NORWEGIAN PROFESSIONAL RECOMMENDATIONS ON THE FOLLOW-UP OF PATIENTS WITH OSTOMY

Prepared by

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As requested by

«The Norwegian Association of Nurses in Ostomy and Continence Care (NANOCC) (SISK in Norwegian) »

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Bergen 2020

NSFs FAGGRUPPE FOR SYKEPLEIERE
I STOMI- OG KONTINENSOMSORG

PREFACE

The following recommendations are formulated following an assignment from *Norsk sykepleierforbunds faggruppe av Sykepleiere i stomi- og kontinensomsorg (SISK)* – «The Norwegian Association of Nurses in Ostomy and Continence Care (NANOCC)», a subdivision of Norwegian Nurses Organization.
The recommendations are based on scientific evidence as well as on the knowledge and experience of the authors accumulated through several years of practice working with ostomy patients. The recommendations describe what a qualitatively sound follow-up of ostomy patients should include. However, the recommendations must be flexibly implemented and customized according to the requirements of each individual ostomy patient. The ostomy nurse must use his/her professional judgement when encountering each patient. Some institutions may at present not be able to implement all aspects of the recommendations. However, they should serve as guidelines and a standard as to what is considered good quality.

Through our contact with ostomy patients, we regularly witness that many patients experience an improved quality of life following their surgery. This may be a consequence of freedom from disease, or the relief from debilitating symptoms. The recommendations will however focus only on the potential challenges experienced following an ostomy operation and organizational aspects regarding the follow-up.

The recommendations have been presented to the patient organizations NORILCO (Norwegian Union for Ostomy, Pouch-surgery and Gastrointestinal Cancer) and LMF (National Union for Digestive Diseases). In addition, the Norwegian Association for Gastroenterological Surgery and the Norwegian Urological Society, both subdivisions of the Norwegian Medical Association have been consulted. We are grateful for constructive feed-back from these organizations.

Bergen July 4th, 2020

On behalf of the subject group

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After work on these recommendations commenced the subject group has changed its name from NSF's Association of Ostomy Care Nurses (SIS) to NSF's Association of Ostomy-and Continence-Care Nurses (SISK)

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1.0 INTRODUCTION

«The Norwegian Association of Nurses in Ostomy and Continence Care (NANOCC) (SISK in Norwegian) » aims among other things to contribute towards a uniform, sound care of patients receiving an ostomy. As part of this endeavour a cooperation with the subject groups for ostomy nurses in Sweden and Denmark was initiated in 1998 aiming to standardize recommendations for the care of ostomy patients. This cooperation resulted in three Nordic standards – one preoperative adressing information and ostomy-site marking, one postoperative adressing the teaching of ostomy care and care of skin-problems that might arise around an ostomy and one adressing ostomy and sexuality.[1-3] The Nordic cooperation was concluded in 2005.

It has however been our experience that the Nordic standards are insufficient in describing fully the care and treatment needed by ostomy patients. As a consequence, the SISK appointed a group to propose a Norwegian standard of follow-up. The recommendations presented here are the result of this work. The main focus of the recommendations is the need for follow-up after discharge from the primary hospital admission.

The word “ostomy” is derived from Greek meaning “opening” or “mouth”. The term describes the process of passing a segment of intestine through a surgically created opening in the abdominal wall thus allowing the passage of contents from the small bowel, large bowel or urine from the body resulting in an ileostomy, a colostomy or a urostomy, respectively.[4]

There are several indications for constructing an ostomy. Colorectal cancer is the most commonly ocurring cancer-form in men and women combined. In 2018, 4088 new cases were reported in Norway.[5] A large proportion of patients with a rectal cancer will require an ostomy, either permanently or temporarily. The overall 5-year survival rate in rectal cancer is now approximately 60%, while patients under the age of 50 have more than 80% 5-year survival rate. The life expectancy in the population is expected to rise. Life expectancy in 2017 was 84,3 years for women and 80,9 years for men, which is a slight increase from 2013.[6] As the number of elderly and elderly having survived a cancer diagnosis increase, the number of patients receiving treatment for colorectal cancer will also increase. Consequently, also the number of patients in need of an ostomy will increase.

In 2018, 2748 new cases of cancer of the urinary bladder or lower urinary tract were diagnosed.[5] Around 50% of these patients will require a cystectomy and some kind of urinary deviation, either a bladder substitute, a continent ostomy or a traditional urostomy. The survival rate for these cancers has also shown an improvement.

The reason for the improved survival rates has been improved surgical technique in combination with chemotherapy and radiotherapy.[7]

Patients with benign diseases may also require an ostomy. The most common diseases are Crohn’s disease, ulcerative colitis and diverticulitis.

In the light of above, the need for ostomies will not decline in the future.

Living with an ostomy, regardless of type and indication, is a challenging situation which may impact physical and mental well-being, the relations towards others, professional life, leisure activities, sexuality and general quality of life.[8,9] Therefore, the patient group will require special care in the rehabilitation phase following the ostomy procedure.

Samhandlingsreformen (the Interaction Reform - reform adressing the cooperation between the different levels in the health services) § 6.4.3[10] defines rehabilitation as “time-limited, planned processes with well-defined goals and remedies in which several professionals cooperate in providing necessary aid to the users’ own efforts in order to achieve optimal function and a sensation of coping, indepence and social interaction and participation in society”. This also describes the process the ostomy patient must go through following an ostomy procedure. As the ostomy will be ever-present and potentially be the cause of a number of problems, the follow-up cannot always be limited in time.

The ostomy patients in these recommendations are patients with colostomy, ileostomy and urostomy. The recommendations apply to both permanent and temporary ostomies. The recommendations do however not apply to patients with continent ostomies and includes patients older than 14 years of age only.[11] The target group for the recommendations are ostomy nurses and administrative personell or bodies responsible for organizing and leading the care for ostomy patients.

The issue to be adressed in the recommendations can be summed up as follows:

In which areas will a person having to live with an ostomy require information, guidance and aid? How should the follow-up after the construction of an ostomy be for the patient to experience optimal life quality and achieve the maximal function and coping, independence and participation socially and in society?

1.1 LIMITATIONS:

Living with the respective types of ostomies may be experienced differently, but there are a number of common problems. For this reason, the challenges and follow-up will be addressed collectively, regardless of the ostomy type involved. Some areas of concern relevant only to certain patient groups will be adressed separately. Other concerns may be irrelevant for some groups. Likewise, we have not discussed the various indications for ostomy construction, nor have we explored specific disease-related complications, symptoms or challenges. Adverse reactions following surgery, or for example short bowel syndrome will similarly not be addressed in the recommendations as these problems fall outside the scope of regular ostomy care and may require additional intervention beyond the general recommendations.

The recommendations include patients with permanent as well as temporary ostomies. Some of the recommendations may not be applicable to patients with temporary ostomies, such as the return to work. Other challenges may on the other hand become more substantial for patients with temporary ostomies, for example skin problems, leakage and dehydration with kidney failure, as seen particularly in patients with temporary ileostomies.[12-14]

We will not discuss challenges and follow-up of patients with continent ostomies, the reason being that these patients have a less visible change of body image, and functional changes that differ from those with conventional ostomies. Continent ostomies create other challenges and require other themes to be addressed at follow-up, and the frequency of follow-up may also differ.

In the Norwegian health services the cut-off age between pediatric and adult care varies between 14 and 16 years of age. In some places a person is considered a child until he/she becomes of age at 18. We have chosen the age 15+ for these recommendations because experience has shown that most patients above this age are willing and able to tend to their ostomy themselves. The recommendations will not discuss the specific challenges concerning the follow-up of children. Many of these challenges will be identical to those facing adults, but children will in addition face challenges applicable only to them. Besides, they are an heterogenous group with needs varying with age.

1.2 CLARIFICATION OF CONCEPTS

Quality of life (QoL):

QoL is a subjective, normative and multidimensional concept. Put simply it may be defined as "the good life". In that sense QoL engulfs all aspects of our existence, even life itself. Many attempts have been made to clarify the significance of a good life. It could be understood as the realization of goals and expectations,[15] happiness,[16] satisfaction in life[17] or mental well-being.[18]

To simplify and pinpoint the meaning of the term, attempts have been made to divide it into several levels: universal or global and health-related or disease-specific QoL.

- General or universal QoL refers to areas considered important to one's existence, such as physical and material well-being, self-realization, happiness, personal developement, relations to others, participation in social events and recreation. Universal QoL can be measured with one simple question using a visual analogue scale, or a questionnaire with multiple questions.
- Health-related QoL describes the perception of health and various aspects such as function, needs, goals and symptoms related to health. It is measured using e.g. Short Form (known as SF-36).
- Disease-related QoL refers to a person's perception of specific ailments or diseases and is measured using a form specifically designed for the actual condition or diagnosis.

All three levels affect each other, and all levels may include physical, social, psychological, spiritual, economical and material aspects. Some forms, e.g. SF36 and Quality of Life Scale (QoLN) calculate a norm score and thereby allow comparing the QoL of different patient populations to the general population.[19,20]

The ostomy patient's QoL will be described further in the recommendations with reference to a number of studies. In these studies, different definitions of the term QoL are used, and QoL at different levels are studied in addition to factors affecting QoL for the ostomy patient. Consequently, it is not possible to exactly define good QoL for the ostomy patient.

Coping with a new life situation

The coping of a new life situation can be defined as "continuously changing cognitive and behavioural efforts to manage specific internal and/or external demands considered challenging, or that exceed the ressources of the person thus threatening his/her well being".[21] When facing challenges of coping, an automatic and usually subconcious assessment of the situation at several levels occur. Lazarus and Folkman name these levels primary assessment, secondary assessment and reassesement.

Primary assessment is the immediate cognitive assessment of the situation and the demands that must be met. The situation is interpreted according to the level of threat to one's self, and how it affects important values and goals. The result of the primary assessment is that the situation is perceived as either neutral, positive or stressful. Expected loss or injury constitutes a threat, which is stressful.

Secondary assessment refers to the possibilities available to master the situation. Included are also the emotions evoked in the situation and the assessment of the possible concequences of choices made for the future.

Reassessment is the evaluation of whether the coping is considered appropriate, and whether or not the situation now has evolved as the person anticipated. If the situation differs from what was expected the person returns to the process and performs a new primary or secondary assessment.

Folkmann and Lazarus describe two main reactions when the strategy of coping fails – problem-oriented or emotion-oriented.

Problem-oriented strategy

Problem-oriented strategy implies finding solutions to or coping with a difficult situation. In addition to the patient attempting to define the problem and finding alternative solutions and assessing them, problem-oriented coping encompasses an internal motivation to change one's action-strategies or develop new ones. The patient assumes an active role leading to personal development because new ways of understanding are created. An example of problem-oriented strategy is when an ostomy patient seeks advice from a health professionsl on how to avoid leakage from the bandage and prevent odours, or how to handle the situation when the ostomy emits sounds in social situations.

Emotion-oriented strategy

The emotional strategy aims to change the perception of the situation rather than remedy the situation itself. This strategy can be used to maintain hope and optimism and to deny reality. The process leads to a distortion of reality or self-deceit leading to behaving as if nothing has happened. In some situations, reality is so demanding at first that emotion-based coping and the use of defence mechanisms are warranted. In this way the situation can be brought under control and the pending challenges can be overcome in the short run. Persons receiving an ostomy that has not been planned preoperatively may in order to manage reality resort to delaying or avoiding altogether taking part in the care of the ostomy or avoid even looking at the ostomy in the postoperative phase. To seek and receive acceptance from close relatives and friends will lead to a perception of self-worthiness and meaning.

It is not self-evident which strategy should be chosen as there is no definite answer as to what good coping means to the individual. The individual's coping strategy will always be affected by the context. It is therefore not possible for an outsider to completely decide whether another person's coping strategy is sound or not.[21,22]

Information, guidance and help – Orem's theory

These recommendations are a follow-up of the previously published "Nordic Standard for Ostomy Care" (pre- and postoperative ostomy care). These have had Orem's nursing theories as part of the theoretical referance framework. We have also chosen to use this theory, as Orem's theory is relevant for the main goal, which is to return the patient to an optimal level of function following the construction of an ostomy.

Orem's theory has three subdivisions: One on self-care, one on the failure of self-care and one on nursing systems. Orem considers the human as a rational, problem-solving and need-satisfying being characterized by certain physiological, psychological and cognitive structures and functions. The nurse must possess insight into this in order to be able to identify the patient's needs and implement appropriate interventions for the patient.

Patients are according to Orem's view persons receiving help or care from health professionals because of an imbalance between the capacity for self-care and the therapeutical demand for self-care. In such cases, the patient experiences a failure in self-care. This failure can be partial or complete and signals why and when a patient requires a nurse, or in other words when the patient or next of kin are unable to perform the necessary self-care that meets all the self-care requirements. Depending on the extent of care needed, Orem divides this into different systems of aid, such as

- *An entirely compensating system*, which is nursing of patients unable to perform self-care on their own accord, or lack the ability to perform independent and controlled movements (e.g. patients unconscious or with reduced motor skills or mental proficiency)
- *A partially compensating system* where both patient and nurse cooperate on the relevant and necessary nursing activities.
- *A supportive and educating system* which is relevant when the patient shall learn to perform the necessary activities in order to satisfy the therapeutic demands to self-care.[1,23]

Orem also mentions different help-strategies that are relevant:

- To act on someone's behalf
- To instruct and guide someone else
- To offer physical and psychological support
- To assure and maintain an environment supportive of the patient's development
- To educate someone else[1]

In an out-patient follow-up situation the degree of self-care failure will of course be individual. The follow-up in the ostomy clinic will reveal the patient's persistent needs, and the ostomy nurse must then clarify whether the patient is capable of handling this him/herself or if further assistance from the nurse is required, in which case the level of assistance must be determined. Usually education, guidance and support will be required for an otherwise self-reliant patient (a supportive and educating system), whereas some patients will require a certain degree of self-help assistance (a partially compensating system).

1.3 PRESENTATION OF GROUP MEMBERS

Torill Elin Olsen:

Registered nurse since 1983. Nurse and departmental head nurse in the Department for Acute and Gastroenterological Surgery at Haukeland University Hospital for 14 years. Founding member of the Association of Ostomy Care Nurses (SIS) in 1990 and leader of the association for 12 years. In 1994 educated ostomy therapist at Sahlgrenska University Hospital in Gothenburg. Started the ostomy clinic at Haukeland Hospital in 1997 where she is still active. Was one of the initiators in starting the education programme in ostomy care at Bergen University of Applied Sciences (from 2018 Western Norway University of Applied Sciences). In 2006 master's degree in nursing science at the University in Bergen. Has participated in the nordic cooperation responsible for the nordic standards of ostomy care. Has been Norway's representative in the World Council of Enterostomal Therapy (WCET)

Anita T. Lindam:

Registered nurse since 1989. Has worked as a nurse at the Gastroenterological/Surgical department at Akershus University Hospital for 11 years. Educated ostomy nurse at Bergen University for Applied Sciences (HiB) in 2000. Started the ostomy clinic at Akershus University Hospital in 2000 and has worked there since. She has followed the programme "Every-day Research" at Akershus University College, and in 2011 master's degree in clinical nursing science at Oslo University College. She has been coordinator for the ostomy nurses in the Association of Ostomy Care Nurses (SIS). Has also been Norway's representative in the World Council of Enterostomal Therapy (WCET).

Liv Guri K. Skogmo:

Registered nurse since 1984. Educated ostomy nurse at Bergen University of Applied Sciences (HiB) in 2001. Has been employed at Ringerike Hospital, gastroenterological department from 1985, interrupted by a one-year break working as a teacher in high school health studies. Has following the ostomy education worked as day-time nurse in a department for somatic medicine in combination with work in the ostomy clinic. Since 2012 worked as nurse responsible for professional development at the sugical/orthopedic department, Vestre Viken Hospital Trust, Ringerike Hospital. Has co-authored a learning- and coping-course, "Improved every-day life with ostomy" in collaboration with representative from NORILCO and the National Competnce Centre for Learning and Coping.

Kirsten Lerum Indrebø:

Registered nurse since 1983. Has worked in the surgical department for gastro/urology at Førde Central Hospital, leading the department as head nurse for 7 years. Started the ostomy clinic in 2000 and has worked there part-time as ostomy nurse since. Since 1998 part-time at Førde Medikal. Has post-graduate education in practice-guidance and palliative care as well as in teaching and working evidence-based. Educated ostomy nurse at Bergen University for Applied Sciences in 2000. Master's degree in nursing science at University of Bergen in 2011. Has been cashier and leader of the Association of Ostomy Care Nurses for 11 years. Has coauthored "Practical Procedures in Nursing" (PPS), VAR Healthcare, Cappelen-Damm publisher, and authored the chapter on ostomy in the book "Utøvelse av praktisk sykepleie" (The practice of clinical nursing), Sykepleieboken 3, Cappelen-Damm publisher. PhD-candidate.

Vigdis H. Dagsland:

Registered nurse since 1990. Worked in Section for Gastroenterological Surgery at Haugesund Hospital since 1992, periodically as assisting head nurse and as nurse responsible for professional developement. Educated ostomy nurse at Bergen University for Applied Sciences in 2000, after which she has run the ostomy clinic in Haugesund Hospital. Master's degree in clinical nursing science in 2017.

We extend our gratitude to the following, additional contributors:

Cathrine Planke Teig, Ostomy Nurse PhD.
Bente Schøtt-Osmo, Research Librarian, VAR Healthcare, cappelen-Damm publisher.

2.0 METHOD

The previous standards, which these recommendations must be viewed in conjunction with, used the method known as “Dynamic Standard Setting System” (DySSSy).[24] Originally this method was used in the preparation of the present recommendations. However, as the work progressed, we saw that knowledge-based standards were more appropriate, and the method was changed. The change of method has led to some additional work effort and delayed the process somewhat.

The group responsible for the recommendations have met three times annually. The sessions have included cooperation with librarian, literature searches, review and assessment of literature and review and assessment of input from group members. In between the meetings each group member has performed separate searches and reviewed literature, as well as writing the assigned segment of the recommendations.

Throughout the process we have performed systematic searches according to the procedure in *Helsebibliotekets retningslinjer* (“Health Library Guidelines”) for the preparation of professional procedures.[25]

Starting the process we searched the following: *Helsedirektoratets* (“Health Directorate’s”) publications on national professional guidelines, National Network for Professional Guidelines, knowledge-based procedures developed internationally, international guidelines, National Institute for Health and Clinical Excellence, Danish Centre for Clinical Guidelines, Joanna Bigs, Up-to-date, Best practice, Clinical Evidence, the Cochrane Library, quality-assessed single-studies MacPlus Search from McMaster as well as MEDLINE, EMBASE, CINAHL and SveMEd. BibSys and Google Scholar have also been used.

Systematic searches have been performed in cooperation with a librarian, and we have received monthly notices on novel articles from 2009 to the end of 2018. The search was performed after having set up a PICO-form, visualizing every possible search-element of significance for our process.

Reviewing and analyzing the search results supplemented by our knowledge and experience has created the basis for formulating a number of recommendations. In order to further substantiate the recommendations single searches have been performed during the process, and we have systematically strived to include recently published articles.

The amount of available literature is substantial, however, also rather limited compared to other themes. Much of the literature consists of professional articles, however these have been included to a limited extent only. We have prioritized single studies, reviews and meta-analyses. There are few randomized, controlled studies within this field. A selection has had to be made, and good quality articles identified. However, no attempts have been made to assess and grade the relevant articles. In addition to international articles published up until and including 2018, some recent Norwegian articles have also been included.

In every search the word “*stomi*” has been replaced with the English terms: Stoma, ostomy, colostomy, ileostomy, urostomy, urinary diversion, enterostomy and ostomates.

Additional search phrases used to strengthen the literature-based foundation for the recommendations:

Recommendation:	**Search phrase:**
1	Ostomy care, education, postoperative, learning, teaching, practical skills
2	Complications, peristomal skin complications, follow-up
3	Complications, stoma/ostomy related complications, follow-up
4	Hernia, parastomal hernia, complications
5	Complications, peristomal skin, follow-up, appliance
6	Colostomy irrigation, colostomy plug
7	Diet, fluid, dehydration, electrolytes
8	Urinary infection, pH, cranberry, urinary sample, bacterial growth
9	Noise, incontinent, flatus, gas, stigma, embarrassment
10	Psychosocial adjustment, body image, social impact, social support, psychosocial adaptation, employment, work
11	Work habit, occupation, lifestyle, travel, leisure
12	Self-image, body image, bodily change
13	Sexuality, sexual problems, sexual function, sexual health, PLISSIT
14	Family, family relations, spouses
15	Likemannsordning, peer support, support group, self-help group, visitor group, visitor program
16	Islam, religion, psychology, spiritual, hope, cultural awareness
17	Follow-up after discharge
18	Follow-up, outpatient, late complication, quality of life
19	Lærings- og mestringssentre, follow-up after discharge, peers
20	Healthcare, health-economy, health-economy consequences, costs, cost-efficiency, health-care costs, complications, effectiveness, efficiency, follow-up

The searches have produced varying results. Some have produced no results, whereas others have produced so many results that further clarification of search-phrases has been required.

All articles have been found in well-recognized databases, which we consider a stamp of quality for the articles. Only a limited number have been found using e.g. Google Scholar, because of the delay in newer articles reaching the major databases. All articles have been read in full text, and the contents assessed by the participants of the group.

Due to the numerous limitations mentioned we have been unable to be strictly selective in choosing which articles to use. According to GRADE-systematization[26] most articles used have been “grade 3” articles. Apart from this no further grading has been made.

3.0 RESULTS

The results chapter is subdivided into two main parts. In part 1 we show that receiving an ostomy has major consequences to all aspects of life, both physical, psychosocially and existentially/religiously/culturally. Therefore, we present recommendations showing the necessity for information, guidance and aid. In part 2 we visualize the necessity for systematic follow-up, and we present recommendations on how follow-up should be structured. The following recommendations are presented:

	Recommendations: 🟦 = Physical factors 🟧 = Psychosocial factors 🟩 = Religious/cultural factors 🟪 = Organizational factors
1	Ostomy-patients should have the procedures for practical ostomy care repeated, elaborated and adjusted.
2	Ostomy-patients should repeatedly receive information on the condition of the peristomal skin, how it should be cared for, and be given the opportunity to receive help should skin-afflictions occur.
3	Ostomy-patients should repeatedly receive information on the normal appearance of the ostomy and be given the opportunity to receive help should any complication with the ostomy occur.
4	Ostomy-patients should repeatedly receive information on the risk of developing a parastomal hernia and be given the opportunity to receive help for assessment and implementation of appropriate measures.
5	Ostomy-patients should receive systematic information, guidance and adaptation of ostomy bandages and additional equipment, if necessary.
6	Colostomy-patients should receive information and, if applicable, training and follow-up regarding ostomy irrigation and alternatives to using ostomy bandages.
7	Ostomy-patients should repeatedly receive information on altered bowel function and consequences of dietary choices and fluid balance, and they should have the opportunity to receive advice and guidance as needed.
8	Urostomy-patients should repeatedly receive information on the prevention, testing and treatment of urinary infection and have the opportunity to receive advice and guidance as needed.
9	Ostomy-patients should repeatedly receive in-depth information on issues of odour and sound and receive information and guidance on the handling of stigmatizing situations.
10	Ostomy-patients should receive information and guidance in relation to the psychosocial challenges of living with an ostomy.
11	Ostomy-patients should receive information and guidance concerning the return to work and leisure activities.

12	Ostomy-patients should be informed on the changes of self-image an ostomy creates and receive guidance on restoring self-image.
13	Ostomy-patients should receive individualized information and advice concerning the impact an ostomy could have on sexuality and appropriate guidance, should the need arise.
14	Ostomy-patients should at follow-up be given the opportunity to be accompanied by a relative or friend.
15	Ostomy-patients should be informed of the possibility to contact a fellow ostomy-patient.
16	Ostomy-patients should be advised and informed on the possible implications that the ostomy may have on religious and cultural aspects.
17	Following the construction of an ostomy, the patient should receive follow-up services from an educated ostomy nurse with updated knowledge.
18	Following the construction of an ostomy, the patient should be followed up by a fully qualified ostomy nurse at 3 weeks, 3 months, 6 months and then annually. In addition, the patient must be permitted and encouraged to make contact in between the appointments, if needed.
19	Following the construction of an ostomy the patient should be followed up by a qualified ostomy nurse in an ostomy clinic in the specialist health care system, in the patient’s home organized through the specialist health services, through the local health services or in group-therapy sessions.
20	The follow-up of ostomy-patients must assure an optimal use of socio-economic resources.

3.1 RECOMMENDATIONS CONCERNING THE OSTOMY PATIENT'S NEED FOR INFORMATION, GUIDANCE AND HELP

3.1.1 RECOMMENDATIONS CONCERNING PHYSICAL CONDITION

Recommendation #1: Ostomy patients should have the procedures for practical ostomy care repeated, elaborated and adjusted.

Recommendation #1 is based on the following literature reviews:

Today, when hospital stays are shorter than before, a substantial need for follow-up concerning ostomy care – including skin care – will arise.[27,28] Training ostomy care and safeguarding against skin problems will prevent conditions such as irritative dermatitis. Salvadalena performed a prospective study on 33 subjects of which 27 had skin problems due to irritative dermatitis, in part attributable to inaccurately customized template.[29]

The ostomy patients were not prepared for caring for their ostomy themselves following discharge. The concerns surrounding their ostomies arose mainly after discharge and were most prominent during the first 2-4 weeks. Throughout the hospital stay a nurse would always be available for advice. The qualifications of the nurses could vary leading to insufficient information being given. It is therefore essential that the follow-up is conducted by a qualified ostomy nurse.[30]

Those receiving instructions leading to self-sufficiency grew accustomed to their new situation earlier and experienced a superior psychosocial adaptation and a higher degree of health-related quality of life. The training leads to improved skills, resulting in reduced costs, a shorter length of hospital stay and improved ostomy knowledge. The qualifications of the staff, the location where the professional training was given, strategies of coping and the structuring of the teaching environment were all important factors for the well-being of the patient. The training required structural education before, during and after discharge alike.[31,32-34]

Patient factors, such as time, cost and the increasing age of patients will all affect the training. Patients from foreign cultures with insufficient language skills will require a different approach.[35]

The ability of the patient to manage ostomy care is important. However, in order for the patient to return to previous levels of activity, other measures in the follow-up must be adressed. This will be discussed further on in the recommendations.[36,37]

Recommendation #2: Ostomy patients should repeatedly receive information on the condition of the peristomal skin, how it should be cared for, and be given the opportunity to receive help should skin afflictions occur.

Recommendation #2 is based on the following literature reviews:

Having an ostomy constructed may result in problems affecting the parastomal skin. Possible causes are e.g. leakage of urine or faeces on to the skin.[38] The parastomal skin may also be adversely affected by the wear and tear caused by the ostomy bandage or additional products.[39] Incorrect execution of ostomy care or incorrect choice of ostomy products may also lead to unnecessary stress to the parastomal skin. The patient may suffer from a disease causing skin problems. In addition, numerous drugs may affect the skin quality adversely.

The occurence and ethiologies of skin complications are documented in several studies.[40,41] Research has shown an occurence rate ranging from 16% to 76%.[27,38,41-43] The wide divergence in occurence rates is a result of a lack of international concensus on definitions of the various parastomal skin complications, interactions and possible triggering factors.[44-46] Several attempts have been made to create standardized classification tools for skin ailments by the manufacturers of ostomy products, but none have been universally approved.[47-49]

Skin afflictions may vary according to the type of ostomy.[27,39,42,50-53] Skin problems may occur shortly after surgery, but they can also persist or occur later. The study of Herlufsen, based on 202 patients with an average ostomy age of 8 years shows an occurence of skin problems in 45% of the patients.[50] Parastomal skin problems are most common with ileostomies followed by urostomies, and least common with colostomies.[39,50]

Often ostomy patiens experience several skin problems simultaneously. A study of 80 patients has shown that up to 53% of ostomy patients had two or more skin problems.[54] The study of Herulfsen also shows that the seriousness of the situation often is underestimated by the patient, since 56% of patients presenting with a serious problem were unaware of this.[50-54] Furthermore the study shows that only 38% af patients with skin problems are aware of this themselves.[50] This leads to the conclusion that patients may consider a persistent skin problem as a normal situation and therefore they will refrain from contacting a health professional.

Parastomal skin complications may lead to leaks and odour problems, thus making every-day life unpredictable. Pittman's study from 2008 shows a significant correlation between the severity of skin problems/leakage problems and difficulties in adaptation.[45,55] Another study from 2017 shows that avoiding or removing parastomal skin problems leads to an increase in general well-being and quality of life for the ostomy patient.[56]

The research has shown that skin problems following an ostomy construction are common. The problems create a need for care.[29,34,57,58] In order to identify possible problems it is important that the patient is informed about what constitutes a normal situation concerning parastomal skin. In the assessment og abnormalities it is of great importance that surgeons, dermatologists and ostomy nurses communicate in order to achieve a correct and adequate follow-up.[39,58-60] Another study has shown that structured patient education on skin care prevents skin complications.[60] Studies imply that a systematic follow-up by ostomy nurses reduce the frequency of skin complications.[61]

Recommendation #3: Ostomy patients should repeatedly receive information on the normal appearance of the ostomy and be given the opportunity to receive help should any complication with the ostomy occur.

Recommendation #3 is based on the following literature reviews:

The shape, size and location of the ostomy on the abdominal wall may influence the occurence of complications.[49,62]

In a literature review of 21 prospective studies Salvadalena finds that the incidence of various ostomy complications range from 12 to 72%.[46] Complications include retraction, hernia, prolapse, necrosis, mucocuteneous separation and stenosis.[63-65] Ostomy complications are most common during the first years following construction, but may occur at any time.[66] In the immediate postoperative period complications such as necrosis and retraction are most common, whereas prolapse, hernia and stenosis most often are seen as late complications.[66]

Ostomy prolapse is most common in “double barrel” colostomies, the incidence ranging from 2 to 46%, while urostomies are associated with an incidence of 1,5 – 8% on average 2 years following construction.[52]

There is also an increase in the incidence of complications associated with diseases such as IBD, cancer or diverticulitis. A study of 320 patients shows that following elective surgery there are significantly more complications in patients with diverticulitis than in those with cancer.[65] Arumugams study of 97 patients shows that in ostomies constructed in an acute setting, increased BMI, diabetes and acute surgery will in itself increase the risk for complications.

Cottam et al find in a prospective study on 3970 ostomy constructions a complication rate of 34%. A predisposing factor seems to be the length of the externalized bowel. The study shows a higher complications rate if an ileostomy is shorter than 20 mm and a colostomy shorter than 5 mm, which is confirmed in a study by Persson et al, which includes 180 patients.[67,68]

In general, the complication rates in ileostomies are higher than in colostomies, 35,6% vs. 21,8%. This has been confirmed in a study by Cottam et al, which has shown loop ileostomies to be the most prone to complications, 38,2% (p=0,001) compared to terminal colostomies at 29,7%.[67]

Attention should be paid to the shaping of the ostomy and the condition of the abdominal wall upon construction of the ostomy.[67,69] The doctoral thesis of Pittman shows a significant increase in complications when the ostomy is located in the vicinity of a skin fold or if the ostomy is low.[70] Bass et al performed a study which included more than 593 ostomy constructions. The patient group which had received information on basic ostomy care and had the ostomy site determined preoperatively had a significantly lower rate of early complications as compared to patients who had not received such attention.[62,71]

Problems with ostomies or parastomal skin afflictions may adversely affect psychosocial adaptation.[1,70,72-74] Similarly there is significant correlation between increased autonomy in ostomy care and the adaptation to a new life situation.[70]

In maintaining a vital ostomy frequent assessments and quick interventions are necessary should complications occur. A cohort study on 204 patients in which 95% were followed up by a qualified ostomy nurse showed that this treatment had a preventive effect on ostomy complications.[59,64]

Recommendation #4: Ostomy patients should repeatedly receive information on the risk for developing a parastomal hernia and be given the opportunity to receive help for assessment and implementation of appropriate measures.

Recommendation #4 is based on the following literature reviews:

Parastomal hernias are considered a common complication following ostomy construction. The literature reports an incidence of 10-50%.[66,75-77], depending on the type of ostomy involved. In a meta-analysis from 2003[78], incidences varied from 4 to 48% for colostomies, 0 to 30% for double-barreled colostomies, 1,8 to 28,3% for terminal ileostomies and 0 to 6,2% for loop-ileostomies. A review from 2007 shows an incidence of herniation in urostomies varying from 5 to 28%.[79] Another review included articles that found the incidence of herniation among urostomy patients to be 17,1%. Two of the studies showed advanced age, high BMI, low Se-albumine preoperatively and previous laparotomy to be risk factors.[80] The hernias may occur several years following construction but are most common the first 2 years.[54]

Risk factors for parastomal herniation are in the literature indicated to be age over 60, over-weight, smoking, chronic cough, poor alimentation at the time of surgery and former surgery for parastomal hernia.[66,75,77,81] Concerning the location of the ostomy, it is commonly recommended to place the ostomy through the rectus abdominis muscle as this is believed to protect from the developement of a hernia.[75] However, there are few studies that support this assumption.[82] Additionally, studies have shown that the placement of a prophylactic hernia net has a good preventive effect.[83,84] Corrective surgery for parastomal hernia has a high recurrency rate.[66]

In 2005 Thompson and Trainor introduced a program for the prevention of parastomal hernias. The program was in two parts, the first being a retrospective study, in which the incidence of hernias was documented.[85] The second part was prospective, introducing the prevention programme itself. The program started 3 months postoperatively and included instructions on strengthening the abdominal muscles and encouraging daily use of a supportive belt, in addition to avoiding heavy lifting the first three months postoperatively. A total of 201 patients participated over a two-year period. The results showed a decrease in hernia incidence from 28 to 14%, the majority of the hernias occuring during the first months after surgery.[86] Thompsen performed a follow-up of the study in 2007 confirming the results. The study included a total of 300 patients over a 3-year period.[87]

In 2013 North performed a similar study using the same preventive programme. However, the programme was started before discharge from hospital. In addition, a Quality-of-life registration was performed at 2, 6 and 12 months postoperatively. 100 patients were included – 40 with a colostomy, 44 with an ileostomy and 16 with a urostomy. The results showed a decrease in hernia incidence from 23 to 15% of the total population after 1 year. In patients who had followed the programme meticulously (100% compliance), the hernia incidence fell to 1%. The QoL-score was highest in patients without a hernia, whereas patients with hernias scored significantly lower on all parametres throughout the study.[88]

Cowin and Redmond performed a study in 2012. A questionnaire was sent to more than 1800 patients. The response rate was 28%, resulting in the inclusion of 322 patients with a parastomal hernia. The average age was 70 years, and the most common ostomy type was colostomy (55%) followed by ileostomy (33%) and finally urostomy (10%). All patients reported problems with their ostomies, including leakage problems (66%) with concomittant skin afflictions and problems with bandaging, discomfort (40%) such as tension and feeling of heaviness in the ostomy area and problems of odours (30%). The most common skin problems were tenderness and thinning of the skin around the ostomy, reddening and itching. In addition, patients reported psychological concerns on living with a hernia, such as anxiety and increased self-centeredness leading to social isolation. The study also revealed that 59% rarely or never seeked help for their problems.[89]

Living with a parastomal hernia has major impact on the patients and their quality of life.[66,78,88-91] The ostomy nurse should have a central role in the follow-up af patients to minimize the problems related to parastomal hernias and contribute with advice on how to prevent such problems.[75,85,87-89.92]

From a public health point of view physical activity is considered important for everyone. However, receiving an ostomy will affect the way physical activity should be performed. When there is danger of serious decline in physical activity due to the fear of developing a parastomal hernia, consulting a physiotherapist might prove helpful.

Recommendation #5: Ostomy patients should receive systematic information, guidance and adaptation of ostomy bandages and additional equipment, if necessary.

Recommendation #5 is based on the following literature reviews:

The construction of an ostomy is a procedure that alters the body appearance and leads to a loss of continence. Urine or faeces must be collected in a secure way, thus preserving the integrity of the patient.

The aim of a well-functioning ostomy bandage must be to ensure a quality that allows the patient to feel safe with regards to leakage of urine or faeces, and odours.[93] The ostomy bandage must have skin-friendly adhesive properties and a versatile design, while simultaneously causing no injuries from wear and tear. When adapting an ostomy bandage, an assessment of the patient’s eyesight, hearing and dexterity, work and/or leisure activities and cognitive abilities must be performed.[94] The patient must receive information and training in the use of ostomy products and learn the correct procedures for changing in order to prevent complications.[95]

Choosing the ostomy bandage cannot be a once only decision, as several of the above-mentioned factors may change. A study has shown that the ostomy gradually alters its shape during the first 2 years following construction, creating a need for adjustments as the changes occur.[68.96] An inadequately customized ostomy bandage may lead to a variety of negative experiences for the patient, e.g. leakage resulting in skin problems.[93] Mechanical wear and tear may also arise from the ostomy bandage, such as lacerations, skin damage caused by convex ostomy plates or discomfort caused by friction between skin and ostomy bandage.

There may also arise a need for ostomy bandages, ostomy skin plates or additional equipment with special functions. In order to use these products optimally, the patient will require assistance in finding the appropriate products relevant to his/her specific needs. Specific needs may arise in ostomies that are low, oval or dobble-barreled.[51,97] Factors affecting the quality of the parastomal area, such as scar tissue, skin folds or bony protuberances may also necessitate the application of an ostomy bandage with specific functions and/or additional equipment. Uncritical use of ostomy equipment may lead to injury, e.g. pressure sores caused by incorrect use of convex plates.[95] It may also lead to purchasing equipment that is inappropriate, due to the desire to try out different products indiscriminately. This will prolong the period of adaptation and lead to a feeling of insecurity. Furthermore, the incorrect use of ostomy products will lead to an increase in cost.[95] The resulting consequences are substantial, both from the patient's point of view, and from a socioeconomical perspective. A study of a 7-week period shows a 2 to 5-fold increase in cost when serious complications are present, as opposed to mild complications.[98]

The ostomy bandage should be safe and functional enough for the patient to feel unhampered by the ostomy. The return to optimal activity must be facilitated, and to achieve this, product guidance is essential. The patient needs encouragement, support and advice in the new life situation. Ramirez et al point out in their qualitative study that fear of or experienced leakage, problems relating to the ostomy itself and its function leads to insecurity, thereby limiting the life of the person.[99] This is also pointed out in the doctoral thesis of Pittman, who has shown a significant correlation between ostomy care and adaptation to an altered life situation.[49] The Montreux study, which included 4739 patients showed a significant improvement in the quality of life in patients who felt comfortable with ostomy care, when they had good relations with the ostomy nurse and were satisfied with the care provided.[100]

Recommendation #6: Colostomy patients should receive information and, if applicable, training and follow-up regarding ostomy irrigation and alternatives to using ostomy bandages.

Recommendation #6 is based on the following literature reviews:

Irrigation of a colostomy involves a systematic introduction of fluid into the colostomy using especially suited equipment every or every other day.[101] This stimulates peristalsis and facilitates the evacuation of faeces from the bowel. This form of bowel irrigation aims to assure bowel emptying during the time of irrigation only, enabling the use of a small ostomy bandage or simply an ostomy plug. [102,104] Most commonly body tempered water is used for irrigation. However, adding various substances to the fluid has been attempted in order to achieve faster and more complete bowel emptying.[105,106]

Studies with a systematic review of the literature show ostomies to produce a series of challenges, e.g. altered body image, uncontrolled bowel emptying and the risk of odours, sounds and leakage from the ostomy.[107,108] Performing irrigation may positively affect several of these problems. A Turkish study showed that those who irrigated reported better quality of life, felt fewer physical limitations, had fewer emotional problems, better social function and better mental health.[109] There are also studies that show that patients with spinal injury and colostomy have significant benefits from irrigation. Irrigation can also be beneficial for patients of muslim faith as it is considered important not to have faeces in the ostomy bag during prayer.[110]

Earlier irrigation was in widespread use. A consequence of novel operative techniques has been that fewer patients today receive a permanent colostomy. This is possibly the reason why irrigation is far less commonly used today, resulting in less experience with the method, in spite of the obvious advantages related to the technique.[103,107] In a Swedish study performed by Carlsson et al ostomy nurses were asked whether they offered training in irrigation. The majority replied that such training was offered, but only 44% of the patients reported remembering having received such information. This contrasts strongly with the finding that 97% of the interviewed patients performing irrigation reported this to be beneficial.[111] The positive experience of irrigating has also been shown in qualitative studies from New Zealand and USA. [99,112] Studies conclude that everone suited for irrigation should be offered training in the procedure.[111]

In 1986 the ostomy plug was introduced as an alternative to ostomy bags, either exclusively or in combination with the irrigation procedure.[111] The ostomy plug may positively affect living with an ostomy, as it leads to the perception of control, and eliminates the problem of sounds from the ostomy.[114]

Recommendation #7: Ostomy patients should repeatedly receive information on altered bowel function and consequences of dietary choices and fluid balance, and they should have the opportunity to receive advice and guidance as needed.

Recommendation #7 is based on the following literature reviews:

An ostomy procedure invariably results in the patient losing control of normal bodily functions, such as micturition or bowel emptying. Many patients perceive this as most stressful and stigmatizing, and it produces a feeling of embarrasment.[115,116]

Following a surgical procedure on the intestinal system it is natural to have concerns about what one can eat. Some patients must, as a direct consequence of the surgery, make necessary adjustments of the daily diet. It is not possible to give unambiguous advice to ostomy patients, as such advice must take into account both the type of ostomy and the amount of remaining functional intestine. The patients will therefore require individualized information in order to assure a balanced and nutritious diet following surgery.[117]

Several studies show that the ostomy procedure affects the patient's dietary choices,[118-120] and many patients experience not receiving the dietary advice they deem necessary following their operation.[119,121] Persson et al examined how 91 patients assessed their own quality of life. This study included both colostomy- and ileostomy patients. Most participants (88%) reported that dietary advice was essential after surgery.[121]

A study performed by Floruta in 2001, a large survey of 604 patients with colostomies, ileostomies or urostomies, showed that 61% of the patients avoid certain foods after surgery. The study further shows that colostomy patients are particularly concerned about gas.[118] This was also shown in Bulman's study from 2001, where 66% of colostomy patients experienced flatulence as their main problem and 50% of the patients had not received dietary advice after surgery.[119]

In 2012 Leanne Richbourg did a study which included 301 patients, 88 with colostomies, 174 with ileostomies and 41 with urostomies. 58% of the colostomy patients and 94% of the ileostomy patients reported that their ostomies affected their dietary choices. Urostomy patients had few issues on diet following their operation, whereas both colostomy and ileostomy patients avoided certain foods in the attempt to prevent problems such as increased output, flatulence, odour, abdominal cramps and gas bloat.[120]

Following an operation that results in a colostomy, the pattern of defecation will change. Individuals with intact gastrointestinal tract will, in addition to peristalsis use abdominal muscles and diaphragm to assure normal bowel movements and maintain a normal pattern of defecation. In colostomy patients, however, this is altered, and the prevention of constipation is of great importance.[122] Constipation can have many causes, and an adequate collection of data is therefore necessary in order to advise the patient on preventive measures. The patient should receive concrete advice on how to make the necessary adjustments.

Intestinal surgery will result in edematous mucosal lining in the bowel lasting several weeks after surgery.[123,124] The patient will require advice on how this will affect the diet considerations both in the short and long term. Certain foods will have the potential for causing obstruction of the bowel and consequently, the patient will need follow-up information.[117,124]

Any patient having had abdominal surgey has the risk of developing adhesions. This is more common following open procedures. These adhesions may cause episodes of bowel obstruction, partial or complete. This may cause the patient great discomfort, and effective preventive measures hardly exist. Counselling by qualified personnel on dietary adjustments and other general advice on how to cope with the early phases of an obstruction episode will prove beneficial to the patients.[117]

An ileostomy procedure may affect absorption and result in fluid- and electrolyte imbalance. This can result in dehydration and ultimately renal failure.[12,14,124-127] A number of patients, up to 16% will develop a "high output" ostomy after surgery.[13] Several studies report readmissions ranging from 15,5 to 20% due to dehydration caused by high output.[14,125-127] Dehydration following ileostomy procedures is a preventable complication and identifying patients at risk is important.[125] Likewise, measures that could reduce the need for readmission should be implemented early. Postoperative administration of diuretics and preoperative steroids are identified as risk factors for readmission in this context.[125,128]

The present practice of short hospital stays and early discharge may represent a risk, especially for ileostomy patients. A review performed by Evangelos Messaris and his colleagues in the USA examined predisposing factors for readmission for patients with loop-ileostomies. They followed up 603 patients over a 20-year period. The results showed a 60 days readmission-rate of 16,9% (n=102), and the dominating cause of readmission was dehydration (41%, n=44). They concluded that these patients must be meticulously followed up in out-patient departments.[125]

Dehydration following ileostomy procedures is relatively common.[11] The degree of dehydration varies in the literature, from 0,8% to 20%.[12,13,125] This is preventable by close monitoring by competent personnel postoperatively and close follow-up by ostomy nurses in the out-patient department so that symptoms may be identified early.[12-14,125]

Deborah Nagle and her colleagues performed a study where all ileostomy patients followed a novel treatment regime. The patients received instruction preoperatively, and this was followed up postoperatively with step-by-step instruction and written material on diet. The patients were followed up regularly by an ostomy nurse in the out-patient department. This resulted in a reduction of readmissions due to dehydration following ileostomy-procedures from 15,5% to 0%.[14]

Instructing the ileostomy patients both pre- and postoperatively to monitor the fluid balance on a daily basis and to recognize symptoms of dehydration, as well as how the individual patient should handle signs of dehydration, is essential.[129-131] It is important to recognize that certain religious communities may have certain dietary preferences which may have consequences for the ostomy patient.[132-134] It is also important to have knowledge of the absorption of certain drugs related to the different ostomy types.[135,136] Contact with an ostomy nurse is essential, as these patients need close monitoring and contact with the health services.[12-14,125,131]

Ostomy patients may also suffer from other conditions that require dietary adjustments. In cases when dietary considerations are numerous and complex, a nutritionist should be consulted.

Recommendation #8: Urostomy patients should repeatedly receive information on the prevention, testing and treatment of urinary infection and have the opportunity to receive advice and guidance as needed.

Recommendation #8 is based on the following literature reviews:

Urostomy patients often have bacterias in the urine.[137] This is most frequently caused by a colonization by bacteria of the intestinal segment used in constructing the urostomy. In some instances, the bacteria can be transmitted from the skin. In many cases this bacteriuria is asymptomatic, but in 23% of the cases a symptomatic urinary tract infection will occur.[138]

In order to avoid facilitating the introduction of bacteriae or bacterial growth, meticulate hand hygiene prior to ostomy care, daily change of ostomy bags and plentiful oral fluid intake to ensure generous flushing of the intestinal segment is recommended. A Swedish study has examined hand hygiene, but was unable to document that poor hand hygiene leads to an increase in urinary tract infections in urostomy patients.[138]

The urine in urostomy patients will often have a pungent odour and be mixed with mucus, which is easily mistaken for a urinary infection. In these cases, it is customary to perform a test of the urine that has remained stagnant in the bag over time. This urine invariably contains bacteriae, leading to unnecessary use of antibiotics. In America, the organization of ostomy nurses have published guidelines for urinary testing in urostomy patients. They point out that urine testing from the bag should not be performed. The “double-catheter”- method is stated as the optimal procedure, but testing using a catheter or simply removing the bag and allowing the urine to drip directly into the test container are also recommended procedures. The procedure used will vary between hospitals.[139] Varsala et al compared urine sampling from urostomies using three different methods, where the urostomy was cleaned using NaCl 0,9% prior to the procedure: Clean method using a catheter, urine dripping from the urostomy and urine sample from a clean urostomy bag. They found no significant difference in bacterial flora between these three methods.[140]

Asymptomatic bacteriuria should as a rule not be treated. Studies performed on patients with a bladder substitute where the bladder is replaced by intestine has shown that even large concentrations of bacteriae in the urine fail to produce symptoms, and consequently should not be treated.[143] However, should a fever or flank pain occur in combination with bacteriuria, treatment using relevant antibiotics should be administered. Therefore, it is important to inform the patients of these considerations. Likewise, it is important that urostomy patients have a place to contact for correct urine sampling and conveying the results of cultures to a physician for correct assessment and, if indicated initiatiation of treatment.

3.1.2 RECOMMENDATIONS RELATED TO PSYCHOSOCIAL FACTORS

Recommendation #9: Ostomy patients should repeatedly receive in-depth information on issues of odour and sound and receive information and guidance on the handling of stigmatizing situations.

Recommendation #9 is based on the following literature reviews:

An ostomy procedure leads to a loss of control of faeces and gas. One experiences that the body changes, that one is not like others. Some choose to be open about having an ostomy, while others choose to keep it a secret in order to avoid stigmatization. Inner strength and ressources will influence the way having an ostomy will be handled. Ostomy patiends need support from an ostomy nurse, other ostomy patients, family and friends.[116,142]

Involuntary gas expulsion, sounds and odours is a challenge which may lead to embarrassment and thus worsen the quality of life. Some feel uncomfortable emptying the bag, particularly in public toilets.[143-145]

Lynch et al performed a telephone interview at 5, 12 and 24 months to describe difficulties that might occur following an ostomy procedure. Parastomal skin problems, gas and sounds from the ostomy bandage were described as the major problems. The problems diminished over time. At 5 months 87,7% of 332 participants had problems with sound, as opposed to 72% of 125 participants at 24 months. Patients having received preoperative information were better prepared for involuntary sounds. In this study 34% had had no contact with an ostomy nurse. The authors emphasized the importance of developing and implementing a nursing plan, allowing the patients to receive the information and follow-up they needed.[146] Richbourg, Thorpe and Rapp performed a similar study with 43 participants. In this study 59% had problems with odours. In this study the average interval between changing bags was 4 days, which may have resulted in clogged filters.[147]

McKenzie et al performed a quantitative study with 84 participants, in which 66% declined to inform others about their ostomy, 50% felt that the body was out of control, 45% felt the ostomy was in control of their life, 47% felt insecure, 55% felt that no one understood them, 37% were anxious about leakage and 25% felt that it was difficult to dispose of the ostomy bag after changing. The ostomy patients needed help for adapting both psychologically and socially. The ostomy nurse has a crucial role in this.[148]

Smith et al performed a study with 195 colostomy patients and 523 patients without ostomy that previously had consented to participating in surveys via the Internet. Colostomy patients who considered the ostomy disgusting felt stigmatized and had poor quality of life. Direct and general feeling of disgust and stigma was linked to the colostomy patients. Furthermore, the study showed that people without ostomy felt repulsed and experienced discomfort when in close contact with colostomy patients.[149]

Several studies addressing the experience of ostomy patients have been performed. Persson & Hellström identified seven areas affected by an ostomy operation. These were alienation of the body, diminished self-image, altered self-image, reduced social life and reduced sports- and leisure activities, in addition to physical challenges. The ostomy nurses having knowledge about these areas, enabled them to offer support and guidance.[150] Annels found that involuntary expulsion of gas could lead to reactions such as discontent, secrecy, “I am not myself”, seeking control, “I smell”, “I am not normal” and “I lead some sort of life”.[115]

Nicholas et al mapped the endeavours, strength and ressources in youths with ostomies. They used interview and focus groups including 20 youths. The participants were strongly affected by having an ostomy, but they demonstrated strength and adaptability. They were focused on body image, independence, secrecy versus transparency regarding ostomies, adaptation over time, the family and coping strategies. Nicholas concluded that it is of great importance to focus on self-image and psychosocial adaptation for these youths and their families in order to reduce stress, embarrassment and shame.[151]

Sun et al examined adaptation to life 5 years following the ostomy procedure, and this study showed that some ostomy patients still felt that their ostomy put limitations on their lives. This was especially apparent around changing ostomy equipment in public toilets, choosing clothes, and using a car safety-belt, which was perceived as irritating to the ostomy mucosa.[143]

It is important that ostomy patients are trained by health professionals and given the opportunity to contact other ostomy patients to address problems like stigma, guilt and shame more easily.[152]

Recommendation #10: Ostomy patients should receive information and guidance in relation to the psychosocial challenges of living with an ostomy.

Recommendation #10 is based on the following literature reviews:

The psychosocial adaptation to living with an ostomy is a complex process affecting altered body-image, self-confidence, skills in ostomy care, social relations towards family and colleagues and the access to support and guidance from the ostomy nurse.[153-155] The contentedness and quality of life is linked to the degree of adaptation to living with an ostomy.[156]

Savard and Woodgate found in a qualitative study among youths with ulcerative colitis that living with an ostomy is intricately connected to difficult emotions. The ostomy caused embarrassment, they felt different, and that the body itself was altered. One could sense the frustration over information having been given too soon – before being emotionally ready to receive it. Some expressed concerns about losing time at school, frequently asking the question “Why me?” Several described limitations in daily life concerning what clothes to wear and social activities.[157] Another qualitative study among young ileostomy patients revealed factors such as pain related to the disease, the sensation of altered body-image and postoperative leakage-events had significant impact on the adaptation to living with an ostomy. The nurse’s efforts to supply adequately adapted information and instructions both preoperatively and later was an important factor.[158]

Other studies show that the dependency on others and having problems with the ostomy prevent social adaptation.[159-161] Zang et al’s study, which included 111 patients showed that less than 50% of the participants had high scores on the scale for adaptation to their new situation. Furthermore, accepting the ostomy enabled patients to return to their previous social life much earlier.[162] Liao and Qin found in a study of 76 ostomy patients that these patients had difficulties in relation to working life and in social events caused directly by problems with the ostomy, such as finding a suitable location for emptying the ostomy bag and leakage situations. Being able to perform practical ostomy care, having the necessary knowledge and being able to maintain hope positively affected overall contentment in life. Furthermore, they found that both the hopes and the practical skills of the patient predicted the degree of future participation in working life and social function.[145]

Ito et al found that ostomy patients had significantly lower score concerning social function and physical role-function than the normal population.[163] In a recent study they found that physical function, role-function and areas of social functions within health-related quality of life was significantly reduced in ostomy patients, which was attributed to the ostomy procedure and the insecurity related to the integration of daily activities with the ostomy existence.[164] In Norway too, a study shows that ostomy patients have a lower health-related quality of life than the normal population in relation to physical role function, vitality and mental and general health.[165] Nichols found in a study of 560 ostomy-operated adults within 2 years that 11,1% of the patients felt isolated, and 9.3% felt very isolated socially. This was most prominent in the first two months following surgery. Furthermore, social isolation was associated with a low degree of contentment with life and poor emotional support. The study showed that the patients profited from contact with an ostomy nurse in reducing social isolation and contributing to improved contentment in life.[166] Another qualitative study by Cerruto et al found two profiles: Those positive to living with an ostomy and who managed to resume their daily life, these were often elderly, had a long period of follow-up and had few complications. The negative profile however was represented by patients with poor quality of life caused by inability to manage the ostomy and who experienced limitations in daily life.[156]

As we see, ostomy patients have challenges with social adaptation. Some challenges are related to areas in which the ostomy nurse through instruction, education, advice and follow-up over time could assist the patient in resuming their social life following an ostomy operation.

Recommendation #11: Ostomy patients should receive information and guidance concerning the return to work and leisure activities.

Recommendation #11 is based on the following literature reviews:

Following an ostomy procedure returning to normal everyday life and resumption of leisure activities may pose a challenge to the patients.[167,168]

A study from England examined the need for rehabilitation following an ostomy procedure. This was a survey where 100 forms were returned, resulting in a response rate of 49%. Both females (42%) and males (58%) were included, the majority having had ostomies for more than one year. The average age was 66 years. Several participants reported additional need for support in order to meet the challenge of returning to work and leisure activities. Only 33% of patients wanting to return to work had done so. The study also showed that the return to social activities actually took longer time than the patients had expected.[169]

Another survey from the USA performed by Nichols and Riemer in 2008,[170] included a large number of ostomy patients (n=819). 38% of these patients reported that their employment conditions and work habits had changed. Patients reporting changes in both occupation and work tasks had approximately a fourfold reduction in life contentment-score compared to those who only experienced a change in work tasks. The results suggest that stability in the work situation affects the total restitution following surgery positively. Furthermore, a recent qualitative study showed that the degree of commitment to the workplace was of paramount importance to rehabilitation.[154]

The patients also experience challenges in leisure activities. Richbourg et al found in their study that 54% had experienced a reduction in leisure activities following surgery. This contributes to the patients' perception of social isolation. Richbourg et al also found that a large proportion (53%) experienced anxiety and depression following surgery.[42]

In a qualitative study from Sweden nine patients were interviewed in-depth 6 to 12 weeks following their procedure. This also revealed difficulties in resuming leisure activities. Changing clothes in the presence of others was perceived as particularly difficult.[150]

MacKenzie et al examined how ostomy care, including the disposal of waste affected the psychosocial function of the patients. Of 86 colostomy patients – 41 males and 45 females – 33% reported avoiding social life and leisure activities due to the possibility of having to change on the ostomy. They feared odours to the surroundings and problems of disposing of waste in a discrete manner.[148]

A study in the Czech Republic[37] focused on the physical and social needs of the ostomy patients following surgery. Ostomy patients from all health regions in the Czech Republic participated (n=109). 61% reported being unable to participate in the same activities as prior to surgery. 23% still participated in sports activities, but to a lesser degree than before surgery. A major part of the patients could not participate at all due to their health condition (60%). Many patients (48%) never visited e.g. cinemas. Some patients were still able to travel as before, but 39% had refrained from this due to the ostomy.

Experience has shown many patients to be anxious about travel, especially international travel including air travel. These patients may require substantial advice and are recommended to contact an ostomy nurse.[171]

Pringle and Swan interviewed 112 patients with a permanent colostomy. The interviews were performed on four occasions – 1 week, 1 month, 6 months and 1 year after surgery. At 6 months 32% had a good social life, whereas 68% did not, in comparison to preoperatively. At 1 year only 33% had resumed their social life.[76]

Recommendation #12: Ostomy patients should be informed on the changes of self-image an ostomy creates and receive guidance on restoring self-image.

Recommendation #12 is based on the following literature reviews:

Receiving an ostomy will for a shorter or longer period of time have an impact on the self-image of a person.[172-176] In a study by Sharpe which included 79 patients with colorectal cancer, data was obtained 9 weeks after surgery and at the end of adjuvant chemotherapy. The study revealed that those with an ostomy had a poorer self-image than those with the same diagnosis, but without an ostomy, and the self-image appeared to deteriorate further during the study period. Those with ostomy and poor self-image suffered to a greater extent from anxiety and depression. The follow-up related to these problems is therefore emphasized as being important.[177]

A metasynthesis of qualitative articles published between 1990 and 2012 synthesize 3 themes: Firstly, an alteration in self-image due to body change and the feeling of being different from others, secondly restrictions in every-day life caused by the ostomy and thirdly overcoming the limitations by seeking help from professionals and support groups.[142]

In a review article from Turkey in 2018 which included 27 studies, themes including poor self-image, low self-esteem, depression, sexual problems and reduced adaptation to living with the ostomy were most frequently reported.[155]

In a qualitative single-study by Persson and Hellström 8 ostomy patients between the ages of 44 and 67 years were interviewed 6-12 weeks following surgery. The informers described a perception of alienation of the body. They feel diminished self-respect and self-confidence.[150] In a qualitative review by Thorpe it has been observed how the perception of bodily changes following an ostomy procedure has been analyzed with reference to 11 qualitative studies. Three main themes have been identified: 1) The perception of “embodied wholeness”, which implies a negative focus on the body, alienation of the body, objectification of the body and loss of adult status. 2) The perception of “disrupted lived body”, which implies altered body appearance, altered body-function and altered body sensations. 3) “Disrupted bodily confidence” which implies a loss of ability to keep body characteristics hidden and a constant danger of disclosure.[178] In a study from 2016 Thorpe describes the consciousness of ostomy patients towards body alterations 3, 9 and 15 months following surgery. Three areas are described: Altered appearance, altered function and altered body experience.[179]

Ramirez et al state in a qualitative study on women with ostomies that the entire personality is affected, and that one no longer feels like “a whole person”.[99]

In a study by Gervas from 2007 the quality of life of 20 patients with rectum amputations were examined at 1, 6 and 12 months postoperatively. The study shows an improvement related to the primary disease, such as fatigue and pain. Concerning self-image, sexual dysfunction and ostomy-related problems, no improvement could be detected even after a year, despite the overall improvement in the quality of life.[180]

Studies have also shown that females who have received an ostomy, struggle with poor self-image to a larger extent than males. Poor body image is in addition a major cause for sexual dysfuncion.[182]

Recommendation #13: Ostomy patients should receive individualized information and advice concerning the impact an ostomy could have on sexuality and appropriate guidance, should the need arise.

Recommendation #13 is based on the following literature reviews:

Having an ostomy constructed will in most cases impact sexuality.[183-185] A review article by Li, reviewing 55 articles on sexuality and colostomy emphasizes that surgical treatment and adjuvant chemotherapy alike also may impact sexuality. Patients that have undergone numerous treatment-modalities often have more extensive sexual problems than patients that have had surgery alone. The different treatment-modalities affect both blood vessels and nerves and result in both anatomical and physiological alterations.[186] Junkin emphasizes in another review article that sexual function is also affected in patients having undergone surgery for cancer of the bladder or prostate as well as gynecological cancer, in addition to certain benign intestinal diseases.[187] In an article by El-Bahnasawy where the sexual function of 73 females having undergone a cystectomy was investigated. It was found that all aspects of sexual function were severely compromised. This includes reduced libido, difficulties in conducting intercourse, dyspareunia and loss of orgasm.[188] In cystectomized males a study including 49 sexually active men revealed erectile dysfunction in 40. Of the nine subjects without, a nerve-preserving procedure had been performed.[189]

Several point out that age is of significance. The elderly experience sexual problems more frequently,[186] whereas younger patients are also concerned about entering committing relationships and partnership, fertility, pregnancy and method of delivery, in addition to heredity-issues regarding the disease that led to the ostomy procedure.[187]

Li also found gender differences in the reviewed articles. Males will more frequently report severe impact on sexuality, whereas females to a lesser extent choose to reply to questions on sexuality. Males report sexual problems such as erectile dysfunction, retrograde ejaculation, reduced libido and orgasm. Altered sexual function in females has not been extensively investigated. However, the problems are likely to be multifactored, to include anatomical and physiological concerns and to a greater extent also psychological and social components. The physical complaints most frequently reported by females are dyspareunia, reduced lubrication, impaired libido and loss of orgasm and the sensation that the vagina is smaller and narrower than previously. In addition, females report more frequently than males following an ostomy procedure a feeling of shame towards the body and the fear that their partner will find them less attractive, leading to a loss of sexual spontaneity.[186]

Li has also investigated the reaction of homosexuals to receiving an ostomy. If male homosexuals practice anal sex, their sexuality will be severely impeded following a rectum amputation. It has been postulated that homosexual males are more attracted to physical beauty, and that this is an essencial component in their sexual arousal, implying that an ostomy may become a serious problem. As homosexuality often is considered in negative terms and consequencially often undisclosed, these patients are prone to inadequate guidance on sexuality following an ostomy procedure. Studies show that homosexual males reveal their orientation more frequently than females, and homosexual females therefore run further risk of receiving inadequate or erroneous information.

The guidance of ostomy patients requires an open and accepting attitude, allowing the patients to feel that sexual advice is possible regardless of sexual orientation. Recently, however it has become clear that too little is known about homosexual ostomy patients and their sexuality.[190] Acceptance and confirmation by the partner are of paramount importance to sexuality, also for ostomy patients. The absence of such confirmation can often result from inadequate information and the fear of damaging the ostomy. The importance of including the partner in both hetero- and homosexual relationships is also underlined in Li's article, however it is stressed that this must be at the request of the patient.[186]

In addition to physical alterations leading to sexual problems, psychosocial and relational challenges caused by the the effect on self-image and self-esteem by the ostomy procedure, the ostomy patient will also encounter challenges with the ostomy itself and the ostomy bandage. This may include the presence of the bag, sounds and the possibility of leakages which will disturb sexual life. These challenges often occur late in the adaptation process.[183,187,191]

Several studies examining the ostomy procedure's impact on sexuality exist, studies that further examine the previously mentioned differences related to gender, type of operation, and age. In one study 20 ostomy patients – males and females aged 50-86 years – were followed up using QoL-tests at 1, 6 and 12 months. All patients were rectum amputated for cancer. A significant improvement of the quality of life occured during the first year. However, these improvements did not include the dimensions related to the perception of self-image and sexual dysfunction.[180] In a study of 66 patients with inflammatory bowel disease operated with proctectomy or proctocolectomy participated. The patients were younger, and all received an ileostomy. An improvement in sexual function was found in males during the first 6 months.[192] In a qualitative study of 30 females with ages ranging from 44 to 93 years operated for colorectal cancer with an ostomy a more nuanced image emerged, as 11 patients reported no problems, 7 experienced sexual problems while the remaining were sexually inactive due to either age-specific factors or the absence of a partner.[193] In a study comparing older males with an ostomy to older men without, one found that the ostomy patients had lower sexual activity and higher degree of erectile dysfuncion.[194] A recent Swedish study from 2018 examining the adaptation to a life with an ostomy, confirms that ostomy patients have the lowest scores on sexuality and self-confidence.[195]

Junkin has in a literature review found support for promoting clear recommendations that nurses caring for patients with serious alterations in body anatomy and function must address sexual concerns related to this with both the patient and family/friends. This must be done regardless of the patient's initiative. In this context it is important to have knowledge of and good attitudes toward sexuality, to accept that it is the responsibility of the health professional to address the issue, to become comfortable discussing sexuality and continuously educating oneself on the topic. When addressing sexuality-topics the PLISSIT-model is referred to as a good framework in which to work. The model consists of "Permission", "Limited Information", "Specific Suggestions" and "Intensive Therapy". Most health workers can address the first two levels, however it is emphasized that referral to a specialist is important when deemed necessary.[187,196] A qualitative study with 10 participants also showed that the challenges related to sexuality following an ostomy procedure were related to both physical, emotional and sociocultural alterations, and the support of a multidisciplinary team is important.[197] This is also confirmed in a study performed by Michalkova.[37]

Recommendation #14: Ostomy patients should at follow-up be given the opportunity to be accompanied by a relative or friend.

Recommendation #14 is based on the following literature reviews:

Next of kin plays a major part in the rehabilitation-phase of the patient following an ostomy operation. This is the case from the time of discharge from hospital, when next of kin often needs to assist in practical ostomy care.[198] They can be a factor leading to an increased sense of content,[170] and one can find a connection between the quality of life of the patient as well as that of the next of kin.[199] Women experiencing support from their spouse, score higher on health-related quality of life.[200] Far from every ostomy patient experience such support. On the contrary, some feel that next of kin simply do not understand the challenges facing the patient.[143] Other ostomy patients fail to communicate their concerns from fear of becoming a burden on their family.[30] Carlsson et al investigated the concerns of the patient and their quality of life preoperatively and at 1, 3 and 6 months. The patients expressed concerns about becoming a burden to others both preoperatively and for the first 6 months following their operation.[160]

Danielsen, Burchart and Rosenberg performed a systematic review from 1950 to 2012 addressing the perception of spouses to their partner having received an ostomy. 16 studies were identified, including 3 qualitative and 3 quantitative. The review showed that next of kin desired further involvement in ostomy training. Furthermore, they wanted more support and advice from health professionals in social adaptation and sexuality, as these were the areas most profoundly affected following the ostomy operation of the spouse. The authors emphasized the importance of health professionals and ostomy nurses having insight into the concerns of patient and relatives, thereby enabling them to offer better guidance and postoperative training.[201]

Palma et al performed a qualitative study with 123 participants where they investigated whether next of kin considered it a burden to perform ostomy care for their spouse. There was a correlation between perceived burden and quality of life-score. The helper was spouse (92%) and woman (97%). By obtaining insight into the caring role of next of kin, both stress and burn-out may be avoided for the next of kin.[292] Another study showed that the extent of help and support received by the patient from the next of kin, varied throughout the life span depending on the health condition of the helper. Health professionals must pay attention to this in order to step up should the amount of help from the partner decrease.[203]

Cakmak, Aylaz and Kuzu found that among 56 couples 33% of the males and 11,5% of the females received help from their spouse in ostomy care. There is a significant difference between the genders.[204]

A qualitative study with 31 participants described that partners taking part in ostomy care could prevent leakages, detect skin changes and aid in establishing good routines. Patients receiving help from their spouse experienced less skin problems around the ostomy. Next of kin felt that participating in ostomy care was a part of caring for one another.[205]

Nicholas et al used a qualitative approach in examining how young patients aged 17 to 24 coped with receiving an ostomy. The role of next of kin was of great importance to them. The youths could experience concerns about observing their parents being apprehensive, and they might feel guilty towards siblings due to their parents being forced to spend so much time with them in hospital. The disease might lead to the relatives over-protecting, leading to a feeling of being treated as a child. The study concluded that it is important for health professionals to help families to communicate in order to minimize the concerns of the youths.[151]

Many couples were sexually active prior to surgery. Following surgery sexual activity was affected by a lack of information, physical and psychological problems and a feeling of shame. In a study of 109 participants 32,1% showed their partner their ostomy. 15,6% felt that receiving an ostomy had affected their relationship. 12,8% were as sexually active as they had been prior to surgery, whereas 62,4% had no kind of intimacy. The study described how a follow-up by an ostomy nurse could contribute to the breaking down of certain barriers which reduce intimacy, or when necessary, identify the need for referral to a psychologist or sexologist.[37]

Recommendation #15: Ostomy patients should be informed of the possibility to contact a fellow ostomy patient.

Recommendation #15 is based on the following literature reviews:

Getting together with people “in the same boat” supporting each other is the basis for establishing numerous organizations for the disabled and so called “peer activities”.

Peer activities is an international phenomenon which is practised in different ways. The first support groups for ostomy patients were established in America in the mid 20th century. United Ostomy Association (UOA) was founded in Cleveland, with support from the surgeon Rupert Turnbull and was an association run by and for ostomy patients.[206] It was started because it was noted that this patient group lacked follow-up in the rehabilitation phase. The work was based on the notion that equals should support one another.[207] This notion spread across the world leading to the establishment of similar organizations. In Norway, NORILCO (Norwegian Association for Ostomy, Reservoir and Gastrointestinal Cancer) was founded in 1971, and the organization was early in initiating peer work.[208]

Peer work in Norway became generally more systematic and recognized when a peer grant was made part of the national budget in 1990.[209] To clarify the term “peer work” and define what was eligible for grants the Social Department issued in 1994 guidelines in which the organized peer work was defined as follows:

> *“Peer work is an interaction between individuals in similar circumstances, or somewhat in the same circumstances where the interaction itself aims to provide aid, support and guidance between the parties” (page 70).*[210]
> *“The basic principle in peer work is that it is built on an active and targeted use of self-based experience. One of the individuals taking part in the interaction has a lengthier and more processed experience than the others. This person is generally referred to as “peer person” (page 70)”.*[210]

Peer work can be practised in numerous ways, including activities such as visitation service in hospitals, home visits, telephone services and peer gatherings which include both patients and next of kin. Lately, internet-based activities such as net-fora have been established. NORILCO utilizes all these activities, and they are especially active in visitation services for ostomy patients in hospitals.

In a qualitative study where 33 ostomy patients participated in focus-group interviews, it was found that the participants greatly appreciated the contact with peer persons. Receiving advice and tips on ostomy equipment was the most highly appreciated activity.[212] In a Danish qualitative study where 15 ostomy patients took part in focus groups, the contact with peers was similarly perceived as desirable, as the advice given by people living with ostomies themselves was considered especially valuable.[213] There are however few studies that have shown that contact with peers actually demonstrates health benefits.[211] However, a qualitative study on 38 cancer patients, their next of kin and peers has shown that peers contributed in promoting hope and mastery. It would also seem to be easier to share experiences with people having had similar experiences as oneself, and the peers characterized the service as meaningful.[214]

International studies show that peer work with ostomy patients is practised in different ways. E.g. hospital-based support groups have been attempted. In these groups no membership is required, they are more informal but include a core of ostomy patients as regular members and other ostomy patients or interested persons dropping in for one or more meetings. These support groups are usually organized in cooperation with ostomy nurses. Regular gatherings are organized in the hospitals with open meetings and lectures on relevant topics and conversations between the people present in the group.[215] In Turkey this has been further developed by arranging full open days for new and experienced ostomy patients, their next of kin, nurses etc. They have performed a study where SF-36 was completed prior to the meetings and 3 months later, and they claim to observe a significant improvement in the quality of life in the patients.[216]

For a considerable number of patients participating in associations or support groups and meeting peers with similar challenges in life is considered a positive and beneficial experience.[217] Such relations could affect the adaptation to a new life with an ostomy. Therefore, contact with other ostomy patients should be encouraged, both pre- and postoperatively.[218]

Recommendation #16: Ostomy patients should be advised and informed on the possible implications that the ostomy may have on religious and cultural aspects.

Recommendation #16 is based on the following literature reviews:

Religious faith and spiritual values play an important role in many patients’ lives when they become ill. In order to offer the best possible support, it is important for health professionals to possess knowledge, as well as having reflected upon what existential, cultural and spiritual values mean to themselves.[219,220]

The spiritual aspect is of great importance for the quality of life and will be affected in patients receiving an ostomy.[221] A study has shown that the patients get a higher score for spritual quality of life the longer the time after the operation has passed. The spiritual aspect encompasses inner peace, hope, “meaning of life”, positive changes and spiritual and religious activities.[222]

Spiritual well-being is significantly associated with psychosocial adaptation,[223,234] and the spiritual and psychological adaptation was better in patients with permanent ostomy compared to those with temporary ostomies.[224]

Mitchell et al found a significant correlation between embarrassment and impact on quality of life. Spiritual activities, such as prayer, meditation and religious activities like attending church led to less embarrassment. Hope, inner peace and the meaning of life led to significantly less embarrassment and improved quality of life.[144]

Simmons, Mackawa and Smith performed a multivariate analysis which included 464 British and 483 Japanese participants who had received ostomies. Areas addressed were acceptance, social commitments, apprehension and anger. The study showed a higher degree of acceptance in British participants, and the major difference was found in acceptance and social commitment.[225]

Some studies show that cultural and geographical differences will affect adaptation after receiving and ostomy,[133,134] A study of colostomy-patients in 11 countries showed that patients from Southern Europe and muslims were most likely to perceive their quality of life adversely affected by receiving an ostomy.[226,227] The study showed that ostomy-patients with a high degree of affiliation to their religious community scored similarly to the western population regarding quality of life. This may possibly be explained by the imam having an important role in the guidance of the ostomy patient on religious matters.[227]

Immigrants' adaptation to the culture and language of a country will be of importance to the quality of life for patients following an ostomy operation. Soulsby, Kelly and Thomas performed a quantitative study of 47 participants examining ostomy-patients from Asia born in England, and ostomy patients living in England but born in Asia. Those born outside England and who were deficient in the English language rarely contacted the health services by telephone. Those born outside England and who needed an interpreter had poorer quality of life than Asians born in England. Between Asians born in England and the English no differences in quality of life were detected.[228]

Zoucha and Zamarripa used Leininger's "Sunrise Model" in a case study where they showed how the nurse could take care of individual cultural needs. They examined physical, religious, cultural, political and economical factors. Family affiliations or kinship and education were examined. It was also important to establish whether the patients used other health providers, e.g. alternative medicine. The nurse's understandig of cultural issues is important, and transparency and reflexion concerning the patient's cultural values and faith will enable the nurse to approach each patient individually, providing nursing services in accordance with the context in which the patient resides. Once the patient feels safe, the nurse's approaches and advice will be accepted and understood more easily, thus enabling the patients to better manage their health challenges themselves.[229]

Among patients with Muslim background social, sexual and psychological matters will be affected. Information is therefore important, so that patients are informed on how to relate to the situation following the ostomy procedure.[230] Kuzo et al (2002) showed that quality of life among patients with Muslim background receiving an ostomy was significantly poorer than among those receiving sphincter conserving surgery.

Muslims following the Koran are encouraged to pray five times daily. Prior to prayer a cleansing ritual called *al-wadhu* is performed. The cleansing signifies purity. This may represent a challenge for people with an ostomy, because prior to each prayer a clean ostomy bag is required. In these cases, a two-part system may be simpler, as only the bag needs replacing. Some Muslims consider the right hand as clean, whereas the left hand is used for hygiene. This may lead to difficulties and require the ostomy nurse to supply advice on finding equipment that can be managed by mainly using the left hand.[231]

Prayer and fasting were factors that significantly affected the quality of life among ostomy patients. In order to regulate the ostomy-output many described the need for dietary restrictions. Some refrained from prayer and fasting during Ramadan because of the ostomy.[232] Sikhs and hindus are often vegetarians. They cannot eat in the same room meat is served. This may constitute a challenge during hospital admissions.[231]

Receiving an ostomy may be challenging for Muslims due to the demand for purity. This may lead to refusal of treatments that may lead to an ostomy. In such cases, information is vital. In some instances, the patient may receive advice from a religious leader,[227,233,234] and/or an Islamic fatwa, which is a judicial assessment in accordance to Islamic law.[235]

In Egypt a significant correlation between the impact of the ostomy on religious rituals and the quality of life was found.[236] This was a small quantitative study with 28 participants. Cleansing prior to prayer was important, leading to the bandage being replaced and the bag emptied several times prior to prayer. The author concluded that these participants were unaware of the Al-Azhar Fatwa, in which disease is mentioned as a legitimate justification for refraining from religious rituals. For some attending the mosque for prayer was difficult, and in 34,78% the reason was ostomy leakage and odours. Some felt guilt when praying at home rather than in the mosque. Fasting during Ramadan was rarely a problem for these participants. Most were concerned about pilgrimage, and 54% were unable to attend due to the ostomy. The authors state that religious aspects must be addressed during the consultaion with the ostomy nurse.

Despite the knowledge that cultural and religious matters will be affected by an ostomy operation, this is not always discussed with the ostomy patient.[221,237] Varma et al dispatched a questionnaire about how ostomy nurses (132 nurses) in England, Europe, the USA, Australia and South East Asia cared for Muslim ostomy patients. This study revealed lacking knowledge on the ostomy's impact on prayer, cleansing and fasting. There was little knowledge on the importance of the imam, and the authors identified the need for a collaberation between religious leaders and health professionals. The authors concluded that a protocol guiding professionals on how to meet patients with Muslim background is needed.[238]

Black has in several professional articles pointed out the importance of health personnel possessing cultural understanding in order to care for the ostomy patient. She claims that acquiring cultural understanding is of particular importance, as global development will lead to health personnel being confronted with an increasing number of patients with other cultural backgrounds.[231,239,240]

3.2 RECOMMENDATIONS REGARDING THE STRUCTURAL CONTENT OF THE OUT-PATIENT FOLLOW-UP PROGRAM

Recommendation #17: Following the construction of an ostomy, the patient should receive follow-up services from an educated ostomy nurse with updated knowledge.

"Enterostomal therapist – ET" or ostomy nurse, which is the chosen term in Norway is a specialist nurse title used all over the world. They have their own organization named World Council of Enterostomal Therapists (WCET), and one of their visions is:

> *"To ensure specialized nursing care is available worldwide for all people with need for ostomy, wound or continence care"*[241]

Internationally, the first ostomy nurses were educated in the 1960s. At recognized hospitals with specialized functions in gastroenterological surgery it soon became obvious that ostomy nurses should be made part of the staff. Norwegians were for many years forced to receive their ostomy nurse training in Sweden, where the term ostomy therapist was used. The Norwegian education for ostomy nursing was not started until 1999, at the Bergen University of Applied Sciences. From the very start the education was based on the WCET's guidelines.[242] The educational program has been gradually expanded over time and is at present approved as a 60 merit points post-graduate education with part time studies over 1,5 years. A minimum of one year's practice with the patient group is required. During the program significant knowledge of diseases and conditions that may result in ostomy will be acquired, as well as surgical, medical and oncological treatment modalities, handling any type of ostomy- and skin-complications, all aspects of living with an ostomy, nursing, treatment and follow-up both pre- and postoperatively as well as in the long term. In addition to theoretical education practical activity under the supervision of an educated ostomy nurse is offered. The education is knowledge-based and enables students to keep updated through learning about research and evaluation of research-based knowledge.[243]

The Norwegian post-graduate education in ostomy care is a result of consultations with medical authorities and is prepared in cooperation with NSF's Association of Ostomy Nurses (SIS). In doing this, an education matching the national requirements is achieved. SIS has prepared function-descriptions for ostomy nurses, some of which are quoted here:

The ostomy nurse shall ensure that the patient group on being confronted with a new life situation through own or substituting ressources may reach the optimal level of:
- Coping
- Self-care
- Quality of life

The ostomy nurse should be able to plan, explain, implement and evaluate the nursing.

The ostomy nurse should be able to prevent physical, psychological as well as social complications.

The function of ostomy nurses can be subdivided into the following four categories:
- Clinical function
- Teaching, guiding, advising and informing
- Professional developement and research
- Coordination and administration

The clinical function includes the following tasks related to the ostomy patient:

The ostomy nurse should independently or in cooperation with other health professionals assume responsibility of the following areas:
- Support and provide guidance related to physical, social, sexual and cultural matters
- Pre- and/or postoperative information and guidance to patients and next of kin or other helpers, when desired
- Preoperative ostomy marking and postoperative evaluation of ostomy placement.
- Teaching of fundamental ostomy care and evaluating ostomy care routines
- Adaptation and evaluation of ostomy equipment
- Knowledge about available aids and reimbursement regulations
- Advice, treatment and evaluation of ostomy-, skin- and wound-complications
- Information and training in irrigation
- Conveying referrals to specialist care outside main treatment department
- Assurance of follow-up in patient's home following discharge/transfer from hospital
- Outpatient follow-up of the patient
- Information and offering contact with patient organizations[244]

As ostomy nurses in Norway have relevant experience before starting their training, the education enables the students to immerse themselves further in ostomy care, both theoretically and practically. They work very close to patients, often in specialized departments or ostomy clinics through a holistic approach. The ostomy nurses have a clarified perception on relating to the waste products of the body. They have a dedicated professional environment both locally and internationally, arranging courses and congresses, thus keeping professional quality in constant focus. It is therefore our conviction that no one is better qualified to care for the ostomy patient than educated ostomy nurses.

Is there any scientific evidence supporting such a statement? As being followed up by a registered ostomy nurse is perceived as indisputable positive, studies where such a service is withdrawn from the patient, will most probably be considered unethical. As a consequence, there are few studies addressing this issue. However, some do exist.

In a study from 1997, 593 patients awaiting elective surgery with a possibility of receiving an ostomy took part. Two groups were retrospectively compared. In one group the patients had their ostomy site marked, was shown an ostomy model and received information from an ostomy nurse. The other group was not prepared by an ostomy nurse. A significantly higher incidence of postoperative ostomy complications occurred in the group that had not been prepared by an ostomy nurse.[62] Similar conclusions have been reached in more recent articles.[59,245]

In a study from 1999 where 94 ostomy patients were included, 69.2% of the patients claimed that without the care provided by the ostomy nurse, they would have handled their ostomy poorly or very poorly.[246]

In a study of 4739 ostomy patients from 16 European countries, the validated instrument “Stoma Care Quality of Life Index” was used. The questionnaire was completed at 3, 6, 9 and 12 months. The quality of life was was significantly better among those satisfied with the care they had received. Likewise, the study shows that those having had contact with an ostomy nurse had significantly higher scores. The study concludes that having contact with an ostomy nurse is important for the patients’ quality of life, in particular 3-6 months following surgery.[106]

In a study from 2007 Richbourg et al found that ostomy patients preferred contacting nurses when ostomy complications occurred. The patients were very satisfied with all aspects of help they received from the ostomy nurse, but less satisfied with help given by home nurse or general practitioner. In spite of this, as many as 20% never sought help for these problems. The article therefore concludes that ostomy patients require long term follow-up by an ostomy nurse.[42]

Another study from Sweden that examined the adaptation to a life with ostomy showed that patients receiving a systematic outpatient follow-up the first year after surgery had a higher score on mastery of ostomy care. They felt well informed and replied that they could easily contact an ostomy nurse or doctor should questions arise.[195]

A qualitative study from 2014 also shows that follow-up by nurses without specialist education and with insufficient knowledge and insecurity in ostomy situations will affect the patients’ ability to cope in a negative way. [247]

Studies also show that follow-up by ostomy nurses is beneficial in terms of quality of life, costs, hospital admission time, prevention of complications and economical consumption of equipment.[248-254] Please refer to Standard 21.

Recommendation #18: Following the construction of an ostomy, the patient should be followed up by a fully qualified ostomy nurse at 3 weeks, 3 months, 6 months and then annually. In addition, the patient must be permitted and encouraged to make contact in between the appointments, if needed.

This professional recommendation reflects how an ostomy operation can affect the patients physically, psychosocially and existentially/religiously/culturally. Based on this the patients are in need of systematic follow-up.[29,42,50,68,76,100,255-260]

Numerous studies have shown the first period following an ostomy operation to be crucial to adapting to life with an ostomy,[76,100,159,255,256] and inadequate follow-up during this period will adversely affect the patients' quality of life.

Follow-up 3 weeks postoperatively:

Skin- and ostomy-complications often occur after the ostomy procedure, as documented in numerous studies, confer recommendations 2 and 3.

A study from Sahlgrenska University Hospital in Gothenburg in 2013 evaluated ostomy related problems and ostomy appearance the first two years following the operation. There were 144 participants in the study with an average age of 67 years. All had an ostomy constructed as a result of an acute operation. The participants were evaluated at 2 weeks, 3 months, 6 months, 12 months and 24 months after discharge. The study showed that the ostomies' size and shape changed throughout the entire study period, but mainly during the first weeks following surgery. These changes necessitated continuous adjustments of equipment.[255]

Another study from Sweden examined ostomy problems following elective surgeries, including 180 patients with colostomy (n=122, 68%), terminal ileostomy (n=20, 11%) and loop ileostomy (n=38, 21%). This study also revealed that skin problems were the most common problem occurring early, within 2 weeks after discharge from hospital. They found this in all groups, the colostomy patients being the group with the fewest problems (53%). Among patients with terminal ileostomies, the study revealed 60 % to experience ostomy problems. Among patients with loop ileostomies, 73% reported problems soon after discharge. This study too shows changes in ostomy size and shape requiring equipment adjustments to be the most common cause of the problems. The study emphasizes the importance of early follow-up in the prevention of ostomy-related problems.[51]

A study from the USA in 2013 examined ostomy complications ocurring during the first 3 months following surgery. The study included 43 patients with recently constructed ostomies, including patients with colostomies, ileostomies and urostomies. The patients were evaluated for ostomy problems four times during the first 3 months, within 7 days and at 2, 6 and 12 weeks following surgery. Despite frequent contacts with the ostomy nurse in the follow-up period 63% (n=27) experienced skin problems, the majority ocurring during the first 20 to 40 days following surgery. The study concluded that regular follow-up for the prevention and treatment of ostomy problems is important.[29]

Follow-up 3 and 6 months after surgery:

Both the above-mentioned studies from Sweden revealed skin and ostomy problems at both the 3 and 6 months consultations for all patient groups.[68,255] The studies showed that ostomy diameter and height continue to decrease mainly during the first 6 months, which necessitates equipment adjustments.[68,255] Salvadalenas study also shows that 61% still had problems 3 months following surgery.[29]

In Herlufsen's study from Denmark 45% of the patients (n=202) were diagnosed with a skin problem, however only 38% agreed on this themselves. More than 80% did not seek help for their skin problems. Many participants in the study wanted contact with an ostomy nurse (77%). Based on the findings in this study Danish researchers suggest regular follow-ups by ostomy nurses to prevent and treat these problems.[50]

The Montreux-study examined the importance of regular follow-ups on the quality of life. This is a large European study with a large number of patients in 16 countries. "Stoma Care Quality of Life Index", an instrument measuring the life quality of the patients was used. The survey was made 1 month following surgery, and at 3, 6, 9 and 12 months. The average age of the patients was 61,6 years (+/- 13,4 years), 53,7% were males and most (66,5%) had a colostomy. The "Stoma Care Quality of Life Index" was quite consistent in all patients from the whole of Europe immediately following surgery and increased steadily over time. There were significant differences during the first 3 months. The "Stoma Care Quality of Life Index" was significantly higher in patients that were satisfied with the care they had received, than in those who were dissatisfied. Patients with a good relationship with their ostomy nurse and who felt comfortable with changing on their ostomies had a higher quality of life-score. The results of this study suggest that the quality of life for ostomy patients change over time, and that availabilty of ostomy nurses is especially important during the first 3-6 months after surgery.[100] Other studies also suggest that contact with an ostomy nurse affects quality of life positively.[259,261,262] Psychosocial adaptation after an ostomy procedure is a complex process affected by several factors, e.g the patient's family, friends and colleagues and the availabilty of support and guidance from the ostomy nurse.[154] Several studies describe problems of accepting their new body, which in turn affects and limits the life of the patient both privately and professionally, note recommendations 9, 10, 11. Additionally, studies show that the ostomy operation in most cases affects the sexuality of the patient, which in turn affects quality of life, note recommendation 13. This is most apparent a certain time following surgery, and experience shows this to be an important topic to address. The challenges of the patient in private and social life are important topics to be discussed at regular consultations thus allowing the patient to cope with their new life situation and achieve the best quality of life possible.

Annual follow-up after surgery:

Several studies and professional articles recommend regular and annual follow-up of patients after an ostomy operation.[29,50,54,76,147,159,255-257,263-265] Several of these studies show problems to exist several years after ostomy procedures.[42,50,257] The patients should be offered regular follow-up as well as a low-threshold opportunity to receive help for their ailments quickly and efficiently.

Skin- and ostomy complications are demanding both for the patients and from a health-economical point of view. Meissner et al present a model for cost-analysis of these problems. They discovered that equipment consumption, and thereby costs, increased substantially in patients with complications, and the increase was proportionate to the severity of the problems.[266] It is therefore beneficial to focus on prevention and early, correct treatment to avoid further deterioration in the patients condition.[248] Regular follow-ups will allow early detection of problems and assure the correct use of equipment, thus avoiding over-consumption of ostomy products and additional products.[29,39,50,252,257]

Several studies have shown that many patients are unaware of their skin problems.[50,54,258,259] In a dialogue study with 733 patients 61% were found to have a skin problem. However, only 29% reported skin problems, when assessed by the ostomy nurse.[259]

Similar results were found in a study by Nyback et al. In their study 199 patients participated, and 44,8% (n=90) had a skin problem, whereas only 43% were aware of this themselves, and only 16% had sought help for their problems. The authors concluded that patients had difficulties in identifying skin problems, due to a lack of knowledge and the notion that the problems were normal for them.[258]

Guidelines and review articles show that the best way of avoiding skin- and ostomy complications is regular follow-up by ostomy nurses.[263,264,267]

The specialist health services of today, where accelerated recovery programs are considered standard, have led to substantial reductions in hospital lengths-of-stay. This leads to intensified ostomy teaching emphasizing training in bandage changes and less time for conversations on other topics, e.g. the return to work and leisure activities. These topics must therefore be addressed at a later date, e.g. in the outpatient consultations.

It is a matter of dispute whether it is ethically acceptable to leave the patients to handle their ostomy problems themselves after an ostomy operation. This may be perceived as breaking the principle of autonomy and justice and the “do no harm”-principle in ethics.[270]

Extensive searches in the literature on the desired contents of the consultations have been performed. This has however been futile, as it appears that no studies on these topics have been performed.

The ostomy nurse group in Western Norway Health Trust performed a study in 2001, publishing it as a poster (attachment no. 1). In this study questionnaires were distributed to all patients with colostomies, ileostomies and urostomies operated over a 15-year period. The patients had attended the ostomy clinics in the Health Trust during the period from January to October 2001. 216 patients replied (response rate 66%). The aim was to establish the importance of systematic follow-up in an ostomy clinic for adaptation to a life with ostomy, and to establish what ostomy patients considered the most valuable contribution of the ostomy nurse. The results showed that 87% considered the offer important or very important for adaptation to a life with an ostomy. The patients stated that control of the ostomy, guidance in ostomy care and the choice of equipment and help with leakages and complications were important topics. Furthermore, the patients wanted to discuss living with an ostomy (53%), dietary advice (52%) and topics surrounding leisure activities, social life, work and sexuality. The study shows that follow-up by ostomy nurses is important in adapting to a life with ostomy.

NORILCO (Norwegian Association for Ostomy, Reservoir and Gastrointestinal Cancer) has published a report on challenges faced by ostomy patients in Norway. The report reveals that the follow-up in Norway is inadequate, and they recommend individually adapted follow-up of the patients. Several participants in the study expressed the need for follow-up up to 3 years following the operation.[271]

Recommendation #19: Following the construction of an ostomy the patient should be followed up by a qualified ostomy nurse in an ostomy clinic in the specialist health care system, in the patient's home organized through the specialist health services, through the local health services or in group therapy sessions.

Receiving an ostomy may cause physical, psychological and social challenges. Previously no systematic follow-up was offered, however patients were encouraged to contact their surgeon, or the appropriate department should problems arise.

NORILCO prepared a report in 2015 on *Challenges with ostomy-operated patients in Norway – a report on follow-up and training following surgery and the functionality of reimbursement regulations for ostomy patients*, which illustrated how ostomy patients experienced their follow-up. One half of the patients that had received an ostomy during the last 3 years, desired a closer follow-up with regular outpatient appointments. One third felt they had not received the help they needed. Among those operated more than ten years previously there were more patients satisfied with follow-up (80%). This may indicate that the present follow-up is inferior to that of earlier years. The reason according to NORILCO is a reduction in the duration of hospital stays, and that patients are forced to travel long distances in order to consult the ostomy nurse.[271] This conflicts with the "Law on Patient- and User Rights" (*Lov om pasient- og brukerrettigheter*) which states that *"The law aims to ensure the population equal access to high-quality services by granting patients and users rights within the health- and care-system".*[272]

In accordance with this report NORILCO has issued their recommendations:

> *The Norwegian Directorate of Health should prepare guidelines for the follow-up of ostomy patients which to a greater extent emphasize training and aftercare of ostomies customized to the individual user.*
>
> *The Health Directorate should prepare a patient course description which includes the interval between the decision to operate is made and the first 3 postoperative years, as a minimum.*
>
> *The course descriptions should define a minimum standard for follow-up after surgery.*
>
> *Clear recommendations and information material should be prepared for recently operated patients.*

Ambulatory services of ostomy nurses organized by health trusts should be established.

In our recommendation the various laws and recommendations in existence have been considered, as well as the research supporting the different suggestions. The follow-up may be performed at different levels.

- Follow-up by ostomy nurses in the specialist health care system.
- Follow-up in Centres of Learning and Coping.
- Follow-up by ostomy nurses in the home.
- Follow-up using electronic media.

Follow-up by ostomy nurses in the specialist health care system:

Information and follow-up of patients are central topics in Norwegian law. The right to information is embodied both in the "Law on Specialist Health Services" (*Lov om spesialisthelsetjenesten*) which states that informing is mandatory, and in the "Law on Patient- and User Rights" (*Lov om pasient- og brukerrettigheter*), which emphasizes the patients' right to be informed.

The Law on Specialist Health Services states in §3-8 *Duties of hospitals* that hospitals are responsible for offering instruction to patients and next of kin. The ability to cope depends on sound instruction, thereby reducing complications and improving the quality of life of the individual. The specialist health services must offer holistic and coordinated services (§2-2) in which information and training is considered mandatory (§3-11).[273]

In 2014 normative cancer assessment and treatment guidelines for colorectal cancer were introduced. These are recommendations from the Directorate of Health concerning pre- and postoperative follow-up. It is clearly stated that hospitals in which ostomies are constructed must also provide pre- and postoperative services for the ostomy patients in addition to follow-up in ostomy clinics. This follow-up must be provided by the specialist health service. This was already included in the Law on Specialist Health Services §3-8 *Duties of hospitals, training of patients and next of kin,* but is expressed more explicitly in the normative cancer assessment and treatment guidelines for colorectal cancer.[274]

Law on Patient- and User Rights §3-2 *The right to information for patients and users* shall ensure necessary information in order for the patient to achieve insight into his/her own state of health and the contents of the health services. The information must be customized to the patients' individual prerequisites, experience and cultural and linguistic background (§3-5).[272]

The Law on Specialist Health Services and the Law on Patient- and User Rights ensure the patients' right to information and training, whereas the Law on Health Personell shall ensure professional soundness. The Law on Health Personell §16 states that enterprises must ensure adequate personell ressources with the necessary qualifications, adequate and sufficient equipment, clear definitions of responsibilities, tasks and authority, necesssary instructions, routines and procedures pertaining to the various assignments.[273]

The Health Economy Management (HELFO), an agency within the Directorate of Health published in 2015 the report "*Management of products- and price list. Subreport 3 Ostomy".* Here it is evident that there is an increased expenditure on ostomy equipment. The report assumes that follow-up by ostomy nurses will lead to better choices in ostomy equipment, thus reducing costs.

In other words, unambiguous laws and recommendations on the follow-up of patients in Norway do exist. What does the literature say on follow-up of ostomy patients in the specialist health services?

Advanced technologies and an increased number of elders in need of care has made it vital to reduce costs while simultaneously maintaining a holistic approach to the human condition. This has according to Norton and Kamm led to numerous nursing outpatient departments.[275] By utilizing nurse specialists a more efficient treatment can be achieved, thereby reducing costs. Ostomy nurses can keep costs down by helping patients to cope with their new situation, by preventing any complications and subsequent readmissions to hospital.[276]

We have found two reviews which show that structured pre- and postoperative patient training will positively affect the psychosocial needs and quality of life of the patients, thereby reducing costs. However, the material was of insufficient size to determine how or where the training should take place.[277,278] Sun et al's qualitative study of survivors of colorectal cancer with ostomies emphasizes the importance of follow-up by ostomy nurses.[143] Fingeren et al from 2018 find in a prospective study of 150 ostomy patients that systematic follow-up by ostomy nurses the first year after construction increases the degree of adaptation to a life with ostomy.[195] Several studies emphasizing the importance of follow-up in ostony clinics exist, however there is little evidence to this effect.

Johnson performed a systematic literature study on whether follow-up after ostomy operations was necessary. The review showed that such follow-up was indeed necessary, as receiving an ostomy leads to physical, psychological and social problems. The review showed that the most efficient model was a structured follow-up in a nurse-run outpatient department with specialist nurses. Ostomy patients receiving structured and intensive follow-up experienced improved quality of life.[256] Some patients failed to seek help even in the presence of ostomy related problems, an observation also made in other studies.[50] This proves that systematic follow-up of ostomy patients is essential.

Ito and Kazuma performed a qualitative study on 133 participants with colostomies to uncover the factors affecting their everyday life. Being able to contact the ostomy clinic was considered important by most. As many as 19% of the participants contacted the clinic more than once a week, 16% twice a month, whereas 41% contacted it less than once a month. 24% had had no contact with the clinic. Those contacting the clinic, felt that receiving advice on handling the ostomy and skin was important. They felt it was important to have a place to contact for advice and help should problems arise. The authors concluded that the study showed the importance of outpatient follow-up, and that the follow-up was easily accessible for the ostomy patient.[279]

A qualitative study where 27 patients who had undergone surgery for colorectal cancer were interviewed (50% having received a permanent ostomy and three patients an ostomy considered to be reversible) revealed a substantial need for follow-up in an ostomy clinic. There was a need for individual information and guidance related in part to psychosocial challenges and information on what to expect following surgery. The ostomy patients received more frequent follow-up than those not having had received an ostomy. However, follow-up was desired by both groups [280]

The follow-up may include individual pre- and postoperative outpatient consultations, as well as telephone consultations. Several studies have shown that telephone consultations in combination with conventional follow-up may improve the patients' quality of life. This is of particular importance during the first phase after discharge, when the need for information is substantial.[42,280,284]

Follow-up in Centres for Learning and Coping:

The follow-up may be supplemented by groups attending either regular or informal meetings. In the informal meetings both ostomy nurses, peer persons and next of kin often attended.[215] At present there is a strong national and international focus on a novel and active patient role, where the patient to a greater extent achieves control over his/her own health. Information and training are prerequisites for this, illustrating a substantial need for courses in learning and coping centres. However, an insufficient number of studies have been performed to date for standardized follow-up schemes for ostomy patients to be made.[278]

The National Competance Service for Learning and Coping within health describes the interaction between specialist and municipal health services where the specialist services organize diagnose-specific courses, whereas the municipalities to a greater extent target large diagnose-groups and offer diagnose-independent events focusing on *living with* prolonged health challenges.[285]

The municipal learning and coping courses may be associated with wellness centres, local medical services, departments for rehabilitation, health centres, GP surgeries or a combination of these. Courses may be organized by one municipality alone, or intermunicipal solutions may be chosen, depending on municipality size, population density and the availability of qualified personnel. This is in adherence to the "the Interaction Reform" (*Samhandlingsreformen*), which assumes a transfer of funds to the municipality to enable them to care for large patient groups with chronic diseases, e.g. COPD (Chronical Obstruction Pulmonal Disease), cancer and diabetes.[286] Ostomy patients will not constitute a large group, but in some instances training by an ostomy nurse may be needed, e.g. in courses held by rehabilitation departments in which ostomy patients may be present, or in health centres.

At present most learning- and coping courses for ostomy patients are organized by the specialist health services. This is advantageous for a small group of patients in need of multidisciplinary, specialized approach.

Learning- and coping courses in the specialist health services now have reimbursement schemes for patient instruction programmes (Directorate of Health: *"Effort-driven financing"* Chapter 5.12.3). Participants need referral from a physician, and the program must include information on the disease, treatment modalities, self-treatment and coping, rights and further follow-up. A physician retains medical responsibility, but training and instructions may be performed by other qualified health professionals in the specialist health services.[287]

The Knowledge Centre (Austvoll-Dahlgren et al) performed a systematic review in 2011 examining group instruction of patients and next of kins. The articles included patients with various diagnoses. Ostomy patients were not included, however cancer patients with different diagnoses were. It was discovered that group teaching had a certain effect on depression, anxiety, quality of life, coping and relationship with partner. No significant health benefit was uncovered from group teaching.[288]

A hospital region in Denmark reports good experience with group teaching organized by an ostomy school.[289] This started as a developement project in 2009 and has since been arranged several times a year. Group teaching consists of single modules over 7 weeks. Teaching is interdisciplinary and is performed by ostomy nurses, surgeons, physiotherapists and social workers. The result of the project was a significant improvement in quality of life in the patients following participation in the ostomy school.[289] Karabulut, Dinc and Karadag performed a qualitative study with traditional follow-up and group teaching. Ostomy patients attending groups had improved social adaptation.[290] In a qualitative study by Danielsen et al from 2013 the participants were advised on living with ostomy and they expressed that group teaching in combination with peer persons could help in coping with stigma.[152] Altunas et al's study of 72 participants showed the health-related quality of life increase in patients having attended group teaching, in comparison to their condition prior to attending the groups.[216] Krusoe et al completed a group teaching program with 5 sessions (38 participants) including training following ostomy procedures. The patients gave positive feed-back on program contents, but wanted further practical training. The study showed that the participation and activity of the patients, self-confidence and health-related quality of life improved following completion of the programme.[291]

Follow-up by ostomy nurse in the home:

The Law on Municipal Health- and Care Services states that those in need, shall receive help at home or in an institution (§3-2) and that the municipality is obliged to facilitate interaction and coordination (§3-4) with county authorities, regional health trusts and the state. The requirements on soundness and adequate professional competance is described in §4-1.[292] Ostomy patients unable to perform ostomy care themselves, have the right to receive help at home or in an institution by persons with professional competance.

The Interaction Reform demands cooperation between municipalities (or cooperating municipalities) and health trusts focusing on patient role, delivering good patient services and cost-efficient solutions.[286] The Interaction Reform has made patients cleared for discharge a municipal responsibility, which in turn leads to earlier discharge from hospital. The result is that an increasing number of ostomy patients will require home nursing for ostomy training following discharge. NORILCO's report shows that patients operated less than three years ago, did not receive the training they needed following their ostomy procedure.[271]

Ambulatory teams of nurses, in which specialist nurses from the specialist health services travel to the municipalities to improve the competance in the municipal health services is in accordance with the Interaction Reform. This transfer of competance results in efficient and qualitatively sound treatment courses for patients in nursing homes, home services and care homes, allowing them to receive correct treatment and thus avoiding readmissions.

Ambulatory treatment implies out-patient consultations carried out by the specialist health services in the patients' home or in nursing homes. This is of particular importance to patients having difficulties in attending regular out-patient appointments, e.g. the very frail or those needing nursing care. Ambulatory treatment is finance-driven,[287] as the ambulatory ostomy nurse may receive reimbursement in accordance with rates for out-patient contact in the patient's home.

Most ostomy nurses in Norway work in hospitals, making hospitals the place where most of the competance is located. The competance among home nurses may vary, making it essential for them to receive training in the care of ostomy patients by qualified ostomy nurses.[293,294] Through support, advice and understanding home nurses can be very helpful to the ostomy patients and their families.[293] Therefore a transfer of knowledge is of great importance, either through ambulatory ostomy nurses or by employing ostomy nurses in the municipal health system. Courses and training are important in improving competance.

Addis performed a study in which one group received home visits at 3 and 6 months following surgery, and one group monthly visits for 6 months. The study showed a significant difference between the two groups. Those receiving monthly visits had a higher quality of life score.[262] Pringle and Swan suggested that a visit in the home by an ostomy nurse during the first 7 days following discharge was important, as the patients met with the greatest challenges within the first days after discharge.[76]

Follow-up using electronic media:

Various electronic media are increasingly being used in our society, also on health-related issues. This may include health information on DVD, PC-based solutions, video-links on broadband, cellphones of all kinds and lately tablets. There are numerous actors on this stage, including ideal organizations such as patient associations with their own webpages with straight forward information, video clips or fora for communicating with like-minded peers, or private citizens blogging about their own health situation and how they handle it. There are also commercial providers selling services and products intermixed with health information, or companies that supply small health-related computer-programmes for use on cellphones or tablets, so-called health apps.

Information exchanged through electronic media may be of varying quality. It may include sound, knowledge-based information, directed information adapted to a specific product or the generalization of experiences made by individual people.[295] It is well-known that younger people often search for health-information in electronic media. Older people are following, if not at the same pace. The patient of today may basically be anything ranging from uninformed, under-informed, well informed, over-informed to incorrectly informed. Electronic health information will never replace the contact between patient and health worker and individualized information. However, public health services will to a greater extent be compelled to utilize the same media as the rest of society. The term e-health has been introduced, aiming for "improvement of quality, security and efficiency within the health services using information technology".[296]

In the "National Action Plan for e-health 2014-2016" published by the Directorate of Health it is stated:

> *"Access to one's own health information and the opportunity to perform health-related tasks on the internet is important in giving the inhabitants a simpler everyday life and the possibility for real influence. Patients should be able to participate in designing their own health services, be in dialogue with their therapists and find relevant information on their own situation and the centres for therapy. Digitalization is a remedy for supplying the users with information on and influence over their own treatment. The increased use of technology by the inhabitants is the basis for a change*

> *in the patient- and user-role. Personal mobile health solutions on the internet, e.g. on cellphones and tablets, will be increasingly widespread in the years to come. In order to accomodate the challenges of tomorrow within care services, new technology, new knowledge and new professional strategies must be implemented (p. 15)".*[297]

Consequentially, it seems evident that the care and treatment of ostomy patients in the future will also be affected by the technological developments, especially within the transfer of information.

Mainly we have descriptions of novel technological solutions when they are implemented in teaching nursing professionals the care of ostomy patients. However, there is literature showing how these solutions have been implemented by and for ostomy patients.

A study examined comments posted on Youtube for medical videos especially dealing with IBD and ostomy. 6000 comments were posted, and they were socially supportive in some way. 64,1% were information-related, 18,3% emotionally related and 8,2% were instrumentally related.[298] In a study from 2014 the quality of information on the internet directed to patients with colorectal cancer was examined. Google-searces using English search terms were performed, and 91 webpages were found. Only 37 satisfied specific demands that had been set up. Only 27% stated references, only 24% dated the information, 51% addressed complications, and 18,9% ostomy related topics. The quality was very varied and proved unhelpful in enabling patients to choose treatment modalities.[299]

A study compared two groups of patients that recently had received ostomies. One group received three individual training sessions with an ostomy nurse, while the other group received two ostomy nurse session and were given the opportunity to watch a DVD containg information whenever they wanted to. There were no differences between the groups neither concerning knowledge on ostomy care, skills in ostomy care or confidence in performing ostomy care themselves.[300] Communicating using text messages has shown positive effects in chronic conditions.[301] The study in the review used cellphones, but not smartphones with internet capabilities. This method has not been tried with ostomy patients, but it is mentioned, as we might observe increased use of the method in the future.[301]

Lo et al found in a randomized study from Taiwan where a comparison was made between standard training after ostomy operations and a multimedia-programme for training, that the patients considered the multimedia training-program superior to standard training.[302]

A review from 2005 showed a potential for improvement in teaching using multimedia solutions, and that the need for teaching by multimedia will increase.[303]

In the future we may experience increased need for web-based information and training, as an increasing number use the web for gathering information. Supervision and follow-up could equally to a greater extent be performed using tele-medicine, because due to long distances, covering the entire country with ostomy nurses may prove difficult.

We have now reviewed various levels of how follow-up of ostomy patients could be performed, in the specialist health services, at learning- and coping courses, in the home or using electronic mediae. The need for follow-up may vary, and occasionally training on several levels simultaneously may be necessary. Follow-up need not be an "either-or".

Recommendation #20: The follow-up of ostomy patients must assure an optimal use of socio-economic resources.

In addition to having lifelong consequences for numerous people, the construction of ostomies also have socio-economical costs. According to a cohort study from the USA ostomy operations will cause work disability for 3-5%.[304] Transferring this percentage to the number of ostomy patients operated in Norway (according to HELFO's calculations) it can be assumed that 429-715 people annually are unable to work following on ostomy procedure.[305] This has both personal and socio-economical implications.

Studies that have been performed suggest that instruction and education increase the probability of being able to work, provide improved quality of life, shorter hospital stays, increased knowledge about and skills in ostomy care and a reduced number of vists to the GP. Furthermore, the readmission-rate decreases. However, further studies are required for unequivocal conclusions to be made.[152,306,307]

Instruction:

With regards to living with a permanent ostomy, it is recommended that patient instruction should focus more on psychosocial aspects rather than technical handling of the ostomy,[278] as the construction of an ostomy influences all functional aspects. In a small study from England preoperative ostomy training has been tested relative to costs within 6 weeks following discharge. The participating patients were divided into two groups, each group receiving a one-hour consultation with a colorectal nurse which included information on the operation, type of ostomy and its function. They had ostomy bandages demonstrated and received written information on ostomy. Patients in the intervention group received in addition two 45-minute's home visits with intensive training in ostomy care prior to construction. Instruction included demonstration of single-part ostomy bandage, training in practical ostomy care and emptying of the ostomy bag. The activities were practised, and the patients' skills were evaluated at the end of the second lesson. This group had fewer unplanned visits than the group that only received standard postoperative ostomy instruction. The study showed lower costs in the intervention group than in the control group.[306]

In Denmark, a study investigating health-related quality of life related to ostomy construction and patient education was performed in 2012-2013. The instruction turned out to positively affect quality of life, reduced the length of hospital stay and improved the level of knowledge and skills in ostomy care. Finally, the study included a cost analysis which showed a significant reduction in the number og visits to the GP and a reduction in readmissions.[308,309]

Patients need quidance on the use of ostomy equipment in order to reduce incorrect and/or excessive use. Studies show that patients receiving training from ostomy- or colorectal nurses have lower costs for ostomy bandages and equipment.[248,249,310]

Complications

Studies show that severe skin conditions increase costs 2-5 times in comparison to mild skin conditions and/or skin complications.[248,266] The incidence of parastomal skin problems is high, and the study of Lyon of 325 patients show that 73% had problems affecting the use of ostomy bandages.[38] Skin problems may cause the ostomy bandage to malfunction, leading to leakages with contamination of the ostomy bandage as well as clothes. The frequency of ostomy changes increases, as does the consumption of ostomy bandages and additional equipment, as well as an increased need for laundry of clothes and bed linen. Skin complications may also require changing ostomy bandage brands and additional equipment, thereby increasing costs until the most appropriate products are found. Leakage, parastomal skin complications and general quality of life are interconnected. The more frequently parastomal complications occur, and the more severe they are, the more quality of life is affected.[70,266,311]

Skin complications may become so severe that the patients are unable to cope themselves, but need help from a GP and other health personnel in the municipality. Should the complications worsen further, health personnel from hospitals may be required to help, or the patients will need readmission into hospital,[312] which will further increase cost.

Altered requirements:

Patients with ostomies require increased accessibility to health services. This is evident in a study from the Netherlands on 408 patients after surgery for rectal cancer. Patients that had received an ostomy in their operation were compared to those with the same diagnosis, but without ostomy. Those having received an ostomy had a statistically significant and clinically relevant poorer physical function, in addition to poorer general condition and quality of life. The ostomy patients also had more frequent visits to their specialist and a higher consumption of medical aid,[174] resulting in higher costs. The needs of the ostomy patients will change over time, in part due to circumstances surrounding the ostomy and the gastrointestinal tract, which are inconstant. Weight changes or parastomal herniation will produce altered contours of the abdominal wall and create new requirements. If the ostomy bandage malfunctions because of these alterations, complications requiring additional equipment may occur. Complications may also lead to a more demanding situation, should leakages prevent activities.[70]

Focus on optimal equipment:

There is a large selection of ostomy equipment, aids and additional products available. In order to choose the optimal ostomy bandage in accordance with the needs of each individual patient, a detailed knowledge of all availabe equipment is essential. Incorrect choice of equipment and/or incorrect usage of ostomy bandages, aids and additional equipment may lead to excessive comsumption and thereby increase costs.[313,314]

Consumption:

Medical consumables such as ostomy bandages, aids and hygienic products are included in the reimbursement regulations. There is no national overview of the number of ostomy patients in Norway, however according to HELFO’s sub-report from 2015 there were 14300 people in need of ostomy bandages in 2014. Statistics show an increase in dispensed ostomy bags of 2,3% from 2010 to 2014. The increase in reimbursement expenditure has been higher than the increase attributable to the increase in the number of users.[305]

The reimbursement regulations are a privilege that must be managed correctly according to needs, with due consideration to costs. Most ostomy patients have a consumption well within the recommended changing frequencies of ostomy plates and bags. However more than 20% of the ostomy bags and 40% of the ostomy plates are dispensed to users with a higher rate of change than recommended. The most significant increase of reimbursements is however related to products referred to as additional aids.[305] Here an increase of more than 50 million NOK has been observed from 2010 to 2014. This group of products includes sealing rings, plate elongators and adhesive removers. These are aids that to some extent can be used less frequently through increased knowledge, correct usage and indication. The patient or those caring for the patient's needs should have acquired knowledge on ostomy bandaging, which in practice allows the patient to feel safer in everyday life regardless of the needs or the level of activity of the patient.

In accordance with the advisory board of HELFO:

> *"...Outpatient follow-up is essential for the guidance to correct use of medical consumables and existing alternatives". (p. 41)*[305]

Follow-up:

Receiving an ostomy alters all areas of function for the patient, thereby altering the rehabilitation period. This requires follow-up through knowledge-based and caring nursing in accordance with the patient's needs, while simultaneously considering (lowest possible) costs. Studies so far are often small, but they show that follow-up by ostomy nurses significantly affect socio-economical savings as optimal use of equipment provides security and improved quality of life for the patient,[310] as well as resulting in fewer medical consultations and readmissions.

The length of hospital stays in the specialist health services has become shorter because the "Interaction Reform" transfers the responsibility for the patient to the municipalities on day 1 once the patient has been cleared for discharge, should he/she be in need of continuous assistance to satisfy his/her needs. The professional council of HELFO claims that shorter lengths of stay has led to a deterioration in the quality of follow-up after ostomy operations.[305] According to the "Interaction Reform" 2012,

> *"...the aim is improved public health and better health- and care-services in a sustainable way. The strategies are more prevention, earlier treatment and better interaction. Patients and users should receive early and sound aid as near to home as possible."*
> *Directorate of Health.*[266]

Personnel in the home nursing services possess basic knowledge on ostomy care. However, the patient needs systematic follow-up after the discharge by qualified personnel that can contribute to the rehabilitation process and prevent complications so that the patient can be optimally rehabilitated.

4.0 DISCUSSION

Summary:

The aim of this work is to visualize the consequences having an ostomy constructed has on life in general, what requirements for follow-up that can be uncovered and how follow-up should be performed in order for the patient to experience coping and an optimal quality of life.

We found by reviewing the literature that ostomy recipients face challenges related to both physical factors, such as damaged skin and leakages, and psycho-social factors that alter the self-image. In addition, they face problems related to work, leisure activities and sexuality. Likewise, religious and cultural challenges may arise, e.g. what Muslims might experience when practising their faith. In other words, receiving an ostomy will affect every aspect of every-day life for the ostomy patient.

Furthermore, we have, based on knowledge from experience and literature reviews, argued for structural changes to be made to the outpatient follow-up. These arguments include who should perform the follow-ups, when the follow-up should be performed and what the follow-up should include. The importance of adhering to legal requirements and ensuring a sound utilization of ressources is also specified.

Comments on literature used:

Within this field publications are largely professional articles and single studies. Very few randomized, controlled trials exist, but there are some reviews and meta-analyses. The studies that have been referred to are both quantitative and qualitative, but several have a small number of participants. We have tried using only articles published within the last 18 years, however in some cases we have been forced to use older articles. As the selection of articles is limited, we also have been forced to refer to studies performed in non-western cultures. This may prove to be a weakness, as living conditions may differ greatly. However, it may also be a strength, as globalization has forced us to relate to people of many different backgrounds. Many aspects on receiving an ostomy are universal. Some aspects, such as the availability of ostomy equipment, reimbursement regulations and the structure of the health services differ so substantially around the world that we, in some cases, have been unable to use some articles.

Discussion on methodology:

"Knowledge-based practice (KBP) implies making professional decisions based on systematically gathered, research-based knowledge, experience-based knowledge and the wishes and requirements of the patient in a given situation".[315]

In creating the recommendations, a considerable amount of work has been done to uncover research-based knowledge that may shed light on the challenges, requirements and necessary care interventions that ostomy patients are faced with. This is confirmed by the literature list, which contains more than 300 references.

Ostomy nurses that have prepared these recommendations have experience from both large and small hospitals and together have accumulated decades of experience from caring for and following up ostomy patients. Collectively there have been innumerable instances in which the members of the work group have been engaged in profound conversations with ostomy patients, and in this way acquired a broad and versatile insight into the life and considerations of the ostomy patient. We will therefore claim that the recommendations also are a result of experience-based knowledge.

However, the work group has not been multidisciplinary, as no users or doctors have been participating. This is a weakness according to present demands. Nevertheless, we feel that the voice of the users has been heard through the included studies, which systematize feedback from a substantial number of ostomy patients from around the globe. The work started as a continuation of the nordic standards, which likewise were not multidisciplinary. We have therefore decided to name this a professional recommendation, rather than a standard.

Discussion on patient-related topics and consequences for the contents of follow-up:

Mastering ostomy care is the most fundamental aspect of a good life living with an ostomy. In the health services of today we are faced with a constant reduction in the length of stay in hospitals. Principles like “Fast Track” or “Enhanced Recovery After Surgery (ERAS)” have become important, allowing the ostomy patient shorter time to learn ostomy care and to cope with reactions to changes that affect the body in a safe environment (see recommendation #1). This puts great pressure on follow-up and accentuates what must be addressed and repeated during the outpatient visits.

In the treatment of rectal cancer, the anastomoses are made at an increasingly low level towards the anal sphincter, which results in an increasing number of loop-ileostomies.[316] This is a very demanding ostomy-type requiring care in choosing ostomy equipment and care for or treatment of the parastomal skin. Loop-ileostomies also require knowledge on dietary choices and fluid balance.[317] (see recommendation #1). Therefore, follow-up of this group is especially important, and more frequent appointments than those recommended may be required.

In society today having a perfect body seems to be increasingly essential. Consequences such as odours and sounds are not permitted, and everybody should work out and be active. This attitude further adds to the challenges of the patient in adapting to a life with an ostomy, a phenomenon which is described in several studies (see recommendations ## 9 and 10). This also necessitates close follow-up over time, providing emotional support, conversations and concrete guidance on choosing equipment and aids, and returning to an active life.

As mentioned in the recommendations, several studies have pointed out factors that influence the quality of life of the ostomy patient:

- Being dependant on others to care for the ostomy must be avoided, and aquiring these skills may require more appointments than those outlined.[318]
- Damaged skin and leakage problems accompanied by odours is closely related to incorrect adaptation of ostomy equipment, and when incorrect changing technique has been practised. This problem will directly affect the quality of life and the ability to participate in work and leisure activities, as well as relations to others.[145] Skin afflictions account for 40% of the reasons why ostomy patients need to contact the health services.[50] This may include anything from superficial dermatitis to extensive skin lesions, in which experience and expertise is paramount for treatment when ostomy equipment must be used. Consequentially, the patient must at an early stage learn how to prevent these problems, identify the normal state of the ostomy, realize when treatment is necessary and have the opportunity to quickly contact professionals should the skin condition deteriorate. As the ostomy and its surroundings change significantly through life, it is important to offer advice during the first year, as described, but also later on, e.g. by offering a low-threshold option to contact a professional. The low-threshold option is an important principle for quick interventions and preventing problems from deteriorating and thereby avoiding readmissions. Skin- and leakage problems have substantial economical implications,

which is referred to in several foreign articles.[248,249,266] Norwegian patients however are spared this inconvenience. Their expenditures are marginal, as most ostomy products are reimbursed in Norway.

- Limitations of daily activities is an additional factor affecting the quality of life. The reasons for these limitations are many. They may be physical, e.g. sounds being involuntarily emitted from the ostomy or general fatigue caused by hypovolaemia or electrolyte disturbances.[319] These conditions are in part diet-related, and may be reduced significantly through correct dietary advice and information and repetition of situations that demand an increase in salt and fluid intake.[14] Conversations and advice on taboo situations such as uncontrollable flatulence-sounds in social relations are also important. Psychological barriers caused by insecurity surrounding bodily changes, the fear of leakages, of what others may think, of entering sexual relations and of not being able to participate in certain activities because of the ostomy, arise frequently.[178] There are examples of emotional coping strategies being used because the patient considers the new situation demanding. It is important to uncover unfortunate coping strategies in these areas, discuss handling and alternative solutions with a qualified person with extensive experience from similar situations. This may lead the ostomy patient towards a more problem-solving coping strategy. Such guidance must often be given over time, allowing the ostomy patient to gradually try out the new strategies.
- Through systematic follow-up these predictive factors can be addressed and processed, in order to prevent the ostomy operation to negatively affect the quality of life. Lopez and Descerados' review showed that the conversation between health personnel and patient is considered the main instrument in adapting to a life with ostomy. For the individual ostomy patient, it is essential to receive a follow-up from the ostomy nurse which is "tailor-made", but nevertheless some topics will surface repeatedly.

Discussion on why ostomy nurses should follow up the patients, and how, where and when consultations with the ostomy nurse should be performed (including structural aspects)

To ensure an individual follow-up a continuous process in developing the best system possible is necessary, so that the patient is able to discuss topics that are experienced as particularly challenging, both physically, psychologically and socially. A simple and promising concept is a routine measuring of factors relevant to ostomy patients. The patients complete standardized questionnaires prior to the appointments, and the replies are discussed during the consultation with the ostomy nurse (clinical feed-back system).[321] Such a way of following up patients is being developed in Norway.

As stated in the professional recommendations, our opinion is that ostomy nurses with approved specialist education in ostomy nursing are best suited to perform the follow-up of ostomy patients. They possess the interest, experience and required theoretical cutting-edge expertise on challenges often facing the ostomy patients. Other groups may claim to be capable of following up ostomy patients, e.g. nurses with basic nursing education, auxilliary nurses or people having ostomies themselves. They will however not be able to acquire the broad theoretically and empirically founded expertise which an educated ostomy nurse will possess. Our claim that having educated ostomy nurses is necessary, coincides with practice elsewhere in the world, and it is supported in recommendations given in international studies.[100,259,261,322] It is therefore crucial for the follow-up of ostomy patients in Norway that ostomy nurses are educated in sufficient numbers, and that a formalized education actually exists to accomplish this.

Presently a rather substantial number of different ostomy products is made available for the ostomy patient. The ostomy nurse must have the necessary overview of and know the characteristics of this equipment in order to ensure that the patients are equipped with the best solutions available. Such insight and overview require “volume training”. Employees in the specialist health services are committed to supplying product-neutral guidance and as such not dictated by demands for profit or commercial interests. As an ostomy nurse one is also responsible for sound ressource-management. Expenditure on medical consumables is steadily increasing. This may have many causes, e.g. an increasing number of elderlies, that more elderlies live at home and the number of people with chronic diseases is increasing in the population. Another possible reason is the increasing availability of novel products that are superior in quality, but much more expensive. The reimbursement regulations are a privilege that must be managed wisely so that consumption matches needs, with due consideration to costs. This implies that the patient receives necessary products and simultaneously avoiding overconsumption, as this may affect the degree of reimburement.

The follow-up of ostomy patients has until today been performed within the specialist health services. This follow-up is actually the responsibility of doctors, but it has to an increasing extent been delegated to ostomy nurses. Some of these patients have such complex and complicated problems that a multidisciplinary cooperation between doctor and ostomy nurse as well as other specialists in the hospital are required in order to optimize follow-up. There is an additional advantage in handling these patients in the specialist health services. As the number of patients is limited, and they live spread out through different municipalities, it is through centralization that a sufficient patient base is achieved for maintaining the necessary competance. In order to achieve the necessary experience and routines it is also of importance that the person responsible for following up ostomy patients sees as many patients as possible. This supports the claim that ostomy patients primarily should be followed up in hospitals in the specialist health care system.

Some ostomy patients are unable to care for their ostomy themselves, or they are too ill to live active lives. This group will be better off being followed up at home. According to the “Interaction Reform” the individual municipalities should to a greater extent be able to take care of this kind of follow-up. The present reality however is that the qualifications of personnel in home care is varied and often insufficient. In order for this to function optimally, extensive training will be needed. Alternatively, municipalities may discover the need and recruit ostomy nurses for the primary health services. Another alternative is employing ambulating ostomy nurses based in hospitals. This may however be an expensive solution where travel distances are long. One may end up seeing only one patient daily, as opposed to maybe six in the ostomy clinic. An additional challenge is related to equipment. Carrying large amounts of products to home visits, or doing two visits – one diagnostic and one therapeutic? A better solution will therefore be for the ostomy nurse to have regular consultation-days at the district medical centres.

In accordance with the “Interaction Reform” it is recommended that several learning- and coping centers are established in the municipalities. The idea behind this is that one can learn from professionals as well as others in the same situation. Group teaching for ostomy patients has been attempted several places and evaluated positively by ostomy patients themselves. Such teaching is therefore an important supplement, but certain elements of the follow-up must always remain individualized, as group sessions are unable to replace individual follow-up, e.g. observation of skin and ostomy and adaptation of equipment.

Novel IT-solutions may provide additional options for follow-up in the future. This may be tele-medicine, communication using smartphones or tablets, where the transfer of both image and sound is possible, thus enabling guidance over the Internet. It is questionnable whether a two-dimentional image of the ostomy with e.g. skin problems is sufficiently informative to form a basis for therapeutic decision-making. The medium may also limit the contact with the patient, thereby affecting the relationship between therapist and patient.

In the professional recommendations we have recommended follow-up at 1, 3, 6 and 12 months following surgery. During the first period after the operation the patients will require mostly concrete help related to ostomy and equipment, as well as support and guidance in adapting to the new life situation. After 3 months the patient has often returned to work, leisure activities and social life and needs advice on these topics. At 6 months the patient has as a rule tried out most life-situations and is starting to direct attention outwards. They will however still need a repetition of certain topics, previously mentioned. There are few studies describing the role of follow-up later than 6 months after surgery. However, quality of life-studies shows reduced quality of life a long time after surgery, which is strongly associated with ostomy complications, leakage and skin-problems.[323] Skin and wound problems are preventable through regular check-ups, good instructions on normal and abnormal skin conditions and a life-long low-threshold option. Such a follow-up will in addition to the effect on the quality of life also prevent unnecessary costs in the form of sick leaves, increased product consumption and hospital readmissions.

Are we alone in making these recommendations?

When searching the literature for these recommendations we have encountered a number of guidelines/best practice recommendations (Ontario,[324] WCET,[325] EAUN,[326] ASCN,[327] AASTN[328]). These often encompass the entire course of treatment of the ostomy patient, starting preoperatively, through the first period following surgery and ending with the postoperative follow-up. They have however not addressed the follow-up as thoroughly as we have. These professional recommendations therefore share thematics with parts of several guidelines/best practice recommendations mentioned above. We have not encountered inconsistencies between recommendations in international literature and our own recommendations.

5.0 CONCLUSION

1. Receiving an ostomy is challenging and affects both physical, psycho-social and religious and cultural factors in life.
2. Ostomy-operated patients should receive a systematic follow-up at 1, 3 and 6 months, then anually in addition to a low-threshold contact-option when desired.
3. Ostomy-operated patients should be allowed to be accompanied by family or friends during follow-up.
4. Ostomy-operated patients should be enabled to contact peer-persons.
5. Ostomy-operated patients should receive follow-up of high quality, which is non-commercial and socio-economically sound.
6. Ostomy-operated patients should be followed up by nurses with additional education as ostomy nurses.
7. Ostomy-operated patients should receive follow-up by ostomy nurses when practically feasible for both patient, health provider, in the specialist health services or municipal health services. individually and/or in groups. Continuity in care and the flow of

information, documentation of nursing interventions as well as professional competance must be assured.

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Individuell systematisk oppfølging hos stomisykepleier hvordan vurderer den stomiopererte det?

En studie utført av ”Stomisykepleiegruppen Helse Vest”

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Bakgrunn:

Personer som har gjennomgått stomioperasjon har tilbud om poliklinisk oppfølging ved stomipoliklinikk betjent av utdannet stomisykepleier. Tilbudet innebærer individuelle konsultasjoner postoperativt etter 3 uker,3, 6 og 12 måneder. I tillegg kan de får telefonveiledning eller time på kort varsel. Etter ett år kan den stomiopererte bestille time ved behov.

Hensikt med studien er å finne ut:

Hvor viktig er oppfølging ved en stomiklinikk for tilpassingen til livet med stomi?

Hvilke områder av det stomisykepleier kan bidra med i poliklinisk konsultasjon anser den stomiopererte som viktigst?

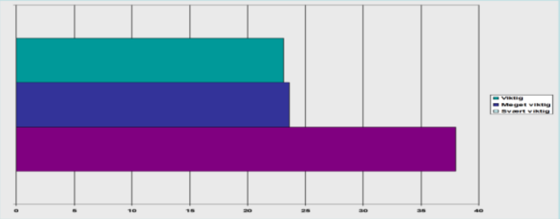
Metode:

Spørreskjema utarbeidet for denne studien

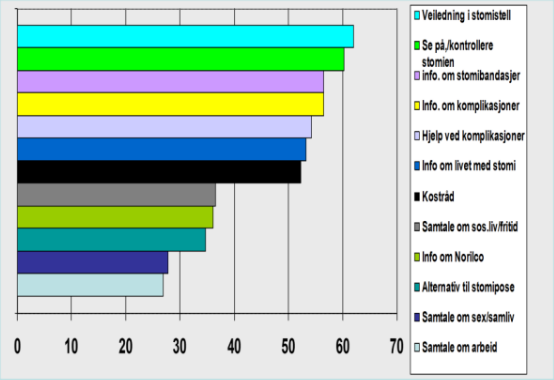
Inklusjonskriterier: colo-, ileo- og urostomiopererte over 15 år som var i kontakt med stomiklinikkene i Helse Vest i perioden 1. januar til 1. oktober 2001 og mentalt i stand til å besvare spørsmålene . 327 fylte inklusjonskriteriene og fikk tilsendt spørreskjema. 216 (66%) svarte.

Resultater

Hvor viktig er oppfølging ved en stomiklinikk?



Hvilke områder er viktigst å ta opp?



Konklusjon:

Oppfølging hos stomisykepleier er viktig for personer med stomi i prosessen mot å tilpasse seg en ny livssituasjon.

Viktigst var veiledning i stomistell og informasjon om stomibandasjer, kontroll av stomi, informasjon om livet med stomi, hjelp ved komplikasjoner og råd om kost.

Individual, systematic follow-up by ostomy nurses

How do ostomy patients evaluate it?

A study by the "Ostomy Nurse Group in Western Norway Health Trust"

by Torill Olsen, Haukeland University Hospital; Anne Rasdal, Haukeland University Hospital; May Kristin Håland, Haugesund Hospital; Anne Viola Fjelde, Stavanger University Hospital; Kirsten Lerum Indrebø, Førde Central Hospital; Åse Hauglum Hommedal, Voss Hospital; Vigdis Dagsland, Haugesund Hospital.

Background:
Individuals having undergone ostomy surgery are offered follow-up in ostomy clinics by educated ostomy nurses. The offer implies individual consultations at 3 weeks, and at 3, 6 and 12 months postoperatively. In addition, they are offered telephone-advice or consultation appointments at short notice.

The aim of the study is to uncover:
How important is follow-up in an ostomy clinic related to the adaptation to a life with ostomy?
Which topics amongst the ostomy nurse's contributions are considered most valuable by the ostomy patient?

Method:
Questionnaire prepared for this study.
Inclusion criteriae: Patients above the age of 15 years with colostomies, ileostomies and urostomies that had been in contact with the ostomy clinics in Western Norway Health Trust betweem January 1st and October 1st 2001 and mentally capable of answering the questions. 327 satisfied the inclusion criteriae and were sent the questionnaire. 216 (66%) replied.

Conclusions:
The follow-up by ostomy nurse is important for ostomy patients in adapting to a new life situation.
Most important was instruction on ostomy care and information on ostomy equipment, checking the ostomy, information on life with ostomy, help with complications and dietary advice.