

## THE LARYNGECTOMY PATIENT'S VIEW OF SOCIAL WORK SUPPORT SERVICES IN A HOSPITAL SETTING

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### INTRODUCTION

A laryngectomy is a surgical procedure entailing the removal of the entire larynx following a diagnosis of an advanced stage or recurrence of cancer of the larynx or hypopharynx (Casper & Colton, 1998:1; Silver & Ferlito, 1996:179; Stell, 1991:212). Severe smoking and alcohol use, especially in combination, can be seen as major risk factors for 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). People at greatest risk of contracting larynx cancer appear to be male smokers between the ages of 45 and 75 years (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, Parikh, Pinni, Parikh & Rao, 1995:121; Frith, Buffalo & Montague, 1985:476; Renner, 1995:216; Ross, 2000:14). This pattern is undergoing change, however, as an increasing number of women and younger persons are presently being diagnosed with cancer of the larynx (Belch & Beamish, 1992:61; Eadie & Doyle, 2005:122; Renner, 1995:216; Ross, 2000:13; Smithwick, Davis, Dancer, Hicks & Montague, 2002:206), mainly as a result of increased tobacco consumption or changes in smoking and drinking behaviour (Dhooper, 1985:217; Doyle, 1994:16; Smithwick *et al.*, 2002:206).

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.

Various factors intensify the laryngectomy patient's need for support, including those listed below.

- The fear, stigma and disfigurement associated with cancer and its treatment frequently result in difficulties in interpersonal relationships (Richardson, Graham & Shelton, 1989:283).
- Dhooper (1985:224) emphasised that patients may feel "ugly" outside of their family relationships and therefore withdraw from others. This may reduce the patient's use of available support systems (Doyle, 1994:262).
- The patient's post-operative inability to talk may jeopardise the availability of social support resources, which are essential for the patient's post-operative adjustment and rehabilitation (Richardson *et al.*, 1989:284).
- Physical implications of surgery may cause the support person to become impatient and, in reaction to this, the patient may experience embarrassment (Richardson *et al.*, 1989:284).
- Richardson *et al.* (1989:284) also mention that negative feedback by people who are potential sources of support for this target group of patients, has the potential to emphasise the patient's disability.

- The laryngectomy experience can be seen as a lonely experience as this operation is seldom performed and patients often do not know other patients who have had such an operation (Renner, 1995:215; Ross, 2000:14).
- The experience of a laryngectomy has the potential to result in a significant decrease in social acceptance, social and sexual activity, and the ability to communicate adequately (Deshmane *et al.*, 1995:128-129).
- Depondt and Gehanno (1995:33) were of the opinion that in sickness the personality of the patient could constitute a major handicap. In this regard they referred to the incidence of substance abuse among these patients, which might contribute to the patient's experience of rejection.
- As it is mostly patients with a history of substance abuse who are diagnosed with cancer of the head and neck region, these patients are often separated from their families or relevant others (Depondt & Gehanno, 1995:33) who could have acted as potential sources of support to them. Laryngectomy patients often choose to separate themselves from their family members or significant others and may experience problems in maintaining support once they have acquired it (Dhooper, 1985:224). Also, the study showed that when patients decided to maintain a sober lifestyle following their surgery, they might lose their friends.
- Blanchard (1982:240) found that families and friends are not always capable of offering the support needed as they are not always equipped to deal with the side-effects of the operation.

Richardson *et al.* (1989:284) distinguish between different types of support, each with its unique qualities and benefits. Graham (2004:134-135) stresses that, besides pre- and post-operative supportive counselling, and the use of educational videos or written materials, a comprehensive rehabilitation plan cannot be achieved without using support groups. Although support offered by 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).

Team members within the hospital setting are in an ideal position to offer support and aftercare to the patient and 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 they are also attending the follow-up clinic on a regular basis. The expertise of various members of the inter-disciplinary team is required to adequately address the needs of the patient and his family, as emphasised by Casper and Colton (1998:35). Casper and Colton (1998:50), Dhooper (1985:220, 225) and Doyle (1994:262) state that the social workers should form part of this inter-disciplinary team as they are equipped with the interpersonal skills to assist in the care, treatment and rehabilitation of the laryngectomy patient.

For the purposes of this study the ecological perspective was the preferred theoretical framework as it identifies and describes the various systems within which the patient functions (Germain & Gitterman, 1996:5-6; Meyer & Mattaini, 1995:16-27; Sheafor, Horejsi & Horejsi, 2000:91-93):

- First, DeSanto, Olsen, Perry, Rohe and Keith (1995:764) and Renner (1995:215-217) pointed out that a laryngectomy has an impact not only on the patient, but also on the family's psycho-social needs;
- Second, the sources of support (Richardson *et al.*, 1989:284) from which the laryngectomy patient and family can potentially benefit tie in with the characteristics of the ecological

perspective, which states that people function in relation to their environment (Sheafor *et al.*, 2000:91). 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 & Galaway, 1979:10);

- Third, Casper and Colton (1998:52) described the rehabilitation of the patient following surgery as a complex process, which should ideally include an understanding of the patient as “a total person” within the patient’s family system (Renner, 1995:215).

From January 2008 until May 2008 a study was conducted at the Tygerberg Hospital into laryngectomy patients’ view of social work support services in a hospital setting. This article will first present an outline of the problem statement underlying the study, the motivation and the goal of the study. The research methodology is discussed briefly and research findings are placed within the theoretical framework of the ecological perspective. After a presentation of participants’ identifying and medical information, aspects such as the role of the social worker and support and aftercare, will be discussed. Empirical data will be discussed and verified with reference to literature. Finally, some conclusions and recommendations are made.

### **PROBLEM STATEMENT**

The need for support for laryngectomy patients and their families was acknowledged in the 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 and friends are not always in a position to offer the required support. The above-mentioned findings served as motivation for the study.

Social workers play an important role in offering support to the laryngectomy patient and family members, taking into account the numerous psycho-social implications arising from this surgical procedure (Dhooper, 1985:225; Kaplan & Hurley, 1979:53). However, it requires intense involvement and specialised skills from social workers who have to deal with the complexity of these patients’ needs with compassion and insight (Dhooper, 1985:225). Support group sessions were initiated in 2006 by the researcher (who is a social worker) and a speech-language therapist at Tygerberg Hospital, and the need for a social work aftercare programme to adequately address the needs of the target group of patients and family members was recognised. Permission to perform this study was granted by the Ethics Committee at the Medical School of the University of Stellenbosch, Tygerberg Hospital.

### **GOAL OF THE STUDY**

The goal of the study was to explore and describe the role of the social worker in offering support and aftercare to the laryngectomy patient and his or her family within a hospital setting.

### **RESEARCH DESIGN AND METHODS**

A combination of mainly qualitative and to a certain extent quantitative approaches (Fouché & Delport in De Vos, Strydom, Fouché & Delport, 2005:73-75) and also a combination of exploratory and descriptive designs (Fouché & De Vos in De Vos *et al.*, 2005:106; Mouton, 2006:53-54) were used to best achieve the goal of the study.

The research population and sample were selected in accordance with the chosen research method. 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, and joined 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 (Strydom in De Vos *et al.*, 2005:206) 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 Delpont (in De Vos *et al.*, 2005:328-329).

Patients included in the sample had to meet the following criteria:

- Having undergone a total laryngectomy as surgical treatment of cancer of the larynx or hypopharynx at Tygerberg Hospital;
- Residing in the service area of Tygerberg Hospital;
- Attendance of the laryngectomy support group (on Wednesdays) after visiting the follow-up clinic or while receiving treatment at hospital;
- Ability to participate in the study, having acquired tracheo-oesophageal voice necessary for a face-to-face interview;
- Surgery to have been more than three month ago. This criterion was set to give them enough time to adjust to the psycho-social implications, without getting too used to their changed situation, as noted by Graham (2004:130).

Data were collected through using research instruments such as a face-to-face interview and semi-structured questionnaire. These have been described as the most basic and common method of collecting data (Babbie & Mouton, 1998:249; Delpont in De Vos *et al.*, 2005:166; Grinnell, 1993:268). 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). 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. Permission was asked to audiotape the interview, as suggested by Greeff (in De Vos *et al.*, 2005:298).

The process of data analysis was conducted in various phases, where answers to open-ended questions were sorted according to themes, sub-themes and categories (De Vos in De Vos *et al.*, 2005:340-342; Marshall & Rossman, 1995:114-115). A colour-coded chart (De Vos in De Vos *et al.*, 2005:338) was designed as a practical aid to relate the literature findings to information gained from the empirical study.

## RESEARCH FINDINGS

Findings of the study regarding laryngectomy patients' need for support in a hospital setting will be presented with reference to the ecological perspective. This section of the paper will present and discuss the identifying details of participants, followed by a discussion of their medical information. Third, an exploration of participants' opinion on the role of the social worker in rendering services to these patients and their relatives will be presented. Fourth, a discussion of support and aftercare being offered to these patients will be presented.

## **Identifying details of participants**

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

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 (15 or 75%) than females (5 or 25%) participated. This is in line with the current trend, namely that more elderly male persons are affected by cancer of the larynx (Renner, 1995:216). Also, 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 risk for females is one in six (Mqoqi, Kellett, Sitas & Jula, 2004:v).

The majority (12 or 60%) of the participants were married. One can expect that participants who are single (8 or 40%) (divorced, separated, widowed or never married) will experience a greater need for support as they lack spousal support. A possible benefit of spousal support is that of promoting speech rehabilitation as the patients have a greater need to use speech (Maas, 1991:1374).

With the exception of one (5%) White participant, all other (19 or 95%) participants were from the Coloured population group. 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. However, it can be useful when working with people from the Coloured population group as the majority (19 or 95%) of participants were from this group. The census results of 2001 (CENSUS, 2001) also indicated that in the Western Cape, which is the catchment area for patients who are treated at Tygerberg Hospital, Coloured persons represent 53.91% of the total population, followed by Black persons (26.69%), White (18.41%) and Indian or Asian (0.99%).

The majority of participants had primary school (9 or 45%) or no (3 or 15%) education, were social pensioners (6 or 30%) and prior to their operation did mostly unskilled work (7 or 35%) or were unemployed (5 or 25%) and fell into a low income group. Eadie and Doyle (2005:120) are of the opinion that 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. Findings of the study therefore confirmed the findings in the literature.

## **Medical aspects of participants' laryngectomy experience**

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

All (20 or 100%) participants had undergone a total laryngectomy as treatment following a diagnosis of larynx cancer. The majority (17 or 85%) had also had additional medical treatment such as block or neck dissections and/or radiotherapy.

Time elapsed since surgery varied between three months and eleven years, with an average time of three years and two months. 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. Patients need time to deal with the "outside world" before realising their own need for support, when they 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 their changed situation. It is in this regard that Graham (2004:130) mentions that the problems that patients face may underscore the need for a holistic team approach and therefore their need for support shortly after surgery.

Sixteen (80%) of the participants' follow-up visits were scheduled on a six-weekly to six-monthly basis, while the appointments of others (4 or 20%) were scheduled on a yearly basis. Follow-up visits allow patients to have contact with support groups at the clinic, available at the hospital. When participants were asked to comment on the purposes of follow-up visits at hospital, the following possible benefits were indicated:

- Medical assessment;
- Identification and treatment of medical problems;
- Motivation to stop alcohol or tobacco use;
- Assessment of nutritional condition;
- Assessment of speech ability and promotion of speech rehabilitation;
- Contact with hospital team members;
- Act as a source of support;
- Contact with other laryngectomy patients.

Nearly all participants viewed the above-mentioned benefits as “definite” purposes for their attendance of the follow-up clinic and therefore experienced the clinic as making a positive contribution towards their medical and rehabilitation progress and their need for support.

### **The role of the social worker**

Laryngectomy patients' opinions regarding the various roles that the social worker can fulfil during social work intervention were explored, as reflected in Table 1.

**TABLE 1**  
**PARTICIPANTS' OPINIONS OF THE SOCIAL WORKER'S ROLE DURING**  
**SOCIAL WORK INTERVENTION**

<b>Theme:</b> Social work intervention to serve the needs of the laryngectomy patient and family members	
Sub-theme	Categories
Source of information	<ul style="list-style-type: none"> <li>• Lack of information about medical issues and post-operative adaptation</li> <li>• Need for support groups</li> </ul>
Problem solving	<ul style="list-style-type: none"> <li>• Need for assistance with post-operative communication</li> <li>• Need for support groups</li> </ul>
Contact with community resources	<ul style="list-style-type: none"> <li>• Benefit of problem solving</li> <li>• Benefit of providing information</li> <li>• Benefit of offering emotional and social support</li> </ul>
Support to the patient and family	<ul style="list-style-type: none"> <li>• Need for emotional and social support</li> <li>• Need for providing information</li> <li>• Need for support groups</li> </ul>
Post-operative rehabilitation	<ul style="list-style-type: none"> <li>• Need for the patient to realise their own responsibility</li> <li>• Need for support groups to solve problems</li> </ul>

A discussion of the social worker's roles is presented below according to the sub-themes and categories as outlined in Table 1, followed by a description of participants' suggestions for greater use of support groups during social work intervention with patients and their relatives.

### **Source of information**

Half (10 or 50%) of the participants acknowledged that the social worker has a role to fulfil in providing information. One area identified by participants as one where they would like to have more information referred to medical issues regarding the operation and their post-operative adaptation. In the words of one of the participants:

*Information you are looking for, will be how it will be, what will happen, how long will it take and what the consequences will be.*

A quarter (5 or 25%) of the participants identified the need for support groups as a suggested method to provide information, as could be seen from one of the participant's responses:

*The best way is to get us together and to listen to us who have had the operation because we managed with it ... then we can share with one another.*

Some participants found it difficult to describe the social worker's role, while one (5%) participant did not think that the social worker could be of help in this regard. The majority (15 or 75%) of participants responded in a positive way when asked about the role of the social worker in providing information. They therefore expressed a need to include the social worker in the process of providing information to patients and families. They preferred to obtain information either on an individual basis or within group discussions. Their views correlate with the literature (Casper & Colton, 1998:50-51), indicating that the social worker has the expertise to help patients form an understanding of the psycho-social implications of the operation. Casper and Colton (1998:50-51) also emphasised that the social worker should offer applicable information and assurances of continuing assistance to patients and their families.

### **Problem solving**

Two (10%) participants were not sure how the social worker could be of help. The role of the social worker was positively associated with problem solving by the majority (17 or 85%) of participants. The first category of problems mainly referred to those associated with assistance with post-operative communication. A practical example was that they were sometimes mistakenly regarded by the public as being deaf (Murrills, 1975:55):

Then they talk to me as if I cannot hear, then I tell them that there is nothing wrong with my ears.

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. Within the hospital setting the speech-language therapist will play an important role in assisting the social worker with this problem-solving role.

The need of support groups was mentioned as second category in the process of problem solving by a quarter (5 or 25%) of the participants. This can be noted from some of the participants' remarks:

*To hear that the other one has the same problem, then we can support one another.*

*To hear from the patients who had their operation longer ago, to explain to those who had their operation a shorter while ago.*

One can expect that for patients who present with a diagnosis of cancer of the head and neck area and who are mainly representative of low socio-economic status, concrete help in terms of financial arrangements will be the most important requirement (Eadie & Doyle, 2005:120). However, 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. 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 arose in dealings with individuals or within group discussions.

### **Contact with community resources**

A quarter (5 or 25%) of the participants could not specify the role of the social worker in this regard, while one (5%) participant felt that the social worker could not be of assistance to him as he lived far from the hospital. One (5%) participant had the insight to mention that the community was not sufficiently prepared to solve problems that patients might experience:

*The support services in the community are not that much aware of the disease. They know very little. It is her (social worker's) task to inform them.*

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. Viewed from the ecological perspective, participants easily identified community resources with which the social worker could possibly connect them. These resources mainly included local day hospitals, clinics or hospitals, social workers within the community or hospice. Little effort was made by participants to describe the specific input of the social worker in the process of contact with these 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 describing the role of the social worker to draw from community resources, participants preferred to focus rather on personal benefits as a result of the social worker's utilisation of these community resources. The benefits were divided into categories, including: problem solving, providing information and offering emotional and social support. Two participants explained their viewpoints as follows:

*I will welcome anyone who can assist me and who can tell me what to do.*

*There are so many organisations, to contact them in order to contact me. They can motivate me and they can talk to me because it can let me keep a good heart.*

These benefits were in accordance with the viewpoint of Dhooper (1985:223), who pointed out that referral to community resources could offer various services to benefit the patient. Ross (1995:1369, 1373) also mentioned that 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 (1995:1372) stated that this co-ordination function was intended "to bring people, services and resources together on behalf of the patient" and form a link between the patient and available resources, which corresponds positively with the ecological perspective.

## **Support to the patient and family**

The majority (17 or 85%) of participants easily related the role of the social worker with support to laryngectomy patients and families. 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 up well with the ecological perspective, where the family system forms part of the various systems within which the patient functions (Renner, 1995:215). 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). One of the participants described this interwoven process of support between the patient and family as follows:

Support to the family must include the family member closest to the patient. 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.

The following categories of social work intervention to serve the needs of the patient and family members were identified by participants: need for emotional and social support, need for providing information, and need for support groups.

In a description of the role of the social worker to support the patient, participants mainly referred to the social worker's role to encourage the patient. Support to patients referred mostly to emotional support which could either be offered individually or within a group setting. Participants' positive response towards this role of the social worker, clearly demonstrated their need for support, which could be observed from the following participant's opinion:

The other people who can talk are not much interested in us who have the stomas. When we are together we can talk to one another.

With reference to participants' description of the role of the social worker to support the family of the patient, an 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.

To provide them (family) with knowledge because as the patient is provided with information regarding his condition, the family must also be aware of how to support the patient.

Practical ways for the social worker to render these services to families of patients 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, empowerment of patients to convey information or advice to families, or offering concrete help to families. Participants suggested that support to families could either be offered on an individual basis or within a group context.

Participants' responses emphasised a view found in the literature which describes 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).

## **Post-operative rehabilitation**

In describing the role of the social worker to promote rehabilitation, thirteen (65%) participants viewed this role in a positive manner. Participants identified categories of responses such as a

need for patients to realise their own responsibility to promote their post-operative rehabilitation, and the need for support groups to solve problems to promote their rehabilitation. These two categories are illustrated by the following verbatim responses of participants:

*The patient must set an aim 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.*

*Because the social worker did not personally experience this trauma, it is important to use other patients who have gone through it, as an example.*

Participants' positive link between the role of the social worker and the promotion of rehabilitation opportunities was in accordance with findings in the literature. Casper and Colton (1998:50) mention that, together with efforts by other team members, the social worker can be valuable in promoting patients' rehabilitation, as the social worker serves the needs of patients and their family members. The use of support groups was suggested largely by eight (40%) to promote rehabilitation, as all participants attended the support group and were familiar with the contents of such group discussions. This is in agreement with the literature (Renner, 1995:219), which points out that rehabilitation is strongly influenced by support from other patients.

### **Summary of the various roles of the social worker**

To summarise participants' opinions on the social worker in rendering services to laryngectomy patients, the following, in order of importance, were indicated: to offer support to the patient and family (17 or 85%), to solve problems (17 or 85%), followed by the social worker's role to provide information (15 or 75%). Contact with community resources and promotion of patients' post-operative rehabilitation received the same score (13 or 65%). As these were put in more abstract terms, participants found it difficult to give their opinions. The majority of participants had no or only primary school training. It was obvious that participants mostly referred to direct service delivery to them 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.

### **Suggestion for the use of support groups**

In defining the role of the social worker, thirteen (65%) participants suggested the use of support groups during social work intervention with laryngectomy patients and their relatives. A summary of participants' reasons for needing support groups during social work intervention with reference to theoretical benefits of support groups is presented below. Some of the identifying and medical details of participants will be related to their responses.

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 (2 or 15.4%) participants who attend the clinic annually, all other (11 or 84.6%) participants who

suggested 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.

**TABLE 2**  
**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"> <li>To provide information regarding the operation and consequences in daily life</li> <li>To discuss post-operative adaptation</li> <li>To talk about uncertainties about the future</li> <li>To listen to others who had a similar experience</li> </ul>	Providing information
Problem solving (5 or 25%)	<ul style="list-style-type: none"> <li>To compare oneself with others by sharing and discussing problems commonly experienced, including physical problems</li> <li>To communicate with others</li> <li>To experience support</li> <li>To learn from patients who had their operation a longer time ago</li> </ul>	Problem solving
Contact with community resources (0 or 0%)	<ul style="list-style-type: none"> <li>None</li> </ul>	Not applicable
Support to the patient and family (4 or 20%)	<ul style="list-style-type: none"> <li>To offer opportunity to identify and share problems and feelings and to find possible solutions</li> <li>To offer support when experiencing emotional problems</li> <li>To share knowledge and empower families to cope with patients at home</li> <li>To get patients together to talk and "share" a similar experience</li> </ul>	Social and psychological support
Promote rehabilitation (8 or 40%)	<ul style="list-style-type: none"> <li>To identify and discuss problems including post-operative adaptation</li> <li>To give advice</li> <li>To share the feeling of having the same experience</li> <li>To think about what had been discussed in order to face challenges in daily life</li> <li>To experience acceptance from others</li> <li>To experience interest shown by hospital</li> </ul>	Promote rehabilitation
Social work intervention in the above areas will improve quality of life		Improvement of quality of life

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, in contrast with eight (61.5%) male patients. All the females (5 or 100%) suggested the instigation 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 of the five (80%) female participants were married, while the fifth one (20%) 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, or never been married). One would expect single patients to experience an increased need for support, as Mathieson, Stam and Scott (1991:153-154) stressed that spousal support can play an important role in encouraging the patient to return to his former levels of functioning. In the words of Salva and Kallail (1989:299), attitudes of the spouse and families "can make or break the patient". However, when the four married female participants described the effect of the operation on their marital and sexual relationships, two indicated that their marital relationship had improved since the operation – one participant acknowledged initial problems but did mention improvement, while the other participant mentioned that her marital relationship had not changed.

### **Additional remarks regarding the role of the social worker**

Although all (20 or 100%) participants had 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. One explanation could be that in the majority (14 or 70%) of cases, surgery had been 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 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.

### **Support and aftercare**

Finally, participants' opinion on potential sources and quality of support currently being received, familiarity with other laryngectomy patients and the benefits or value of support groups were explored.

### **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, which demonstrated the items possibly to be included in the laryngectomy patient's eco-map (Compton, Galaway & Cournoyer, 2005:352-353; Meyer & Mattaini, 1995:18-19; Tracy & Whittaker, 1990:461-470). 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. Participants were asked to rate the quality of these sources of support as either *strong*, *poor* or *stressful*.

Support from parents (where applicable), from children in the home (where applicable), the church, other patients in the group, and team members at the hospital, was rated as hundred percent "strong" by all (20 or 100%) participants. This was followed by support from the spouse (91.7%), from children out of the home (92.9%), grandchildren (94.1%), and friends (95%), which was rated at almost hundred percent "strong". Support received from other family (16 or 80%) and community health centres (14 or 70%), although rated lower than the above, still received a high score.

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.

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). Viewed from an ecological perspective, a person acts in relation to the various systems in his environment. These systems interact with one another in order for the patient to cope, survive or to compete for resources needed (Sheafor *et al.*, 2000:91). Laryngectomy patients therefore have to be seen in relation to various sources of support in their environment in their efforts to adapt to their changed circumstances.

### **Acquaintance with any other patients who have had the same operation**

Only one-quarter (5 or 25%) of participants knew other laryngectomy patients. This corresponds well with the literature, which states that a laryngectomy experience can be regarded as a lonely experience as this operation is not often performed and patients seldom know other patients who have had such an operation (Renner, 1995:215; Ross, 2000:14). Lack of contact with other patients may result in not experiencing the potential benefits of support. Added to patients' loneliness may be reactions of withdrawal or isolation. These reactions intensify their need for support. For these participants, contact with other laryngectomy patients was not always beneficial, as Richardson *et al.* (1989:284) have warned.

Two of the five (40%) participants mentioned a negative experience in their contact with other laryngectomy patients because these patients did not maintain a sober lifestyle, which they experienced as demotivating:

*He is of no help to me ... he continues his lifestyle and I continue with mine, he is a guy who still drinks.*

More than half of these five (3 or 60%) participants rated their contact with other patients as positive as they benefited from sharing experiences, problems, practical hints and ideas. This finding corresponds with the literature (Murrills, 1975:55; Renner, 1995:219), which points out that the emotional trauma after an operation can best be understood by those sharing a similar experience. Ross (2000:20) also mentioned that the needs of laryngectomy patients and their relatives can best be understood by fellow patients. To observe other patients who are in the same position was also mentioned as being of help:

*It is good, because then we can communicate about our problems or what to do with the problems.*

*It lets me feel good, it encourages me. When we are in contact with each other, then we can talk.*

### **Description of the benefits or value of support groups**

Support groups were rated by all (20 or 100%) 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. Guidelines as used in the literature (Birkhaug, Aarstad, Aarstad, Olofsson, 2002:198; Graham, 2004:132-133; Richardson *et al.*, 1989:290-291) were used to identify possible benefits of support group attendances. These benefits 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. Some of the participants' verbatim responses illustrate their personal experience of these benefits:

*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.*

*To attend something like this is very informative because you can learn a lot from other people.*

*I don't think that I spoke as well as he did so soon ... you are inspired by others, you feel good.*

*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.*

*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.*

*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.*

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 (Graham, 2004:131-133). All (20 or 100%) participants mentioned that all themes should be included in group discussions. Learning how to stop smoking and drinking was also included as a potential topic for group discussions. Eighteen (90%) participants agreed to include this as a possible topic for group discussions, while one (5%) participant was not sure and the other (1 or 5%)

participant disagreed, citing its sensitivity. Additional themes for discussion as suggested by participants included a discussion of family relationships and how to adapt to these relationships after surgery.

### **Additional remarks**

The majority of participants described the quality of support currently being received from various sources as strongly beneficial. All (20 or 100%) 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, as the average time since surgery was three years and two months. It is important to note that all participants attended the support group as this was a condition for inclusion in the study. According to Salva and Kallail (1989:299), those involved in a support group had already demonstrated their positive post-operative adaptation, which could have had an effect on their positive responses.

### **DISCUSSION AND CONCLUSIONS**

The role of the social worker as team member constitutes a valuable contribution towards the laryngectomy patient's rehabilitation needs, as the social worker serves the needs of the patient and family members, as noted by Casper and Colton (1998:50). An exploration of the laryngectomy patient's need for support in a hospital setting, showed that participants linked the various benefits of support groups in a positive manner with the various roles of the social worker, as described in the literature (Casper & Colton, 1998:50-51; Dhooper, 1985:225; Kaplan & Hurley, 1979:53; Kleinsasser, 1988:258; Ross, 1995:1371-1372). To fulfil these social work roles during social work intervention with the patient and his family, the social worker should ideally focus on the following aspects of service delivery:

First, with reference to the finding in the literature that an increasing number of younger people and females will be affected by a laryngectomy in future, social workers will then have to deal with a different type of demand for social support. More male persons of a younger age will in future be spouses of a laryngectomy patient and will therefore be one target group to benefit from social support.

Second, the unique context of the hospital setting offers an excellent opportunity to provide aftercare and support to laryngectomy patients attending the follow-up clinic on a regular basis, as it offers the laryngectomy patient the ideal chance to meet other laryngectomy patients. To this end, the social worker should be equipped with knowledge of the following aspects and use the following skills:

- Knowledge of the medical aspects of the etiological factors, diagnosis and treatment of cancer of the larynx;
- Use of this knowledge of the etiological factors of larynx cancer (substance abuse, especially smoking) to initiate community precaution programmes;
- Engage in multidisciplinary teamwork in order to meet laryngectomy patients' medical and rehabilitation requirements and their need for support;
- Focus on support services to laryngectomy patients and their families when attending the follow-up clinic at the hospital.

Third, 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 patients and families, and promotion of rehabilitation opportunities. Participants indicated that these services should either be offered on an individual level, family counselling

and/or the use of support groups. During social work intervention the social worker should rely on the following capacities inherent in the social work profession:

- Comfortable with and sensitive to personal feelings and experiences in dealing with cancer patients in general, and laryngectomy patients in particular;
- Knowledge of the patient's rehabilitation process in order to provide appropriate information – the use of pamphlets, and audio-visual aids are suggested;
- Capacity to assess and solve problems (practical or emotional);
- 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;
- Knowledge of and experience in the availability and mobilisation of community resources;
- Ability to offer support to patients, taking into account their physical, social and psychological needs;
- Potential to offer support to families of patients as the family is the closest system in which patients function; change in one of these systems will also affect the others;
- Expertise to participate actively in the patient's post-operative rehabilitation process.

Fourth, various sources of support contribute to best meet the different needs of laryngectomy patients. 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. Support groups are indispensable in rendering support services to laryngectomy patients and their families, to which end the various roles of the social worker will be assumed in a creative way. The social worker should focus on the following areas of service delivery in order to meet these patients' need for support:

- Awareness of the various potential sources of support and professional skills to mobilise them;
- Knowledge of the theoretical departure points of the ecological perspective which describes the functioning of a person in relation to his environment;
- An innovative approach in using support offered by team members and other laryngectomy patients in a hospital setting when offering social support to laryngectomy patients and their families;
- The use of support groups as part of a holistic treatment approach to serve patients' and their relatives' need for support.

## **RECOMMENDATION**

In view of the results of this exploratory and descriptive investigation, it is suggested that further research should focus on the development of social work programmes for healthcare professionals. This may contribute towards professionals' knowledge of, and insight into, offering appropriate support services to best meet these patients' need for support, because the person who has undergone a laryngectomy usually feels isolated as the community is not always sufficiently prepared to adequately address their needs.

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