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Patients' experiences of living with a stoma in rural areas in Northern Sweden

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ABSTRACT

Introduction: Stoma complications are common and interfere with many aspects of everyday life. Stoma problems are usually managed by a specialised stoma nurse, a service not present in the rural areas of South Lapland in Sweden. The aim of this study was to describe how stoma patients in rural areas experience living with a stoma.

Methods: A qualitative descriptive study with semi-structured interviews were conducted with 17 stoma patients living in rural municipalities and who received a part of their care at the local cottage hospital. Qualitative content analysis was employed.

Results: Initially, the stoma was experienced as very depressing. Participants had difficulties in properly managing the dressing. Over time they learned how to properly care for their stoma, making their life easier. Both satisfaction and dissatisfaction with the healthcare were experienced. Those who were dissatisfied expressed a lack of competence in dealing with stoma-related problems.

Conclusions: Living with a stoma in a rural area in northern Sweden is experienced as a learning process and acceptance of the stoma's existence is important. This study emphasises the need for increased knowledge of stoma-related problems in rural primary healthcare in order to help patients cope with everyday life.

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Introduction

In northern Sweden, 54% of all rectal cancer patients undergoing tumour surgery receive a permanent stoma at index surgery [1]. Quality of life of rectal cancer patients operated with resection of their cancer and receiving a stoma has been shown to be inferior to similar patients without a stoma [2]. As well as those receiving a stoma following rectal cancer surgery, a smaller proportion of the roughly 4000 patients diagnosed with colon cancer each year in Sweden also received a stoma [3]. A stoma may also be used in inflammatory bowel disease (IBD), urinary bladder cancer, conditions with faecal incontinence and diverticular disease [4–7]. The variety of indications suggests that life with a stoma may be influenced by factors other than the stoma itself. For example, those who receive a stoma after cancer surgery, the stoma can be a symbol of cancer survival [8]. Whether the stoma is intended as permanent or temporary has also been shown to be an influencing factor [9]. Patient education is recognised as a positive influence on the quality of life among stoma patients [10]. To be able to accept and adapt to life with a stoma is frequently mentioned in previously published studies [11].

The process of acceptance can be found in the theory of body-subject by Maurice Merleau-Ponty [12]. This theory states that the body exists from *my own view* and not being purely an object. This theory is often exemplified by the cane of a blind man; this cane not being only a cane, but instead a device to perceive the world. In the same way, a stoma or for example a leg prosthesis affects how a person experiences or accepts their body.

Stoma complications are varied and common [13]. Previous studies have described parastomal hernia, bulging, stenosis, skin complications, retraction, prolapse and intestinal obstruction [14–17].

Having a stoma interferes with many aspects of everyday life [18,19]. Examples of commonly occurring problems are social restrictions, difficulties with ostomy appliances, appliance leakage, pain, limitations of activity, cosmetic problems, and difficulties with clothing [20–22]. Previous research has shown that having a stoma could affect a person´s work and financial situation, as well as relationships [19,23].

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Parastomal hernia and bulging are considered the most important complications. Surgery for bulging alone is sparsely reported. Surgery for parastomal hernia is performed but is afflicted with high risk for recurrence, morbidity and even mortality [24]. A recent study reported that surgery for parastomal hernia is seldom performed in Sweden [25]. The lack of effective surgical treatment means that many stoma patients must endure their problems for the remainder of their life.

Stoma-related problems are often managed by a specialist stoma nurse at a surgical department [26]. Stoma patients are followed up by a stoma nurse when available, and not the surgeon [27]. Patients receive instruction on stoma care by a stoma nurse before discharge from hospital and this appears to improve quality-of-life [28].

The geography and infrastructure of northern Sweden means a long time travelling to receive specialised care for those living in rural areas. Surgical competence regarding routine colorectal cancer surgery and specialised stoma nursing care are restricted to the two large hospitals in the region and are not available in rural areas. Six municipalities in northern Sweden lack a general hospital. Instead, these municipalities have extended primary care at cottage hospitals with a limited number of beds. These healthcare centres are staffed by primary care physicians with access to beds, and are open for emergencies 24/7 [29]. The catchment area of these six communities together is slightly larger than Belgium and the mean population density is 0.93 inhabitants per square kilometre [30]. Previous studies have indicated that both stage of colorectal cancer at diagnosis, as well as, general prognosis, are negatively associated with longer distances to the diagnosing facility of colorectal cancer and rural environment [31]. The poorer prognosis and the fact that specific stoma competence is not easily accessible in these sparsely populated rural areas could very well have a negative effect on the quality of life of stoma patients in northern Sweden. A negative effect on global quality of life of stoma patients, as well as more pain and stoma related problems is illustrated in the results in a thesis from rural Northern Sweden 2020 [32]. Survival from colon and rectal cancer is increasing [33,34], when survival rates increase, secondary outcome parameters such as quality-of-life become more important.

The aim of this study was to describe how stoma patients in rural areas experience living with a stoma. A secondary aim was to describe stoma-related problems that occur and how the process of seeking healthcare is experienced.

Materials and methods

A descriptive qualitive study using semi-structured interviews. The study was reported according to the Consolidated Criteria for Reporting Qualitative Research Recommendations (COREQ) [35].

The interviews were conducted by the first author, a male M.D and PhD. Apart from participating in two courses in qualitative research at postgraduate level, S. N had no previous experience of semi-structured interviewing. He had the experience regarding stoma related problems comparable to a PhD-student in the subject and a non-specialised M.D.

To be able to recruit all possible stoma patients living in South Lapland, we used the National Drug Prescription Register from The National Board of Health and Welfare in Sweden. Data were requested on all patients above the age of 18 prescribed stomal dressing between 2011 and 2014 and living in the six rural municipalities in South Lapland. These municipalities were chosen as they lack general hospital services. Instead, inhabitants of these municipalities rely on a cottage hospital for medical care. All participants were assigned an anonymous code for the duration of the study.

By using a register, we were able to include participants with different stoma indications (Cancer, IBD, constipation and incontinence (both urinary and faecal). Urostomy, ileostomy and colostomy patients were all included. Inclusion criteria were: 18 years and older; having had a stoma for more than one year; an underlying diagnosis of cancer, IBD, constipation or incontinence; and living in one of the six sparsely populated rural municipalities in South Lapland, where it is up to 360 kilometres to specialised care. Exclusion criteria were: inability to understand written or verbal information; cognitive impairment; or inability to speak Swedish.

Participants were collected using a purposive sampling from register data to achieve a variation regarding sex, age, type of stoma and which of the six communities they were living in. The first contact was made by telephone, where a brief introduction to the study was given. In conjunction with the interview, the informant received written information on the study and gave written informed consent prior to inclusion. All participants were given the opportunity to withdraw from the study during and after the interview.

All data were collected from face-to-face interviews that took place at the home of the patient with one exception, when the interview instead took place in the former workplace of the patient. In 3 of the 17 interviews, the partner of the informant was present at the request of the informant. In the remaining 14 interviews, only the interviewer and informant, who had no previous relationship with the former, were present. Before the interview, the participant was aware of the interviewer's interest in the research topic since this had been disclosed in the verbal and written information. Otherwise, the participants had no further information regarding the interviewer.

A question guide was used for data collection, see Appendix. The interview questions were constructed to address the aims of the study and after discussion between three of the authors (S.N, K.S, A.E.L) and a specialist stoma therapist with many years' experience in stoma care. A.E.L is an associated public health/nursing professor with experience in qualitative research methods. K.S is a professor in surgery. The interview contained both open and follow-up questions, see appendix for complete interview guide. The design of the interview was tested at the first two interviews followed by discussion between two of the authors (S. N, A.E.L). These interviews were included as further adjustment was deemed unnecessary.

All interviews were audio-recorded digitally and transcribed verbatim in Swedish by a medical secretary. All participants were asked if they would like to partake of the transcribed interviews, but this was declined in all cases. Repeat interviews were not carried out. No field notes were taken since the verbatim transcription was carried out soon after the interview. All interviews took place in January and February 2019.

The method used to analyse data was qualitative content analysis according to Graneheim & Lundman 2004 [36]. Meaning units relevant to the aim in the transcribed interviews were identified, condensed and labelled with codes close to the text with a low abstraction level. The codes were then abstracted and sorted into subcategories and further abstracted and sorted into categories derived from the data. The process of abstraction and sorting subcategories and categories was on a higher grade of abstraction than the codes, but still on a descriptive level. An example of the analysis process is provided in Figure 1. Quotations are used to illustrate all subcategories and categories in the results, to illustrate the consistency between the data and the findings presented.

Data were coded by two authors (K.S and A.E.L), besides the interviewer, one with considerable knowledge regarding stoma-related problems (K.S) and one a novice on the subject (A.E.L). A discussion among the authors was carried out during the coding and sorting of data in order to consolidate the results. The quality and diversity of the data was discussed repeatedly among the authors during the time period of the interviews. Data collection ended when the collected data was judged to sufficiently be able to answer the research questions. Microsoft Excel 2016 (Microsoft Corp, Redmond, WA, USA) was used to structure and analyse data.

Ethics

This study was approved by The Regional Ethics Committee in Umeå, Sweden (Dnr 2016/155–31) and followed the principles of the Helsinki Declaration. In order to keep strict confidentiality, the names of municipalities were not mentioned in the results section, since the number of individuals in each municipality is small. Some dates may also have been changed for the same reason.

Consent

All participants included received verbal and written information about the study and signed an informed consent form prior to inclusion.

Results

Participants and interviews

Register data revealed 131 unique individuals prescribed stoma dressings, of which 85 were still alive 2 April 2017 when register data were received. Twenty-one possible participants were selected according to the inclusion criteria and contacted by phone. Seventeen agreed to take part and were included in the study, after informed consent, four disapproved participation. None of the 17 individuals included dropped out of the study during or after the interview. Nine of the participants were male and eight females. The age of the participants ranged between 65 and 86 years (median 73 years). All lived at home with a distance to the closest hospital of between 55 and 250 km (median of 110 kilometres), and 11 lived with a partner. The participants had had their stoma between 5 and 43 years (median 12 years). Three participants had an ileostomy, nine a colostomy and seven a urostomy. Two participants had both a urostomy and a colostomy. The interviews lasted between 10 and 79 minutes (mean duration 29 minutes). In total, three categories and ten subcategories were interpreted from the data. The three categories were: 1. Living with a stoma is experienced as a learning process, and acceptance of its existence is crucial 2. Experiencing problems related to the stoma is common and affects everyday life negatively 3. The process of seeking health care contains experiences of deficiencies and continuity. For subcategories see Table 1.

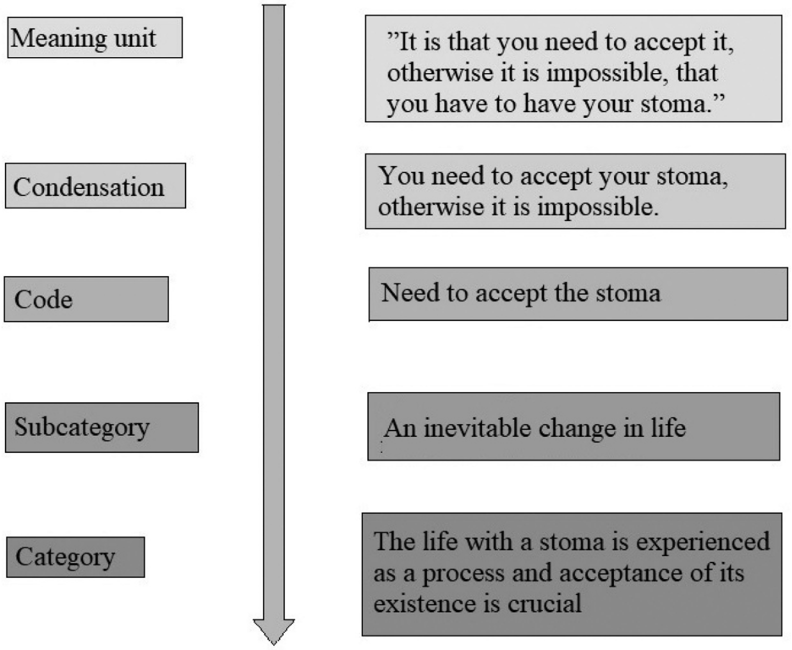

Figure 1. Example of the analysis process.

Living with a stoma is experienced as a learning process, and acceptance of its existence is crucial

The participants described their experience of living with a stoma as a learning process. The initial period after surgery was experienced as difficult and very depressing due to their inability to properly manage stoma dressing due to lack of routine. Stoma leakage in sensitive situations led to the depressing thought that this could be the situation from now on. As time went by, however, the situation changed, and things became much easier. Participants described how they gradually learned how to clean and change the stoma dressing and understanding in which situations their stoma was likely to cause problems. Eventually, came the need for acceptance, a central message that came over in the interviews. To come to terms with a stoma was described as something that became easier with time. This category was abstracted from four different subcategories: 1. An inevitable change in life; 2. Importance of leisure activities; 3. Striving for a normal life; and 4. Being convinced that the stoma has led to a positive change in life.

> *To live with a stoma constitutes no obstacle. You get used to it. Actually, it's no big deal.*

An inevitable change in life

Participants experienced that having a stoma led to a major change in life. This change was described as inevitable, and that the stoma symbolised the end-stage of their individual disease. Some described that they initially experienced their stoma as something unnatural and unpleasant. Having to spend time dressing and looking after the stoma every day was experienced as a large change in life. One thing that varied greatly was the time required for daily stoma care. For some it only took minutes while for others it took hours, a few had not one but two stomas to manage. Those who took the longest time regarded the stoma as causing major changes in life that restricted their freedom and that this was hard to come to terms with. Those who lost little time described stoma care as a minor task in an otherwise ordinary life. The process of changing the stoma bag was described as a meticulous process that with time had changed to suit their situation.

> *Changing the stoma bag is a fast and convenient process.*

> *No matter what, it takes time; seventy-five minutes for the colostomy and ninety minutes to change all parts of the urostomy.*

Change in life was also stated to be highly dependent on the context of life in general. Participants who had had their stoma for decades described how the situation changed as they grew older, their leisure activities changed or decreased, and they retired from work.

Table 1. Categories and subcategories analysed from the interviews.

Category	Subcategory
Living with a stoma is experienced as a learning process, and acceptance of its existence is crucial	An inevitable change in life Importance of leisure activities Striving for a normal life Being convinced that the stoma has led to a positive change in life
Experiencing problems related to the stoma is common and affects everyday life negatively.	A lack of understanding amongst the general population Stoma-related symptoms are varied, unpredictable and often persistent An undeniable obstacle to many personal, social and leisure activities
The process of seeking health care contains experiences of deficiencies and continuity.	Experiences of inequity Lack of resources and competence regarding stoma-related problems Positive experiences of continuity.

This contextual perception of the stoma was further exemplified by how differently stoma complications are perceived. Stoma bulging, for example, could be experienced as something negatively affecting both self-esteem and body image, while others experienced this problem as totally manageable.

> *The stoma ruins your body because you never become yourself again.*

> *The only way to handle the "stoma belly" is to accept it.*

The extent to which the stoma led to change in lifestyle also depended on which leisure activities and hobbies the participants enjoyed and whether they could still manage these.

Importance of leisure activities

Participants were happy to be able to carry out their favourite leisure activities and hobbies. These activities, even if the type of activity varied considerably, was commonly described as a feeling of freedom. To still be able to hunt, fish, ski, drive a snowmobile and spend time out in nature was deeply appreciated, and this lifestyle was described as being an advantage when living in a rural area.

> *I believe it is an advantage, because you live another life. Being out in the wilderness.*

Other participants described that still being able to do handcraft, bowling, choir singing or judge at dog shows were things that helped them live a normal life despite their stoma(s). Being able to do the things in life that matters was mentioned in conjunction with the experience that having a stoma did not constitute an obstruction to their way of life.

Striving for a normal life

At the beginning of the interview, participants described that having a stoma had not prevented them living a normal life. The questions regarding the effect of their stoma on self-esteem, body image and social life were met with surprise. Participants answered that having a stoma made no difference because they lived a normal life. Some participants experienced that their stoma did not affect relationships with their partner, and some considered their sexual life not to be affected in a negative way. These opinions often came from those who had not suffered a stoma complication, bulging, parastomal hernia or pain.

> *Today, everything is just as it used to be.*

Almost without exception, as the interview proceeded it became obvious that the participants had been forced to make sacrifices in their personal life because of the stoma. The meticulous and, in many cases, daily repeated process of stoma care affected everyday life negatively, but this became an integral part of normal life and was seen as being a part of the learning process of how to manage and thereby accept the stoma.

> *As long as I manage my part, my stoma works fine. I am the one in charge.*

For many participants the stoma itself was seen as a positive thing in life, something that affected their general view of the life.

Being convinced that the stoma has led to a positive change in life

The participants' experience of having a stoma varied depending on which disease they suffered from. Those with IBD had often suffered for several years prior to getting their stoma and felt as though they had been cured. They expressed a relief of no longer having to endure the symptoms of the disease that tormented them for years.

> *Having a stoma is the best thing I have done.*

> *I received my stoma on the 21th of March 1988. Since then, I have worked every single day and never had problems.*

Others with cancer experienced their stoma to be a symbol of their survival from cancer, which was perceived as something to be proud of. Participants could also experience the stoma as something convenient because its location was easily accessible when suffering from viral gastroenteritis or when taking long rides on a snowmobile.

> *I use to tell people that having a stoma is easier than not having one.*

Experiencing problems related to the stoma is common and affects everyday life negatively

An experience of varied and unpredictable symptoms from their stoma was described. These symptoms and the lack of understanding amongst the general population caused problems in everyday life for informants. One experienced a considerable variation in quality of stoma dressings between different manufacturers of which made unpredictability worse. Worries about these symptoms took up a considerable amount of time. This category was abstracted from three different subcategories: 1. A lack of understanding amongst the general population; 2. Stoma-related symptoms are varied, unpredictable and often persistent; 3. An undeniable obstacle to many personal, social and leisure activities.

> *When the stoma leaks you get urine on your clothes, and that is highly unpleasant. I´ve been through this many many times, not to mention at night. But then, it comes on the bedclothes instead.*

A lack of understanding amongst the general population

Behaviour of people around sometimes made matters worse. Informants felt this lack of understanding where they were advised to "just reverse your stoma and the problems will disappear". Having to explain that their stoma was actually permanent was perceived as a burden. Others had been insulted by upsetting comments about smell by friends and family. This lack of understanding upset some participants badly. Some had gone as far as avoiding food likely to cause gases to avoid embarrassing social situations.

> *I have a relative who went to the bathroom when I had been there to empty my stoma bag. She came back and said ´I will never go in there again´.*

Stoma-related symptoms are varied, unpredictable and often persistent

Informants described a plethora of symptoms related to stoma complications. One of the most common complaints was leakage of faecal contents or urine, and this symptom was regarded as unpredictable and caused constant concern. In some cases, the reason for leakage was parastomal hernia or bulging, but others saw it as something totally out of the blue. Others were unfortunate to have malplacement of the stoma because of urgent surgery where no stoma marking was done. In some cases, high stomal flow prevented planned activities, as well as causing skin irritation and excoriation. One participant had shingles that interfered with the stoma – an unpleasant and painful experience. One became alarmed when he suffered a stomal prolapse.

> *"It leaks. I have to wash my clothes every day, my underpants as well. It pours like water. Every day. I am so sick of this situation".*

An undeniable obstacle to many personal, social and leisure activities

Having to avoid taking a sauna or a swim, because of the stoma, was perceived by many as something negative. Both disappointment and sorrow over not having a sex life after receiving a stoma were described. Those who received the stoma early in life remembered having to stop playing football and became a football referee instead. Because of a poor body image, tight clothes were avoided for aesthetic reasons and others avoided going to dances. Since symptoms were perceived as unpredictable, travelling, especially with strangers, was avoided. Some were upset over the need to plan bus rides depending on the behaviour of their stoma. A few had avoided visiting friends and relatives living far away for the same reason, and one participant sometimes avoided going outside altogether. Sitting in a car, bus or airplane sometimes provoked stoma leakage and embarrassing situations.

> *One thing I find troublesome is travelling. I have experienced it in a car once (leakage), it was not pleasant. It started pouring from the stoma when I left the hospital by a taxi. In those situations, you should actually tell the others, but I did not. I sat there pressing, trying to keep it together. It was stupid, there were many people in the car.*

The process of seeking health care contains experiences of deficiencies and continuity

Participants in this study had had more or less contact with the healthcare service regarding their stoma. Initially almost everyone had contact with the cottage hospital for help with their stoma. Those with frequent problems had developed direct contact with the stoma care nurse at the university hospital. Satisfaction and trust were feelings expressed by those who had a positive experience of the care they received at the cottage hospital. Others expressed dissatisfaction over the inadequate help provided by the cottage hospital regarding stoma-related problems and felt they were being a burden when receiving treatment. Participants considered that it would be better if competence regarding stoma-related problems was available closer to home and believed that inequalities in care are due to the geographical impact on infrastructure. This category was abstracted from three different subcategories: 1. Experiences of inequity; 2. Lack of resources and competence regarding stoma-related problems; and 3. Positive experiences of continuity.

> *I have always said that nurses are angels, but I have also experienced the opposite. That they should not work in healthcare but in a different job.*

Experiences of inequity

For the participants, differences in care available to other patient categories and to people living in more densely populated areas were perceived as inequality. The process of ordering stoma dressings was by some experienced as being a bother compared to diabetes patients ordering their equipment. It was described that those with diabetes have a prefilled form for ordering equipment whereas those ordering stoma dressings have to fill in the form by hand. Furthermore, that there are specialised nurses for diagnoses such as COPD, but not for stoma patients, was perceived as unequal care. Some avoided seeking medical advice because of the distance to the nearest specialised care and the long time they expected to be waiting for help. The weeks after receiving their stoma were difficult for the participants, and this was made worse by long travelling time and frequent visits to the university hospital soon after index surgery.

> *At the same time, you are not a cow but a man of flesh and blood. We all deserve to be treated equally. Unfortunately, that is not the case.*

Participants experienced that these inequalities existed purely on a geographical basis, *i.e.* because they lived in a rural area. Access to competence regarding stoma-related problems was difficult, and many felt that further education for healthcare staff working in a rural environment should be encouraged.

Lack of resources and competence regarding stoma-related problems

Participants repeatedly criticised the lack of continuity in primary care and perceived a lack of knowledge about stoma-related problems at the cottage hospitals. Some stated that this lack of continuity led to nonchalant treatment and to physicians not knowing their medical history. The unpredictability of medical competence regarding stoma-related problems was perceived as frustrating. Participants could understand these weaknesses since the staff were obviously under stress. Participants had experienced a shortage of stoma dressings in the pharmacy.

> *I was admitted to the surgical ward. I met five different nurse assistants. None of them had changed a stoma bag before they met and helped me. I could not do it myself because I was bedbound at the time.*

Positive experiences of continuity

Despite the opinions stated above, participants found having access to the cottage hospital gave them a feeling of security, and that living in a rural area makes no difference as far as healthcare is concerned. One participant had constant contact with the same physician regarding stoma-related problems, and this was perceived as effective and positive. Participants remembered receiving adequate information about their stoma at the time of index surgery. Some of those living closer to the university hospital, had continued meeting the same specialist stoma nurse at the university hospital, which was considered positive. Others, who lived further away, met the stoma care nurse only once, at the time of index surgery, and thereafter all contact regarding stoma-related problems was with the cottage hospital.

> *I believe the healthcare system works really well, I have never had any problems. I have heard a lot of complaints from others but I never had any problems even though I have had frequent need of it.*

> *I 'm called to the cottage hospital every time I ring and tell them I need help. They help immediately. It feels wonderful. They admit me for a couple of days.*

Discussion

For individuals living in rural areas in South Lapland, northern Sweden, life with a stoma is experienced as a learning process. This study shows that acceptance of its existence is crucial for patients to be able to cope with their new life, many of whom felt that the stoma had radically changed their life. Participants described the stoma initially as something unnatural and unpleasant, though with time they learned how to manage their stoma and life became easier. The pleasure of still being able to practice leisure activities and hobbies was an important component for acceptance. Still being able to do the things that they valued in life caused participants to admit that having a stoma did not constitute an obstruction to living an ordinary life.

Participants had made sacrifices to some extent regarding their daily activities. Even so, acceptance of their stoma made it possible for some to experience it as being a positive change in life because of its convenience. Participants accepted their stoma as a symbol of the disease that they had defeated; the stoma was now not something unnatural and unpleasant, but a reminder that they had survived cancer or become free of symptoms from their IBD.

One way of understanding this process of accepting a new body is Merleau-Ponty's concept of body-subject. In *Phenomenology of Perception* [12], Merleau-Ponty draws a line between being a physical object and a physical subject, or body-subject. He believes that the body lacks characteristics of being purely an object. An object is believed to be able to lose or gain characteristics or to be seen from different perspectives yet still being the same object. The body however does not exist in the same manner as an object, the body persists from *my* point of view. As opposed to an object, Merleau-Ponty believes that *my own body* is always perceived by itself. Having a stoma changes the perception of what was once perceived as the body-subject. Acceptance of this change, *i.e.* that during the acceptance process participants perceive their stoma as a part of their own body subject, may explain the results of this study.

The experiences of the healthcare system varied among those interviewed. The absence of competence in stoma-related problems in rural areas compared to that at the university hospital was perceived as an inequality. Participants told of difficulty in getting help with their stoma-related problems. This was an inconvenient process and finding someone willing to take responsibility was difficult. The only contact with stoma care nurse that many had was in conjunction with index surgery. Now they had to depend on contact with the cottage hospital for advice, where competence was experienced as variable. Danielsen *et al* showed that patients attending organised education from staff with extensive experience of stoma patients, had a significant rise in quality-of-life. There is thus reason to believe that stoma care provided by the cottage local hospitals is inadequate [28], and that increased collaboration between the specialist unit and primary healthcare must be encouraged. Lack of communication between colorectal cancer care providers has been shown to lead to the perception of inadequate healthcare [37]. Given the long distances involved in these rural areas, such collaboration could, be carried out using e-health solutions; techniques that have been shown to be feasible in this particular region [38].

Lack of continuity in the primary healthcare system, *i.e.* constantly having to meet a new doctor with little idea of the patient´s history, was experienced as cumbersome and frustrating. This is not a unique problem for rural areas, but nevertheless is annoying for the individual patient. Lack of continuity is not only a subjective problem for the patient but has also shown to have an negative effect on mortality [39].

The process of ordering stoma dressings via the healthcare system's webpage was experienced by some as unfair. Patients with diabetes, for example, have a prefilled form for ordering their equipment while a stoma dressing order must be filled in manually. This is a relatively easy problem to fix; a change that will have a positive impact on the lives of stoma patients in rural Sweden.

Generally, participants perceived the existing healthcare system positively. That the cottage hospital is open day and night gave patients peace of mind. Participants could have met the same physician for their stoma-related problems for many years, a fact some had experienced as very convenient. Those who had regular contact with a specialist stoma care nurse were very satisfied. Others, whose only contact with a stoma care nurse was in conjunction with index surgery often remembered that the help and information they received was good. This positive experience of the specialist stoma nurse has been described previously [40].

Stoma-related problems vary and are unpredictable. Sudden stoma leakage could greatly inhibit the participant's freedom. A constant worry caused by unpredictable stoma-related problems has previously been described in a similar study, but not focused on living in a rural area [41]. To cope with this situation, creativity and planning are essential if the patient is to partake in personal and social activities.

The results of this study, where the life with a stoma is experienced as a process are consistent with other studies [42,43]. That life experience is a factor that determine the way patients adapt to their stoma has been illustrated by Capilla-Diaz et al. [19], what our study adds to the scope is the rural Nordic experiences. Experiences of how it is to change a stoma bag while working as a lumberjack in minus 20 degrees Celsius adds an important perspective to previously published studies regarding quality of life of rural material of stoma patients [44]. Interestingly, the need for acceptance to be able to adapt with the stoma seems to be similar to results from non-rural studies [42,43].

In this study results show that the disease that led to the stoma could affect how the stoma was experienced. If the reason was emergency surgery, the experience was traumatic while to those who received a stoma after planned cancer surgery it could act as a symbol for surviving cancer. This symbolism has been showed in previous non-rural studies [8,42], but the experience of the convenience of having a stoma while riding a snow mobile is not previously described which adds a rural perspective.

In this study, most of the commonly occurring major stoma problems [45] were described among the participants, which suggests that the study cohort was representative and strengthens the credibility of the study. Since stoma dressings are subsidised in Sweden, recruitment of participants from the drug prescription register increased the likelihood that all stoma patients living in the rural area in this study were available for inclusion. That data was coded by two authors besides the interviewer also increases the credibility. The interviewer and the informant had no doctor-patient relationship, increasing the confirmability of this study. All results presented in this study are exemplified by one or more quotations, showing consistency between data and findings, which increases the dependability of the study.

The interviews were conducted with participants living in a rural area in northern Sweden, and we consider the applicability and transferability of our results to stoma patients living in other rural areas to be good and is a strength of this study. On the other hand, you can imagine the applicability and transferability to patients living in more urban settings would be doubtful. On the other hand, experience of symptoms described by participants in this study should not differ that much from symptoms perceived by stoma patients living in an urban setting. A lack of specialised stoma care could affect symptoms negatively, leading to biased answers compared to patients living close to a well-functioning specialised stoma care unit. Nevertheless, how symptoms are experienced as a result of lack of specialised care and the effect of these symptoms on everyday life is not less true for participants included. The transferability of findings to patients with dementia and those not speaking Swedish, the dominant but not the only spoken language in Sweden, is very limited. The transferability to younger individuals is also reduced since all participants were older than 65. The number of participants in the study was judged to be sufficient since no further information appeared after 13 interviews. A weakness of this study is not using the principles of *information power* when deciding about sufficient sample size. Maltetud et. al have published a model for determining sample size in qualitative studies based on; aim, specificity, theory used, quality of dialogue and strategy for analysis [46]. Instead, we continuously discussed merely the quality and diversity of data. However, a high proportion of all available rural living stoma patients were included in this study.

Conclusions

In this qualitative study on stoma patients, perceived experiences of living with a stoma in a rural area was that acceptance of the stoma is crucial. General practitioners and nurses in primary care need to have a better understanding of stoma-related problems since these are common and strongly affect the lives of these patients. Despite previous research showing the advantages of continuity in primary care, this remains a problem in rural areas. Increase in cooperation between primary healthcare and specialised units would improve both continuity and understanding of stoma-related problems. A way of facilitating the initiation of such cooperation, is undertaking future research studies which describe the experience of the practitioners in rural areas as well as in specialist units regarding their experience of rural stoma patients. E-health solutions have been shown to be feasible within the region studied and could be implemented in stoma care; tools for examining the stoma from a distance could ease the situation. Minor practical changes, such as an easier process for ordering stoma dressings on the healthcare provider's webpage, would make life easier for rural stoma patients in Sweden.

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APPENDIX

Interview guide

1. Can you tell me what it is like to live with a stoma?

- Describe an ordinary day for you
- What do you like to do?

2. Has your life changed since you received the stoma?

- How has your life changed?
- Are there any activities that you no longer can or are willing to do after having a stoma? Give examples
- Has the stoma affected the way you act in the social context? How?
- Has the stoma effected your leisure activities or hobbies? How?
- Has the stoma affected the relationship or sexual life with your partner? In which ways? If "yes", was that something you recieved information about prior to surgery?

3. Have you had any problems related to the stoma?

- What was the nature of these problems?
- Do you contact your GP when you have problems related to your stoma? If"no", why not?
- Have you ever contacted your local nurse or GP when you have had problems with your stoma?
- Who did you contact when you had problems with your stoma?
- Have you had contact with a stoma care nurse? Where? When?
- Could you attend the university hospital department to have your stoma examined if needed?
- Do you believe you have received proper information regarding your stoma? Give examples
- Do you believe that living in a rural area affects your life with a stoma? Give examples

4. Can you tell me how you manage your stoma?

- Tell me how you change your stoma bag

5. Have you experienced that having a stoma effects your everyday life?

- Have you experienced that the stoma affects your self-esteem? Give examples
- Have you experienced that the stoma affects your body image? Give examples

6. Is there something else that you would like to tell me about your stoma?
7. Is there anything you believe other people about to get a stoma should know?

- Something you didn't t know when you got your stoma?
- Is there anything you have learned during your time with a stoma that you would like to share with others?

8. Do you have any suggestions on what could be done to ease the situation for stoma patients living in a rural area?