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Colorectal cancer survivors' adjustment to permanent colostomy in Switzerland: A qualitative analysis

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Abstract

Colostomized colorectal cancer survivors present physical, psychological, and social difficulties after treatment, which complicate their return to normal life. Nevertheless, we lack insight into their lived transition experience after treatment in Switzerland. We led nine semi-structured interviews with participants who had a colostomy for a mean of 16.4 years. The participants' mean age was 73.1 years. Through an inductive thematic analysis, we highlighted several adaptation difficulties. Their body image was poor, and they behaved differently than before the surgery. For fear of being rejected, they concealed their colostomy. However, they felt isolated and often wished for more support. They may be in a vicious circle where their difficulties are maintained. We advocate that supporting survivors psychologically beyond the end of their treatment is essential to facilitate adjustment and overcome cancer.

Keywords

colorectal cancer, colostomy, inductive thematic analysis, qualitative study

Colorectal cancer (CRC) is the third most prevalent cancer worldwide, and the survivors frequently experience invasive treatments (Globocan, 2020). In Switzerland, CRC incidence rates are 46.4 for women and 60.3 for men per 100,000 (National Institute for Cancer Epidemiology and Registration (NICER), 2023), while worldwide rates stand at 22.4 for women and 27.1 for men per 100,000 (Globocan, 2020). The treatment for CRC may involve a surgical operation, resulting in 11.8%–17.3% (depending on the operation type) in a permanent colostomy (Burghgraef et al., 2024). To date, no statistical data is available regarding the prevalence of colostomy among patients who have received treatment for CRC in Switzerland.

A colostomy is a surgical operation that involves connecting the colon or the small intestine to the skin. After surgery, a portion of the intestine remains visible on the abdomen, creating a stoma. The colostomy may be

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temporary or permanent (Guetz et al., 2008; Lanz et al., 2017). Its purpose is to replace the rectum; the feces go from the intestine to the colostomy, where a pouch stuck to the skin stores them. The pouch should be regularly changed (sometimes more than twice daily).

Overall, cancer, treatment, and having a colostomy involve several physical, psychological, and social negative consequences, which may result in a diminished quality of life in colostomized CRC survivors (Grant et al., 2011). Regarding the physical level, 49% of colostomized CRC survivors modify their daily activities (Feddern et al., 2015). Individuals with colostomies often experience not only regular pain, fatigue, sleep disturbances, or neuropathies resulting from treatment but also find themselves impaired in performing certain activities (i.e. gardening or swimming). This situation can lead to a diminished sense of agency in survivors (i.e. "feeling of control over actions and their consequence," Moore (2016)), which may imply a reduced ability to take actions and control aspects of their own lives (Drury et al., 2017; Feddern et al., 2015; Grant et al., 2011; Han et al., 2020a, 2020b). Around 60% of colostomized CRC survivors may suffer from sexual difficulties (erectile dysfunction in men, vaginal dryness leading to dyspareunia in women) (Sutsunbuloglu and Vural, 2018; Tao et al., 2014). Moreover, using a pouch to store feces presents several disadvantages. The pouch content may leak or smell (Feddern et al., 2015; Liao and Qin, 2014). The skin around the stoma has to be regularly washed to prevent infection or irritation because of fecal acidity (Lanz et al., 2017). In addition, colostomized CRC survivors lose their ability to retain feces and flatulence. It may cause discomfort and a sense of disability (Thorpe and McArthur, 2017). Furthermore, colostomized CRC survivors frequently report bowel dysfunction causing diarrhea or constipation (Han et al., 2020b; Thorpe and McArthur, 2017).

Regarding psychological difficulties, the consequences of the surgery may make colostomized CRC survivors feel disfigured (Thorpe et al., 2009) and less attractive (Tao et al., 2014), negatively impacting their body image and global self-esteem (Ferreira et al., 2017; Ohlsson-Nevo et al., 2012; Thorpe and McArthur, 2017). They may suffer from anxiety (Xu et al., 2018) or stress (Thorpe and McArthur, 2017). Chongpison et al. (2016) reported that 31% of the permanent colostomized presented depressive symptoms. Additionally, several colostomized CRC survivors suffer from fear of cancer recurrence (Ohlsson-Nevo et al., 2012). The overall feeling reported by survivors is that their bodies betrayed them (de Figueiredo and Alvim, 2016; Thorpe and McArthur, 2017; Thorpe et al., 2009).

Finally, colostomized CRC survivors are concerned with several social difficulties. Because of their altered body image, they may isolate themselves (Tao et al., 2014) and not seek romantic relationships (Ramirez et al., 2014). For those in a committed relationship, the fear of the partner's gaze sometimes leads to difficulties in the couple's relationship (e.g. stopping bed-sharing) and couple breakup (Lim et al., 2015; Sun et al., 2013; Thorpe and McArthur, 2017). Colostomized CRC survivors may stop social activities because of physical difficulties (e.g. golf) or of fear of revealing their colostomy (e.g. swimming) (Grant et al., 2011; Sun et al., 2013). They may feel like a burden to their family (Lim et al., 2015), which leads them to avoid asking for support (Ohlsson-Nevo et al., 2012).

Studies (Lim et al., 2015; Ohlsson-Nevo et al., 2012; Sun et al., 2013; Thorpe et al., 2009) indicate the significant number and severity of difficulties that colostomized CRC survivors face in returning to a state of "normalcy" after treatment. However, as demonstrated by Thorpe and McArthur (2017), some individuals can successfully adjust after a colostomy, allowing them to lead normal lives and feel integrated into society.

Objectives

This study aims to explore the difficulties emerging through the transition from illness to survivorship experienced by Swiss colostomized CRC survivors. So far, international studies have shown broadly similar results regarding the difficulties of colostomized CRC survivors after treatment (Lim et al., 2015; Ohlsson-Nevo et al., 2012; Sun et al., 2013; Thorpe and McArthur, 2017). The situation in Switzerland needs to be examined, as post-treatment data are lacking. Perceived health status in Switzerland is higher than the Organization for Economic Co-operation and Development (OECD) average (4.2% of the Swiss population aged 15 years and over consider themselves in poor or feeble health in 2019, compared with an average of 8.5% in OECD countries) (OECD, 2021). Switzerland is among the countries with high survival rates after cancer (Allemani et al., 2018). In this regard, it is essential to point out that studies (Adeponle et al., 2012; OECD, 2021) showed that the context (i.e. socio-economical, cultural, or national) influences the adaptation of individuals during their return to normal functioning or regarding their perceived health status. The contribution of this study will be to explore the situation in a country with an excellent healthcare system. This study will thus contribute to the knowledge base on adaptation to colostomized CRC survivors in countries with different healthcare systems.

Methods

Design and procedure

We opted for a qualitative research design to investigate the lived transitional experience of permanent colostomized CRC survivors. The topic is often a taboo subject for colostomized CRC survivors. A face-to-face interview remains a rare opportunity to gather relevant data. This methodological approach enables the investigation and validation of the lived experiences of colostomized CRC survivors through an inductive thematic analysis (Braun and Clarke, 2019, 2022).

For this experiential qualitative research design, we employ Braun and Clarke's (2006, 2019) inductive thematic analysis framework based on a critical realism ontology and a constructionist epistemology (Guba and Lincoln, 2005). The inductive thematic analysis is particularly well-suited for this research. Its coding approach enables a comprehensive and nuanced understanding of personal experiences within their sociological and cultural contexts. The choice of this methodology reflects our commitment to authentically conveying the diversity of experiences of colostomized CRC survivors. We recognize language as a mediator through which the reality of survivors' experiences is partially accessible to researchers. It enables a comprehensive understanding of personal experiences within particular social and medical contexts induced by colostomy (Braun and Clarke, 2022; Braun et al., 2019).

We recruited permanent colostomized CRC survivors in the French-speaking part of Switzerland. The study's inclusion criteria were to be colostomized CRC survivors, be at least 18 years old, and speak French, which is the language of the study material. The ethical committee of the state of Vaud (CER-VD) approved this study (decision number 2018-00676). The Ligue vaudoise contre le cancer financially supported this study.

To recruit colostomized CRC survivors, we have contacted the presidents of two support groups of colostomized individuals located in Switzerland: Ilco Vaud and Ilco Neuchâtel-Jura-Jura Bernois (Ilco, 2024). Both were interested in the study. They allowed us to present our study during one of their general meetings. We distributed the study information sheet validated by the ethical committee. Through these meetings, we met around 70 members. Among them, 15 individuals showed their interest. We planned a face-to-face semi-structured interview at the participants' homes and collected their written consent. Participants did not get financial compensation, but we offered them some chocolate for their time at the end of the interview.

Participants

Among the 15 interested individuals, one withdrew due to additional medical difficulties, one did not manifest further interest, and four were not eligible for the study. Even though they had an ostomy, it was not related to CRC. Thus, the final sample comprised nine participants (four women and five men). They lived with a permanent colostomy for an average of 16.4 years (SD = 11.8, range = 0.5–35.0, median = 18.0). Their mean age was 73.1 years (SD = 9.5, range = 56.0–88.0, median = 73.0). Seven were engaged in a couple's relationship. Among them, six lived with their partner. One was widowed. All participants were retired except one, who was unemployed at the time of the interview. Two had a school education, five had an upper secondary education, and two had a higher education.

Interview

We developed a semi-structured interview guide. It explored four different topics: (i) lived experience of the illness; (ii) relationships with close, everyday relationships and social activities; (iii) coping strategies and available resources; (iv) recommendations and future projects.

The first author conducted the interviews in French under the supervision of a senior researcher trained in qualitative methods. They took place between July 2018 and November 2018. They lasted an average of 66.56 minutes (SD = 17.54, range = 38–97, median = 68). All were audio-recorded and then transcribed verbatim to be analyzed. The first author did the transcription. The translations from French to English of the excerpts presented in this article were made by Sandra Vuilleumier.

Analysis

We analyze the transcripts using a thematic analysis (Braun and Clarke, 2006, 2019; Braun et al., 2019). Our results predominantly rely on inductive reasoning, and we elaborate on their implications in the context of existing literature during the discussion.

The first and third authors read the transcripts verbatim several times to familiarize themselves with the data. They then generated codes that they grouped into categories from the verbatims. Codes represent a unique idea or basic information (Braun and Clarke, 2006, 2021, 2023). A unique relationship links the codes belonging to a category. Categories were then regrouped into themes, which organize the data into a central idea or concept and account for a significant amount of the data (Braun and Clarke, 2019; Braun et al., 2019; Clarke and Braun, 2016).

As critical realist researchers, we acknowledge our impact on study participants (e.g. what they tell us or who participates). In addition, we are convinced that our subjectivity shapes our comprehension of the analysis and data collection. Our sensitivity leads to different interpretations during data analysis that result from subjectivity, enabling the development of a critical reflection (Braun and Clarke, 2019; Braun et al., 2019). We limited our subjectivity when undertaking the analysis by discussing the interviews and the analyses. Nevertheless, it heightened our introspection and fostered a more comprehensive perspective. The insights and the experience shared allow us to broaden our thinking. Furthermore, we used a diary after each interview, transcription, and data analysis. It facilitated the documentation of our feelings and ideas, mitigating the influence of biases such as preconceived ideas, thereby enhancing the reliability of our results. Although this approach may marginally diminish reflexivity, the benefits outweigh this concern (Ahern, 1999; Tufford and Newman, 2012).

The first and third authors were responsible for the data collection and analysis. At the time of the interviews, the first author pursued a master's degree in health psychology. His professional trajectory included several years of experience in medical care as a healthcare aide in a hospital and treatment and rehabilitation centers. Additionally, he contributed to public health research within a foundation and engaged with several political university authorities. These multifaceted experiences endowed him with a deep understanding of the challenges arising from illness. However, a reticence to broach sexuality may have inadvertently limited the depth of study outcomes. The third author, with over two decades of experience as a nurse in diverse healthcare settings, transitioned to a role as a psychologist specializing in qualitative research in health psychology. Accumulating extensive expertise in health research, from diseases to healthcare education, she guided and supported the first author through the analytical process.

Results

We categorized the lived experience of Swiss colostomized CRC survivors into four themes: (i) the colostomy: a handicap for daily activities; (ii) redefining the self: navigating through identity shifts, self-perception, and psychological support following a colostomy; (iii) relation with medical staff: between trust and understanding needs; and (iv) the eternal dilemma: disclose or not one's health condition to receive support. In the following section, we describe each theme.

The colostomy: A handicap for daily activities

Participants perceived colostomy as a handicap that can impede or even stop some activities. Some participants put their disability into perspective; for example, P2 (woman) explained: "Compared to someone who is missing an arm, I can work." However, others, such as P1 (man), insisted: "it is a major disability. It is not a small disability, it's very important."

Participants' self-perception influenced their engagement in activities and vice versa. Some took back control of their life, as P1 (man) who expressed that he "has plans for the future because we think we're in good shape physically, and we can still do things together." Some adapted and showed resilience, such as P8 (woman) stating: "You gain confidence, and then it's okay." Most of them agree that they have no choice but to adapt. P2 (woman) resigned: "Partly, I told myself this is how it's going to be. I have no choice now."

However, concerns about pouch leakage or perceived physical limitations led to refraining from engaging in activities they enjoyed, fostering social isolation. P1 (man) reported that "we cannot rely on the pouch." P9 (woman) resumed it: "We used to go to the beach often to swim. And we stopped that because I said no." P4 (man) confirmed: "Let's say that we're not as free as we used to be." These thoughts led some to stay at home where they felt safer: "Because, as to going out, we do it less and less because if we go to the movies or to see a play and if it starts to smell bad, it's a disaster." (P4, man). All participants experienced at least one pouch leakage. P3 (man) recalled: "It happened to me that I was eating at friends' houses, and during the meal [. . .], I felt 'Oh shit!'. There was pressure, it swelled up, it wasn't stuck right. There was a lot of it in my pants." Even at home, participants and their relatives suffer from these inconveniences, as P1 (man): "And then at night, well, it's a disaster. Oh well, that's unpleasant, for me and for her who does the laundry."

Driven by fear of pouch leakage or smell, participants remained alert concerning their colostomy. They always carry some material to change the pouch to be confident. They exhibited behaviors bordering on obsessive-compulsive disorder. P2 (woman) described her rituals: "I also have some reflex gestures [she puts her hand on the pouch]. I move my hand and tada. I touch it just like this with my hand, and there we go, no worries."

Means of travel influenced the scope of activities that could be carried out. Preferences leaned toward options allowing quick stops in case of pouch leakage. Long journeys required extensive mental and material preparation. P5 (woman) illustrated the challenges: "If I wanted to leave for two or three days, it's okay. Now, I have to think about what I need to take, if I have enough or not enough."

Colostomized CRC survivors faced challenges related to constipation or diarrhea that impaired their ability to engage in activities, as P5 (woman) attested: "Because of food, I don't feel free. Maybe sometimes I can eat. But it depends on what I want to do next few nights." However, for others, food remained one of the few areas where they could fully exercise their autonomy and maintain a sense of personal liberty. P4 (man) remarked: "The food, I don't care, and I don't want to care. If I have trouble, I know why. But I don't want to begin to restrict myself on everything, let's say." P7 (man) followed the same reasoning: "I want morels mushroom, well sometimes I eat morels mushroom. But it doesn't necessarily do any good. And then the morels mushroom come out here." Such coping strategies appear prevalent among those who mention an experience of social isolation in their interview and may predict a support need.

Finally, the colostomy impeded the sexual life. Good communication within the couple mitigated the effects, although significant changes in sexuality were acknowledged. P1 (man) asserted that "sexuality is fucked" and P2 (woman) declared: "What changes in the daily life is having sexual relations; that's undeniable."

Redefining the self: Navigating through identity shifts, self-perception, and psychological support following a colostomy

Having a colostomy requires adaptations and often becomes a source of anxiety. Talking about the colostomy and recalling the associated events caused much stress for some participants: "It embarrasses me, and it reminds me of the whole process. All of it, from the beginning. It's embarrassing me. Really, it embarrasses me." (P4, man). Cancer, treatments, and colostomy negatively altered the image of colostomized CRC survivors, as P9 (woman) highlighted: "When I have to look at myself, that's the worst part. When you have to lower your head and then see, take care of it. It's not easy." and P2 (woman) described her discomfort: "When I look at myself in the mirror in the morning, obviously I feel different." Many felt less self-confident than before the cancer. However, some coped by personifying their colostomy, assigning nicknames such as "my friend" or "Brutus." By perceiving the colostomy as external, it lessened the threat to their identity.

Despite experiencing psychological difficulties, colostomized CRC survivors expressed reluctance to seek the help of psychologists. The support and understanding provided by the ostomy nurses appeared sufficient for them. The few who consulted a psychologist expressed disappointment, as they had hoped for immediate relief. Several mentioned that they employed a relativization strategy by comparing their experiences to those enduring tremendous suffering.

However, many colostomized CRC survivors also expressed a focus on the positive aspects of their life, such as P1 (man): "Well, listen, we enjoy life, the emotions we have, we have developed them. We've become sensitive to many things." Aligning with personal values becomes a priority for most, such as P2 (woman): "When you've been through what I've been through, you want to focus what's essential. [. . .] To agree with my choices and stop, in a way, enduring 'professional choices', things that don't suit me, actually."

Relations with the medical staff: Between trust and understanding needs

The cancer diagnosis was frequently unexpected and shocking and left the participants in a vital emergency, prompting them to take any measures necessary to survive. P2 (woman) confided it: “Obviously, I collapsed there, so, uh.” Furthermore, P9 (woman) said: “I said to myself, that’s it, everything is falling apart, what’s happening?” Some presented sequelae of the diagnosis announcement corresponding to a fear of recurrence, as P4 (man) evidenced: “[The doctor] gave me very a very low survival chance.” Since this event, he feared a recurrence. Others, like P5 (woman), remained apprehensive, stating: “I don’t know if, as the doctor tells me: ‘cancer can be completely cured’, but balanced [. . .] Once we enter there, we are constantly monitored until the end of our days.”

While they entrusted their physicians with the responsibility of treating them, many participants were not aware of the nature and implications of a colostomy. P5 (woman) indicated: “No, he didn’t explain to me what an ostomy was. Only that there was a surgery.” Finally, for some, the colostomy symbolized victory over cancer. A few embraced optimism, exemplified by P7 (man) statement: “I said: ‘Ah, I got my pouch. I’m good for 20 years.’ ”

At the hospital, participants acknowledged the value of caregivers. Stoma therapists provided extensive counseling and support after surgery. However, most CRC cancer survivors required more support upon returning home after surgery. P3 (man) explained: “But the ostomy girl [i.e., ostomy nurse], she comes every ten days, but that’s not enough in the beginning.” Despite this favorable perception of healthcare professionals, tensions arose when dealing with non-specialist nurses who lacked knowledge about colostomy. P1 (man) recalled where he felt like a burden: “I want to change the pouch. Could you be there for the material, just in case. . . And [the nurse] came but half-heartedly, right. She didn’t like it. [. . .] And then, she said to me, well if it’s okay, I won’t come back. She didn’t care at all. It wasn’t her business.”

Finally, participants expressed the feeling that there was a disinterest in the medical and nursing staff for some of their comorbidities, such as prolapsus, skin irritation, or blood in the feces. It rose doubts about the skills and knowledge of the caregivers. A few participants lost confidence in medical staff and felt neglected, as P7 (man): “I think they don’t know. They don’t know. We don’t know who to ask to get an answer. To say, this is how it is, that’s all.”

The eternal dilemma: Disclose or not one’s health condition to receive support

Colostomized CRC survivors faced a dilemma. They might need more support but also want others to consider them normal. Although those around the participants assisted them in many tasks, such as mowing the lawn or moving the vacuum cleaner across floors, and accepted their colostomy, many participants were often afraid to disclose their medical condition even to their relatives. They wore loose-fitting clothes, high-waisted pants, or even a belt to conceal their pouch.

More than half of the participants feared to shock others if they allowed them to see, hear, or feel their colostomy. P3 (man) asserted: “Of course, it can bother others. What’s that thing? Uh, he’s got something coming out of his belly. What the hell?” P4 (man) approved: “If it starts to stink, do you believe he’s going to say to me: this one, he’s farting, or what is he doing? He doesn’t know that I have an ostomy, let’s say. [. . .] No, exactly, I can’t do anything about it, but the thing is, he doesn’t know that I have an ostomy.” Therefore, they concealed their condition. It happened that their fears took shape, as P3 (man) experienced it: “She probably smelled it, a little bit of it. And then, she got up and ran away.” Such behavior hurt, offended, and reinforced a negative self-image. Participants felt “put aside, pestiferous.” (P3, man). P5 (woman) mentioned: “It shocks me that he has to react this way.” Contrastingly, a lack of reaction from their surroundings boosted their confidence in their body image. P6 (man) noted that their colleagues simply “don’t care,” providing a positive contrast to his fears of rejection.

Overall, participants expressed positive relationships with individuals in their immediate social circle, as P9 (woman) stressed: "And sometimes we laugh about [the pouch]. Depending on the noise, we laugh about it. And there is no embarrassment. We never hide anything from each other. With some friends there is no embarrassment. It goes very well."

Regarding their professional lives, some participants disclosed their health issues to their employers, whereas others concealed them because of apprehension regarding termination. Divulgating their condition allowed them to adjust their workload and receive support. In addition, they felt relieved to appear freely, as P2 (woman) mentioned: "I had written in my email that I was open to all questions, that we could discuss it, and that there were no taboos. That's it. But it was lucky I did it! Because if I hadn't, it would have been difficult." On the opposite, concealing the pouch was distressing.

Participants reported that society at large remained mainly unaware of the challenges they have to face and their specific needs. One recurring issue encountered by the participants pertained to the coverage provided by health insurance companies, as they noted that their medical equipment was essential and that they could not forego its use.

Participants sought a substantial amount of information, primarily relying on professionals and support groups for assistance. Such groups provided a space to talk without taboos. Inexperienced colostomized individuals benefited from the experience of others. P3 (man) said he could: "give advice, reassure them, tell them that no one kicked the bucket. That we can battle through. That we must keep smiling, that we must go forward. That we must not retreat into the grave, that we must move forward. No, if I can do anything to help, I gladly will. There is no problem."

Discussion

The descriptive examination of data allowed for a comprehensive understanding of the observed phenomena, shedding light on four themes. We explored the potential links and associations between themes and the literature in the discussion.

Our participants face enduring physical, psychological, and social difficulties after treatment completion. These difficulties significantly impact daily life and are not merely a matter of managing the pouch. The following section discusses the key elements that contribute to the state experienced by colostomized CRC survivors.

The first theme focuses on the disability associated with colostomy, leading to stopping activities. Our findings match those of Thorpe and McArthur (2017) regarding the complaints of having a disability, resulting in a diminished sense of agency and negatively influencing engagement in activities (Drury et al., 2017; Feddern et al., 2015; Han et al., 2020a, 2020b). Our results suggest a reciprocal relationship between self-perception and activities. The literature does not mention this relation but describes colostomized CRC cancers as feeling betrayed by their bodies (de Figueiredo and Alvim, 2016; Thorpe and McArthur, 2017; Thorpe et al., 2009). A sense of betrayal may be associated with a low self-image, potentially leading to stop activity. However, our results confirm that colostomized CRC survivors must adapt to their colostomy. Lim et al. (2015) reported similar challenges among participants based in Singapore. What distinguishes our study is the assumption of rituals that could be associated with obsessive-compulsive tendencies in the long run. Colostomized CRC survivors attempt to control the pouch. The control of the pouch could also involve nutrition and, therefore, digestion. Through food, colostomized CRC survivors could influence digestion and thus experience a sense of freedom, constituting a novel perspective. According to the disabling effect of the colostomy and the digestion, our results show that colostomized CRC survivors pay attention to transport modalities. It illustrates the breadth of their challenges within mundane contexts. To our knowledge, it is the first study to highlight this aspect. Concerning sexuality, survivors also perceive colostomy as a handicap. Both our participants and those of Sutsunbuloglu and Vural (2018) and Tao et al. (2014) express disruptions in sexuality. While discussion may help manage these difficulties, there is a significant impact.

Our results from the first themes enhance our understanding of adaptation colostomy over time. A vicious circle may ensue: a leaking pouch leads survivors to stop the activity; they retire to their home, where they feel safe; when survivors attempt the activity again, they focus on their pouch, and at the slightest doubt, they stop the activity; the conclusion would then be that the activity is not suitable because of their disability. Some authors (Blows et al., 2012; Little et al., 1998) have employed the concept of liminality (Van Gennep, 1969) to describe the sense of disorientation that cancer survivors experience, as they do not feel that they belong to either healthy population or the group of cancer patients. This concept could be related to the experience of survivors caught in a vicious circle. However, a virtuous circle may arise with survivors who try activities and do not experience leakage from the pouch. They are likely to explore alternative activities and gradually engage in them, leading to increased self-confidence and a greater sense of comfort. Although this hypothesis requires validation, it could explain the various levels of adaptation reported among survivors in studies (Lim et al., 2015; Sun et al., 2013; Thorpe and McArthur, 2017).

The second theme highlights the alteration of the self-image of colostomized CRC survivors. Regardless of the country, survivors feel disfigured and less confident than before the cancer (Ferreira et al., 2017; Ohlsson-Nevo et al., 2012; Thorpe and McArthur, 2017; Thorpe et al., 2009). To mitigate their apprehension, our participants personify their colostomy. This coping method was not previously described in scientific literature. Surprisingly, they felt confident about getting over the situation without formal psychological assistance. The latter contradicts the results of Anderson et al. (2013), which indicated that most of their participants wished to receive psychological support. Many of them sought advice on their lifestyle. In our study, ostomy nurses provided this support, which may explain the difference. Nevertheless, it highlights that medical staff should give more information about the potential benefits of seeking assistance from mental health professionals. Such support will likely shorten the time required to change survivors' perceptions of their condition and facilitate their adjustment to the colostomy in fostering psychosocial resources (Mosher et al., 2016). Nevertheless, colostomized CRC survivors also express some significant life changes. They focus on the positive aspects of their life and live according to their values. Our results align with the studies of Appleton et al. (2013) and Anderson et al. (2013). It illustrates that colostomized CRC survivors can experience comfort and maintain a good quality of life.

The third theme, "links with the medical world," illustrates the dependence of CRC patients on their doctors to manage their health problems. Colostomized CRC survivors encounter many challenges when they return home after surgery. Our results show that they feel isolated and need more support. Lim et al. (2015) found similar results in Singapore. Studies on other cancers acknowledge that survivors feel emptiness after treatment (Crispin et al., 2013; Matthews and Semper, 2017; Powers et al., 2016). In addition, the fear of recurrence remains widespread, as Ohlsson-Nevo et al. (2012) demonstrated. Our results suggest that how the diagnosis is announced might increase it.

The fourth and last theme highlights the difficulties encountered by colostomized CRC survivors concerning the social domain. The desire for more support conflicts with the need to conceal the colostomy. This dilemma extends to their professional lives because they fear being fired. These findings are consistent with the studies conducted by Ohlsson-Nevo et al. (2012) and Little et al. (1998). We observed that colostomized CRC survivors who openly discuss their colostomy often receive positive support from others. The adjustment process depends on verbal and non-verbal communication skills (Sun et al., 2013; Thorpe and McArthur, 2017). Conversely, concealing the colostomy leads to feeling exposed, different, and sometimes isolated (Thorpe and McArthur, 2017). Colostomized CRC survivors suffer from societal misconceptions regarding their needs and difficulties. It may explain why many participants felt closer to others in remission than those who had never had a health problem, as highlighted by Little et al. (1998). This phenomenon may exacerbate the isolation experienced by colostomized CRC survivors, potentially leading to distress or suffering. Many turn to support groups for information and social integration, as also reported by Appleton et al. (2013). Peers in these groups provide empathetic support and understanding for adjustment difficulties.

We anticipate that most of our findings should be transferable among countries characterized by analogous healthcare systems. Novel insights exemplified by manifestations of rituals that could lead to obsessive and compulsive tendencies or the choice of food to experience a sense of freedom may even remain invariant across healthcare systems. However, specific outcomes, notably those associated with the utilization of public transportation networks, should be considered with attention. Congruent results may only be expected in countries featuring comparable extensive transport infrastructures. Other findings, such as the way the diagnosis is conveyed exerts an influence on the fear of cancer recurrence, may be dependent on the healthcare system.

This study presents some limitations. Firstly, it is essential to note that six out of the nine participants in our sample have been living with a colostomy for over a decade. This prolonged experience may have induced a habituation effect, potentially diminishing the perceived problematic effects associated with colostomy. Secondly, we recruited our participants from support groups. The population represented by these support groups may look for support, which could introduce a bias in our results (Wright, 2016). Nevertheless, this effect would offset the first limitation. Finally, we recruited our sample by convenience sampling. Therefore, isolated colostomized CRC survivors may not be represented in the study. Several individuals declined to participate in the study, explaining that they did not feel ready to discuss their experience. It is possible that our results underrepresent the proportion of colostomized CRC survivors who experience profound unease or isolation.

Conclusion

This study aimed to explore the experience of Swiss colostomized CRC survivors through their transition from illness to survivorship. Colostomized CRC survivors experience profound psychological and social challenges. Anxiety and fears of recurrence, often intensified by the announcement of the diagnosis, can lead to obsessive-compulsive disorder. The sense of vulnerability further complicates adaptation to the stoma, perceived as a definitive handicap with implications for daily activities and intimate aspects of life as previously acknowledged in other studies (Drury et al., 2017; Feddern et al., 2015; Thorpe and McArthur, 2017).

Positive factors, including a constructive attitude toward the stoma and cancer and resignation, offer some resilience. However, the overall impact on self-perception is substantial, influencing activities, self-image, and relationships. Difficulties with digestion contribute to isolation, particularly in fear of leakage, with eating as a symbolic bastion of freedom for some.

Despite the evident psychological difficulties, a noteworthy finding is the reluctance of colostomized CRC survivors in Switzerland to seek professional help. It underscores the importance of targeted prevention and normalization efforts in addressing the unique challenges faced by this population. As highlighted in other studies, a shift in behavior is observed as they strive to align with their values and life goals (Anderson et al., 2013; Appleton et al., 2013).

The relationship with healthcare providers is nuanced, with stoma therapists receiving accolades. At the same time, some doctors and nurses are perceived as showing minimal interest in survivors' difficulties, leading to a potential erosion of confidence in medical care. Socially, survivors express a desire for more support while concealing their colostomies due to a pervasive fear of dismissal or rejection. The societal misunderstanding of their needs further exacerbates this challenge.

Clinical implication

Living with a colostomy is a very challenging experience, and people must have the opportunity to return to a comfortable life after treatment. The difficulties faced by colostomized CRC survivors can result in isolation and dissatisfaction with their lives. Therefore, it is imperative to prevent such negative post-treatment trajectories. One solution involves providing psychological support from the end of treatment until colostomized CRC survivors regain their sense of well-being. Mental health professionals should emphasize that psychological support may not yield immediate results but is beneficial over time, as Mosher et al. (2016) suggested. Early and long-term support from health psychologists can enhance the likelihood of successful individual adjustment for colostomized CRC survivors.

Author contributions

Thierry Mathieu: writing, conceptualization of the study, data analyses and interpretation. Sarah Cairo Notari: contribution to the writing of the introduction and the discussion. Fabienne Fasseur: data analyses, contribution to the interpretation of the data and to the writing of the discussion. Nicolas Favez: contribution to the writing of the introduction and the discussion; supervision of the analyses.

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Data sharing statement

Due to the nature of this research, participants did not agree for their data to be shared publicly, so supporting data is unavailable.

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Ethics approval

The ethical committee of the state of Vaud (CER-VD) approved this study (decision number 2018-00676).

Informed consent

Participants provided written informed consent.

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