

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



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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.

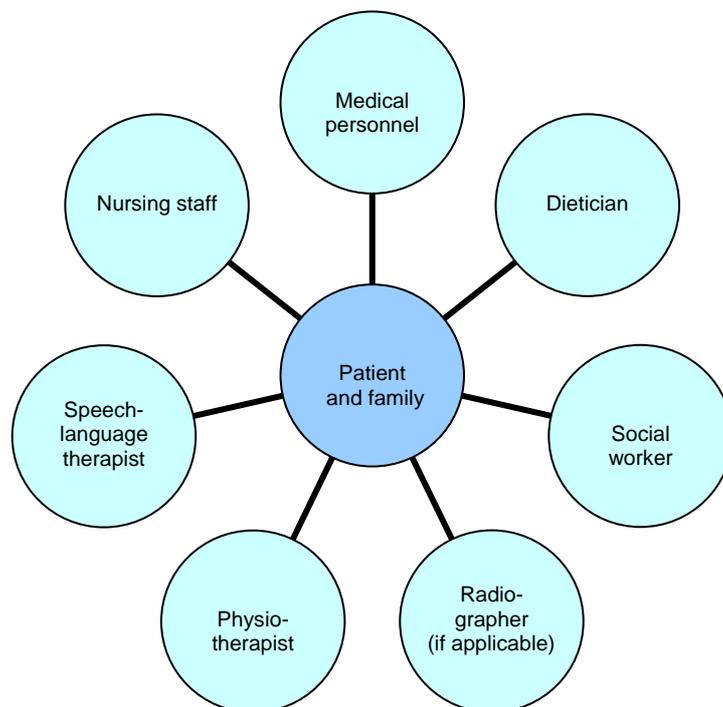


Figure 2.1: Schematic illustration of some of the team members

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

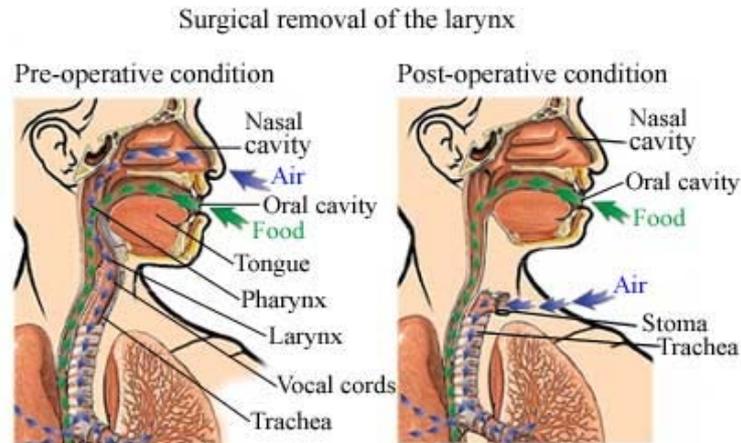


Figure 2.2: Surgical removal of the larynx (pre- and post-surgery)

[Source: "Laryngectomy" 2005. [http://catalog.nucleusinc.com/images/matl/thumbs/94\(94445.jpg\)](http://catalog.nucleusinc.com/images/matl/thumbs/94(94445.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.

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.

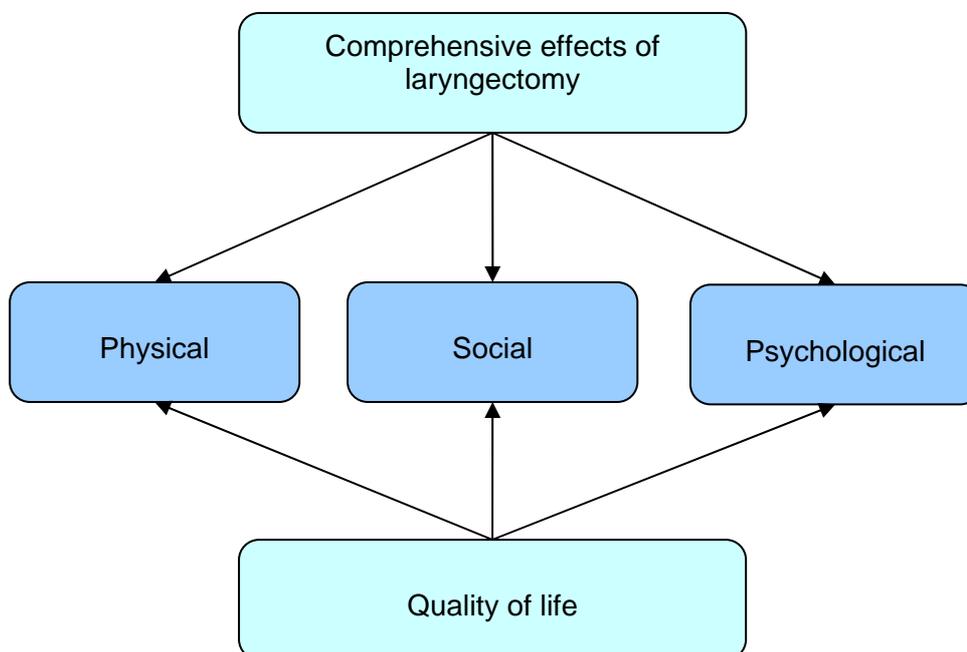


Figure 3.1: The comprehensive effects of a laryngectomy versus multi-dimensional aspects of quality of life

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.

- 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.

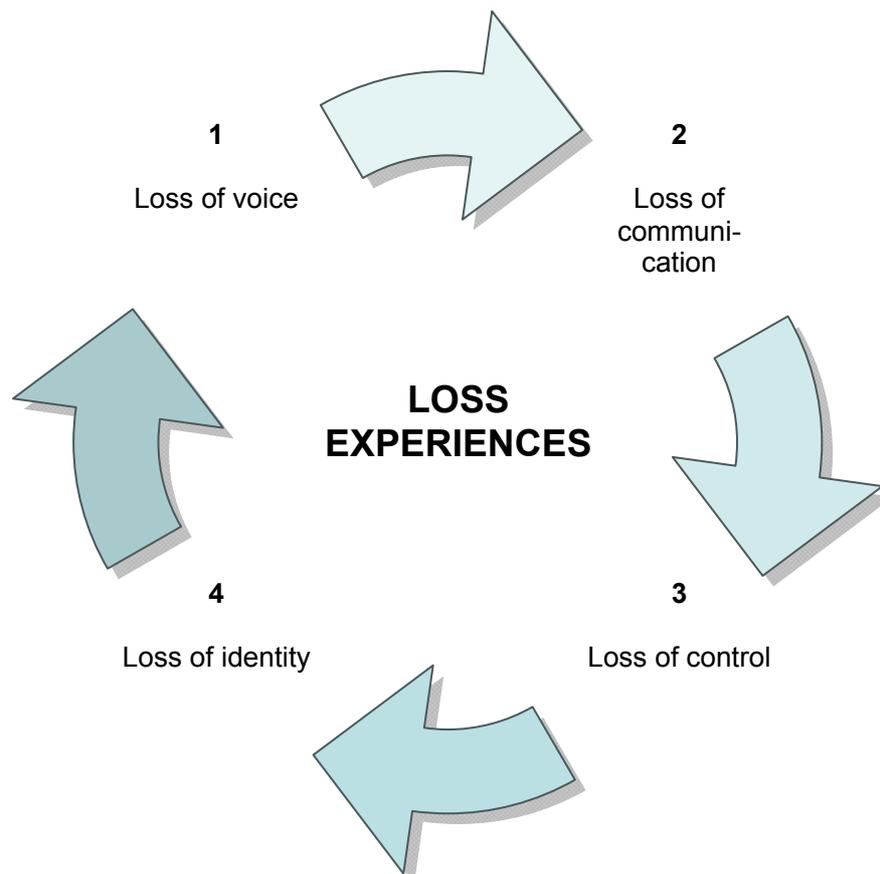


Figure 3.2: Various experiences of loss

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.

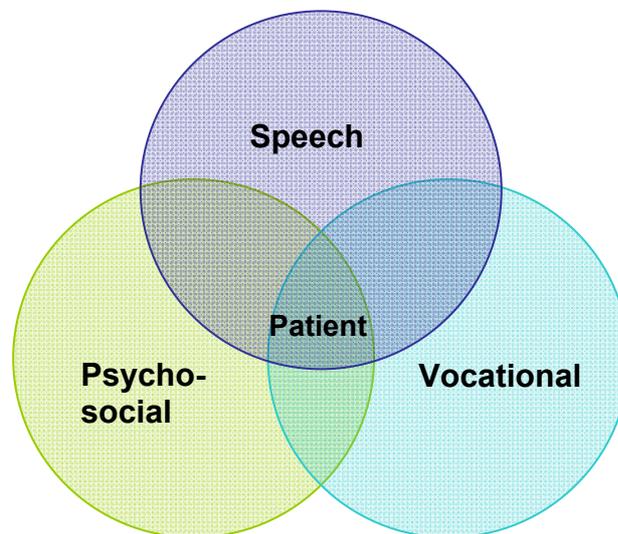


Figure 4.1: Components of rehabilitation

(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

(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.

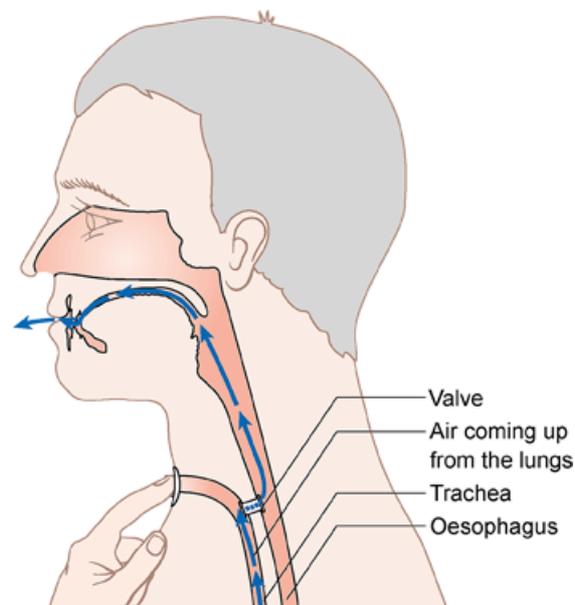


Figure 4.2: An illustration of the process of speech production in a laryngectomy patient

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

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.

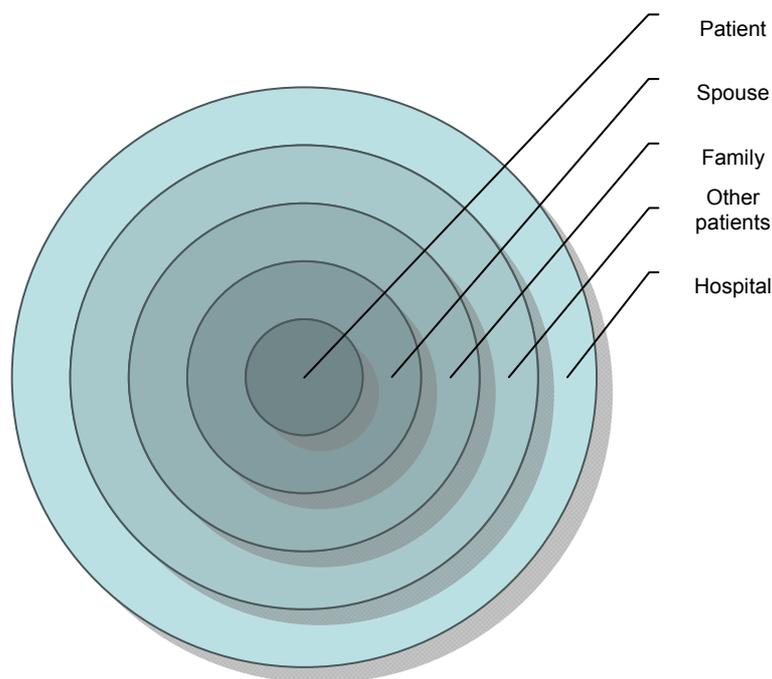
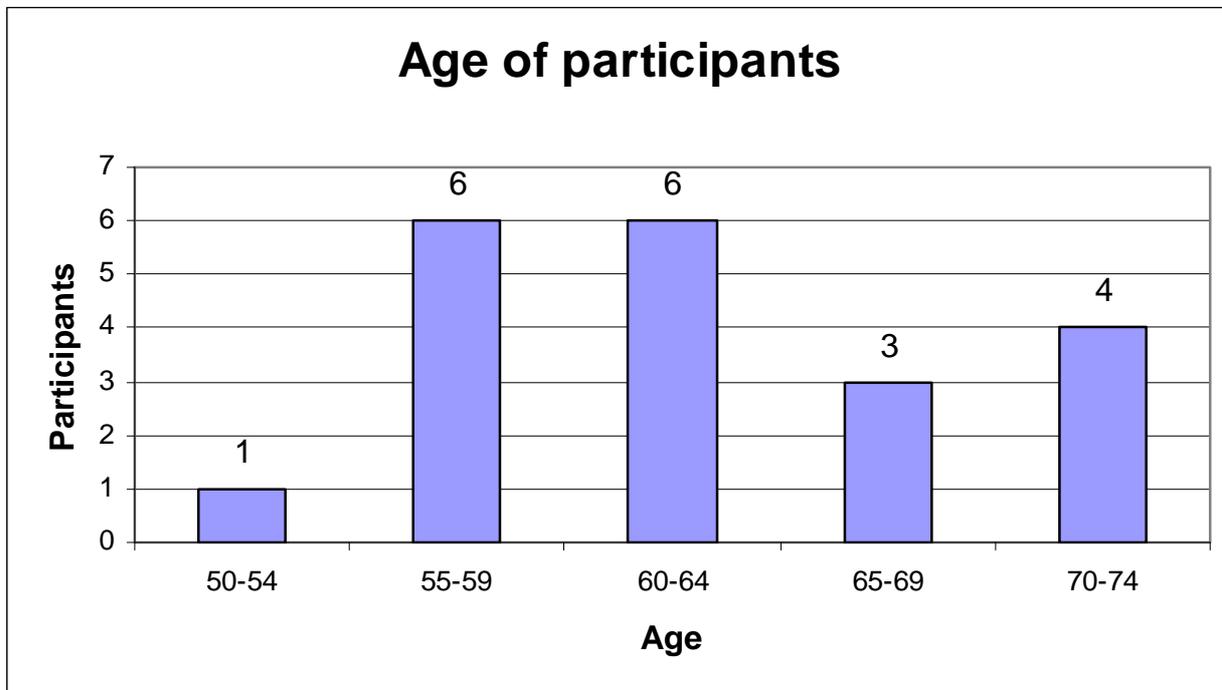


Figure 4.3: Various sources of support within the context of the ecological perspective

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

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.

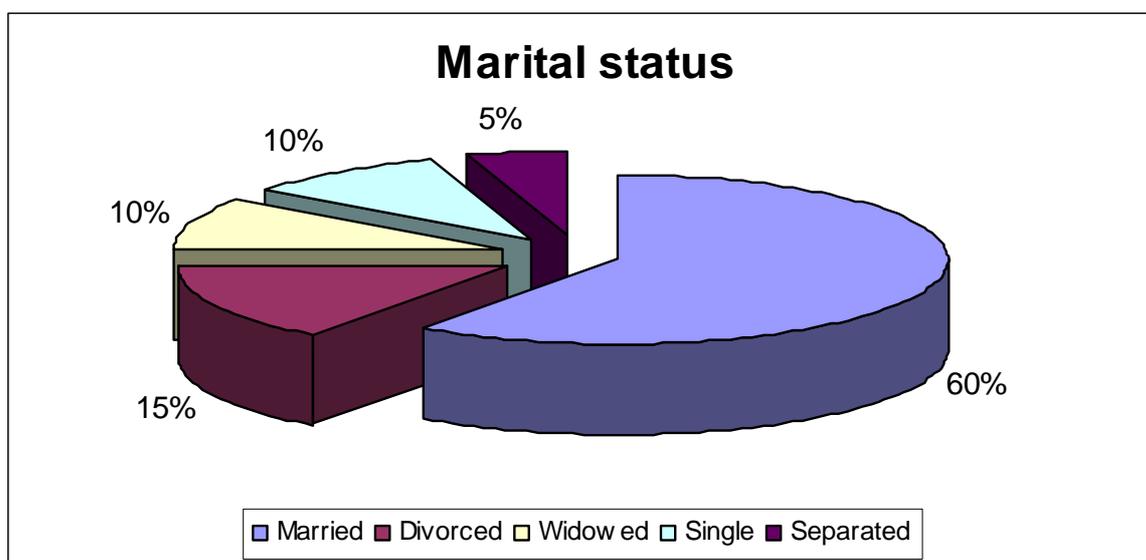
Cancer of the larynx is predominantly a disease of the elderly (late middle age or retirement) and therefore many laryngectomees may experience additional age-related medical problems like respiratory problems due to a history of heavy smoking over a long period of time (Renner, 1995:216; Ross, 2000:14). 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

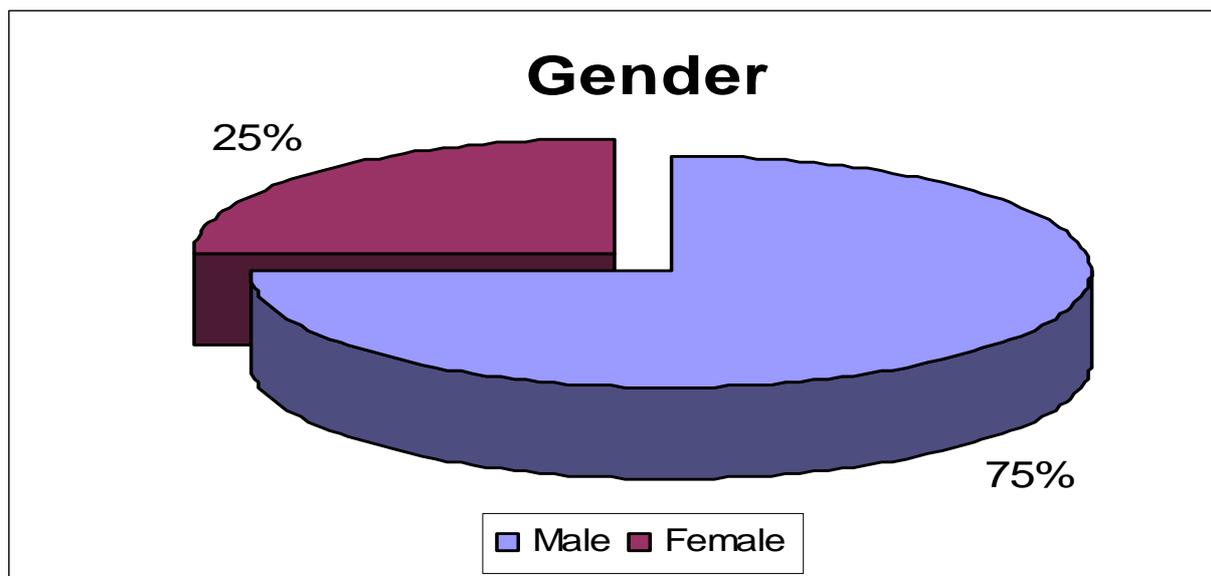
In the second place, enquiries were made about the marital status of participants, and this information is presented in figure 5.2.



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



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.

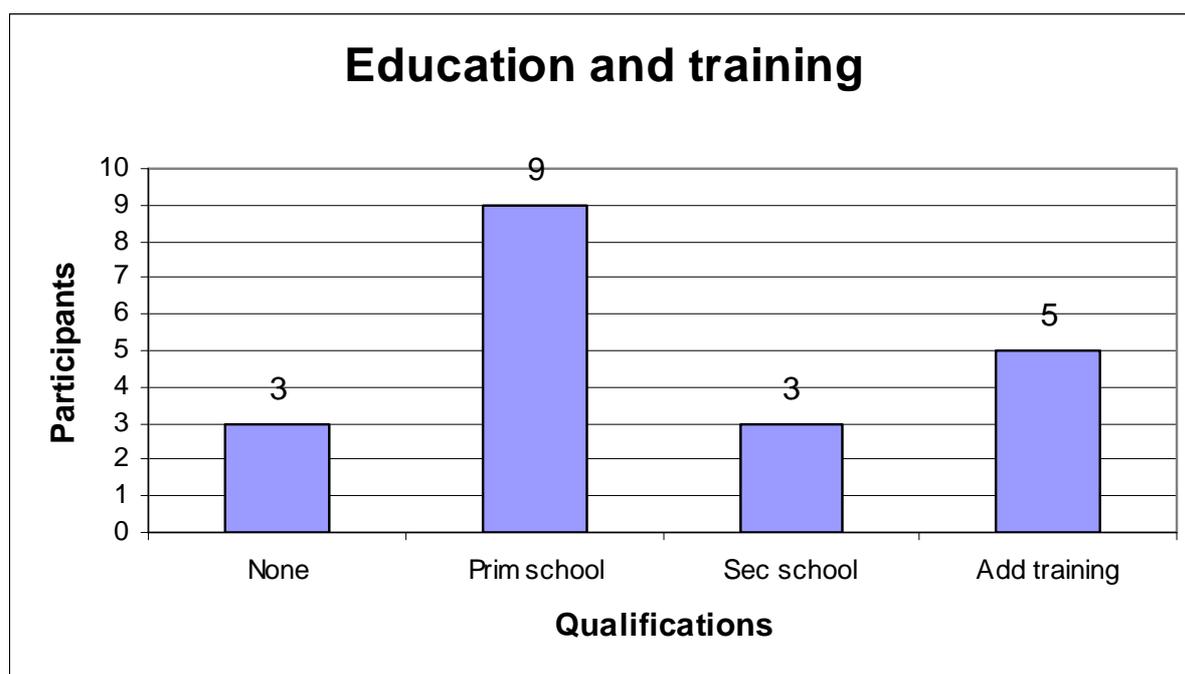
Although all laryngectomy patients experience similar problems, literature (Salva & Kallail, 1989:292, 300-301; Ulbricht, 1986:131) confirmed that women will experience certain additional difficulties and adjustments which will place extra demands on their experience of their femininity. Richardson and 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

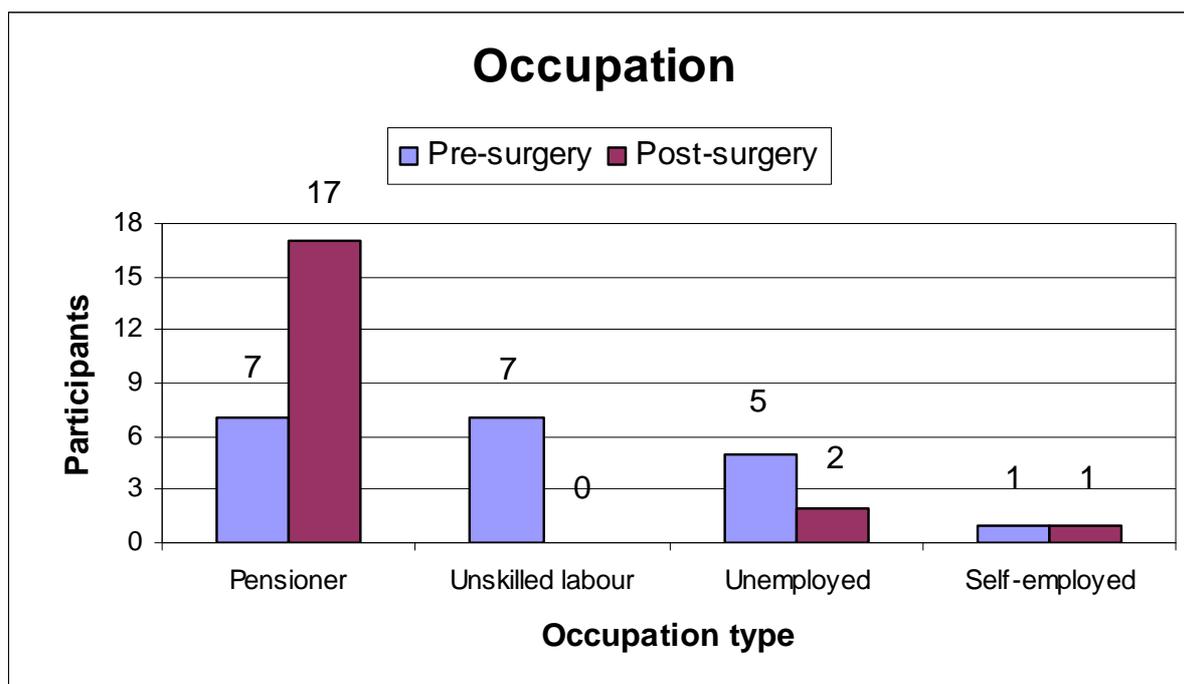
Three (15%) participants had **no** scholastic training. Nine (45%) participants had **primary school** training. These can be divided into one (5%) who had passed Grade 3; three (15%) Grade 5; three (15%) Grade 6 and two (10%) who completed Grade 7. Only eight (40%) participants had **secondary** school 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)

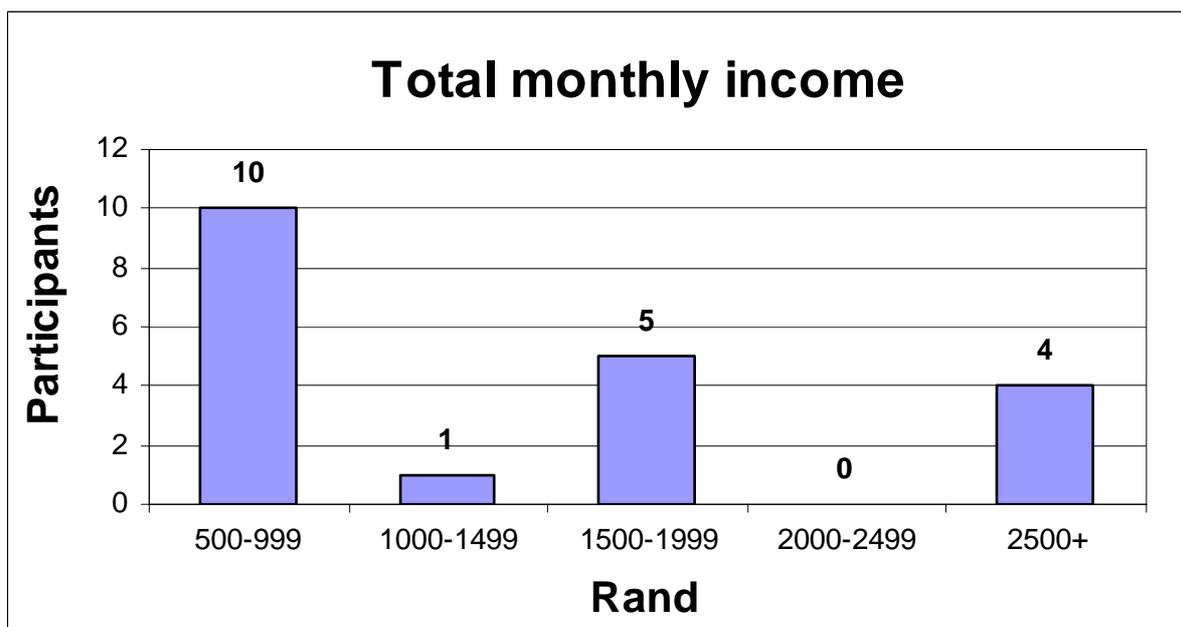
Previous and current occupation of participants was investigated in the sixth place. Figure 5.5 illustrates changes in participants' occupation after surgery.



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,



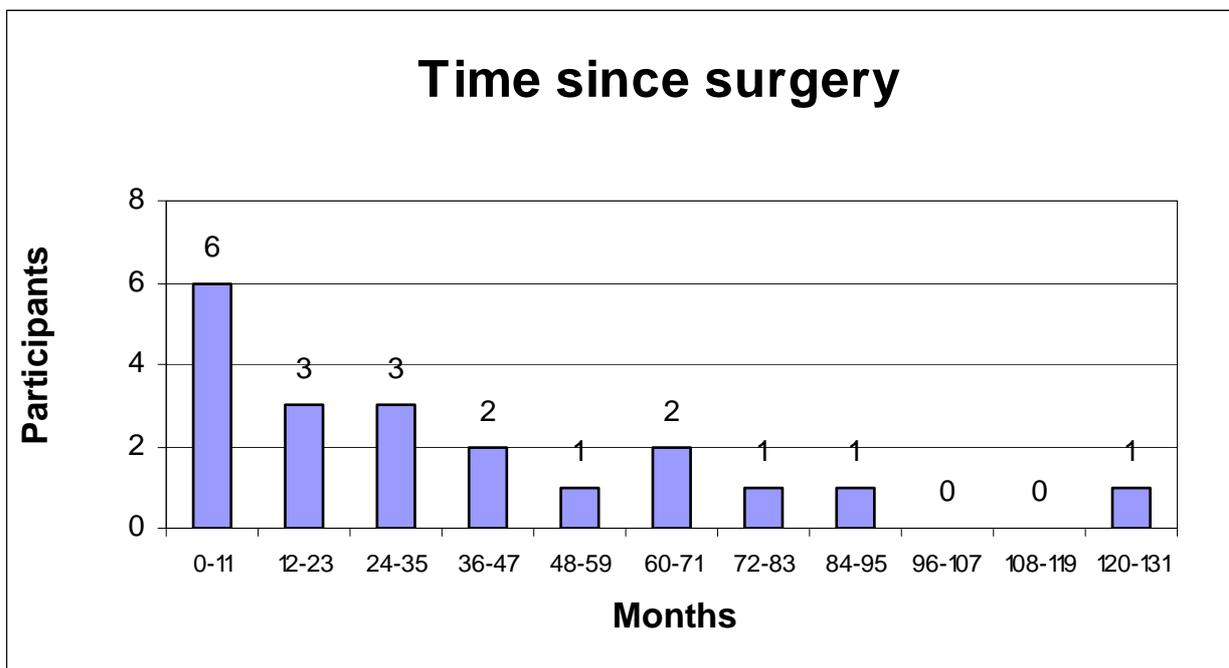
n=20

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

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.



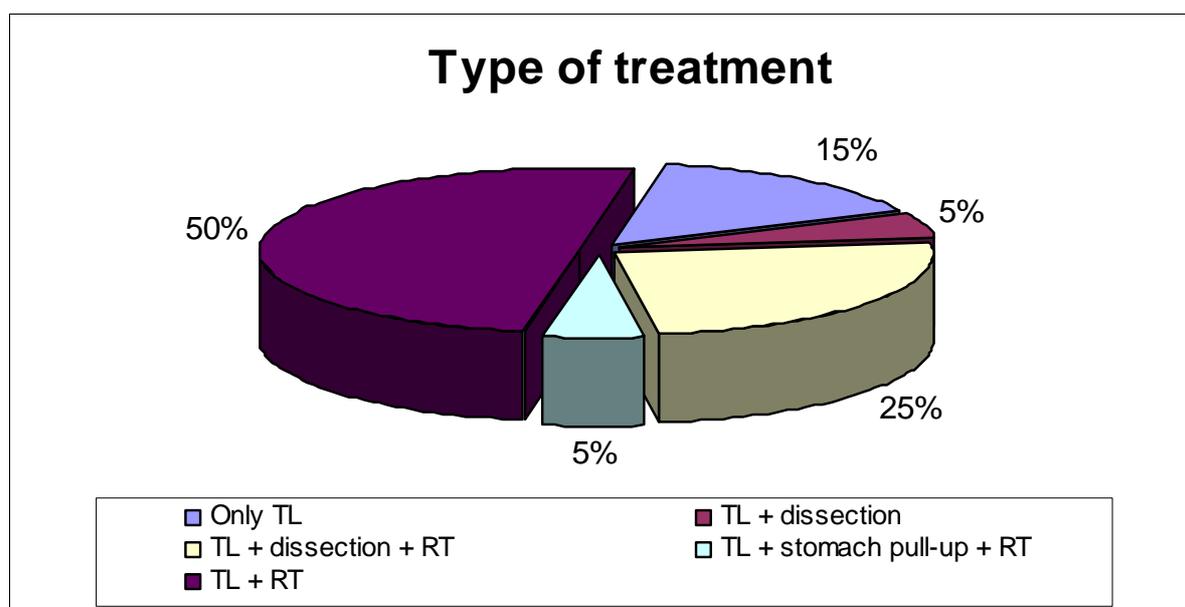
n=20

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

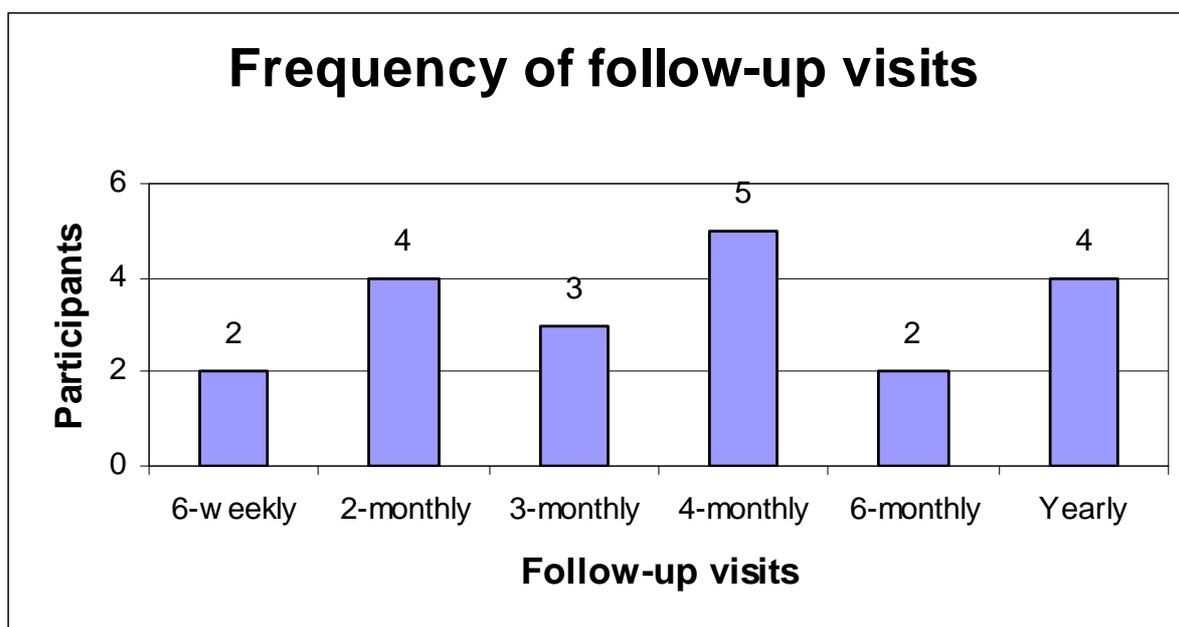
Legend: TL = total laryngectomy; RT = radiotherapy

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.



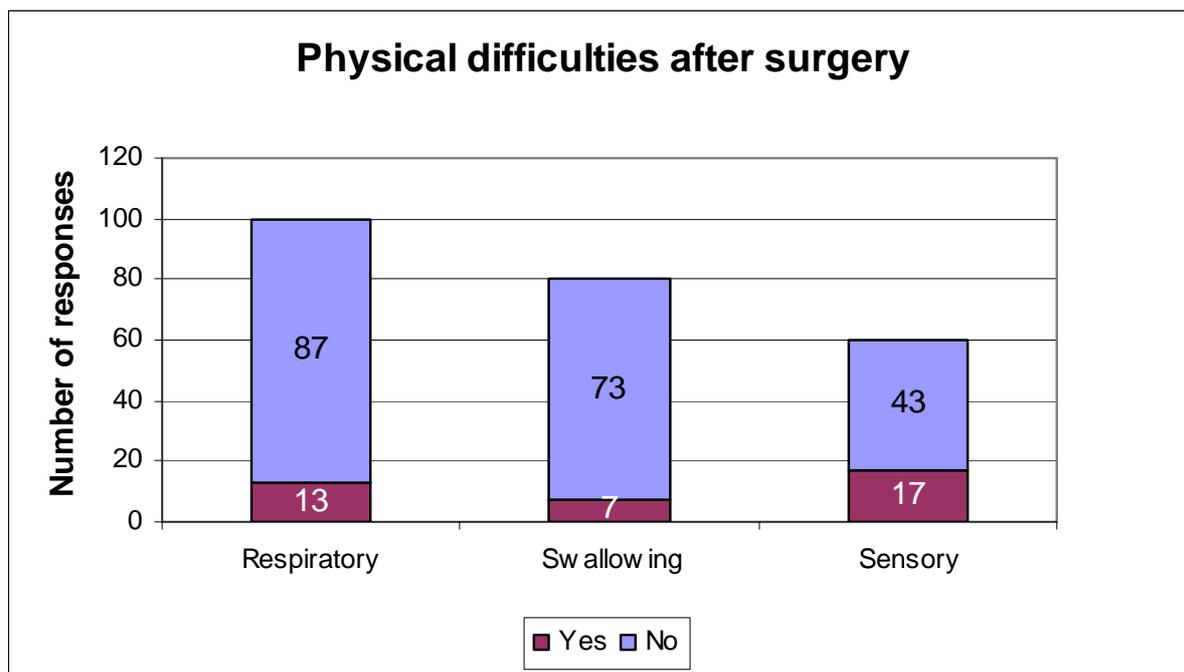
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Figure 5.9: Frequency of participants' follow-up visits to the clinic

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.



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).

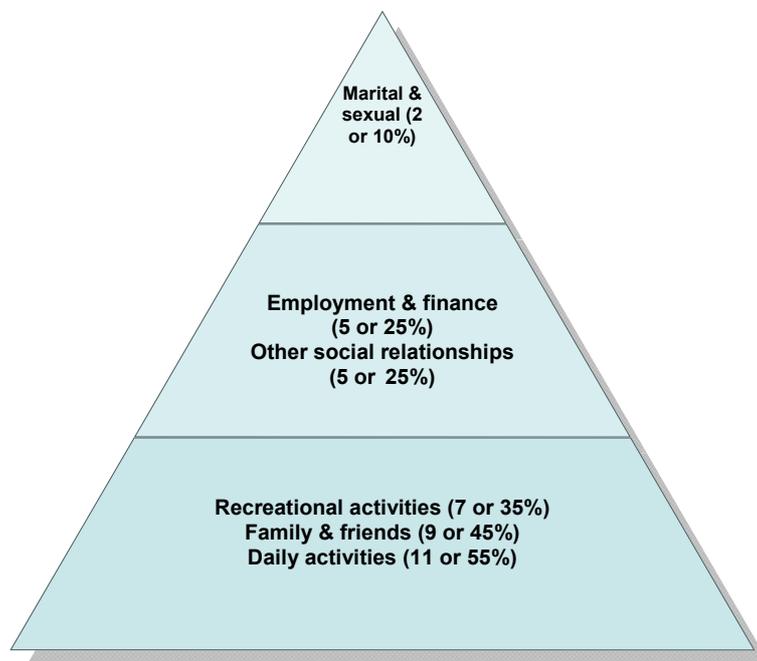
- *Discussion*

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.*

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**.

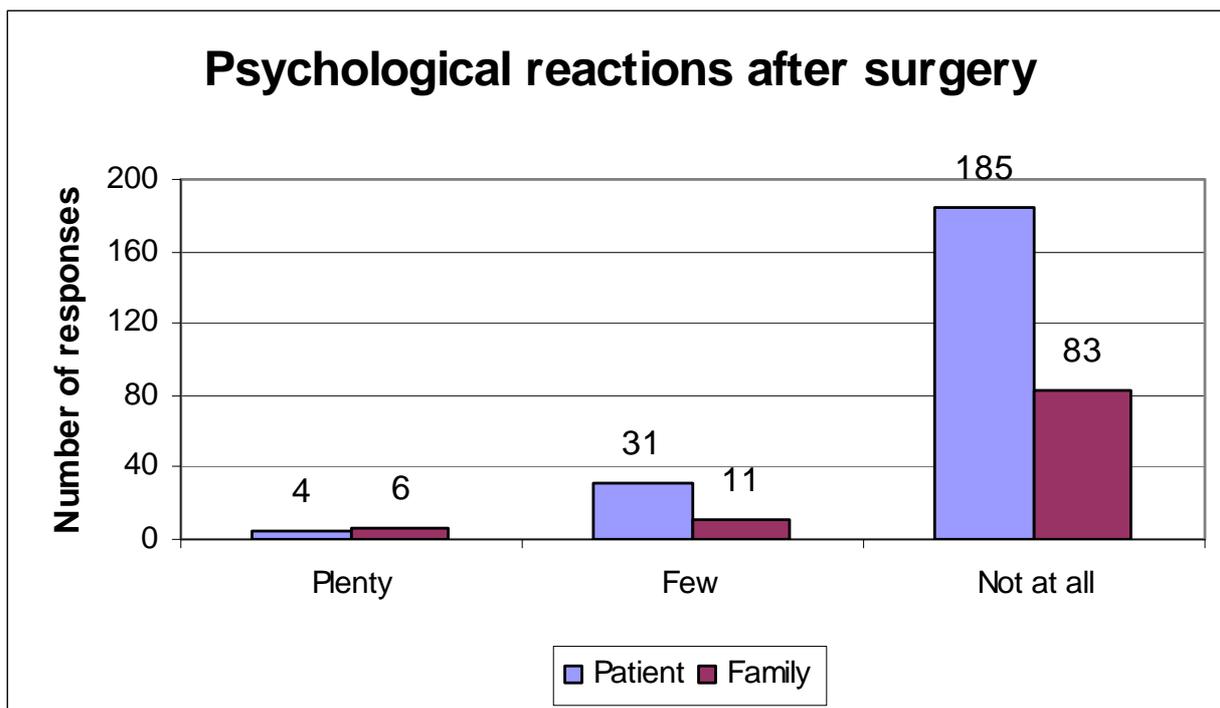
The area of social functioning mostly influenced by the laryngectomy experience, was that of participants’ **daily activities**, no matter how much time has elapsed since surgery. This could be due to the fact that participants could easily refer to practical and everyday situations. The majority (12 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



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

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	