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ADJUSTMENT PROBLEMS AND THEIR EFFECT ON THE SOCIAL FUNCTIONING OF THE OSTOMATE AND HIS FAMILY

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OPSOMMING

Die navorser het 'n studie in Pretoria se omgewing gedoen om vas te stel watter aanpassingsprobleme die ostomaat en sy gesin ondervind en wat die invloed daarvan op hulle maatskaplike funksionering is. Daar is van toegepaste navorsing met 'n verkennende navorsingsontwerp gebruik gemaak. Gedurende die tydperk waartydens die studie gedoen is, is alle ostomate wat die Stomakliniek van die Nasionale Kankervereniging: gebiedskantoor Pretoria; die stoma – afdelings by die Pretoria Akademiese - en Kalafong Hospitale besoek het, betrek. Daar is bevind dat die ostomaat verskeie maatskaplike aanpassingsprobleme ervaar. Hierdie probleme is ten opsigte van die fisiese, emosionele, sosiale en seksuele funksionering geïdentifiseer. Die operasie het sodanige invloed op die ostomaat dat die multi – dissiplinêre span voor en na afloop van die operasie, 'n belangrike rol in die aanpassing van die ostomaat en sy gesin behoort te speel.

INTRODUCTION

The researcher did a study in the Pretoria area with the purpose of establishing the adjustment problems of the ostomate and the effect it has on the social functioning of the ostomate and it's family. Any ostomate who visited the stoma clinic of the National Cancer Association Area office: Pretoria, the stoma departments of the Pretoria Academic - and Kalafong Hospitals, during the time of the study, were approached. The involvement of the multi-disciplinary team, specifically the medical social worker, with the ostomate and his/her family was also explored.

OSTOMY/OSTOMATE

An ostomate is a person who has undergone a surgical procedure where a part of, or the whole abdominal tract or bladder is removed. This procedure has to be done due to abnormalities, disease or trauma to the abdominal area or bladder. A surgical opening is made in the abdominal area and the waste materials or urine are disposed of in a disposable bag on the outside of the body. This procedure is called an ostomy and can be a temporary or permanent solution. *"Ed Campbell, a past president of UOA, says flatly: '... an ostomy is not an illness. It is the fully manageable result of a procedure to cure an illness or to remedy a disorder'"* (Mullen & McGinn 1980:173).

TYPES OF OSTOMY PROCEDURES

The different types of ostomy procedures named by Convatec (1997:1) are discussed in table 1:

TABLE 1

TYPES OF OSTOMY PROCEDURES

OSTOMY PROCEDURES	TYPES	
1. COLOSTOMY	Cecostomy Ascending colostomy Transverse colostomy	Double-barrel transverse colostomy Descending colostomy Sigmoid colostomy
2. ILEOSTOMY	Ileostomy (incontinent) Continent Ileostomy	 Ileoanal Reservoir
3. OSTOMIES IN THE URINARY SYSTEM	Ileal Conduit Nephrostomy Indiana Pouch	Ureterostomy Cystostomy

REASONS FOR THE OSTOMY PROCEDURE

The reasons for the ostomy procedure are identified in Coloplast (1995:10) and are discussed in table 2:

TABLE 2

REASONS FOR OSTOMY PROCEDURE

TYPES	CONDITIONS	
1. COLOSTOMY	Carsinoma Obstruction Irradiation damage Faecal incontinence Congenital abnormalities	Diverticular disease Chröhn's disease Bowel ischaemia Trauma Hirschsprung's disease
2. ILEOSTOMY	Chröhn's disease Familial polyposis coli Irradiation damage Meconium ileus	Ulcerative colitis Obstruction Trauma
3. UROSTOMY	Carcinoma Disorders of the spinal column Urinary incontinence	

Adjustment problems occur due to the ostomy. Problems could occur in the physical, emotional, social and sexual functioning of the ostomate and his/her family.

Adjustment problems experienced by the ostomate and his/her family

Physical problems experienced by the ostomate

The ostomate is firstly confronted by the physical appearance of the ostomy and is immediately concerned with the physical problems that are experienced with the ostomy. Physical problems that tend to occur are:

- Unpleasant odors and sounds – According to Geiberger (1997:3): *"The modern odorproof pouches, if kept clean and changed regularly, should free you from this worry"*. This problem can be controlled by eating food that does not cause odors and gas.
- Diarrhea – This problem can cause social isolation and again occur less frequently if the correct eating habits are followed.
- Problems with the pouch – The ostomate can experience problems with the fitting of the pouch and this problem must be tended to before and after the operation until the problem is solved. In Kelly and Henry (1993:108) it is stressed: *"Learning to use an appliance is like learning to ride a bicycle: once you are learning to do it, it can seem impossible to master. By the time you are home from hospital, however, fitting the appliance will seem a matter of course. Remember, don't let the appliance master you, become the master of it"*.
- Leakage – This is a problem that is very important to the ostomate according to Phillips (1986:153): *"One of the primary concerns of every ostomate is leakage. Fear of 'tell - tale spots' appearing on clothing, puddles or other signs, can be very anxiety - provoking"*.
- Skin irritation – Can be caused by uncontrollable leakage, reckless removal of the pouch and allergies.

The ostomate not only has physical problems but because they are not always prepared before the operation, they also experience emotional problems as a result of the ostomy procedure.

Emotional experience of the ostomy

In a study conducted by Sprangers, Taal, Aaronson and Te Velde (1995:362) problems regarding the emotional functioning of the ostomate did occur. The young female ostomates showed signs of depression. Some of the ostomates indicated loneliness, anxiety, discomfort, helplessness and there were even some that wanted to commit suicide.

Shock, denial and aggression are also normal reactions the ostomate experiences as a result of the feeling of loss according to Benirschke (1997:1): *"It's perfectly normal to experience anxiety, fear, and concern for your future"*.

The ostomate's self-esteem and self-image are also effected by the ostomy and Delvin and Pelmin in Salter (1995:6) are of the opinion that this usually occur during the first year following the operation: *"They felt the need to look and feel good so that they could appear as confident as possible in front of others, but some were afraid to venture too far from home"*.

Depression occurs that effects the ostomate's body, mind, relationships and social life, according to Phillips (1986:66). This depression is caused by uncertainty about their future, prognosis, changes in their lifestyle, family conflict and broken relationships.

These emotional problems have an effect on their sexual relationships.

Sexual functioning of the ostomate

The sexual problems that occur can be temporary or permanent and Mullen and McGinn (1980:136) stressed that: *"The incorrect assumption is sometimes made that the sex drive and sexuality end with a disability such as a stoma"*.

Sexual problems can occur due to physical problems such as:

- Tiredness;
- physical fatigue;
- the use of medication and/or alcohol;

- the presence of the stoma, a fear of unpleasant odors;
- a fear that the pouch can be damaged; and
- physical pain and discomfort.

(Compare, Gambrell 1973:7; Phillips 1986:250; Johnson & Peters 1980:4; Mullen & McGinn 1980:136; Schindler 1985:102.)

The male ostomate can experience problems with impotency and Binder (1973:5) stresses that: *"... certain procedures may interfere with the nerve pathways which control the sexual functions of the male genitalia"*.

The female ostomate on the other hand can experience problems with pain and discomfort especially if the rectum is removed, Mullen and McGinn (1980:143) stresses that: *"although it may take time for muscles, nerves and blood vessels disturbed during surgery to get back to normal, this is a temporary problem"*. The female also tends to worry about hygiene and unpleasant odors. No problems can occur regarding pregnancy if discussed with the doctor before the ostomate decide to have children.

The impaired self – image has an effect on the sexual functioning as stressed by Hampton and Bryant (1992:16): *"Sexuality is influenced by feelings of attractiveness and desirability. Each person needs to feel desirable, and the degree of impairment of his or her body image influence the person's recovery into a loveable partner"*.

Depression, anxiety and fears influence the sexual relationship and Phillips (1986:251) stresses that: *"If you and your partner can share thoughts and feelings, you'll be in much better shape to work out any sexual problems that may occur after ostomy surgery"*.

The ostomate experiences problems regarding the social functioning.

Social functioning of the ostomate

The ostomate experiences problems with social functioning although *"Numerous surveys have shown that most ostomates lead full and active working, sporting, social and sexual lives"* according to Bokey and Shell (1980:101).

Travel and holiday arrangements, sport activities and visits to and from family are influenced. Visits to restaurants and film theatres as well as domestic tasks can also be influenced although minor adjustments can overcome these problems. The ostomate's working environment are in some cases influenced depending on the type of work the ostomate is doing. It is important that the ostomate should discuss the procedure with the people working with them. In some cases problems can occur regarding the physical care of the stoma and bathroom habits.

According to Benirschke (1997:1): *"It's true that your operation will require adjustments in your life. Depending on your age and physical condition, these adjustments could be far - reaching or relatively minor. Nevertheless, once you recover from surgery and learn how to manage your ostomy, you will probably be able to lead as full a family, social, and work life as before the operation"*.

The role of the enterostomal therapist and medical social worker in the multi-disciplinary team

The team members who are actively involved with the ostomate are the doctor, nurse, enterostomal therapist and the medical social worker. According to Bryant (1993:576): *"Complete*

recovery from surgery requires a multi-disciplinary health care team so that physical and mental health can be restored and adjustment to the many changes occur".

The enterostomal therapist

The enterostomal therapist (stoma therapist) has an important role in the recovery of the ostomate and according to Orem in Blackley (1992:16): *"Nursing (is) concerned with the individuals need to cope with deviation from health, to regain and maintain a state of self-caring and to sustain the status of health".*

Specific roles and tasks are performed by this therapist before and after the operation. These tasks are:

- A detailed description of the changes that will occur as a result of the surgery;
- a detailed description and explanation of the positioning and appearance of the stoma, the handling of the stoma and maintenance of the stoma;
- information and brochures are provided to the ostomate and family;
- the professional handling of questions by the ostomate and focussing on specific problems;
- before the operation the therapist decides with the ostomate the stoma site. Certain aspects like sport and religious considerations are kept in mind and the therapist sees to it that the stoma site will be comfortable for the ostomate;
- the different pouches that are available are discussed. The therapist explains the procedure that is followed to change the pouch, how to clean and maintain it. Information is given about skincare, leakage and unpleasant odors and noises;
- tips are also given about diet and a dietitian is contacted if needed by the ostomate;
- the therapist selects a pouch, before the operation if possible, and sees to it that the correct pouch is chosen so that the ostomate can use it after operation. This gives the ostomate time to recover for two to three days after the operation before the pouch is needed to be changed;
- a family member is present with the changing of the pouch to ensure that the ostomate will have someone to assist him/her if possible;
- general guidelines are given regarding hygiene;
- travel arrangements, physical and social activities and sexual functioning are discussed with the ostomate;
- possible complications, the signs, symptoms and treatment are discussed; and
- information about the buying of ostomy products are given to the ostomate and family.

The medical social worker

Medical social work is according to Barker (1991:141): *"The social work practice that occurs in hospitals and other health settings to facilitate good health, prevent illness and aid physically ill patients and their families to resolve the social and psychological problems related to illness".*

The medical social worker has an important role and function in the lifes of the ostomate and his/her family as stressed by Skidmore, Thackery and Farley (1994:146): *"It intervenes with medicine and treatment of illness at the point where social, psychological and environmental forces impinge on role effectiveness".*

In the literature there is no specific focus on the role of the medical social worker regarding the ostomate, although specific roles and tasks can be identified. The medical social worker has a role as information provider and supporter for the ostomate and his family. Although the ostomate

regards the stomatherapist as an important person, is it not always possible for the stoma therapist to provide physical and emotional support. The medical social worker can focus on the social adjustment of the ostomate and his/her family.

The medical social worker focuses on the interaction patterns, communication and role changes as stressed by Ziperstein (1992:6): *"The weight of serious illness is carried not by the patient alone, but by the entire family. Family members both influence and are influenced by a member's illness".*

During the intervention the medical social worker focuses on the shock, anxiety, aggression and denial experienced and problem solving skills are integrated. Vukovich and Grubb (1977:68) stresses that: *"The anxieties of the family are easily transmitted to the patient and may slow his progress. Family counseling promotes understanding and reduces these anxieties".*

The social worker supports the ostomate through motivation and encouragement. Fears and anxiety are dealt with in a matter - of -fact and in a sympathetic way, the ostomate is helped to avoid considering himself a unique problem.

In the working environment the social worker can be of assistance to help the ostomate adjust by contacting the employer and/or employees and explaining the situation. This will only be done if the ostomate gives permission to the social worker.

Sexual problems can be discussed and the social worker can help the ostomate to ventilate feelings of failure. It is important that the ostomate and his/her partner must understand the impact that the ostomy can have on the sexual functioning and that these problems can be temporary. According to Romano (1982:194): *"In so doing the counselor, both establishes a norm that sexuality does not cease to exist as a result of illness and educates the patient so that side effects are properly attribute to external causes rather than being seen by the patient as signs of personal loss or failure".*

The social worker can refer the ostomate and his/her partner to urologists or sex therapist if needed.

Milestones in Blackley (1992:18) identified aspects on which the social worker can focus to assess whether the ostomate have adjusted to his/her situation: religious practice outside the home environment, visits to and from the family, visits to restaurants, film theaters or shops, return to work, sport, sexual interaction, travel and holiday arrangements and participation in support groups.

Empirical Research

Introduction

Applied research was undertaken and the researcher used the exploratory design. The research strategy that was used is the field study. Natural observation was done through structured questionnaires. Any ostomate who visited the stoma clinic of the National Cancer Association Area office: Pretoria, the stoma departments of the Pretoria Academic - and Kalafong Hospitals, during the time of the study, were approached.

The following important data was gathered after processing the empirical findings:

- 50 respondents were approached, 60% (30) male and 40% (20) female.
- 58% (29) respondents were White and 42% (21) respondents were from other population groups - 36% (18) Blacks, 2% (1) Asian and 4% (2) Coloured.
- Most of the respondents were older people and the age varied from 9 years to 89 years.
- 64% (32) were married, 16% (8) unmarried, 10% (5) were widows/widowers, 2% (1) was estranged from his partner and 4% (2) divorced.

- Most of the respondents 32% (16) passed standard 8 and 30% (15) matriculated. This is probably due to the fact that most respondents were older people and from other population groups.
- 36% (18) of the respondents were pensionars, 16% (8) housewives, 2% (1) was to young to work and 24% (12) were unemployed.
- The colostomy procedure was the highest because of the high incident of colostomy procedures with older people, 68% (34). Of the male respondents 10% (5) had to undergo urostomy procedures and 22% (11) of the respondents had to undergo ileostomy procedures.
- Of the ostomy procedures 64% (32) were due to cancer, 18% (9) trauma, 14% (7) inflammatory diseases, 2% (1) birth defect and 2% (1) intestinal obstruction.
- The respondents who had the ostomy procedure less than a year ago were 28% (14), 22% (11) had the procedure 1-2 years ago and 22% (11) had the procedure 3–5 years ago, 28% (14) had the procedure more than 5 years ago. In total 72% (32) had the operation more than a year ago and it was difficult for these respondents to recall the information needed for the study.

TABLE 3

THE PERSONS WHO SUPPORTED THE OSTOMATE BEFORE AND AFTER THE OPERATION

PERSONS N = 50	BEFORE OPERATION		AFTER OPERATION	
	YES	NO	YES	NO
Spouse	48% (24)	52% (26)	54% (27)	46% (23)
Friend	24% (12)	76% (38)	28% (14)	72% (36)
Doctor	74% (37)	26% (13)	76% (38)	24% (12)
Nurse	50% (25)	50% (25)	60% (30)	40% (20)
Stoma therapist	36% (18)	64% (32)	60% (30)	40% (20)
Social worker	2% (1)	98% (49)	8% (4)	92% (46)
Minister	36% (18)	64% (32)	38% (19)	62% (31)
An ostomate	8% (4)	92% (46)	8% (4)	92% (46)

- The respondents were mostly supported by the doctor 74% (37) before the operation and 76% (38) after the operation.

TABLE 4

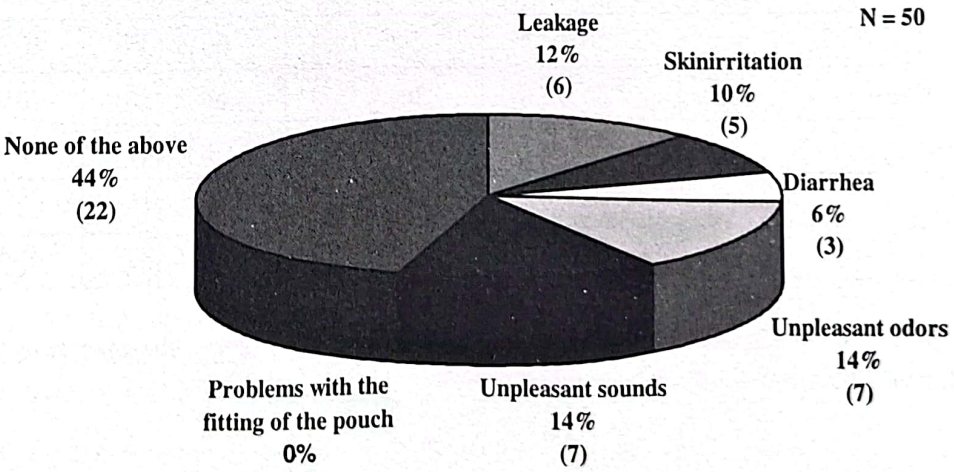
ASPECTS THAT WERE ATTENDED TO BY THE MEDICAL STAFF BEFORE THE OPERATION AND ASPECTS RESPONDENTS WOULD HAVE WANTED THE MEDICAL STAFF TO ATTEND TO AFTER THE OPERATION

ASPECTS ATTENDED TO N = 50	BEFORE OPERATION		AFTER OPERATION	
	YES	NO	YES	NO
Emotional support	48% (24)	52% (26)	92% (46)	8% (4)
Practical guidelines	48% (24)	52% (26)	94% (47)	6% (3)
Information service to family	42% (21)	58% (29)	84% (42)	16% (8)
Information service to patient	54% (27)	46% (23)	94% (47)	6% (3)
Opportunity for questions given to patient	52% (26)	48% (24)	94% (47)	6% (3)
Opportunity for questions given to family	44% (22)	56% (28)	86% (43)	14% (7)
Visiting the patient regularly	56% (28)	44% (22)	88% (44)	12% (6)

- The need for the aspects to be attended to after the operation were much higher than the aspects that were attended to before the operation.

FIGURE 1

PHYSICAL PROBLEMS



- The most important physical problem identified by the respondents were unpleasant odors and sounds. Of the respondents 44% (22) marked "none of the above" which stressed that the physical problems were not that important problem.
- The male repondents 60% (18) and female respondents 60% (18) experienced shock directly after the operation. Of the male respondents 33% (10) experienced aggression while 15% (3) of

the female respondents showed signs of aggression. Anxiety was experienced by 47% (14) of the male respondents and 20% (4) of the female respondents directly after the operation.

- Of the male respondents 90% (27) and 90% (18) of the female respondents had a need for support directly after the operation.
- Of the white respondents 69% (20) accepted the situation and 62% (13) of the other population groups accepted the situation directly after the operation.
- Of the other population groups 62% (13) experienced shock and 33% (7) aggression directly after the operation.
- During the time of the research 87% (26) of the male respondent and 80% (16) of the female respondents accepted the situation. Of the male respondents 27% (8) and 25% (5) of the female respondents did feel uncertain during the time of the research.
- Of the female respondents 20% (4) and 10% (3) of the male respondents experienced anxiety and helplessness during the time of the research.
- Loneliness, depression and sorrow were experienced by 15% (3) of the female respondents during the time of the research.
- Of the female respondents 10% (2) and 7% (2) of the male respondents felt rejected during the time of the research.
- During the time of the research a higher percentage of the other population groups felt optimistic 52% (11) than the 45% (13) of the white respondents.
- None of the other population groups felt lonely although the white respondents 17% (5) experienced loneliness.

TABLE 5

EMOTIONS SHARED WITH PERSONS DIRECTLY AFTER THE OPERATION AND PERSONS WITH WHOM THEY WOULD HAVE WANTED TO SHARE EMOTIONS WITH

PERSONS	EMOTIONS SHARED N = 50		EMOTIONS WANTED TO SHAREE N = 50	
	YES	NO	YES	NO
Spouse	48% (24)	52% (26)	56% (28)	44% (22)
Family/Friends	28% (14)	72% (36)	28% (14)	72% (36)
Doctor	54% (27)	46% (23)	62% (31)	38% (19)
Nurse	42% (21)	58% (29)	48% (24)	52% (26)
Stomatherapist	40% (20)	60% (30)	64% (32)	36% (18)
Social worker	6% (3)	94% (47)	46% (23)	54% (27)
Minister	42% (21)	58% (29)	40% (20)	60% (30)
An ostomate	8% (4)	92% (46)	32% (16)	68% (34)

- Of the respondents 54% (27) shared feelings with the doctor and 62% (31) wanted to share emotions with the doctor.
- The stomatherapist was envolved with 40% (20) of the respondents and 64% (32) wanted to share emotions with the stomatherapist.
- Only 6% (3) shared emotions with the social worker and 46% (23) wanted to share emotions with the social worker.
- Of the male respondents 53% (16) travel arrangements were influenced and 37% (9) of their sport activities were influenced. The male respondents domestic tasks were also influenced by 30% (9).
- Of the female respondents 15% (3) travel arrangements were influenced and 25% (5) of the female respondents domestic tasks were influenced.
- The other population groups 21% (6) visits to family were influenced.
- Of the other population groups 5% (1) visits to restaurants, filmtheatres and shops were influenced in contrast with the higher 48% (14) of the white respondents.

TABLE 6

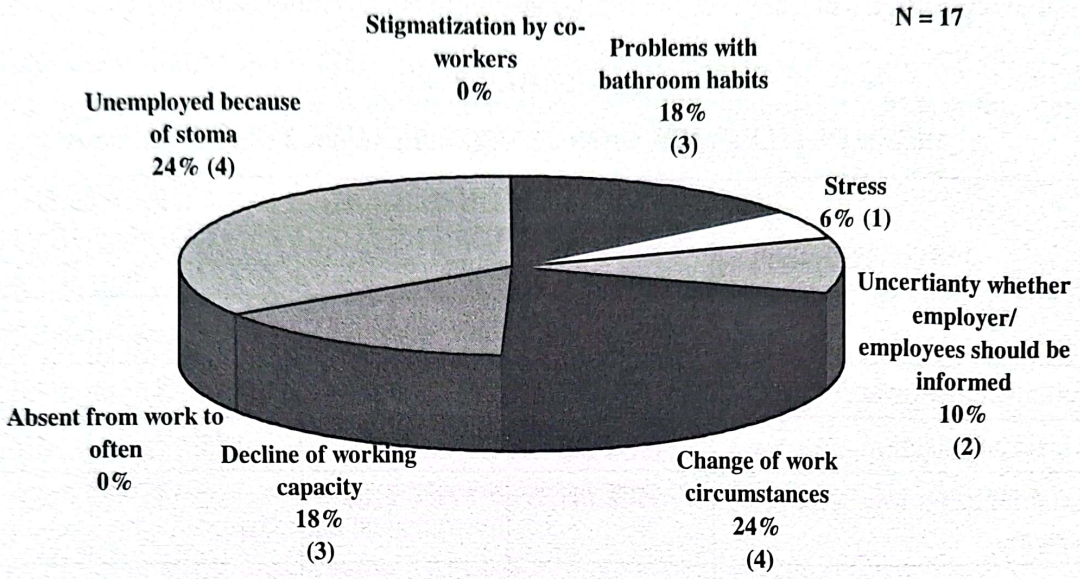
ASPECTS THAT INFLUENCED THE SOCIAL FUNCTIONING

ASPECTS THAT INFLUENCED THE SOCIAL FUNCTIONING N = 50	YES	NO
Ashamed of the stoma	12% (6)	88% (44)
Care of the stoma	44% (22)	56% (28)
Medical treatments	4% (2)	96% (48)
Emotional problem	10% (5)	90% (45)
Afraid that the stoma might be damaged	24% (12)	76% (38)

- The highest respons were 44% (22), care of the stoma and 24% (12), afraid that the stoma might be damaged.
- Of the respondents 17 were in a working situation.

FIGURE 2

PROBLEMS CAUSED IN THE WORKING SITUATION



- Of the respondents 24% (4) had to change their work and 24% (4) are unemployed because of the ostomy.
- Of the respondents 20 had an active sexual life.

TABLE 7

PROBLEMS EXPERIENCED WITH THE SEXUAL FUNCTIONING

PROBLEMS EXPERIENCED	MALE RESPONDENTS N = 14		FEMALE RESPONDENTS N = 6	
	YES	NO	YES	NO
Physical discomfort	43% (6)	57% (8)	17% (1)	83% (5)
Pain	21% (3)	79% (11)	17% (1)	83% (5)
Fatigue	7% (1)	93% (13)	17% (1)	83% (5)
Problems with erection	50% (7)	50% (7)	0%	100% (6)
Problems with ejaculation	14% (2)	86% (12)	0%	100% (6)
Problems with orgasm	21% (3)	79% (11)	17% (1)	83% (1)
Decline in a descire for a sexual relationship	43% (6)	57% (8)	67% (4)	33% (2)

- Of the male respondents 50% (7) experienced problems with erection and 67% (4) of the female respondents experienced a decline in a desire for a sexual relationships.
- Of the male respondents 43% (6) experienced physical discomfort and 21% (3) pain.
- Of the female respondents 21% (3) experienced problems with orgasm.

TABLE 8

ASPECTS THAT INFLUENCED THE SEXUAL FUNCTIONING

ASPECTS	MALE RESPONDENTS N = 14		FEMALE RESPONDENTS N = 6	
	YES	NO	YES	NO
Selfconcious towards partner	57% (8)	43% (6)	67% (4)	33% (2)
Afraid of rejection	36% (5)	64% (9)	17% (1)	83% (5)
Experienced a low self-esteem	29% (4)	71% (10)	17% (1)	83% (5)
Experience anxiety and stress	21% (3)	79% (11)	0%	100% (6)
Feels depressed	21% (3)	79% (11)	0%	100% (6)
Appearance of the stoma	64% (9)	36% (5)	33% (2)	67% (4)
Physical presence of the stoma	71% (10)	29% (4)	67% (4)	33% (2)
Afraid that the stoma can be damaged	71% (10)	29% (4)	50% (3)	50% (3)

- The male respondents were mainly affected by the physical presence of the stoma 71% (10) and they were afraid that the stoma can be damaged 71% (10).
- The female respondents were selfconcious towards their partner 67% (4) and 67% (4) were also affected by the physical presence of the stoma.

CONCLUSION

- In this study it was confirmed that the medical social worker has an important role regarding the ostomate and his/her family. The ostomate's social functioning is influenced and the social worker has specific roles and tasks to perform.
- The involvement of the social work profession with the ostomate and his/her family should be encouraged and emphasised. In the study conducted, physical, emotional, sexual and social problems were identified.
- In-depth training should be conducted by the stoma therapist and social worker in order to provide information to the multi-disciplinary team about the problems that are experienced by the ostomate and his/her family.

- The lack of information about the ostomate and the services that are provided to them can be solved by the stomatherapist and social worker by providing information to those who needs it.
- The ostomate and his/her family should be provided with intensive care and support before and after the operation. The service that is being provided by the stoma clinics should be coordinated by the social worker that the support cover the emotional and practical problems.

In this study the ostomate and his/her family and the problems they experienced with their social functioning were explored. There is still a great need for futher in depth research in this field in order to get more information on a scientific basis. Aspects that can be researched are:

- The problems experienced by the young ostomate and his/her family.
- The specific problems experienced by the ostomate who had the procedure less than 11 months ago in relation with the problems experienced by the ostomate who had the procedure longer than 12 months ago.
- A specific study of the problems experienced by the other population groups in South Africa.
- A study of the different ostomy procedures and the reasons for the procedures. Specific focus can be on trauma or the young ostomate who has a stoma due to birth defects. These ostomates' acceptance and adjustments can be compared.
- The multi-disciplinary team's concept of the ostomate and his/her problems and how the intervention are influenced by this.

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