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How does stoma affect female patients?

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ABSTRACT

The aim and objective of this thesis are to understand how female patients cope up with stomas in their daily lives. The hypothesis was carried out using a quantitative research method. If a person has negative thoughts and feelings about his or her body dissatisfaction can spread. Environmental influences have a massive role in how people perceive and feel about their own body. Family, friends, teachers and the media they all have an impact on how that person sees and thinks about themselves and their appearance. Nurses are in a significant role to help the awareness to be spread around. The research question for this thesis: “How much women pay attention to their body after stoma surgery?”

“How can nurse and relatives support stoma patient to have a good quality of life?”

A survey in English and Finnish was sent to different places such as Ibd support group, Chron and colitis Ry and Chron disease, ulcerative colitis & Inflammatory Bowel Disease group. The survey includes 15 questions and aims at women between 20 and 40 of age. The result from 40 respondents shows that the stoma has made a severe impact on young women regarding appearance, confidence and relationship even though the stoma has minimal effect on the social life, work or study. Most of the respondents think about the stoma many hours a day. From the thesis findings, we discussed the role of nurses and gave some suggestions on how to support a person with a stoma.

Keywords: Stoma, woman, body image, survey

TIIVISTELMÄ

Tämän opinnäytetyön tavoitteena on ymmärtää, miten naispuoliset, 20-40 -vuotiaat potilaat selviytyvät avanteen kanssa päivittäisessä elämässään. Elämä avanteen kanssa tulisi olla tietoisempaa ja puhuttua, eikä häpeällistä. Työssä käytettiin määrällistä tutkimusmenetelmää. Jos henkilöllä on kielteisiä ajatuksia ja tunteita omaa kehoaan kohtaan, tyytymättömyys voi alkaa levitä. Ympäristöllä on valtava rooli siinä, miten ihmiset tuntevat ja kokevat oman kehonsa. Perhe, ystävät, opettajat ja mediat - ne kaikki vaikuttavat siihen, miten henkilö näkee ja tuntee oman itsensä. Sairaanhoitajilla on suuri rooli tietoisuuden levittämisessä

Tutkielman kysymykset ovat:
"Kuinka paljon naiset kiinnittävät huomiota kehoonsa avanneleikkauksen jälkeen?”

"Kuinka hoitaja sekä omaiset voivat tukea tarpeeksi avanneleikattua ylläpitämään hyvää elämänlaatua?”

Kysely lähetettiin eri paikkoihin niin suomeksi kuin englanniksi, kuten: Ibd-tukiryhmä, Chron ja colitis Ry ja Chron-tauti, haavainen koliitti ja tulehduksellinen suolistosairaus. Kyselyssä on 15 kysymystä ja tarkoitettu 20 - 40-vuotiaille naisille.
Tuloksissa 40. vastaajasta osoittaa, että avanne on vaikuttanut vahvasti heidän ulkonäköönsä, luottamukseen sekä parisuhteeseen vaikka avanteella on hyvin vähän vaikutusta sosiaaliseen elämään, työhön tai opiskeluun. Suurin osa vastaajista ajattelee avannetta monta tuntia päivässä. Opinnäytetyön tuloksiin viitaten, keskustelimme sairaanhoitajan roolista ja annoimme ehdotuksia siitä, miten tukea avanneleikattua potilasta.

Avainsanat: avanne, nainen, kehonkuva, kysely

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1 INTRODUCTION

In Finland, intestine illness becomes very common today (Yle 2018). The prevalence of chronic inflammatory bowel disease is also related to the standard of living; it is less common in low-income countries and is becoming more familiar with rising living standards and urbanisation. The highest incidents have been published in Northen Europe and Canada. Finland has been noticed as a clear South-North gradient, which the Northern countries are. The most common age in getting ill in Chron's disease and ulcerative colitis is 20 to 25 years. In Finland, there are 32 000 chronic inflammatory intestinal diseases patients. (Färkkilä 2013, 472-473.)

The genetic and environment factors are two main features in the pathogenesis of inflammatory bowel diseases. As mentioned above the high prevalence of IBD is observed in Northern Europe and Canada compared to that of Asia, and Asian immigrants to Europeans. However, the increasing of the phenomenon in both genetic/geographic groups has been reported recently. Explanation for the trend of the increasing incident is the adaptation of westernization and industrialization. Moreover, vitamin D has been studied as an important factor in the immune system and intestinal barrier function. In Northern countries, where the sun disappears for a longer period of time than in other countries, the deficiency of vitamin D has contributed to the flare up of the IBD. (Schultz & Butt 2012, 1-2.)

As nursing students, the authors have done training in internal medicine ward where we encounter a few patients with inflammatory bowel disease. The interest grew more prominent after the authors have seen how patients struggled with their new attached friend. The purpose of this research is to be able to understand how patients live with their stoma and how stoma affects patient’s lives. The biggest challenge of the stoma is mentally adapting difficulty, change of body image and the difficulty of accepting abnormal anatomy and continually having a stoma (Järvinen 2013, 503). The goal of nursing is to help patients to cope up with different stages of life so that they can change their habits to improve health and well-being life. For this nurses’ support is needed (Sosiaali- ja terveysministeriö 2003, 18). As nurses, the authors’ most concern is how to implement the finding of this thesis in maintaining the quality of life for stoma patients.

Based on the quality of life survey, the questionnaires were carried out to get awareness on how young women aged between 20-40 deal with a colostomy bag as their lifetime friend. The Survey was sent to different places such as Inflammatory Bowel Disease support group, Chron and colitis Ry and Chron disease, ulcerative colitis & Inflammatory Bowel Disease group. The survey includes 15 questions. It took over three months to get enough answers.

With the result of this study, information about the patient’s life with stoma was able to draw out. This information will help nurses to deepen their understanding towards stoma patients. Health care professional is obliged to improve and maintain their professionalism (Sosiaali-ja terveysministeriö 2003, 15).

2 THE AIM AND PURPOSE OF THE THESIS

The purpose of the research is to get awareness of female patients with a stoma in sustaining their daily lives. Authors’ objective for this thesis is to be able to understand how women live with a stoma and how nurses can support patients.

Mattila’s (2015, 27) study about the emotional and informal support of an adult patient and family member during hospitalization shows that the patients are satisfied with nurses, kindness, encouragement, comfort, listening and informal support of the illness and care. However, patient is more likely to receive information such as laboratory outcomes or medication. Instead of conversation about feelings of illness and what the illness implies to the patients and the effects it has on his or her life are less likely to occur.

Illness and hospitalization create different kinds of emotions such as hopelessness, loneliness and isolation. It’s is very important to deal with these emotions and maintain good mood and hope. Patients want to maintain a sense of dignity, respect and integrity. (Mattila, 2015, 23-25). Through this study authors try to develop the quality of stoma patients’ care. Nurses and nursing students can use this research in the care work of patient.

Many types of research and statistics are showing that women have low self-esteem (Girls Rule Foundation, 2018). One of the most significant projects on women’s self-esteem published by Dove showed that 72% of girls feel tremendous pressure to be beautiful. The burden seems to be more heavier for those with permanent stomas. The Quality of Life Questionnaires inspired our questionnaires for Patients with Ostomy (Grant et al 2012). The questionnaires were designed to identify how much female patients pay attention to their colostomy bags.

Illness and stoma surgery is a crisis for a patient and for a close relatives. Patients may be depressed, fearful, and problems may arise in adapting a stoma. Previous psychological problems, incomplete preoperative control, post-operative physical problems, and negative experience in the forebrain are the risk factors for having mental issues. Problems can be avoided or reduced by mapping the patient's psychological condition, providing adequate information, and handling patient's feelings before surgery. The guidance can be used to think about the treat and to find solutions to them. Nurse can help the patient by talking about problems in concrete terms. Patient's experience of his or her own ability to handle the stoma is psychologically important. (Liimatainen 2007, 17.)

Our research question for this thesis is:

“How much women pay attention to their body after stoma surgery?”

“How can nurse and relatives support enough stoma patient to have a good quality of life?”

3 INFLAMMATORY BOWEL DISEASES

3.1 Inflammatory bowel disease

Chronic inflammatory bowel diseases are listed in Chron's disease and microscopic colitis, like collagenic colitis and lymphocytic colitis. Ulcerative colitis is limited to the large intestine, but Chron's disease instead involves the entire digestive tract. (Färkkilä 2013, 472.)

Ulcerative colitis is a chronic inflammatory disease which is limited to the colon mucosa. The typical symptom of ulcerative colitis is diarrhoea, and over 90% of the patients’ faeces exists blood. Crohn's disease is chronic inflammation, and it is periodically occurring in any part of the digestive tract, which is not only limited to the mucosa but can be transmural inflammation and reach to the intestinal wall layers. For this reason, Crohn's disease is often associated with complications, such as bowel obstructions, abscesses, inflammation of the channels. (Sipponen 2013, 478-479.)

The emergence and occurrence of inflammatory intestinal diseases in developed countries are much more common than in developing countries. The most common age in getting ill in Chron's disease and ulcerative colitis is 20 to 25 years. In Finland, there are about 32,000 people with chronic inflammatory bowel diseases that are getting financial compensation from Kela. The incidence of correspondingly is about 595/100 000. (Färkkilä 2013, 472-474.)

3.2 Stoma

Untreated, severe colitis may result in fulminant colitis related to toxic cholondonosis and perforation risk, which may continue to arrhythmia, sepsis and even to death (Färkkilä 2013, 497). Understanding the immunological mechanisms of chronic intestinal diseases has brought new therapeutic possibilities to calm the inflammation down, but there is no healing treatment at the moment. The goal of drug therapy is to induce and maintain remission. (Sipponen 2013, 488.)

Primarily ulcerative colitis is treated with medications. Still, almost half of the patients are treated before a long surgery. The bowel inflammation is improved by surgery as the target organ or colon is removed. For the ulcerative colitis surgery, there are mainly three different reasons, such as acute non-medicated colitis, chronic disabling colitis and colitis-related cancer or cancer. The first surgical treatment of ulcerative colitis occurred at the change of the twentieth century. This made it possible that the flask could be flushed with various fluids. Later tested in the colon resection, which often led to the size of the recess and ultimately the removal of the rectum in several stages. From the year 1950, the most commonly used and most effective cutting methods were either colectomy and ileorectal linkage or proctectomy and permanent everted ileostomy (Järvinen 2013, 500-502.)

Location is always marked before surgery. Location is selected smooth, enough large skin area which stays in the same size when the patient is lying down, standing or sitting. Choosing a suitable place for stoma is important later in order for the patient to see the stoma. If the stoma is put in a difficult place such as near costal arch or groin bend, it can be difficult for the patient to take care of it. The disjoint of the illeum has to be long enough so that it stretches easily without tension through the open abdominal wall. The intestine’s head is turned in the way that after the surgery, the intestine’s head stays 1-2cm above the skin. In this way, faeces are directed straight to the bag without irritating the skin. (Husa 1992.)

Finnish Nils Kock developed a continent in Göteborg in 1969. It is a drainable catheter ileostomy, which involved the built ileum attached to the abdominal wall “Ileum tank”. The joints used to treat ileostomy in the surrounding skin, and they have developed so that the advance does not prevent normal life, work or exercise. (Järvinen, 2013, 502.)
The biggest disadvantages of ileostomy are a psychological adaptation, changes in the body image and difficulty in accepting the abnormal anatomic condition, resulting from surgery, and the continuing need for an external stoma bag. (Järvinen 2013, 503.) The stoma is a new way to allow intestinal waste to leave the body (McGee 2016).

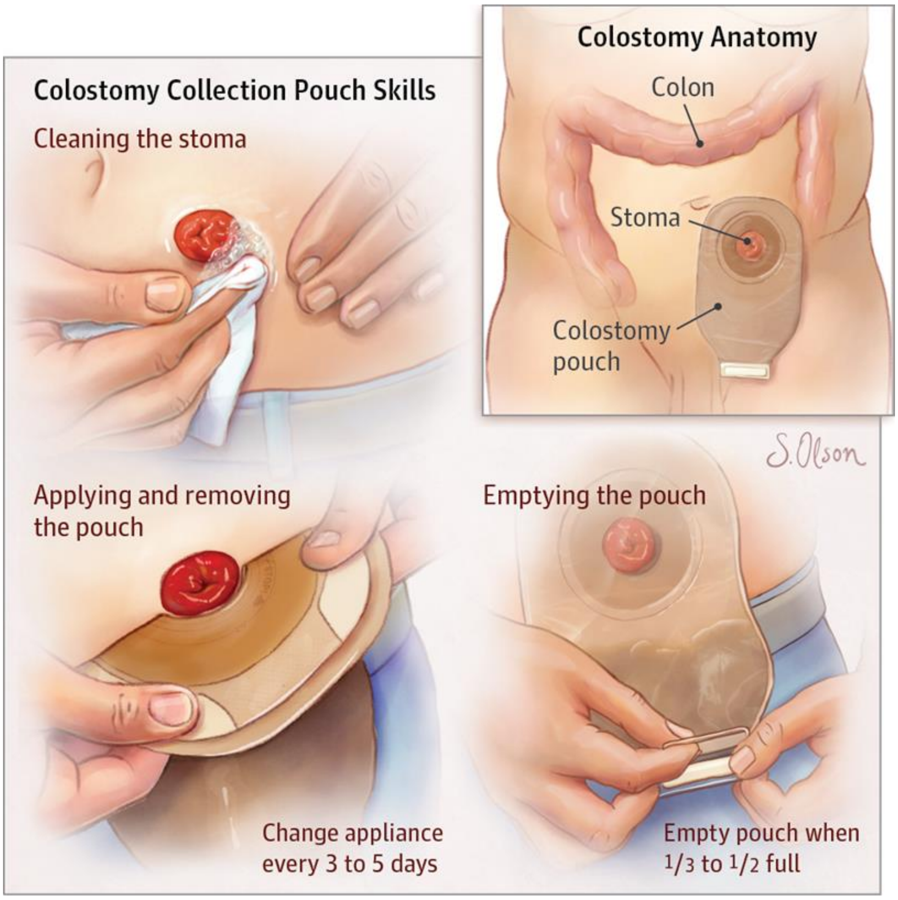


FIGURE 1. Colostomy Collection Pouch Skills (McGee, 2016).

3.3 Caring path

Early stages of the different inflammatory bowel diseases, such as extracellular culture and faecal calcification assay, can be done in the primary health care. In the event of an illness, the patient should be directed without delay to the colonoscopy to set the diagnosis and start the treatment as soon as possible. Pharmacotherapy of chronic inflammatory bowel disease is included in the lower ERF (compensation group). Diagnosis and assessment of the need for medical treatment are required to be based on internal medicine, gastroenterology, pediatric or surgical specialist, medical examinations or hospital examinations. In order to apply for a benefit, the doctor's B statement and the patient's application are needed. Especially, recoverable medicines include 5-ASA, corticosteroids, metronidazole, azathioprine, 6-mercaptopurine, methotrexate and ciclosporin. (Sipponen T. 2013, 516.)

Nurses are in a unique position when it comes to supporting the patient from recovering the surgical operation and building a new body image. The right support has a straight connect to the patient's rehabilitation. Nurses must have a more in-depth look to understand psychologically the situation. Nurses helping the patients surviving from a trauma, usually have a deeper understanding by their own life experiences and it gives them the deeper skills to help the patient. (Pudner 2010.)

Depending on the crisis, there are different ways that the nurse should support and help the patient to survive both mentally and physically. In the pre-and post-operative work, it is essential that the care worker is not only focusing on the physical recovering, but the mental recovering as well. The crisis care is supporting the patient in facing the crisis and surviving and coping from it. The patient needs her own space and time to handle the crisis, and the primary responsibility is with herself. The traumatic crisis is usually followed by an unexpectable happening, like getting ill. In a challenging traumatic crisis, the need for the psychiatric help is estimated, if the symptoms are staying strong over one month and making a living hard. (Mustajoki et al. 2010, 602-603.)

Kela (Finnish social insurance institution) organises adaptation training courses for long-term cures, for which a B statement is required. The patient organisation Chron and Colitis also organises RAY-supported (Finland’s slot machine association) adaptation training courses. A person suffering from chronic inflammatory bowel disease may also qualify as a disability allowance for financial compensation. Especially when the illness or injury causes the applicant harm, need for help, need for service support and extraordinary expenses. In order to apply for a disability benefit, a C statement and a patient-filled application are required. (Sipponen T, 2013, 516.)

4 BODY IMAGE

Body image is the perception that a person has of their physical self, but more importantly the thoughts and feelings the person experiences as a result of that perception. It is important to understand that these feelings can be positive, negative or a combination of both and are influenced by individual and environmental factors. (Healey 2014, 1.)
When a person has negative thoughts and feelings about his or her body dissatisfaction can spread. Environmental influences play a significant role in how people perceive and feel about their body. A person's family, friends, teachers and the media all have an impact on how that person sees and feels about themselves and their appearance. People of all ages are prone to images through media such as TV, magazines, internet and advertising. The ideal demonstrated in these images has been edited by stylists and digital manipulation. The ideal they create cannot be or achieved in real life. If a person feels that they do not measure up in comparison to these images, feelings of body dissatisfaction can intensify and have a damaging impact on that person's psychological and physical wellbeing. (Healey 2014, 1-2.)

Body image is a concept that Paul Schilder has investigated in the year 1935. Schilder was a very popular neurologist and psychoanalyst who had an interest in people's thoughts about their bodies. He knew that the body image consists of not only physiological and neurological but also the psychological side. He used to say: "Body image is that image of our bodies that we edit in our minds." In other words, he must have meant that how we feel about ourselves and our bodies. He thought that how we feel our bodies are the base of the whole life experiences. After Schilder, our body images have been more complicated and more productive because of the narcism and the early communicating theories (Valkonen-Korhonen et al. 2003,135-136).

Women are often more familiar with the humiliation towards their bodies. Women and their genital areas are often humiliated around the world. The humiliation can cause lots of shame for women instead of feeling proud of the sexuality. In Nordic countries, women are often able to work independently and have their autonomies. The inner shame among women could be more investigated. Women tend to have their fantasies and ideas of how their lives as a woman or a mother should be. Women have lots of pressure not only towards themselves but also, for their husband and children as well (Reenkola 2014, 68-70).

Naturally, girls are raised differently from boys from the very early stage of their lives. Women are often categorised to be specific type by their original appearance. Often women are thought to be smaller, shorter, more emotional and social than men. It can be tough for women to live with these prejudices and especially when an unexpected illness steps in (Villka 2010, 9-10).

5 RESEARCH METHODOLOGY

5.1 Quantitative Research method

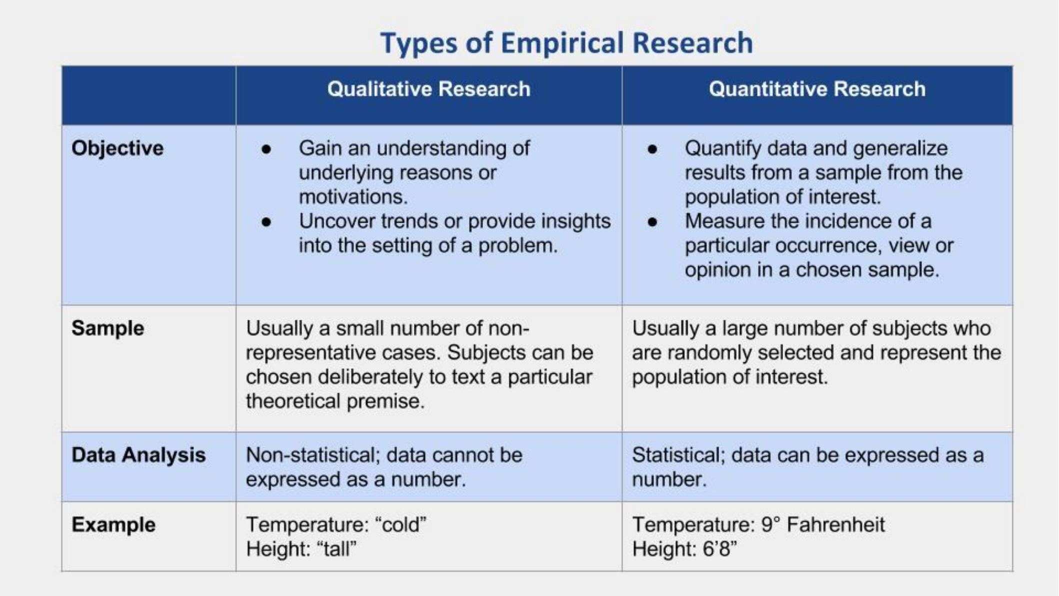
There have been questions being asked which methodology should be used to answer the research question. Qualitative research with qualified interviews was the first choice to implement. However, despite how much effort the authors have put in looking for interview candidates; no one has accepted the interview invitation. Therefore, the original plan has been changed. Another possible way to collect opinions or ideas from the specific population is quantitative survey research.

In order to explain why we chose the quantitative approach, the authors would like to extend a bit more on the difference between qualitative and quantitative so that readers can have a clearer view on our decision.

Quantitative method in the research gives more space for the analysis that is being surveyed. The difference between the quantitative and qualitative methods are that qualitative method is often more focused on the certain experience. In quantitative method the questions are usually not very deep, they concentrate on very important questions and the survey will not spread too far. (Curtis & Drennan 2013, 130.)

There are no precise numbers of how many people preferred using a quantitative approach to the qualitative approach; however, when talking about logic and accuracy of data, many people believe that numbers explain more than words. In contrast, qualitative research deals with non-numerical data to answer its research question. (University of Southern California, 2018.)

TABLE 1. Difference between Qualitative and Quantitative research (River Campus Library 2017)



Types of Empirical Research

	Qualitative Research	Quantitative Research
Objective	• Gain an understanding of underlying reasons or motivations. • Uncover trends or provide insights into the setting of a problem.	• Quantify data and generalize results from a sample from the population of interest. • Measure the incidence of a particular occurrence, view or opinion in a chosen sample.
Sample	Usually a small number of non-representative cases. Subjects can be chosen deliberately to text a particular theoretical premise.	Usually a large number of subjects who are randomly selected and represent the population of interest.
Data Analysis	Non-statistical; data cannot be expressed as a number.	Statistical; data can be expressed as a number.
Example	Temperature: “cold” Height: “tall”	Temperature: 9° Fahrenheit Height: 6’8”

All of our theoretical resources came from books, journals and digital articles. The internet-based samplings that authors have conducted were sent to two different groups: Chron and Colitis Ry and to IBD support group, an Inflammatory Bowel Disease association that aims to provide support for people with IBD.

The success of a scientific survey requires that the researcher can take a broad view of the respondents' time, desire and skills to respond to the survey. Carefully design and testing of the form is crucial to the success of the research, but a good survey is not enough it’s own. (KvantiMOTV 2010.) It would had been better if the survey should have been tested before publishing it to the real target.

Because this topic is very sensitive, no qualified patients could be found to do the interview. Authors agreed to release a survey where all respondents are anonymous. This confidential survey is a “sweeter” version of the interview which allows participants to answer questions without deepening their sorrow.

In the form of research, it is important to seek a comprehensive, but simple and easy-to-understand questionnaire (KvantiMOTV 2010). The moderate length of the form and the clarity of the appearance are very important both for the defendant and later for the data recorder (KvantiMOTV 2010). A total number of questions was 15. There are questions about their life and status but also about feelings about their stoma.

It took over three months since the survey was launched to acquire the required response. Some people saw our survey as an emotional attack on their “bodily flaw”. Not only they did not answer to the survey, but they also reported so that the survey was removed and we were blocked from the group. Still, it was not the only drawback in our work.

5.2 Data Analysis

1. Question: How old you are

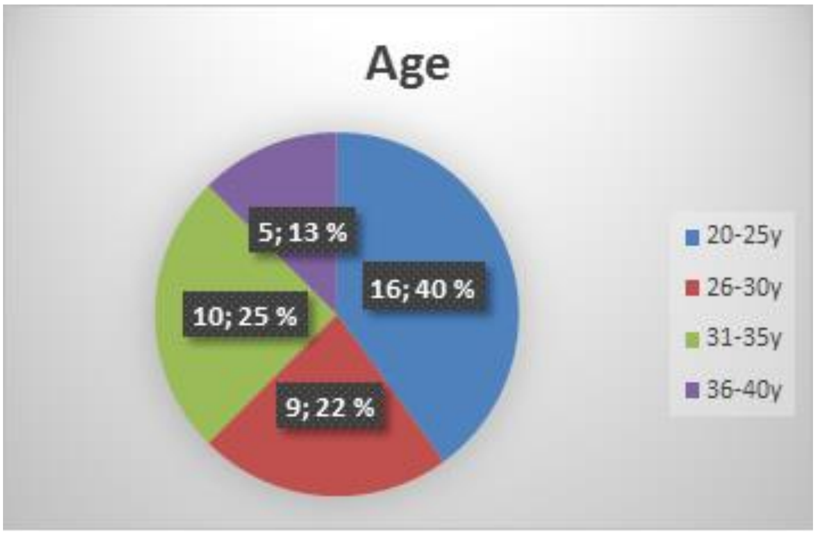


Figure 1. Most of them were aged between 20-25 years. Young people are more active on the internet (Valtari, M. 2017). Least answers were from women aged between 36-40 years with 13% of the total amount of answers.

2. Question: Marital status; Single, widowed, married or cohabiting, separated/divorced

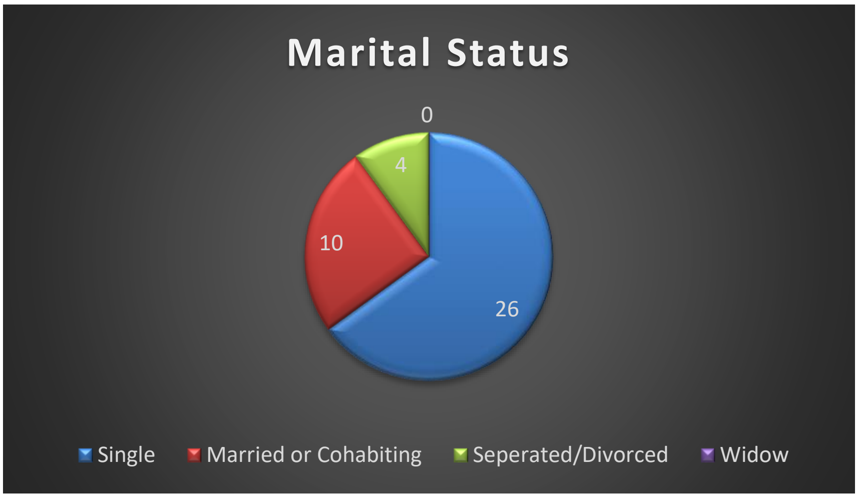


Figure 2. 26 percent of the correspondents were single. 10 percent were married or cohabiting, and the rest 4 percent were separated or divorced.

3. Question: If single, separated, divorced, or widowed, are you currently in a long-term relationship; Yes/No.

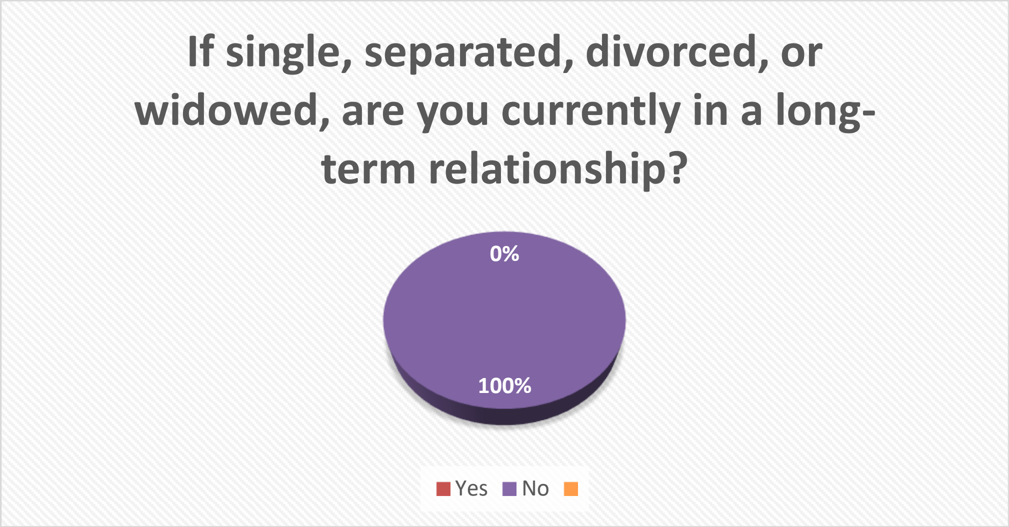


Figure 3. 100 percent of those who are not married, or cohabiting are not in a long-term relationship. The changes in marital status and single has been observed since 1970. With the contribution of the women’s movement, women since then became independent and they don’t have to bear the burden of the tradition family. Since women became more educated, they don’t accept the old-fashioned social term. They would rather being on their own than being with someone who don’t treasure them or delay their progress either in life or career. (Pan 2004, 15-16).

4. Question: Current employment; Unemployed, employed or self-employed, long term sick leave, student, full-time housewife.

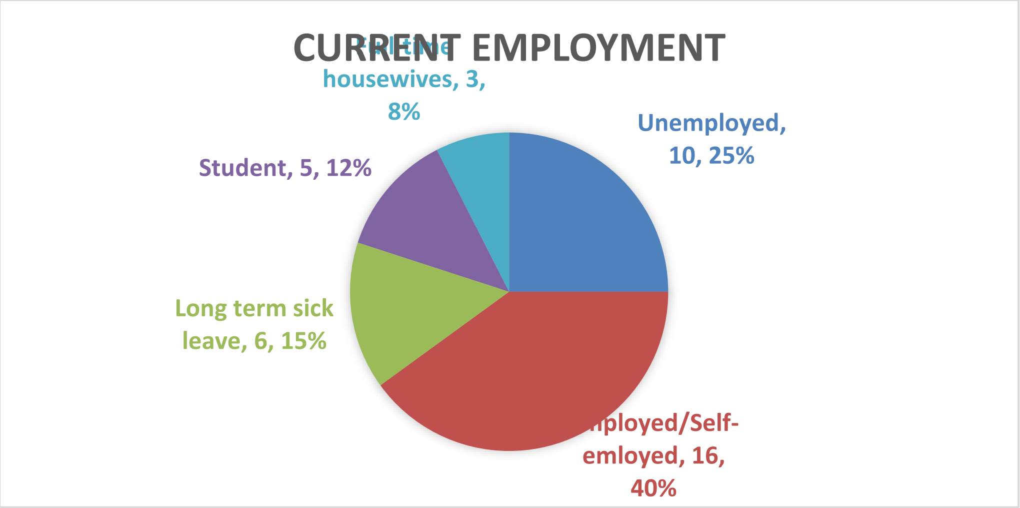


Figure 4. 40 percent of respondents were employed and 25 percent were unemployed. 15 percent were in a long-term sick leave and 12 percent were students. The smallest group, 8 percent of the correspondents were full-time housewives. Most of the respandents were working. Patients can return back to work 8-12 week after surgery (Dansac 2007).

5. Question: On an average day, how many minutes or hour(s) do you currently spend thinking about your stoma? Please add up all the time that your stoma are at the forefront of your mind and make the best estimate.

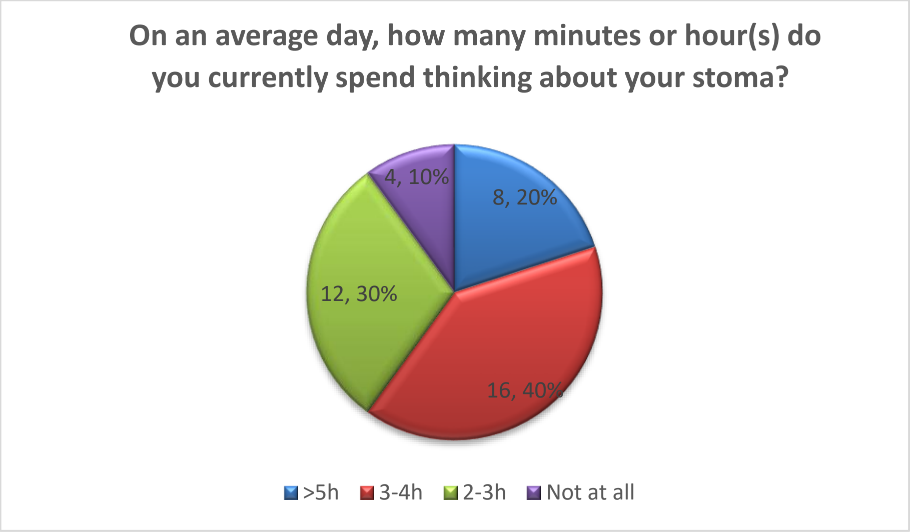


Figure 5. 40% of the correspondents were thinking about it 3-4 hours per day. 30 percent thought about it 2-3 hours per day and the rest of the group were thinking about the stoma less than 5 hours in a day. It’s takes time for patient to accept stoma into their lives (Dansac 2007).

6. Question: How often do you deliberately check your stoma? Please include looking at your stoma in a mirror or other reflective surfaces like a shop window or looking at it directly or feeling it with your fingers; Scale 0-10, Never/countless.

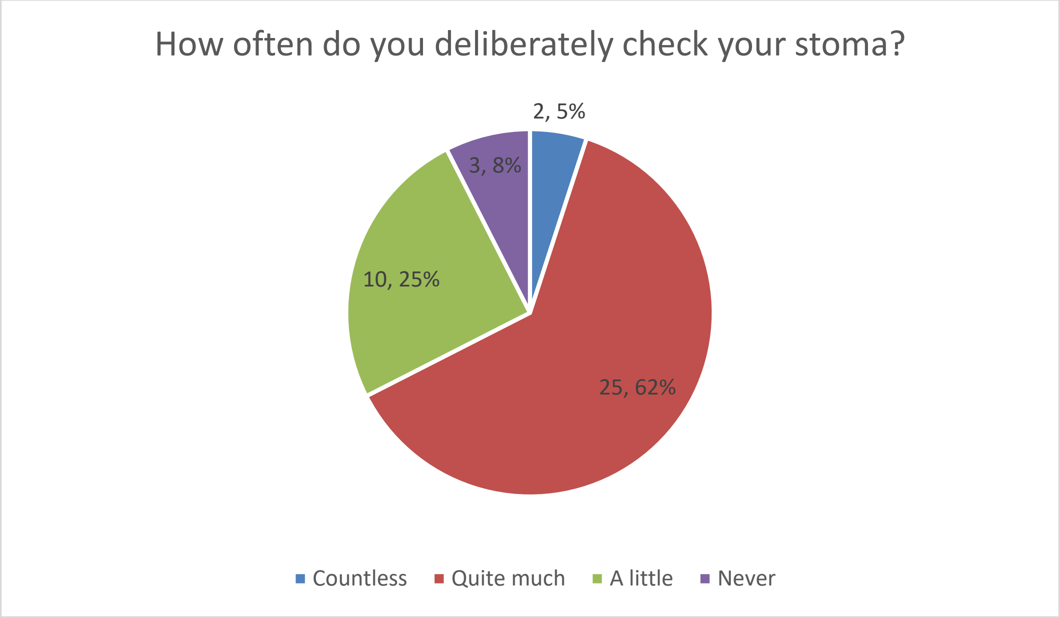


Figure 6. Results from the research on sensitivity to disgust to life with colostomy carried out by Smith et al indicate that there is a coherrent link between disgust sensitivity and feelings of stigmatization. For example the fear of leakage is one of the disgust sensitivity that most patients feel bothered (Smith et al 2007). That explains why 2,5% checks on their bags countlessly and 25,62% checks many times a day. Rest of the correspondents checks at least a few times a day. Only 3,8% rarely checks the bag.

7. Question: How much do you feel your stoma is currently ugly, unattractive or ‘not right’; Scale 0-10, Very ugly/Not at all

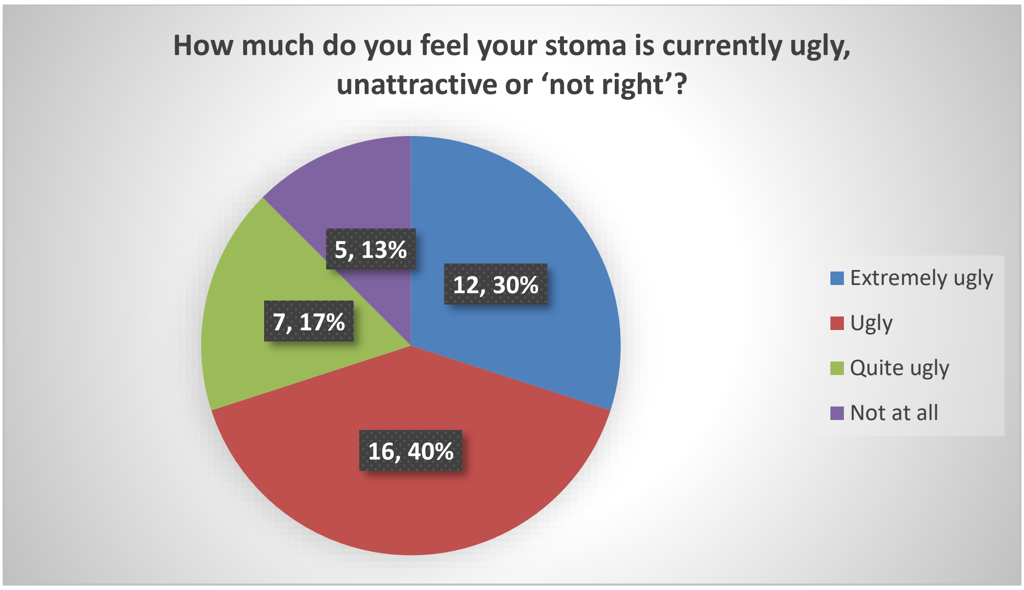


Figure 7. 30 percent felt that it is extremely ugly and then 40 percent felt it ugly. There was 17 percent who felt it quite ugly and, also some felt that it is not ugly at all. A little less half of respondents felt bad about themselves. To be able accept stoma it is important that nearby and friends in patient s' life react to the stoma as a something normal (Liimatainen, T. 2007, 51).

8. Question: How much does your stoma currently cause you a lot of distress; Scale 0-10, Always/Never

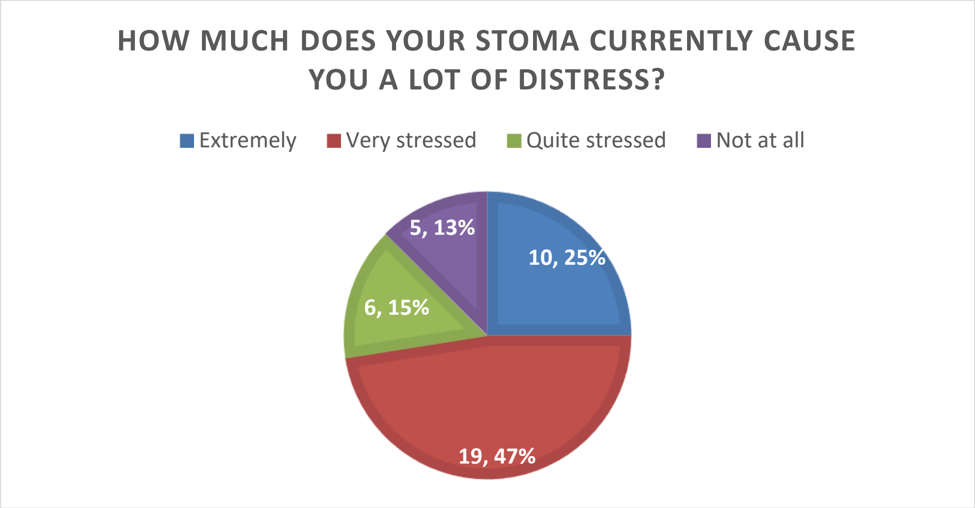


Figure 8. This question showed that 47 percent of respondents felt very distress about their stoma and 25 percent of them felt extremely stressed .15 percent felt quite stressed. Small group, 13 percent felt not stress at all. Permanent stoma

always means a major change for the patient. The patient is often more worried about the stoma bag than can the disease be treated effectively (Husa 1992)

9. Question: How often does your stoma currently prevent you from your hobbies or activities; Scale 0-10, Always/Never

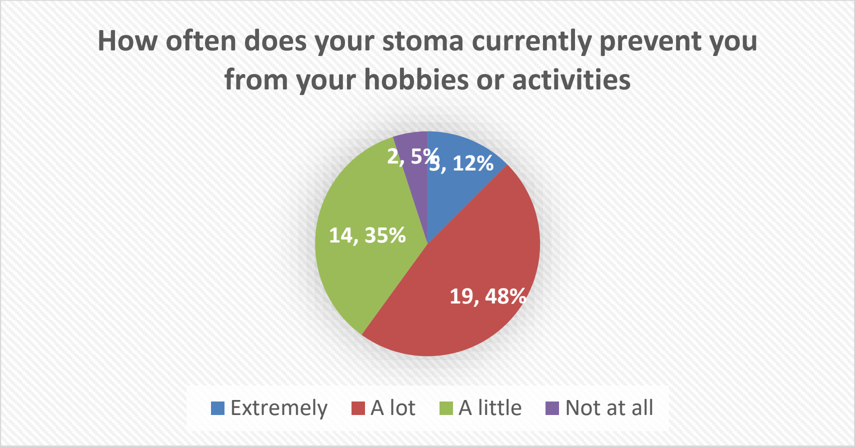


Figure 9. Meaning of this question was to find out does the stoma prevent correspondents from their hobbies/activities, 48 of the correspondents felt that the stoma prevented them from their hobbies/activities and 35 percent felt it only a little. 12 percent of the total amount of correspondents felt that the stoma is preventing them extremely from their hobbies. Small group, 2.5 percent felt that the stoma did not prevent them from their hobbies or activities at all. After surgery, It's takes time to recover, so they can't start exercise immediately. The patient can also loss their will for exercise because of the stoma. (Liimatainen 2007,51).

10. How much are you concerned about your stoma; Scale 0-10, All day long/ Not at all.

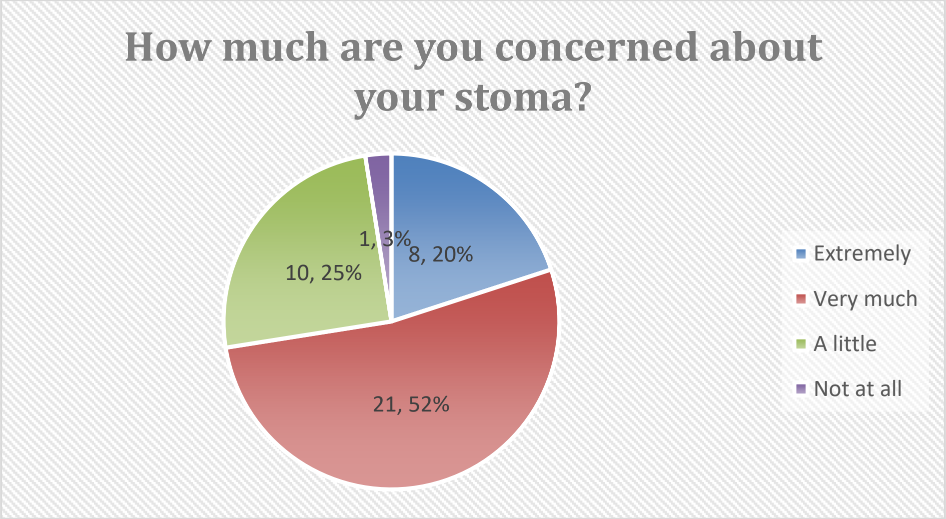


Figure 10. 52 percent of the respondents were very concerned about their stomas. 25 of the group felt only a little concerned about their stomas. Extremely stressed felt 20 percent of the correspondents and 3 percent of the total group felt not stress at all.

11. Question: If you have a partner, how much does your stoma currently have an effect on your relationship with your current partner? If you do not have a partner, how much does it have an effect on dating or developing a relationship; Scale 0-10, Extemely/Not at all.

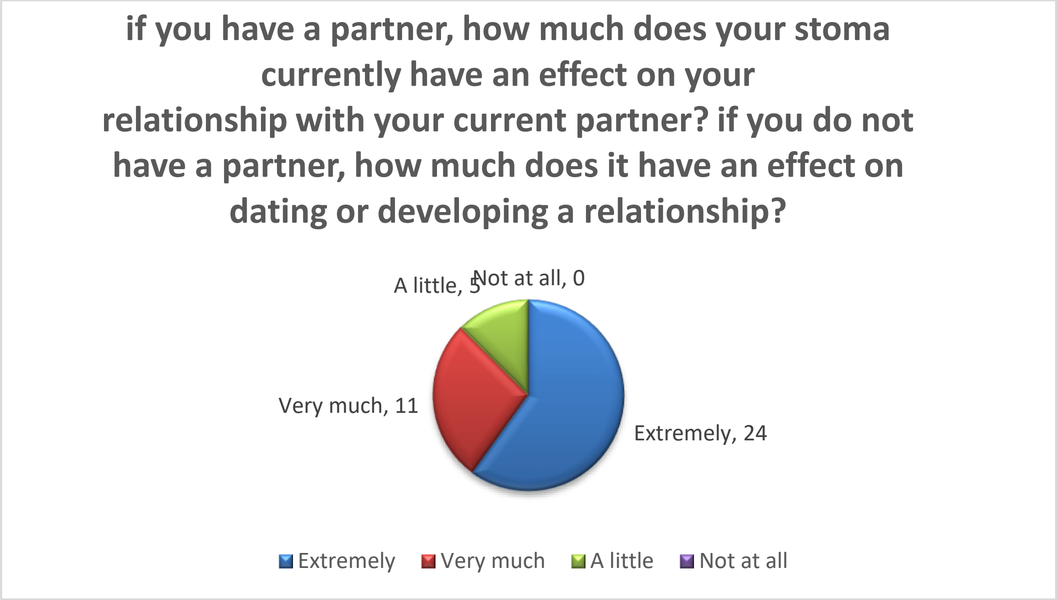


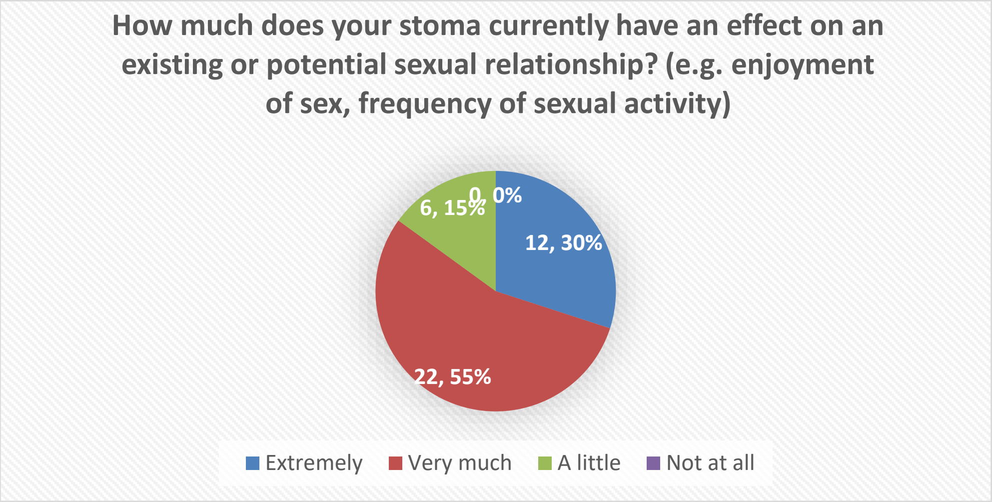
Figure 11. To know about how, did the stoma effect correspondent lives this question was about that. 24 people of the correspondents felt that the stoma had an

extremely a lot of effect on their relationships. 11 people of the group felt it very much and 5 people in the group felt it only a little bit. Some patients may step away from friends and relatives. It might be a sing of depression or away of accepting stoma. (Liimatainen 2007, 51.)

12. Question: How much does your stoma currently have an effect on an existing or potential sexual relationship? (e.g. enjoyment of sex, frequency of sexual activity; Scale 0-12, Extremely/ Not at all.

Figure 12. To be able understand correspondent sexuality this question was to find out how, does it effect's that part of their lives. 55 percent of the total amount of the respondents were thinking that the stoma has very much effect on their sex lives. 30 percent of the group felt it had an extremely big effect and 15 percent felt it only a little. None of the correspondents thought it has no effect at all. In Liimatainen's study, partner's point of view there had been changes in sex life. According to them, it had become a planned thing, and didn't happened spontaneously anymore. They felt that changes in sexuality were harder for the patient than for the partner. (Liimatainen 2007, 51.)

13. How much does your stoma currently interfere with your ability to work or study; scale 0-10, Very much/Not at all.



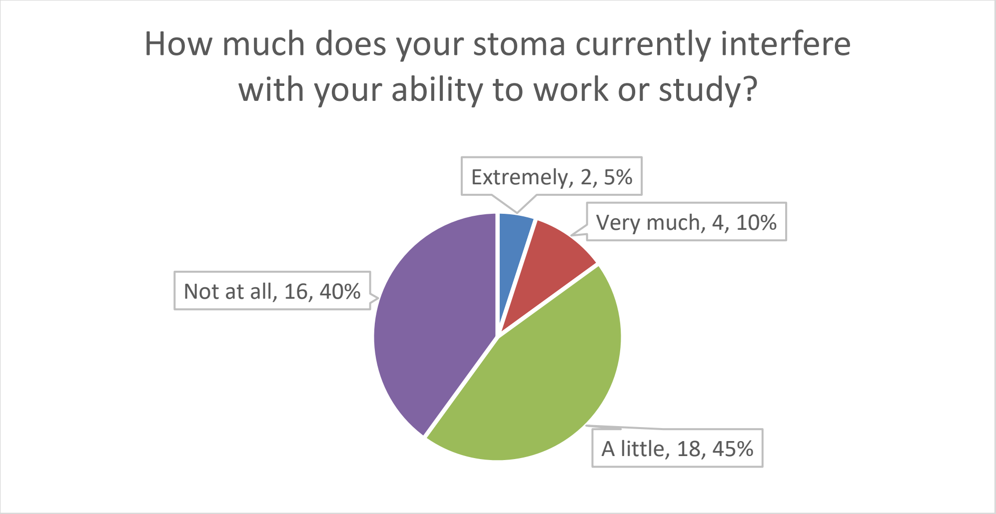


Figure 13. Also, this question showed, how much stoma effects correspondents' everyday life. The biggest group, 45 percent, felt that stoma interferes a little of their ability to work or study. The second biggest group, 40 percent felt that the stoma don’t disturb their ability to work or study at all and 10 percent felt that it interferes very much. Small group, 5 percent felt it extremely lot. It’s possible to live normal human life with the stoma, to maintain relationships, work and hobbies. However, hard physical exercise and work must be avoided. (Husa 1992.)

14. How much does your stoma currently interfere with your social life; Scale 0-10, Very severely/Not at all

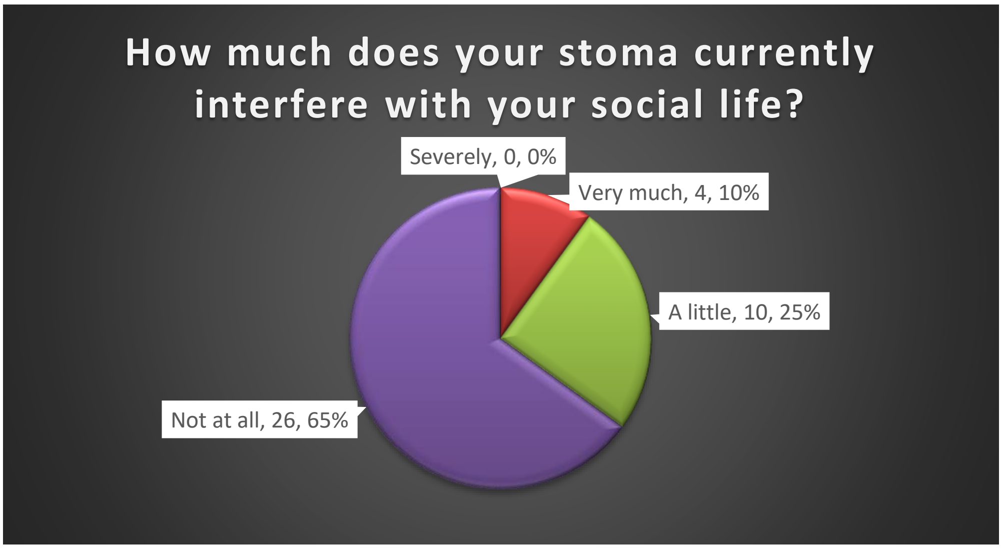


Figure 14. 65 percent felt that their stomas don’t interfere their social life at all. 25 percent felt it only a little bit and 10 percent felt it very much. None of the

respondents felt that it has a direct impact of their social life. After surgery, returning to work usually takes 8-10 weeks. Stoma does not change person in a relation to their relationships. (Dansac 2007.)

15. Do you feel your stoma is noticeable to others; Scale 0-10, Very noticeable/Not at all.

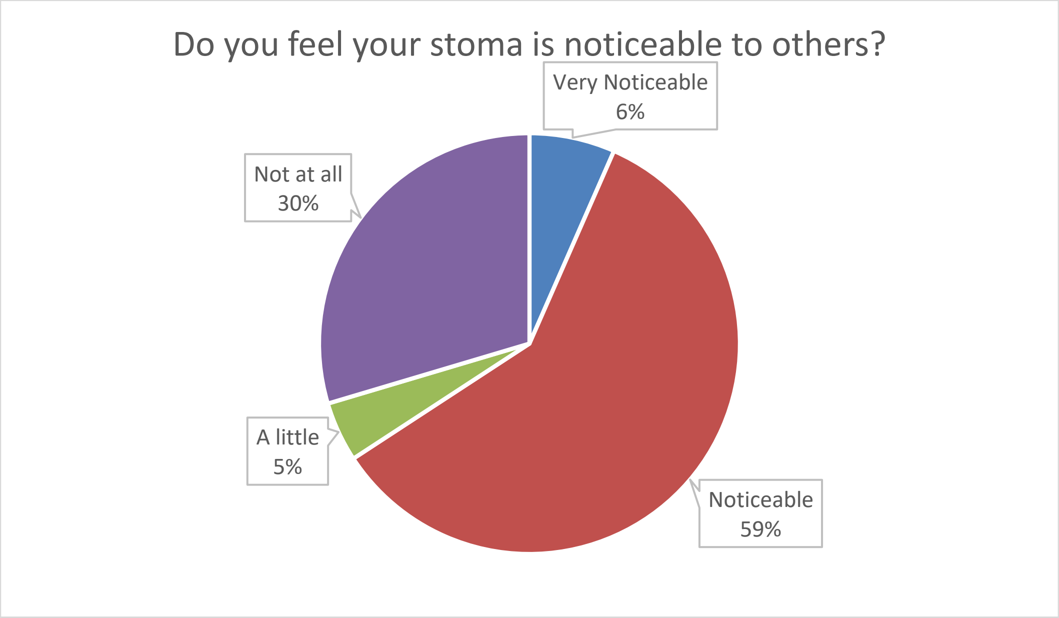


Figure 15. Last question was very important. It showed how much respondents felt that stoma is noticeable, 59 percent of the respondents felt that their stoma is very noticeable, and 30 percent felt it is noticeable at all. 6 percent of the group felt it very noticeable and 5 percent a little bit. Some patient thinks that others will see a humb under their clothes. In fact, very few people notice it or realized what it is. (Dansac 2007)

The results show that patients experience that stoma bag is noticeable, that's why they feel that it interferes their social and everyday life. A questionnaire is presented at the end of this work.

Anonymously answering on the internet creates its own challenges, human at any age or genre could answer the questionnaire. So the answers are not entirely reliable. Respondents may have difficulties in assessing their behaviors, so their answers may not be precise.

6 RESEARCH FINDINGS

From the completed questionaires to the analysis of data, the authors have used the inductive approach. Usually quantitative research is associated with deductive approach and quantitative is with inductive approach. However, they can be complementary to each other. In the inductive approach, data are first collected, then the authors start to observe and find patterns in the data and from those patterns, a set of theory is developed to explain for those patterns. (Blackstone 2014.)

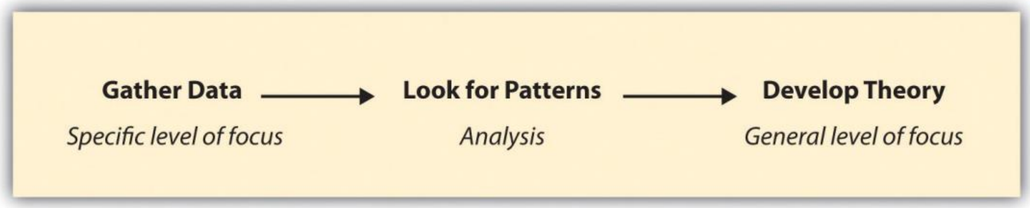


FIGURE 2. Inductive Reseach (Blackstone 2014)

The study often refers to a theoretical framework, theoretical review or theoretical background. In this sense, the theory is used to create a basis for research; to point out the "place" of research among other studies and to direct research. The theoretical framework contains a central topic and related material, not any collection of irrelevant and unconnected theories. In practice, this means, for example, a review of a scientific discussion on topics, represented by literature and other written material. (Saaranen-Kauppinen&Puusniekka 2006.)

In a study by Lehto-Järnstedt et al. (2002), cancer patients feel that they have received the most support from their spouse, but the support given by nurses and doctors is almost as significant. Illness causes patient fear and uncertainty. Anxiety is associated with illness and surgery and everyday life situations. Patients need support from the nursing staff for treatment of fear and insecurity. Patients receive adequate psychosocial support from nursing staff, but more spiritual support is needed. Women consider emotional support necessary, but they feel that nurses do not have enough time. (Liimatainen 2007, 14-15.)

Nurse point of view, one of the nurses' ethical principles is that the nurse helps people of all ages in different situations. The nurse serves individuals, families, and communities. The nurse aims to support and increase the personal resources of individuals and improve their quality of life. To be able to work according to ethical principles, this study is important. It is a way to take a peek of the stoma patient’s mental wellbeing. Another nurses' ethical principles are, the nurse treats the patient as a fellow human being; she listens to the patient and empathizes with him. The relationship between nurse and patient is based on open interaction and mutual trust. (Sairaahoitaja liitto 1996.)

To be able to understand and support the patient mentally, nurses must understand how the patients feel about herself. Getting an answer through this research nurses can have some understanding about how patient cope up with a stoma and how they can maintain their quality of life.

The quality of life question came up when the data was analyzed. The results show how much patients care about their stomas and stoma is something that doesn’t belong to the natural body yet still visible there. The stoma is one of the practical solutions for colorectal cancer, and the survival rate is growing thanks to the development of science in the medical field. Another similar quality of life research was done in 2014 by Liao and Quin has also found out that patients with a stoma reported difficulties in work and social situations, with sexuality and body image, and with stoma function. The findings suggested that stoma patients need more support from healthcare providers, from society and especially from their families. Post-colostomy care is as important as hospital care to educate patients sufficient knowledge to cope up with the fear. The disgusting feeling not only comes from inside the patients but also from the fear of being stigmatized by others. The fear reaction might be associated with lower well-being (Smith et all 2007).

The results of this research lead to another question: how to improve the quality of life for patients with permanent colostomy bags. From the nurses' point of view, it is important to be aware of a change in the stoma patient is not only physical changes but also on the emotional side. With this study, nurses can picture out how stoma patients live with a stoma. Further research in this field is necessary for healthcare providers to improve their services

7 ETHNICS AND RELIABILITY

Authors assumed that life with stoma sets restrictions and that it is challenging to live a normal life. Through this survey understanding for stoma patients has grown a lot.

In the ethical survey, the people who are being surveyed must be respected. Their humanity and rights are making the limits of what kind of surveys can be done (Saaranen-Kauppinen &Puusniekka 2006).

One of the ethical principles of the science that are very near to us is privacy and data protection. Privacy protection is part of the rights protected by the Finnish constitution and is also an essential principle in research ethics. The most crucial issue in the protection component for data collection, processing and data publishment is data protection. (Tutkimuseettinen neuvottelukunta 2017.)

The research of the ethics principles of privacy are divided into three parts:

1 protection of the research material and confidentiality
2. the retention or destruction of research material
3. research publications.

The principles of the starting point are the attempt to combine the philosophy of confidentiality and the sincerity of science. The principles of privacy protection did not apply to publicly available public material and disclosed information that may concern individuals and their activities in politics, business, government and culture. However, privacy guidelines and data protection principles must be respected in the case of documents concerning court hearings and court decisions. (Tutkimuseettinen neuvottelukunta 2017.)

In this research, it was accomplished by the fact that the respondents were anonymous, and no contact information was collected in connection with the questionnaire. During the questionnaire release, respondents were told where the answers were received and why they were justified. The collected data were analysed and collected in the thesis.

To data protection and response, the questionnaire must be formulated so that the respondents do not have to worry about abusing the information they provide (KvantiMOTV 2010). It is important to tell and justifies why and where the answers are used.

The stages of a traumatic crisis are a shock phase, a reaction phase, handling phase and a re-orientation phase. The shock phase starts right at the beginning of the crisis. During the shock phase person is not able to handle the cause of the crisis and may even deny it. After the shock phase starts the reaction phase, where person starts little by little to foam an idea what has happened and why. After these two phases starts handling phase where person starts to understand and don’t deny the cause anymore. Person realizes that change and lost's are real. Last phase is re-orientation. Re-orientation phase has slowly begun to turn into life and experience of that own self. They are albe to live with that cause an it’s no longer in their mind. The pain can rise up time to time, but there is also joy in life and person can focus on the future and confidence for life returns. (Suomen mielenterveysseura, 2018.)

This questionnaire was shared on an internet group where people had some bowel disease, but the response was entirely different than we had been waiting for. The target group was offended about our survey, perhaps of the way we approach them or they may be in a phase that is still denying the situation they are living right now. Research authors realised that this area is susceptible. By changing the approaching method, people started to answer the survey. Approaching method went like this: “We are future nurses, and we are doing thesis work on this subject. It is interesting to us because that way we can provide better care and understanding for our patients. When a nurse understands the patient, she can help and support him/her in many different ways”.

If researchers had made a survey by interviewing, the results would be based on the experience and life of certain people. But by anonymously in internet it received 40 people 's experiences and respondents were able to answer it whenever they have time. It would had been better to test the survey with someone who has any kind a disease. It would had been good to have an opinion about the survey. It might not had changed anything but at least authors would approach in the beginning differently to the target group.

8 CONCLUSION

This research can be utilised to understand how much stomat can effect on woman’s perception of themselves and their lives in many ways. Although the questionnaire was for women only, authors cannot be sure that only women have responded to the questionnaire. The question was open on the internet, so about the respondent's gender is not completely sure. Answers were thought to achieve Finnish people, but also from abroad. In the survey, it would have been good to have a question about where the respondent is from.

A typical woman with a stoma bag, who answered to our survey was young aged 20-30, unsecure who is not in a relationship. Everyday life is going well and stoma don’t prevent from hobbies and work, but the thoughts about the stoma comes in mind on leisure time. So, authors come to conclusion that emotional side and understanding about the illnesses in large part for accepting stoma. As it has shown in may other studies too.

In this study, it was highlighted how important the role of the nurse is in the treatment of a stoma patient. Knowledge, support, and understanding what a nurse can give to a patient is significant after surgery. The professional and empathy shown by the nurse can make the patient feel better. The role of the nurses also in support of the relatives and in informing them about stoma has a large part in the treatment.

Liimatainens’ (2007, 37-38) master thesis study was about stoma patients and their family members support and coping up from family member perspective. The survey was for understand what the patients’ needs from nurse and family members and what kind a support family members need during the care in hospital. Liimatainen’s study shows that stoma patients need emotional care from nurses and they felt important that nurses maintain hope. It helped patients cope up and support them from their situation.

The first four questions as shown in figure 1,2,3 and 4 were general questions about respondents age, status and current employment. By analysing the answers of the survey, most of the respondents were 20-25 years. In Finland 4-5 people per 1,000 fall ill to bowel disease, It often starts with young adults, aged 20-35

(Mustajoki 2017). This can be explained why the most of respondents are that aged. Their illnesses can still be fresh case.

Questions in figure 5,6 and 7 were for picturing life with a stoma, what respondent think and how they feel. One of the thesis questions got answers from these survey questions. Most of the respondents believe and pays much attention to their stoma many this in a day. Only 3,8% rarely checks the stoma bag.

Questions number 8,9,10 were for notice how much stress, what does it prevent you from and how much concern they are about it. When stoma patients have peer support, support from their family and friend it might help them to maintain their life as it was before. Peer support is one way for accepting stoma and the changes that come with it. Getting ill and having a stoma bag into the body cause a lot of worries and negative thought (Dansac 2007).

Questions 11,12,13, and 14 were to about life in a relationship, sexuality, work and social life. Our second thesis question was about how nurses and relatives can support enough stoma patient to have a good quality of life; this rises through these questions when patients accepts the new situation and can handle possible restrictions what might come with it, for example in sexuality life after surgery can continue as it was. When people around the patient are aware of the new situation and have enough information about it, it becomes more comfortable for the patient to maintain a excellent quality of life. In Liimataine’s (2007) study shows that when relatives get enough information about the care of stoma, it is easier for them to accept the new situation. When relatives and friends around the patient accept the situation, it is easier for the patient also accept it as well as the change of the body itself. The effects of stoma surgery are individual and are influenced by the social, physiological and spiritual factors of the patient. Support from friends and family member was communication, counseling, and concrete help, such as invite to eat. The closest relatives of the patient went to the hospital at the patient, but friends and acquaintances were backed up and gave more support to the close person so he could benefit from the patient's support. (Liimatainen 2007, 39)

Nurse’s professionalism and the knowledge about stoma guarantees individual support and guidance of the patient. Trust and interaction between nurse and patient are in a big role. Having a good interaction patient can trust and feels better about herself. The nurse should know the patient's background and life experience as well as the experience of the illness. He must also know about the patient's social life, culture and belief.(Liimatainen 2007, 14)

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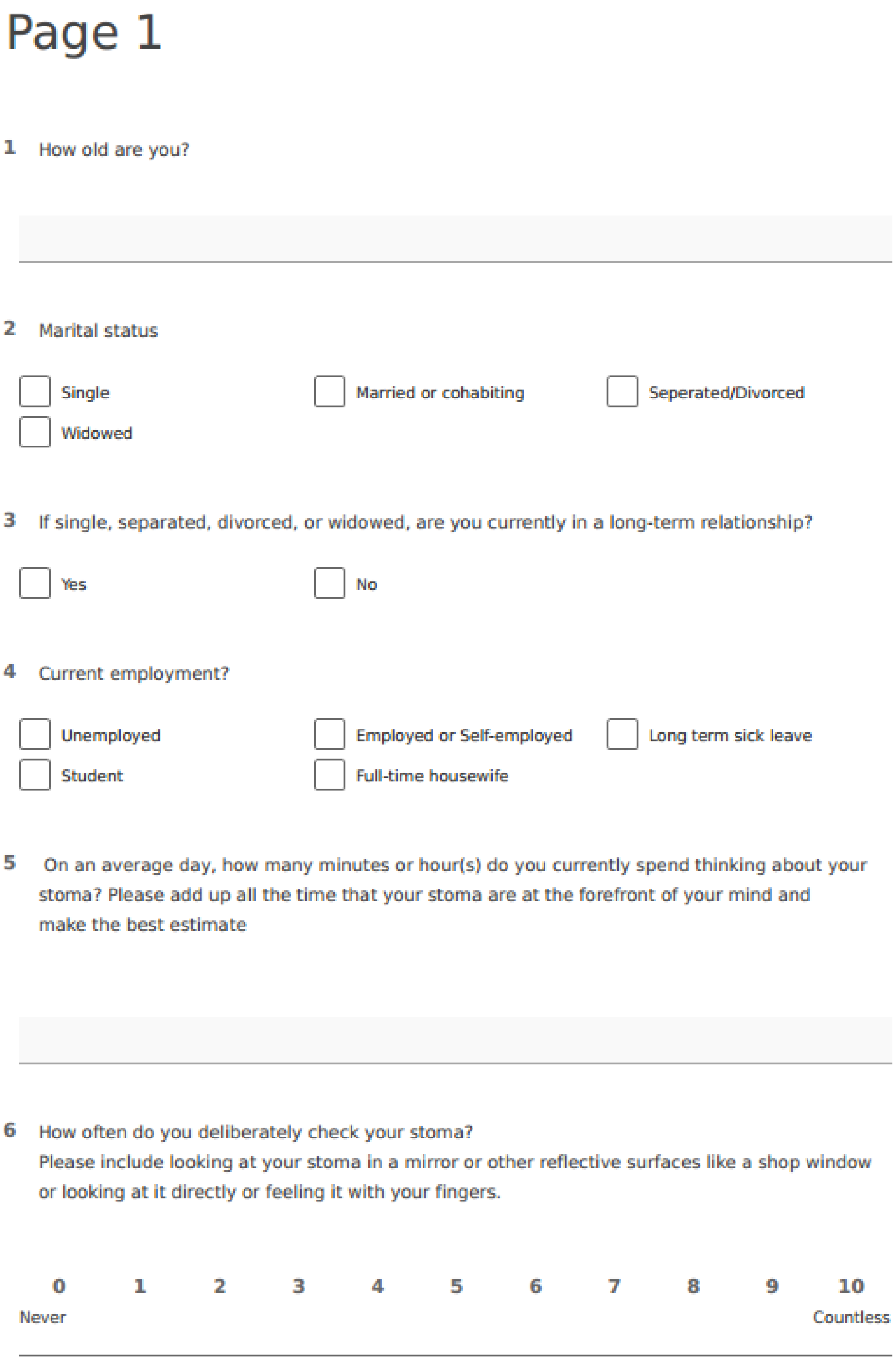
APPENDIX



Page 1

1 How old are you?

2 Marital status

☐ Single ☐ Married or cohabiting ☐ Seperated/Divorced
☐ Widowed

3 If single, separated, divorced, or widowed, are you currently in a long-term relationship?

☐ Yes ☐ No

4 Current employment?

☐ Unemployed ☐ Employed or Self-employed ☐ Long term sick leave
☐ Student ☐ Full-time housewife

5 On an average day, how many minutes or hour(s) do you currently spend thinking about your stoma? Please add up all the time that your stoma are at the forefront of your mind and make the best estimate

6 How often do you deliberately check your stoma?
Please include looking at your stoma in a mirror or other reflective surfaces like a shop window or looking at it directly or feeling it with your fingers.

0	1	2	3	4	5	6	7	8	9	10
Never										Countless

7 How much do you feel your stoma is currently ugly, unattractive or 'not right'?

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
Very ugly										Not at all

8 How much does your stoma currently cause you a lot of distress?

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
Extremely										Not at all

9 How often does your stoma currently prevent you from your hobbies or activities?

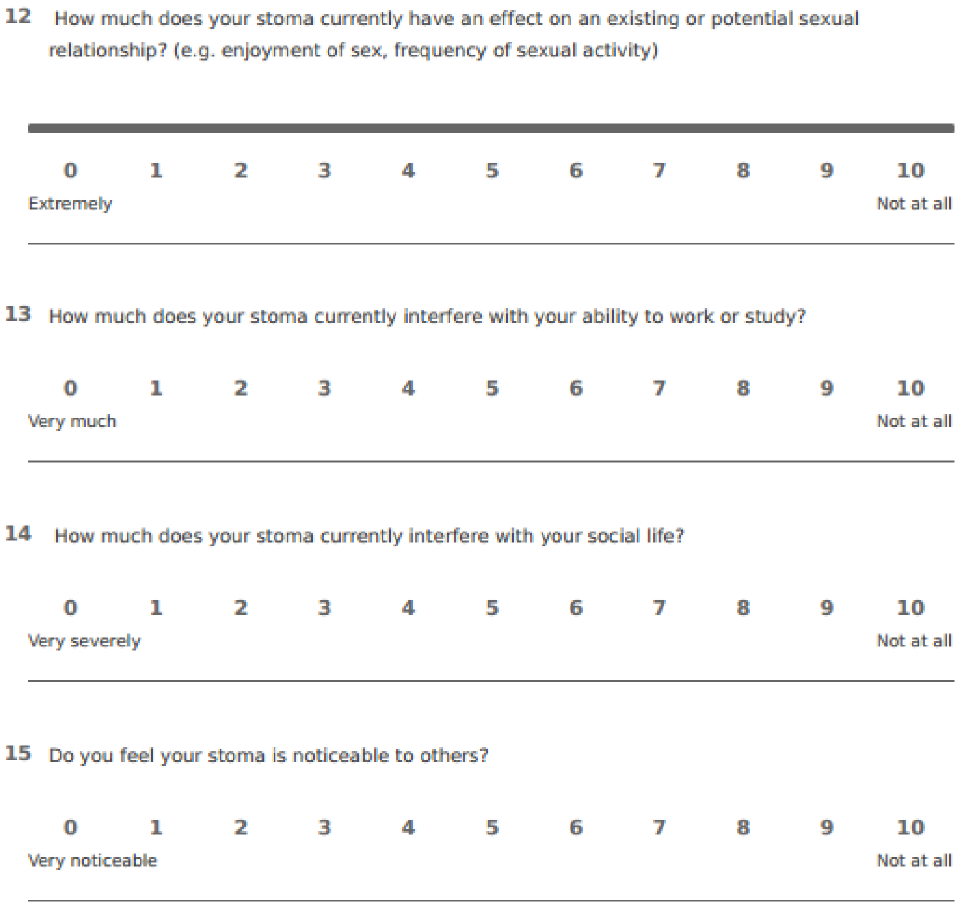
0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
Always										Never

10 How much are you concerned about your stoma?

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
All day long										Not at all

11 If you have a partner, how much does your stoma currently have an effect on your relationship with your current partner? If you do not have a partner, how much does it have an effect on dating or developing a relationship?

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
Extremely										Not at all



12 How much does your stoma currently have an effect on an existing or potential sexual relationship? (e.g. enjoyment of sex, frequency of sexual activity)

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
Extremely										Not at all

13 How much does your stoma currently interfere with your ability to work or study?

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
Very much										Not at all

14 How much does your stoma currently interfere with your social life?

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
Very severely										Not at all

15 Do you feel your stoma is noticeable to others?

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
Very noticeable										Not at all