assessed the quality of their social support from various sources, as being strong.

In **conclusion**, social support can contribute to the limitation of physical difficulties as experienced by laryngectomy patients.

Recommendations

- The social worker should have knowledge of the various **physical symptoms** laryngectomy patients might experience following surgery.
- The social worker should have expert knowledge and skills to offer **social support** to patients to limit their experience of physical difficulties.
- The social worker should utilise **support groups** in order to minimise the physical effects of surgery as group members could share practical hints and ideas.

7.2.3.2 *Social implications*

The social implications of a laryngectomy extend to relationships with family and friends, marital and sexual relationships, relationships with others, daily life activities, and employment and financial impact.

In the study just more than a third of the participants acknowledged that following surgery, the initial adjustment with **friends** and **family members** was difficult. Lack of normal speech and communication ability and having to learn an altered method of speech or communication pattern was mostly responsible for their feelings. Some participants mentioned that their social contact had been reduced after surgery as

they were maintaining a sober lifestyle. This has to be placed in the context that substance abuse as etiological factor is generally associated with a diagnosis of cancer of the head and neck region. Almost half of the participants confirmed that their relationships with friends and family were not affected. Some participants benefited from their laryngectomy experience as uncertainty diminished with the diagnosis of cancer, or stated that the operation had been helpful to maintain a sober lifestyle.

Where applicable, more than half of the participants mentioned that their operation had not affected their **marital** or **sexual relationship**. Some participants identified initial problems such as the spouse not knowing how to take care of the patient, or talking less, due to change in communication ability, while some participants mentioned that their relationships had improved. One participant referred to changes in social roles after his operation as he increasingly became aware of his own mortality and tried to function more independently now. None of the participants reported sexual problems as a result of their laryngectomy. The interviewer tried to explore this topic in more detail, but participants did not indicate any problems in this regard. This tendency is in accordance with literature observing that it is a sensitive subject and that people seldom talk about it. Another explanation could be that they really did not experience sexual problems. It is important to note that the majority of participants were males, who seldom talk about such feelings spontaneously.

One fifth of the participants identified problems in **other social relationships**, due to the tendency that the public might find altered ways of communication not normal, and less acceptable and intelligible. They reported feelings of discomfort and avoidance by others or that they were mistakenly considered deaf. As a result, these participants now socialised to a lesser extent. Nearly one-third of the participants did not identify problems. Some participants described it as a positive experience and although social problems were initially experienced, it improved after they successfully managed to learn post-operative speech. A few participants mentioned that they were not frequently in contact with others and therefore found it difficult to answer this question.

The majority of participants acknowledged change in **daily life activities** since surgery. Changes mentioned were representative of their **physical** (stoma care, diet, eating, swallowing, showering), **social** (communication problems, decreased ability to continue with outdoor activities, tendency to stay more indoors, limitation in work ability, change in social roles, restriction on telephone conversation, slower tempo to perform daily activities, and the need to plan before doing something) and **psychological** (change in personality) functioning, in other words, their quality of life experience. Three participants identified no changes and some participants could not specify to what extent the operation had changed their daily life activities. Participants easily responded to this question, as it referred to practical situations in their everyday life.

A quarter of the participants had to make dramatic changes to their **leisure time activities** but managed to find creative ways to do so. Some participants found their change in leisure time activities as positive as they could now participate in creative activities instead of former activities involving substance abuse. Some participants reported that they felt as if they could do more now, due to improved health. Limitations in leisure time activities were described as doing things more slowly or staying indoors more. It can be **concluded** that in some cases, change in leisure time activities will be inevitable. Patients are in need of support to adequately address their need to adapt to change in these activities.

Regarding **employment** and **finance**, one-quarter of the participants identified financial difficulties as they either had had to terminate their previous employment, experienced lack of additional income, or experienced increased expenses. Two female participants identified emotional problems when not being able to continue with their previous work. The majority of participants identified no problems regarding their present employment or finance. Some participants had even benefited from their laryngectomy experience as they were now receiving a social pension in comparison with previous unemployment. It is important to note that the majority of participants had either no, or only primary school, education.

It can be **concluded** that a laryngectomy experience has the ability to affect the laryngectomy patients' social functioning, including relationships with friends and

family, marital and sexual relationships, other family relationships, daily life activities, recreational activities and their employment and finance. Impact on daily life activities was most mentioned by participants, and represented some aspects of their physical, social and psychological functioning. Their experience of quality of life was affected. This effect on their social functioning could leave laryngectomy patients with feelings of social isolation and depression. It also impacted on their social interactions with others as they tended to withdraw from them. Finally, it leads to their increased **need for support** as they removed themselves from the very persons who could possibly offer the needed social support. This is especially applicable in the case of patients who present with a cancer diagnosis of the head and neck region, as substance abuse is an etiological factor to this diagnosis. These are normally the people who have poor social support systems.

Recommendations

- The social worker should identify the **problematical areas** of laryngectomy patients' social functioning in order to provide applicable support to meet their needs.
- The social worker should, from an **ecological perspective**, explore the potential effect of a laryngectomy on the various systems with which a laryngectomy patient interacts, such as: family, friends, spouse or others, in order to address their needs.
- The social worker should explore and have an understanding of the potential effect of a laryngectomy on **practical issues** like daily activities, employment and finances.

7.2.3.3 Psychological implications

When investigating the psychological implications of the diagnosis and operation on the **patient** and **relatives**, nearly half of the participants identified no problems as experienced by themselves or on behalf of their relatives. Six participants identified no problems regarding their own or their relatives' reactions and feelings. With the exception of one participant, all participants had their surgery between one and eight years ago and rated their quality of social support from the different support systems as strong.

It can be **concluded** that time elapsed since surgery, and social support, play an important role in the patients' psychological adaptation after surgery.

Only two participants acknowledged a negative change in the experience of their **self-image** by referring to the frustration in the process to learn to talk again, and mutilation due to surgery. Two participants responded with ambivalence towards their experience of their self-image, as surgery had limited their strength and abilities, but had extended their lives. More than three-quarters of participants identified either no change or a positive change to their self-image after surgery. These were the participants who were thankful for their health and knowing that there was nothing they could do to change their condition. Therefore they decided to accept it. The term "self-concept" is abstract and could possibly have contributed to participants' responses where no problems were identified.

Only four participants said that the operation had caused a negative effect on their **body-image** by referring to change in their work tempo as everything now took longer to do, to change in communication method, the experience of having less energy, and change in their breathing process. The other participants either identified no change or a positive change in their experience of their body-image. This is in contrast with literature which observed that surgery was mostly seen as mutilating, as it was visible and obvious. In comparison with their former health condition, participants now experienced improvement in health and an increased amount of energy, and therefore did not complain about change in their physical condition.

It can be **concluded** that a small percentage of participants experienced their self- and body-image in a negative way. The quality of support patients experienced contributed to this finding.

Half of the participants had a positive experience with **loss of communication** as they adapted to their new communication pattern. Two participants reported that they talked less since their operation. The other participants' referred to adaptations they had to make to adjust to a new technique of communication. These adaptations included handling of the public who often wrongly assume that the patient is deaf, adjustments to means of communication or not always having the confidence to

speak in public. Only patients who successfully managed to learn tracheo-oesophageal speech were selected to participate in the study. This could have contributed to participants' positive experience of loss of communication.

The aspect most negatively experienced by participants, was their **loss of voice**, as more than half of the participants had experienced problems in this regard. These problems included loss of self-expression, powerlessness and frustration, guilt, and disappointment for not presenting in time for less debilitating treatment. Negative experiences have the potential to result in social isolation. Some suggested ways of dealing with this loss experience were mentioned, such as to concentrate on positive abilities, to decide not to react immediately, and to feel part of a conversation when you succeed in your attempt to communicate.

It can be **concluded** that various experiences of loss accumulatively contribute to the patient's need for support, including loss of communication and loss of voice. This could leave laryngectomy patients with social withdrawal and isolation, leading to feelings of depression which negatively influence the patient's ability to initiate support or make use of available support.

One-quarter of the participants identified negative reactions to **other people's behaviour**. These included: sympathy which could be destructive at times, social rejection, or being treated as if they were deaf. The majority had a positive experience of other people's behaviour. As this is an operation which is seldom performed, the majority of participants had to explain the nature of the operation and its effects to other people. When measuring the acceptance of others, some participants referred to the absence of negative behaviour, such as they "did not become angry" or "did not treat us as inferior". Other participants described social acceptance from others by referring to people who involved them in social events or continued to visit them, or when others accepted their altered method of speech. One participant mentioned that according to him, others did not always know how to treat a patient when things were not well.

It can be **concluded** that the majority of participants had experienced positive behaviour from others. A factor which contributed to this positive experience was

their ability to explain their medical situation to others, with the feeling that they were accepted. When negative incidents did occur, patients tried to solve them by discussing them with the initiator of the incident.

It is important to take into consideration that only patients who had successfully managed to learn trachea-oesophageal speech and who attended support groups, were asked to participate in the study. It can be assumed that these participants had a positive attitude towards their laryngectomy experience and post-operative recovery, which could have contributed towards their positive experiences.

An **overall conclusion** about participants' experiences of the psycho-social implications of a laryngectomy is that the combination of the physical, social and psychological effects of a laryngectomy has the potential to influence the patient's overall functioning and therefore his quality of life experience.

Recommendations

- The social worker should be aware of the various **psychological reactions** patients and families may experience following a laryngectomy.
- The social worker should have the expert knowledge and skills **to take care** of identified psychological reactions.
- The social worker should build positively on the patient's strengths in order to contribute towards a positive experience of **self-image** and **body-image**.
- The social worker should have sensitivity for and insight into the various **experiences of loss** patients have to deal with.
- The social worker should have an innovative approach in order to motivate patients to find creative ways to alter **leisure time activities** where applicable.
- The social worker should have professional skills to utilise **social support** to limit the physical, social and psychological effects of a laryngectomy upon patients and their relatives.

7.2.4 Support and aftercare

Support from parents (where applicable), from children in the home (where applicable), the church, other patients in the groups, and team members at the

hospital, was rated as hundred percent by participants. This was followed by support from the spouse, from children out of the home, grandchildren, and friends, which was rated at almost hundred percent. Support received from other family and community health centres, although rated lower than the above, still received a high score. The majority of participants found the sources of support as listed, as representative of their needs. Viewed from an ecological perspective, a person acts in relation to the various systems in his environment. For the patient, these resources interact with one another in order to cope, survive or to compete for needed resources. The laryngectomy patient therefore has to be seen in relation to various sources of support in his environment in his efforts to adapt to his changed circumstances.

It can be **concluded** that various sources of support contribute to best meet the different needs of laryngectomy patients. Within a hospital setting, it is important to note that participants view support offered by team members and other laryngectomy group members as strongly positive.

Only one-quarter of participants was known to the other laryngectomy patients. More than half of these participants rated their contact with other patients as positive as they benefited from sharing experiences, problems, practical hints, and ideas. To observe other patients who are in the same position, was also mentioned to be of help. Two participants mentioned a negative experience in their contact with other laryngectomy patients due to the fact that these patients did not maintain a sober lifestyle which they experienced as demotivating.

It can be **concluded** that a laryngectomy can be regarded as a lonely experience as patients seldom know other patients in similar circumstances and most often have no one with whom to compare their situations.

Recommendations

- The social worker should be aware of the various potential **sources of support** patients may possibly benefit from.

- The social worker should have knowledge of the theoretical departure points of the **ecological perspective** which describes the functioning of a person in relation to his environment.
- The social worker should have professional skills to **mobilise** applicable **sources of support** to best benefit the needs of patients, which will be in accordance with the ecological perspective.
- The social worker in a **hospital setting** should in a positive way use support offered by team members and other laryngectomy group members to meet the patients' need for support.
- The social worker should be **innovative** in offering support to patients as undergoing a laryngectomy is a lonely experience as patients seldom know other laryngectomy patients.

Support groups were rated by all participants as contributing largely towards problem-solving, provision of information, promotion of rehabilitation, emotional and social support, and an improvement in their quality of life. The benefits of support groups corresponded well with the various roles of the social worker as discussed earlier, namely to provide information, to solve problems, to support patients and families, and to promote rehabilitation opportunities. Themes for discussion represented educational (physical aspects such as diet, stoma care), speech rehabilitation (learning and practicing speech), social interaction (communication skills) and support counselling (to cope with daily situations and problem-solving) topics. All participants mentioned that all topics should be included in group discussions. Additional themes for discussion as suggested by participants included a discussion of family relationships and how to adapt to these relationships after surgery.

It can be **concluded** that support groups are indispensable to render support services to laryngectomy patients and their families, whereby the various roles of the social worker will be assumed a creative way.

Recommendations

- The social worker in a hospital setting should consider the use of **support groups** as part of a holistic treatment approach in order to support patients and families and to effectively serve their need for support.

7.2.5 General comments

Participants mostly indicated their appreciation for being involved in this study. They did not add any information that was not included in the questionnaire or the interviews. It can be **concluded** that participants shared everything they wanted to and were satisfied.

7.3 FUTURE RESEARCH

In view of the results of this explorative and descriptive investigation, it is suggested that further research regarding these patients' need for support should focus on the following:

- The development of **social work programmes** for health care professionals in order to effectively support these patients and their families. This may contribute towards professionals' knowledge of and insight into offering appropriate support services to best meet these patients' need for support, as the laryngectomy experience can be regarded as a lonely experience and the community is not always sufficiently prepared to adequately address their needs.
- Laryngectomy patients' **limitations** and **strategies** in their efforts to cope with daily life activities within a "normal-speaking" society: a social work perspective.

From personal experience gained from participating in support groups with laryngectomy patients the following area for future research is recommended:

- The role of **pre- and primary school children/grandchildren** in the immediate rehabilitation of laryngectomy patients.

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ANNEXURE A

**UNIVERSITY OF STELLENBOSCH /
UNIVERSITEIT VAN STELLENBOSCH**

**DEPARTMENT OF SOCIAL WORK /
DEPARTEMENT MAATSKAPLIKE WERK**

SEMI-STRUCTURED INTERVIEW SCHEDULE / SEMI-GESTRUKTUREERDE ONDERHOUDSKEDULE

The laryngectomy patient's need for support groups in a hospital setting: a social work perspective. / *Die laringektomie-pasiënt se behoefte aan ondersteuningsgroepe in 'n hospitaalopset: 'n Maatskaplike Werk-perspektief.*

All the information recorded in the questionnaire will be regarded as confidential. Individual views or respondents' names will not be made known. / *Alle inligting wat deur die vraelys ingewin word, sal as konfidensieel beskou word. 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>	Live together/ <i>Leef saam</i>	Single/ <i>Ongetroud</i>	Separated/ <i>Vervreem</i>	Divorced / <i>Geskei</i>	Widow(er)/ <i>Weduwee/ Wewenaar</i>
<input style="width: 100%; height: 20px;" type="text"/>	<input style="width: 100%; height: 20px;" type="text"/>	<input style="width: 100%; height: 20px;" type="text"/>	<input style="width: 100%; height: 20px;" type="text"/>	<input style="width: 100%; height: 20px;" type="text"/>	<input style="width: 100%; height: 20px;" type="text"/>

1.3 Race / *Bevolkingsgroep*

Black / Swart	Coloured / <i>Kleurling</i>	White / Blank	Asian / Asiër
<input style="width: 100%; height: 20px;" type="text"/>	<input style="width: 100%; height: 20px;" type="text"/>	<input style="width: 100%; height: 20px;" type="text"/>	<input style="width: 100%; height: 20px;" type="text"/>

1.4 Gender / *Geslag*

Male / <i>Manlik</i>	Female / <i>Vroulik</i>
<input style="width: 100%; height: 20px;" type="text"/>	<input style="width: 100%; height: 20px;" type="text"/>

1.5 Education and training / *Opleiding*

No school training/ <i>Geen skoolstudiese opleiding</i>	School Std passed/ <i>Skoolst. geslaag</i>	Trade / <i>Ambag</i>	Technicon, college, university (specify) / <i>Technikon, college, universiteit (spesifiseer)</i>

1.6 Occupation / *Beroep* (specify / *spesifiseer*)

	Before surgery / <i>Voor chirurgie</i>	After surgery / <i>Na chirurgie</i>
Unemployed / <i>Werkloos</i>		
Social pensioner / <i>Maatskaplike pensioenaris</i>		
Skilled or unskilled labourer / <i>Geskoolde- of ongeskoolde arbeider</i>		
Professional / <i>Professioneel</i>		

1.7 Specify your and your spouse/life partner's current **total** monthly income. /
*Spesifiseer u en u eggenoot/leuensmaat se huidige **gesamentlike** maandelikse inkomste.*

R 0 - R 499		R1 500 - R1 999	
R 500 - R 999		R2 000 - R2 499	
R1 000 - R1 499		R2 500 +	

2. MEDICAL ASPECTS OF A LARYNGECTOMY AND FUNCTIONING OF THE SOCIAL WORKER AS MEMBER OF THE MULTI-DISCIPLINARY TEAM / *MEDIESE ASPEKTE VAN 'N LARINGEKTOMIE EN FUNKSIONERING VAN DIE MAATSKAPLIKE WERKER AS LID VAN DIE MULTI-DISSIPLINêRE SPAN*

2.1 MEDICAL ASPECTS / *MEDIESE ASPEKTE*2.1.1 Date of surgery / *Datum van chirurgie* _____2.1.2 Type of treatment / *Tipe behandeling*

Total laryngectomy / <i>Totale laringektomie</i>	Radiotherapy / <i>Radioterapie</i>	Neck dissection / <i>Nek disseksie</i>	Other (specify) <i>Ander (spesifiseer)</i>

2.1.3 What is the frequency of your follow-up visits to the clinic? / *Wat is die gereeldheid van u opvolgbesoeke aan die kliniek?*

6-weekly / 6-weekliks		4-monthly / 4-maandeliks	
2-monthly / 2-maandeliks		6-monthly / 6-maandeliks	
3-monthly / 3-maandeliks		Yearly / jaarliks	

2.1.4 What is in your opinion the purpose of attendance at the follow-up clinic at the hospital? / *Wat is na u mening die doel van bywoning van die opvolgkliniek by die hospitaal?*

Purpose / Doel	Definite/ Definitief	Probable/ Miskien	Not at all/ Glad nie
Medical assessment / <i>Mediese ondersoek</i>			
Identification and treatment of medical problems/ <i>Identifisering en behandeling van mediese probleme</i>			
Motivation to stop alcohol / tobacco use / <i>Motivering om met rook- en drankgewoontes op te hou</i>			
Assess nutritional condition / <i>Evalueer voedingstoestand</i>			
Assess speech ability and promote speech rehabilitation / <i>Evalueer spraakvermoë en moedig spraak-rehabilitasie aan</i>			
Contact with hospital team members / <i>Kontak met spanlede by die hospitaal</i>			
Act as a source of support / <i>Dien as 'n bron van ondersteuning</i>			
Contact with other laryngectomy patients / <i>Kontak met ander laringektomie-pasiënte</i>			

Other (specify) / *Ander (spesifiseer)*: _____

2.2 THE ROLE OF THE SOCIAL WORKER / *DIE ROL VAN DIE MAATSKAPLIKE WERKER*

How do you think the social worker could help you and other patients who have also had such an operation: / *Hoe dink u kan die maatskaplike werker vir u en ander pasiënte wat ook so 'n operasie gehad het, help:*

2.2.1 to provide information (regarding your illness, where to find help) / *om inligting te verskaf (in verband met u siekte waar om hulp te kry)* _____

2.2.2 to deal with problems / *om probleme te hanteer* _____

2.2.3 to contact people or organisations in your area who offer the help you may need / *om met persone of instansies in u omgewing te skakel sodat u die hulp kan kry wat u nodig mag hê* _____

2.2.4 to offer support to you and your family / *om ondersteuning aan u en u familie te bied* _____

2.2.5 to make it easier to adapt to an altered lifestyle (rehabilitation) / *om dit makliker te maak om by 'n veranderde lewenstyl aan te pas (rehabilitasie)* ____

3. PSYCHO-SOCIAL EFFECTS OF A LARYNGECTOMY / PSIGO-MAATSKAPLIKE EFFEKTE VAN 'N LARINGEKTOMIE

3.1 PHYSICAL EFFECTS / FISIESE EFFEKTE

Which of the following **problems** do you currently experience regarding your diagnosis and treatment? / *Watter van die volgende probleme ervaar u huidig rakende u diagnose en behandeling?*

3.1.1	Respiratory problems / Asemhalingsprobleme	Yes / Ja	No / Nee
	Care and cleaning of the stoma / <i>Sorg en skoonmaak van stoma</i>		
	Coughing / <i>Hoes</i>		
	Sleep / <i>Slaap</i>		
	Fatigue / <i>Moegheid</i>		
	Infection / <i>Infeksie</i>		

3.1.2	Swallowing problems / Slukprobleme	Yes / Ja	No / Nee
	Chewing / <i>Kou</i>		
	Eating / <i>Eet</i>		
	Swallowing / <i>Sluk</i>		
	Drinking / <i>Drink</i>		

3.1.3	Sensory impairment / Sensoriese verlies	Yes / Ja	No / Nee
	Smell / <i>Reuk</i>		
	Taste / <i>Smaak</i>		
	Hearing / <i>Gehoer</i>		

3.2 SOCIAL EFFECTS / MAATSKAPLIKE EFFEKTE

Describe the influence of the operation on the following social aspects of your life: / *Beskryf die invloed van die operasie op die volgende maatskaplike aspekte van u lewe:*

3.2.1 Relationship with friends and/or family members / *Verhouding met vriende en/of familieleden* _____

3.2.2 Your marital and sexual relationship / *U huweliks- en seksuele verhouding* ____

3.2.3 Social relationships outside the family unit / *Maatskaplike verhoudinge buite familie verband* _____

3.2.4 Your daily activities / *U daaglikse aktiwiteite* _____

3.2.5 Your recreational activities / *U vryetydsbesteding* _____

3.2.6 Your employment and financial position / *U werk- en finansiële posisie* _____

3.3 PSYCHOLOGICAL EFFECTS / *PSIGIESE EFFEKTE*

3.3.1 Which of the following reactions and feelings do you currently experience regarding your diagnosis and treatment / *Watter van die volgende reaksies en gevoelens ervaar u tans rakende u diagnose en behandeling?*

Reactions and feelings / <i>Reaksies en gevoelens</i>	Plenty / <i>Baie</i>	Few / <i>Bietjie</i>	Not at all/ <i>Glad nie</i>
Shock / <i>Skok</i>			
Anxiety / <i>Angs</i>			
Withdrawal / <i>Onttrekking</i>			
Isolation / <i>Isolasie</i>			
Fear / <i>Vrees</i>			
Helplessness / <i>Hulpeloosheid</i>			
Frustration / <i>Frustrasie</i>			
Denial / <i>Ontkenning</i>			
Anger / <i>Woede</i>			
Grief / <i>Rou</i>			
Depression / <i>Depressie</i>			

3.3.2 Which of the following describe your family's current reactions and feelings regarding your diagnosis and treatment? / *Watter van die volgende beskryf u familie se huidige reaksies en gevoelens ten opsigte van u diagnose en behandeling?*

Reactions and feelings / <i>Reaksies en gevoelens</i>	Plenty / <i>Baie</i>	Few / <i>Bietjie</i>	Not at all/ <i>Glad nie</i>
Guilt / <i>Skuld</i>			
Overprotection / <i>Oorbeskerming</i>			
Anger / <i>Woede</i>			
Fears and concerns / <i>Vrees en bekommernisse</i>			
Withdrawal / <i>Onttrekking</i>			
Acceptance / <i>Aanvaarding</i>			

3.3.3 How did your operation influence the way you think about yourself and see yourself? / *Hoe het u operasie die manier waarop u oor uself dink en u uself sien beïnvloed?* _____

3.3.4 How did your operation influence the way you think about your body (altered appearance, sound of voice, stoma)? / *Hoe het u operasie u siening van u liggaam beïnvloed (veranderde voorkoms, klank van stem, stoma)?* _____

3.3.5 How do you experience communication with other people since your operation? / *Hoe ervaar u kommunikasie met ander mense na u operasie?* ____

3.3.6 How do you feel now that you cannot talk or express yourself (laugh, cry, shout, whistle, sing) in the same way as before your operation? / *Hoe voel u nou dat u nie meer op dieselfde manier kan praat of uself kan uitdruk (lag, huil, skree, fluit, sing) as voor die operasie nie?* _____

3.3.7 How do you experience other people's behaviour towards you since your operation? / *Hoe ondervind u ander mense se optrede teenoor u na u operasie?* _____

4. AFTERCARE AND SUPPORT SERVICES / NASORG EN ONDERSTEUNINGSDIENSTE

4.1 How would you describe the support you currently receive from the following resources? / *Hoe sal u die ondersteuning wat u tans van die volgende bronne ontvang, beskryf?*

Sources of support / <i>Bronne van ondersteuning</i>	Strong/ <i>Sterk</i>	Poor/ <i>Swak</i>	Stressful/ <i>Spannings- vol</i>	NA/ <i>NVT</i>
Spouse / <i>Eggenoot(e)</i>				
Life partner / <i>Saamleefmaat</i>				
Parents / <i>Ouers</i>				
Children in home / <i>Kinders in huis</i>				
Children out of home / <i>Kinders elders</i>				
Other family / <i>Ander familie</i>				
Grandchildren / <i>Kleinkinders</i>				
Neighbours / <i>Bure</i>				
Friends / <i>Vriende</i>				
Church / <i>Kerk</i>				
Community Health Centre / <i>Gemeenskaps Gesondheidsentrum</i>				
Laryngectomy patients in your group / <i>Laringektomie-pasiënte in u groep</i>				
Multi-disciplinary team members in hospital setting / <i>Multi-dissiplinêre spanlede in hospitaalopset</i>				

- 4.2 Are you familiar with any other patients in your area who have had the same operation except for those you have met in the group? / *Is u bekend met ander pasiënte in u omgewing wat dieselfde operasie gehad het buiten die wat u in die groep ontmoet het?*

Yes / <i>Ja</i>	No / <i>Nee</i>

- 4.3 If your answer to question 4.2 was YES, how would you describe the value of contact with these patients? / *Indien u antwoord op vraag 4.2 JA was, hoe sal u die waarde van kontak met hierdie pasiënte beskryf?* _____

- 4.4 You are currently attending the support group for laryngectomy patients at Tygerberg Hospital. Please answer the following questions: / *U woon tans 'n ondersteuningsgroep vir laringektomie-pasiënte te Tygerberg Hospitaal by. Beantwoord asseblief die volgende vrae:*

4.4.1 Describe the benefits / value of attending these groups: / *Beskryf die voordele / waarde van bywoning van hierdie groep:*

Potential benefit / value / Moontlike voordele / waarde	Great/ Baie	Little / Bietjie	None / Geen
Problem-solving / <i>Probleem-oplossing</i>			
Act as a source of information / <i>Dien as 'n bron van inligting</i>			
Promotes adaptation after your operation (rehabilitation) / <i>Bevorder aanpassing na u operasie (rehabilitasie)</i>			
Provides support to cope with your feelings (emotional support) / <i>Voorsien ondersteuning om u gevoelens te hanteer (emosionele ondersteuning)</i>			
Provides support in your relationship with other people (social support) / <i>Voorsien ondersteuning in u verhouding met ander mense (maatskaplike ondersteuning)</i>			
Improves quality of life / <i>Verhoog kwaliteit van lewe</i>			

Other (describe) / *Ander (beskryf)*: _____

4.4.2 Which of the following are in your opinion the most relevant themes for discussion during group discussions? / *Watter van die volgende is na u mening die mees gepaste onderwerpe vir bespreking tydens groepbesprekings?*

Themes for discussion / Onderwerpe vir bespreking	Yes / Ja	No / Nee	Uncertain/ Onseker
Learn how to cope with the physical aspects of the operation / <i>Leer hoe om die fisiese aspekte van die operasie te hanteer</i>			
Learn how to follow a balanced diet / <i>Leer hoe om 'n gebalanseerde dieet te volg</i>			
Learn how to take care of the stoma / <i>Leer hoe om die stoma te versorg</i>			
Learn how to talk again after your operation / <i>Leer hoe om weer te kan praat na u operasie</i>			
Learn how to practice newly acquired speech / <i>Leer hoe om nuut aangeleerde spraak te oefen</i>			
Learn how to use communication skills / <i>Leer hoe om kommunikasie-vaardighede te gebruik</i>			
Learn how to solve problems / <i>Leer hoe om probleme te hanteer</i>			
Learn how to stop alcohol or tobacco use / <i>Leer hoe om die gebruik van drank of sigarette te staak</i>			

4.4.3 Suggestions for any other themes of discussion? / *Voorstelle vir enige ander onderwerpe vir bespreking?* _____

5. COMMENTS / KOMMENTAAR

**THANK YOU VERY MUCH FOR YOUR CO-OPERATION /
BAIE DANKIE VIR U SAMEWERKING**

ANNEXURE B



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY
jou kennisvenoot • your knowledge partner

6 September 2007

Ms BH Steyn
Department of Social Work
Tygerberg Academic Hospital

Dear Ms Steyn

RESEARCH PROJECT: "A HOSPITAL BASED SOCIAL WORK AFTERCARE PROGRAM FOR LARYNGECTOMY SUPPORT GROUPS"
PROJECT NUMBER : N07/07/162

At a meeting of the Committee for Human Research that was held on 1 August 2007 the above project was approved on condition that further information that was required, be submitted.

This information was supplied and the project was finally approved on 6 September 2007 **for a period of one year from this date**. This project is therefore now registered and you can proceed with the work. Please quote the above-mentioned project number in all further correspondence.

Please note that a progress report (obtainable on the website of our Division) should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly and subjected to an external audit.

Patients participating in a research project in Tygerberg Hospital will not be treated free of charge as the Provincial Government of the Western Cape does not support research financially.

Due to heavy workload the nursing corps of the Tygerberg Hospital cannot offer comprehensive nursing care in research projects. It may therefore be expected of a research worker to arrange for private nursing care.

Yours faithfully

CJ VAN TONDER
RESEARCH DEVELOPMENT AND SUPPORT (TYGERBERG)
Tel: +27 21 938 9207 / E-mail: cjvt@sun.ac.za
CJVT/pm

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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
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ANNEXURE C

DEELNEMERINLIGTINGBLAD EN -TOESTEMMINGSVORM

TITEL VAN DIE NAVORSINGSPROJEK: Die laringektomie-pasiënt se behoefte aan ondersteuningsgroepe in 'n hospitaalopset: 'n Maatskaplike Werk-perspektief.

VERWYSINGSNOMMER: N07/07/162

HOOFNAVORSER: Mej B H Steyn

ADRES: Tygerberg Hospitaal, Departement
Maatskaplike Werk, Privaatsak X3, Tygerberg,
7505

KONTAKNOMMER: (021) 938 5092 / (021) 938 5684

U word genooi om deel te neem aan 'n navorsingsprojek. Lees asseblief hierdie inligtingsblad op u tyd deur aangesien die detail van die navorsingsprojek daarin verduidelik word. Indien daar enige deel van die navorsingsprojek is wat u nie ten volle verstaan nie, is u welkom om die navorser daaroor uit te vra. Dit is baie belangrik dat u ten volle sal verstaan wat die navorsingsprojek behels en hoe u daarby betrokke kan wees. U deelname is **volkome vrywillig** en dit staan u vry om deelname te weier. U sal hoegenaamd op geen wyse negatief beïnvloed word indien u sou weier om deel te neem nie. U mag ook te eniger tyd aan die navorsingsprojek onttrek, selfs al het u ingestem om deel te neem.

Hierdie navorsingsprojek is deur die **Komitee vir Mensnavorsing van die Universiteit Stellenbosch goedgekeur** en sal uitgevoer word volgens die etiese riglyne en beginsels van die Internasionale Verklaring van Helsinki en die Etiese Riglyne vir Navorsing van die Mediese Navorsingsraad (MNR).

1. Wat behels hierdie navorsingsprojek?

Die navorsingsprojek sal by die Afdeling Stralingsonkologie, Tygerberg Hospitaal uitgevoer word.

Die doel van hierdie navorsingsprojek sal wees om laringektomie-pasiënte se behoefte aan nasorg en ondersteuning in die hospitaalopset beter te verstaan. Inligting wat ingesamel word, sal gebruik word om riglyne vir 'n nasorg ondersteuningsprogram aan pasiënte en hul families op te stel. Die volgende prosedure sal op hierdie navorsingsprojek van toepassing wees:

- Op dieselfde datum as wanneer u vir mediese behandeling of opvolgbesoek by die kliniek van die afdeling Stralingsonkologie Tygerberg Hospitaal aanmeld, sal u genader word oor moontlike bywoning en deelname aan 'n ondersteuningsgroep vir laringektomie-pasiënte. Groepbesprekings vind weekliks op Woensdae by die Oor- Neus- en Keelheeskunde Kliniek plaas.

- Na afloop van u bywoning van die ondersteuningsgroep, sal u genader word oor u bereidwilligheid om aan hierdie navorsingsprojek deel te neem.
- Die navorser sal 'n eenmalige persoonlike onderhoud aan die hand van 'n semi-gestruktureerde vraelys met u voer. Hierdie onderhoud sal in die privaatheid van die maatskaplike werker verbonde aan die Afdeling Stralingsonkologie, se kantoor gevoer word.
- Na afloop van onderhoudvoering met al die deelnemers in 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 Magistergraad in Maatskaplike Werk, sal resultate aan die opleidingsinstansie, naamlik die Universiteit van Stellenbosch beskikbaar gestel word. Hierdie inligting sal bekend gemaak en kan gepubliseer word sonder dat vertroulikheid ingeperk word. Hierdie navorsingsverslag kan ook gebruik word vir publikasies byvoorbeeld in akademiese tydskrifte of vir opleidingsdoeleindes naamlik lesings of voordrag tydens 'n kongres. U kan na afloop van die projek die navorser nader rakende die bevindinge van die projek indien u hierin sou belangstel.

2. Wat sal u verantwoordelikhede wees?

'n Eenmalige onderhoud sal deur die navorser met u gevoer word. Dit word van u verwag om vrae wat aan u gestel word so eerlik moontlik te beantwoord. U sal geen verdere verantwoordelikhede ten opsigte van die navorsingstudie hê nie.

3. Sal u voordeel trek deur deel te neem aan hierdie navorsingsprojek?

U antwoord sal saam met al die ander deelnemers aan die studie se antwoorde verwerk word, ten einde maatskaplikewerk dienslewering ten opsigte van laringektomie-pasiënte en hul familieleden te verbeter. U bydrae sal dus tot voordeel van dienslewering aan hierdie pasiënte wees.

4. Wie sal toegang hê tot u mediese rekords?

Inligting wat ingesamel word sal as vertroulik beskou word en sal beskermde hanteer word. Die deelnemer sal anoniem bly indien dit gebruik sou word vir 'n publikasie, tesis of lesing. Die navorser sal die enigste persoon wees wat toegang tot u mediese rekords sal hê.

5. Is daar enige koste verbonde aan deelname?

Daar sal nie vir u koste aan verbonde wees indien u aan die navorsingstudie deelneem nie. Onderhoude sal geskeduleer word vir dieselfde datum as waarop u u mediese behandeling ontvang, sodat geen addisionele vervoerkoste benodig 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. Is daar enigiets anders wat u moet weet of doen?

U kan die Komitee vir Mensnavorsing kontak by telefoonnommer 021-938 9207 indien u enige bekommernis of klagte het wat nie bevredigend deur die navorser hanteer is nie.

VERKLARING DEUR DEELNEMER

Met die ondertekening van hierdie dokument onderneem ek,, om deel te neem aan 'n navorsingsprojek getiteld: Die laringektomie-pasiënt se behoefte aan ondersteuningsgroepe in 'n hospitaalopset: 'n Maatskaplike Werk-perspektief.

Ek verklaar dat:

- Ek hierdie inligtings- en toestemmingsvorm gelees het of aan my laat voorlees het en dat ek die inhoud daarvan ten volle verstaan aangesien dit in 'n taal geskryf is waarin ek vaardig en gemaklik mee is.
- Ek die geleentheid gehad het om vrae te stel en dat al my vrae bevredigend beantwoord is.
- Ek verstaan dat deelname aan hierdie navorsingsprojek **vrywillig** is en dat daar geen druk op my geplaas is om deel te neem nie.
- Ek te eniger tyd aan die navorsingsprojek mag onttrek en dat ek nie op enige wyse daardeur benadeel sal word nie.
- Ek gevra mag word om van die navorsingsprojek te onttrek voordat dit afgehandel is indien die navorser van oordeel is dat dit in my beste belang is, of indien ek nie die navorsingsplan volg waartoe ooreengekom is nie.

Geteken te (plek)op (datum)2008.

Handtekening van deelnemer

Handtekening van getuie

VERKLARING DEUR NAVORSER

Ek (*naam*) verklaar dat:

- Ek die inligting in hierdie dokument verduidelik het aan
.....
- Ek hom/haar aangemoedig het om vrae te vra en voldoende tyd gebruik het om dit te beantwoord.
- Ek tevrede is dat hy/sy al die aspekte van die navorsingsprojek soos hierbo bespreek, voldoende verstaan.
- Ek 'n tolk gebruik het/nie 'n tolk gebruik het nie. (*Indien 'n tolk gebruik is, moet die tolk die onderstaande verklaring teken.*)

Geteken te (*plek*) op (*datum*)2008.

Handtekening van navorser

Handtekening van getuie

VERKLARING DEUR TOLK

Ek (*naam*) verklaar dat:

- Ek die navorser (*naam*) bygestaan het om die inligting in hierdie dokument in Afrikaans/Xhosa aan (*naam van deelnemer*) te verduidelik.
- Ons hom/haar aangemoedig het om vrae te vra en voldoende tyd gebruik het om dit te beantwoord.
- Ek 'n feitelik korrekte weergawe oorgedra het van wat aan my vertel is.
- Ek tevrede is dat die deelnemer die inhoud van hierdie dokument ten volle verstaan en dat al sy/haar vrae bevredigend beantwoord is.

Geteken te (*plek*) op (*datum*)2008.

Handtekening van tolk

Handtekening van getuie

ANNEXURE D

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

TITLE OF THE RESEARCH PROJECT: The laryngectomy patient's need for support groups in a hospital setting: a social work perspective.

REFERENCE NUMBER: N07/07/162

PRINCIPAL INVESTIGATOR: Miss B H Steyn

ADDRESS: Tygerberg Hospital, Social Work Department,
Private Bag X3, Tygerberg, 7505

CONTACT NUMBER: (021) 938 5092 / (021) 938 5684

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the researcher any questions about any part of this project that you do not fully understand. It is very important you are fully satisfied that you clearly understand what this research entails and how you could be involved. Your participation is **entirely voluntary** and you are free to refuse to participate. This will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you have agreed to take part.

This study has been **approved** by the **Committee for Human Research at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the International Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

1. What is this research study all about?

The research study will be conducted at the Department of Radiation Oncology, Tygerberg Hospital.

The aim of this research study is to gain a better understanding of the laryngectomy patients' need for care and support following surgery. Information gained in this study will be used to present guidelines for a social work aftercare support programme within a hospital setting.

The following procedure will be applicable to this research project:

- On the same day as your medical treatment or follow-up appointment at the Department of Radiation Oncology, Tygerberg Hospital, you will be approached to participate in the support group for laryngectomy patients. This event takes place every Wednesday at the Ear, Nose and Throat Clinic.

- After you have attended the support group, you will be approached to voluntarily participate in a research study on this topic.
- A single face to face interview will be conducted by the researcher with the aid of a semi-structured questionnaire. This interview will take place in the privacy of the researcher's office in the Gene Louw Building.
- 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 Masters 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.

2. What will your responsibilities be?

During a single interview you will be expected to answer the questions in the questionnaire as honestly as possible to contribute towards the value of the study. You will have no further responsibilities towards the research study.

3. Will you benefit from taking part in this research?

Your response will be processed together with those of all the participants of the research study in order to improve social work service delivery towards laryngectomy patients and their relatives.

4. Who will have access to your medical records?

Information collected will be treated as confidential and protected. If it is used in a publication, thesis or lecture, the identity of the participant will remain anonymous. The researcher will have access to your medical records.

5. Are there any costs involved?

There will be no costs involved for you, if you do take part. Interviews will be scheduled on the same day as your appointment at the clinic, so no additional transport fee will be applicable. If it should happen that interviews with all the participants on that specific day may not be possible, and you therefore have to travel to the hospital especially for the purpose of the research study, the researcher will accept responsibility for your transport fees.

6. Is there anything else that you should know or do?

You can contact the Committee for Human Research at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by your researcher.

DECLARATION BY PARTICIPANT

By signing below, I agree to take part in a research study entitled: The laryngectomy patient's need for support groups in a hospital setting: a social work perspective.

I declare that:

- I have read or have had this information and consent form read to me and I fully understand the contents thereof as it is written in a language in which I am fluent and comfortable with.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests, or if I do not follow the agreed study plan.

Signed at (*place*)on (*date*)2008.

Signature of participant

Signature of witness

DECLARATION BY RESEARCHER

I (*name*) declare that:

- I have explained the information in this document to
- I have encouraged him/her to ask questions and have taken adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above.
- I did/did not use an interpreter (*If an interpreter is used then the interpreter must sign the declaration below*).

Signed at (*place*) on (*date*)2008.

Signature of investigator

Signature of witness

DECLARATION BY INTERPRETER

I (*name*) declare that:

- I assisted the investigator (*name*) to explain the information in this document to (*name of participant*) using the language medium of English/Afrikaans/Xhosa.
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her questions satisfactorily answered.

Signed at (*place*) on (*date*)2008.

Signature of interpreter

Signature of witness

ANNEXURE E

INCWADANA ENIKA UMTHATHI-NXAXHEBA IINKCUKACHA NGOPHANDO NEFOMU YESIVUMELWANO

ISIHLOKO SEPROJEKTHI YOPHANDO: Inkxaso enikwa ngoonontlalo-ntle iqela elityandwe iingqula emva kweeyure zokusebenza, oku kusenzelwa esibhedlela.

INOMBOLO YESALATHISI 10996885 University of Stellenbosch

UMPHANDI OYINTLOKO uNkszn Beatrix Hendrina Steyn

IDILESI : Tygerberg Hospital, Social Work Department, Gene Louw Building, Private Bag X3, Tygerberg, 7505.

INOMBOLO YOQHAKAMSHELWANO (021) 938 5092 / (021) 938 5684

Umenyiwe ukuba uthathe inxaxheba kwiprojekthi yophando. Nceda uthathe ixesha ukufunda ulwazi oluchaziweyo apha, oluza kucacisa ngeenkukacha zale projekthi. Nceda ubuze abasebenzi abenza ezi zifundo okanye ugqirha nangayiphi na indawo ongayiqondi ngokupheleleyo kule projekthi. Kubaluleke kakhulu ukuba ucacelwe ngendlela eyanelisayo, uqonde ngokupheleleyo okuqulathwe lolu phando nokuba ungabandakanyeka njani. Kwakhona, ukuthatha inxaxheba kwakho **akunyanzelekanga kwaphela kukuzivolontiya nje** kwaye uvumelekile ukwala ukuthatha inxaxheba ukuba uyafuna. Ukuba uthi hayi, oku akuzi kukuchaphazela kakubi nangayiphi na indlela. Ukwavumelekile ukurhoxa kwezi zifundo nanini na, nokuba ubuvumile ukuthatha inxaxheba ekuqaleni.

Esi sifundo sivunywe **yiKomiti yoPhando ngoMntu kwiYunivesithi yaseStellenbosch** kwaye siza kwenziwa ngokwemigaqo nemimiselo yokuziphatha ngendlela kwi- *International Declaration of Helsinki*, iMigaqo yaseMzantsi Afrika yokuSebenza kakuhle kwizibhedlele neBhunga loPhando leZonyango (MRC) iMigaqo yokuziphatha ngokusesikweni kuPhando.

Esi sifundo sophando singantoni?

Isifundo sophando siza kwenziwa kwiSebe lokuyanga Umhlaza ngoGesi kwiSibhedlele saseTygerberg. Le iza kuba kuphela kwendawo apho izifundo zophando ziza kwenziwa khona. Zingamashumi amabini zizonke izigulane eziza kubandakanywa kule projekthi yophando.

Injongo yolu phando kukufumana ulwazi olungcono ngokubonisa inkathalo nokufikelelisa uncendo kwizigulane ezityandwe ingqula. Ulwazi olufunyenwe kwesi sifundo luza kusetyenziselwa ukondlalela inkqubo yokunika inkxaso kwizigulane ngoonontlalo-ntle emva kweeyure zomsebenzi. Okwangoku, asazi nto malunga neembono zomsebenzi wobuntlalo-ntle ngokuphathelene noku.

Lo mgaqo ulandelayo uza kusebenza kule projekthi yophando:

- Kwakolo suku lokufumana unyango lwempilo okanye ukuphinda uye kujongwa ngokwexesha omiselwe lona kwiSebe lokuNyanga Umhlaza ngoGesi kwiSibhedlele saseTygerberg, uza kucelwa ukuba uthathe inxaxheba kwiqela elixhasa izigulane ezityandwe ingqula. Esi siganeko senzeka rhoqo ngeveki (ngoLwesithathu) kwigumbi elisecaleni kwegumbi likagqirha nelenzelwe ukubonana nezigulana kwiKliniki yeNdlebe, iMpumlo noMqala.
- Emva kokuba udibene neli qela limalungu axhasanayo, uza kucelwa ukuba uthathe inxaxheba ngokuzivolontiya kwizifundo zophando ngalo mba.
- Udliwano-ndlebe lokubonana ubuso ngobuso luza kwenziwa ngumphandi ngoncedo lwemibuzo elungisiweyo. Olu dliwano-ndlebe luza kwenzeka bucala kwi-ofisi yomphandi kwiSakhiwo saseGene Louw.
- Iimpendulo zabo bonke abathatha inxaxheba kwizifundo ziza kuphendlwa, emva koko kuza kwenziwa ingxelo yophando. Njengoko umphandi esenza esi sifundo ukuzalisekisa iimfuno zeSidanga esiPhezulu kuMsebenzi weNtlalo-ntle, iziphumo zesifundo sophando ziza kubakho kwiziko lezoqeqesho, kwiYunivesithi yaseStellenbosch. Olu lwazi luza kupapashwa kodwa amagama abo bathabathe inxaxheba aza kugcinwa eyimfihlo. Ingxelo yophando isenokusetyenziswa nakwamanye amaphepha-ndaba okanye ezinye iincwadi, umzekelo iijenali ezisetyenziswa zizifundiswa.

Yintoni ebangele ukuba ucelwe uthathe inxaxheba?

Ucelwe ukuba uthathe inxaxheba kwezi zifundo zophando kuba:

- Utyandwe ingqula ukuze unyangelwe umhlaza womqala;
- Ubuyinxalenye yeqela elixhasanayo lezigulane ezityandwe ingqula kwiSebe lokunyanganga Umhlaza ngoGesi kwiSibhedlele saseTygerberg.
- Ufakelwe isixhobo esisebenza okommizo noqhoqhoqho bedibene ukuze kuphume ilizwi kwaye uza kukwazi ukuthetha ngeli xesha kusenziwa udliwano-ndlebe lobuso-ngobuso nomphandi.

Iza kuba yintoni uxanduva lwakho?

Kuza kulindeleka ukuba uphendule imibuzo eza kufundwa ngumphandi ephepheni ngokunyanisekileyo ukuze ube negalelo ekubekeni esi sifundo kumgangatho ophezulu. Oku kuza kubandakanya nje kuphela udliwano-ndlebe olunye. Alukho olunye uxanduva oza kubanalo kwesi sifundo sophando.

Ingaba ikhona into oza kuyizuza ngokuthatha inxaxheba kolu phando?

Iimpendulo zakho nezabanye ziza kuphendlwa ukuphucula ukuhanjiswa kweenkonzo zentlalo-ntle kwizigulane ezityandwe ingqula nezizalwane zazo. Njengoko kukho ulwazi oluncinane ngokweembono zomsebenzi wobuntlalo-ntle malunga noku,

igalelo lakho liza kunceda ekunikezelweni kweenkonzo kuzo zonke izigulane ezityandwe ingqula.

Ingaba bukhona ubungozi obukhoyo ekuthatheni kwakho inxaxheba kolu phando?

Akukho bungozi ekuthatheni kwakho inxaxheba kule projekthi yophando.

Ukuba awuvumi kuthatha inxaxheba, zeziphi ezinye iindlela onokuzisebenzisa ukuze ufumane unyango?

Akusayi kudlelwa ndlala ngenxa yeso sigqibo. Unyango lwakho uza kuhlala ulufumana ngendlela yesiqhelo kwisibhedlele ohamba kuso.

Ngubani oza kufikelela kwiingxelo zam zonyango?

Ulwazi oluqokelelweyo luza bekwa phantsi kokhuseleko luthathwe njengoluyimfihlelo. Ukuba luyasetyenziswa kwizinto ezipapashiweyo okanye kwiithisisi, iinkcukacha zomntu othathe inxaxheba azizi kuchazwa. Umphandi uza kufumana iingxelo zakho zonyango ezifana nomhla nohlobo lotyando namaxesha ekliniki.

Kuza kwenzeka ntoni kwisihlo esingaqhelekanga somenzakalo othile owenzeka ngenxa yokuthatha kwakho inxaxheba kwesi sifundo sophando?

Akukabikho zehlo zingaqhelekanga okanye menzakalo orewuboniwe ngenxa yokuthatha inxaxheba kwezi zifundo zophando.

Ingaba uza kuhlawula ngokuthatha inxaxheba kwezi zifundo okanye zikhona iindleko ezikhoyo?

Hayi, awuzi kuhlawulwa ngokuthatha inxaxheba kwezi zifundo. Akukho zindleko zikhoyo xa uthatha inxaxheba. Udliwano-ndlebe luza kwenziwa ngolwa suku kufuneka uye ngalo ekliniki, ngoko akukho mali yokukhwela yongezelelekileyo. Ukuba kunokwenzeka ukuba udliwano-ndlebe nabo bonke abathatha inxaxheba ngolwa suku alukwazi kwenzeka, kuza kufuneka uye esibhedlele ingakumbi ukuba kungenjongo yezifundo zophando, umphandi uza kuthatha uxanduva lokujongana nemali yokukhwela.

Ingaba ikhona enye into ekufuneka uyazi okanye uyenze?

Ungaqhakamshelana neKomiti yoPhando ngoMntu kwa-021 938 9207 ukuba unenkxalabo okanye izikhalazo ezingajongwanga ngokwaneleyo ngulowo ukuphandayo. Uza kufumana ikopi yolu lwazi nefomu yesivumelwano ukuba uzigcinele.

Isivumelwano salowo uthatha inxaxheba

Ngokutyikitya ngezantsi, Mna ndiyavuma ukuthatha inxaxheba kwisifundo sophando esibizwa ngokuba: yiNkqubo yenkxaso enikwa ngoonotlalo-ntle iqela elityandwe iingqula emva kweeyure zabo zokusebenza, oku kusenzelwa esibhedlela.

Ndiyavuma ukuba

- Ndilufundile okanye ndilufundelwe olu lwazi nefomu yesivulewano kwaye zibhalwe ngolwimi endilwaziyo nendikhululekileyo ukulusebenzisa.
- Ndibenalo ithuba lokubuza imibuzo kwaye yonke imibuzo yam iphendulwe ngokwanelisayo.
- Ndiyaqonda ukuba ukuthatha inxaxheba kwesi sifundo akunyanzeliswanga kwaye khang ndinikwe uxinezelelo ngokuthatha inxaxheba.
- Ndingakhetha ukuziyeka ezi zifundo nanini na kwaye andizi kohlwaywa okanye ndibekwe ityala nangayiphi na indlela.
- Ndingacelwa ukuba ndiziyeke izifundo phambi kokuba zigqitywe ukuba umphandi ubona oko kunokundinceda, okanye ukuba andisilandeli isicwangciso sesifundo ekuvunyelwene kuso.

Kutyikitywe (*indawo*) e..... *usuku*) ngomhla we-) ngo-2007.

Ukutyikitya kothatha inxaxheba

Ukutyikitya kwengqina

Isivumelwano somphandi

Mna (*igama*) ndiyavuma ukuba:

- Ndizicacisile iinkcukacha ezikolu xwebhu ku.....
- Ndimkhuthazile ukuba abuze imibuzo kwaye ndithathe ixesha ukuyiphemdula
- Ndanelisekile ukubona ukuba uyiqonda ngokwanelisayo yonke imiba yophando, njengoko ichaziwe ngentla.
- Ndisebenzise/andisebenzisanga toliki (*ukuba itoliki isetyenzisiwe kufuneka ityikitye isivumelwano esingezantsi*).

Sityikitywe (*indawo*) e..... ngomhla (*usuku*) we-ngo-2007.

Isivumelwano setoliki

Mna (*igama*) ndiyavuma ukuba:

- Ndimncedisile umphandi (*igama*) ukucacisa iinkcukacha ezikolu xwebhu ku..... (*igama lalowo uthatha inxaxheba*) ndisebenzisa ulwimi lwesi-Afrikansi/lwesiXhosa.
- Simkhuthazile ukuba abuze imibuzo kwaye sithathe ixesha elaneleyo ukuyiphendula.
- Nditolike okuchanekileyo ebendikuchazelwe.
- Ndanelisekile ukuba lowo uthatha inxaxheba uwuqonda ngokupheleleyo umxholo wolu xwebhu lwemvume echaziweyo kwaye yonke imibuzo yakhe yaphendulwa ngokwanelisayo

Kutyikitywe (*indawo*) e..... Ngomhla (*usuku*) we..... ngo-2007.

Ukutyikitya kwetoliki

Ukutyikitya kwengqina

ANNEXURE F



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY
jou kennisvenoot • your knowledge partner

10 August 2007

Ms BH Steyn
Department of Social Work
Tygerberg Academic Hospital

Dear Ms Steyn

RESEARCH PROJECT: "A HOSPITAL BASED SOCIAL WORK AFTERCARE PROGRAM FOR LARYNGECTOMY SUPPORT GROUPS"

At a meeting that was held on 1 August 2007 the Committee for Human Research considered your application for the approval and registration of the abovementioned project.

In principle the Committee is in agreement with the project, but requested that you should attend to the following matters before the project could be finally approved:

1. The sample size should be justified scientifically.
2. The certified Xhosa version of the participant information leaflet and consent form should be submitted.

On receipt of the additional information/corrected document(s) the application will be reconsidered. **Please mark all the corrections/amendments clearly in order to allow rapid scrutiny and appraisal.**

Please note that the application for the approval and registration of this project would be cancelled automatically if no feedback is received from you within 6 (six) months of the date of this letter.

Yours faithfully

CJ VAN TONDER
RESEARCH DEVELOPMENT AND SUPPORT (TYGERBERG)
Tel: +27 21 938 9207 / E-mail: cjvt@sun.ac.za

CJVT/pm

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Fakulteit Gesondheidswetenskappe • Faculty of Health Sciences



Verbind tot Optimale Gesondheid • Committed to Optimal Health
Afdeling Navorsingsontwikkeling en -steun • Research Development and Support Division
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E-pos/E-mail: rdsdinfo@sun.ac.za

ANNEXURE G



UNIVERSITEIT
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TAALSENTRUM
LANGUAGE CENTRE
IZIKO LEELWIMI

16 August 2007

Dear Beatrix

I hereby confirm that the following translation has been done by the Language Service:

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

The document has been translated from English to isiXhosa and electronically delivered on 16 August 2007.

Please contact me should you have any enquiries.

Regards

Alta van Rensburg
Acting Head: Language Service
Stellenbosch University Language Centre
Tel: 021 808 2231
Fax: 021 808 2863
E-mail: avrens@sun.ac.za

ANNEXURE H

COLOUR CODED CHART

1	IDENTIFYING DETAILS	
1.1	Age	
1.2	Marital status	
1.3	Race	
1.4	Gender	
1.5	Education and training	
1.6	Occupation (before and after surgery)	
1.7	Current total monthly income	
2	MEDICAL INFORMATION OF LARYNGECTOMY AND ROLE OF SOCIAL WORKER IN HOSPITAL SETTING	
2.1	Date of surgery	
2.2	Type of treatment	
2.3	Frequency of follow-up visits	
2.4	Purpose of follow-up visits	
2.5	Role of the social worker	
2.5.1	In providing information	
2.5.2	In solving problems	
2.5.3	In contacting community resources	
2.5.4	In supporting the patient and family	
2.5.5	In promoting rehabilitation	
3	PSYCHO-SOCIAL EFFECTS OF THE LARYNGECTOMY	
3.1	Physical effects	
3.2	Social effects	
3.2.1	Relationships with friends and family members	
3.2.2	Marital and sexual relationships	
3.2.3	Other social relationships outside the family	
3.2.4	Daily activities	
3.2.5	Recreational activities	
3.2.6	Employment and financial position	

3.3	Psychological effects	
3.3.1	Reactions and feelings of the patient	
3.3.2	Reactions and feelings of the family	
3.3.3	Self-image	
3.3.4	Body-image	
3.3.5	Loss of communication	
3.3.6	Loss of voice and self-expression	
3.3.7	Experiences of other people's behaviour	
4	AFTERCARE AND SUPPORT SERVICES	
4.1	Description of quality of current support	
4.2	Acquaintance with other laryngectomy patients	
4.3	Value of contact with other laryngectomy patients	
4.4	Attendance of support groups	
4.4.1	Description of the benefits / value of attending groups	
4.4.2	Themes for discussion	
5	COMMENTS	

ANNEXURE I

CONTEXTUAL FRAMEWORK FOR SUPPORT GROUPS TO LARYNGECTOMY PATIENTS IN A HOSPITAL SETTING: A SOCIAL WORK PERSPECTIVE

