

Adults' and their care partners' perspectives of living with a stoma: a qualitative descriptive, community-based inquiry

ABSTRACT

Individuals living with ostomies in small communities rely on friends, family, and health-care professionals for support, otherwise, they risk becoming isolated, which may affect quality-of-life.

Objective This study explored how individuals and their partners manage ostomy care and engage in daily activities.

Method This study utilised semi-structured interviews to explore perspectives of six participants living with an ostomy and two care partners in eastern Canada. Participants were recruited through a hospital ostomy service and community libraries. Adults with ostomies and their partners willing to articulate the journey of living with a stoma were recruited. All data were analysed using reflexive thematic analysis.

Results Participants were challenged to receive consistent support from an ostomy nurse. Partners were not included in education sessions. Participants quickly adopted an independent self-management approach, were resilient and resourceful. Consistent connection to the ostomy clinics and accessible face-to-face or online supports were lacking. Participants searched web-based platform for support to manage complications.

Conclusion Nurses specialised in ostomy care are in a position to support adults living with ostomies, and their care partners. Consistent, relevant education and supports should be offered by interprofessional teams.

Keywords qualitative research, ostomy, quality-of-life, well-being, care partners

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INTRODUCTION

Ostomies are created for multiple conditions^{1,2} yet, adults living with an ostomy are often called an out-of-sight population.³ This may be related to privacy of dealing with leakage, flatus, constipation, change in appearance and sexual problems and feeling unwell and or depressed.³ Once the stoma is created, the client's pain and discomfort may be reduced from their original complaint and quality of life may improve,⁴ yet, they may face complications such as blockages, bowel obstructions, hernias, skin irritation and or infection.^{3,5,6} The long-term management of the ostomy and associated complications often falls to the patient and care partners.^{7,8} Adults with an ostomy report emotional stress, loss of privacy and body image challenges.⁹ Caregivers describe emotional and social stress due to the burden of care, such as managing leaks, supplies, skin irritation/infection, post-operative/procedure pain and dressings, travel and organising medical appointments.^{10,11} Patients also express dissatisfaction when health-care professionals lack knowledge of stoma care, sexual health, loss,

change or adaptations to patient's employment, menopause or those living with fertility issues^{12,13,18} Patients would prefer to heal and have alongside an interprofessional team for long-term assistance.⁷ Patients also report stress related to multiple surgeries and changes to travel and daily routines (such as fatigue, sleeplessness) and fear of fecal/urine leaks in public or social settings.^{4,11,14}

Finally, researchers describe the benefits of phone support for patients as an effective way to trouble-shoot potential or actual stoma/skin problems; as well, patients gain emotional support and a review of ostomy education and management skills.¹⁵ Furthermore, adapting to living with an ostomy improved when the client had a supportive care partner/family member¹⁶ and ostomy education from knowledgeable nurses.¹⁷ Understanding the supports needed by people living in small and rural communities is especially important, as they may not have an ostomy nurse/service readily available.¹⁹

GOAL OF STUDY

We explored the perspectives of adults living with an ostomy and the perspectives of their care partners in small communities. This is an important study as there are 13,000+ intestinal ostomies created yearly in Canada.²⁰

METHOD AND PROCEDURES

Design and sample

We used a descriptive research design, particularly important in health studies to explore participants' experiences in naturalistic settings.^{21,22,23} This approach gives voice to individuals' perspectives and also supports presentation of

the themes in everyday language, making them accessible to participants and broader audiences.^{24,25}

This study was framed in the Chronic Care Model (CCM) to allow a systematic analysis of the findings.²⁵ The CCM is a framework for managing chronic diseases. It emphasises patient-centered care, self-management and improving patient outcomes.^{27,28}

Data collection and research ethics

University ethics board approval was obtained. Participants were recruited and each was given a *Letter of Information* and an *Informed Consent* form. Each completed 45–60 minute interviews at a preferred location.

DATA ANALYSIS

Thematic analysis was employed to analyse the data from eight participants.^{28,29} We used ATLAS.ti²⁹ to organise, sort and code the data into key meaningful themes.²⁹ The researchers also read and re-read the data in a reflexive manner (for trustworthiness).²⁸ This reflexive stance allowed us to critically engage with the stories and ensure the themes were grounded in the participants' experiences.

FINDINGS

Participants shared their perspectives on living with and caring for an ostomy in small communities (475–6000 population). Interviews were conducted in participants' homes, with six adults and two male care partners (See Table 1). A \$20 gift card was provided to each.

Participants described undergoing multiple surgeries, diagnostic procedures, and interventions (such as colectomies,

Table 1. Participants demographics

Person	Name*, age, type of stoma (NA if partner)	Age at first surgery, diagnosis	Age at 2nd surgery	Employment / income	Ostomy teaching	Ostomy support group
1	Emma, 81, ileostomy	63, ulcerative colitis	66, rectal leakage	Retired at 66. Worked in service industry 40+ years	Yes	Yes
2	Grace, 71, ileostomy	18, Crohn's with 5-6 revisions	23, large bowel removal	Retired at 65	Yes	No
3	Alex, 77, colostomy	72, stage 3 cancer	72, stoma necrosis 5 days post-op	Works full time	Yes	No
4	Kendra, 31, ileostomy	30, ulcerative colitis	To be planned	Works full time	Yes, post operative	Intermittent online
5	Patsy, 66, colostomy, now ileostomy	33, cervical cancer	33	Disability pension started at age 33	Yes	No
6	Martha, 56, ileostomy	19, Crohn's		Works full time	minimal	No
7	Andrew, 46, NA			Works full time	none	No
8	William, 76, NA			Works full time	none	No

*names are pseudonyms used in the narrative analysis.

proctectomies) for conditions such as Crohn's disease, ulcerative colitis (UC) and colorectal cancer. With each intervention they described stories of resilience, adaptability, and the critical role of support systems. Each story reminds us of the importance of listening to stories of those who live with ostomies, as each offers a unique perspective.

HISTORY OF ILLNESS – MULTIPLE SURGERIES

Grace faced years of declining health that began with subtle symptoms. Once active and healthy, working in the service industry, her body began to betray her with persistent stomach pain and discomfort. Over time, she lost 60 pounds (27.2kg), weighing just 65 pounds (29.5kg). Her husband, recognising the severity of her health, took her to emergency with sepsis. She was transferred to a provincial speciality team for six weeks, a period that took a physical and emotional toll. During this time, nurses trained her husband to manage the stoma, but it was ultimately Grace who took charge insisting she had an “appliance to manage not a bag”. Her independence and determination to adapt became central to her life. Her husband **William** vividly recalls the helplessness he felt seeing her so sick, yet their shared resilience helped them navigate the challenges together.

Alex a retired grandfather, found life profoundly altered by a stage three cancer diagnosis. Years earlier, he had ignored a fecal screening test, but when a second test arrived, he completed it. The results led to an immediate diagnosis and colostomy surgery. Complications ensued, including tissue necrosis that required a revision. Over the next year, Alex endured months of chemotherapy and radiation. Despite these challenges, he remained steadfast in maintaining an active life, often driving across the province to visit family/friends. Now, he advocates for cancer screening, manages his stoma and shares his story so others will engage in preventive screening. He credits his resilience to his family, work ethic, and determination to live.

Kendra, a 31-year-old mother, underwent ileostomy surgery after six years of battling UC. The surgery was urgent and unavoidable, arriving at a time when she was raising her one-year-old son. Balancing recovery and motherhood were daunting, but her husband, **Andrew**, provided unwavering support, taking on household duties, childcare, and meal preparation. Kendra leaned on her family for strength and together began to rebuild their lives. Since the surgery, they have embraced travel, day trips, and family outings, finding joy in their renewed ability to live freely. Andrew reflected on his role, expressing surprise that he was not taught how to help with the stoma, but stepped up, nonetheless. For Kendra, family support was essential in navigating the emotional and physical demands of living with a stoma.

SELF MANAGEMENT

Participants described developing effective self-management skills. After initial adjustment to the stoma each owned and took on their stoma care.

Emma's independence and adaptability helped her navigate challenges, such as managing ostomy supplies and public outings. If she did not, she asked or checked, ensuring she could confidently go out in public. For her, adapting was key. Every five to seven days, she would change the flange/pouch and barrier wipes. The new loop and hook (Velcro) system for her bags, were far cry from the plastic clips she struggled with for 22 years; technology developments were a relief—as arthritis now riddles her hands. These minor adaptations, learned through experience, made life manageable. From the start, Emma managed her ostomy independently. It was how she had been raised, independent, always finding a way to keep going. It was an ostomy visitor, that once visited and inspired her after surgery, telling her she could still dance and swim with an ostomy. For Emma, this conversation is a constant reminder to live life to the fullest when doubt creeps into her life. Yet, there were challenges such as red, raw skin and necrosis around the stoma. However, she coped, using wipes to protect her skin and slipping paper towels under her pouch to absorb sweat. She wore an ostomy belt, although it did not fit perfectly, she adapted and found a seamstress to tailor it to her needs. The same thought applied to her undergarments—adaptation, comfort, making life work for her.

Kendra's journey with UC had been a long and arduous one. For six years, she was gravely ill, missing up to two days of work every week. Her teenager suffered in silence during those years, missing the joy of sports outings with her mother. Emma's body was frail, her diet restricted to chicken and carbohydrates, and she passed out due to low iron. Her husband held the family together, taking their daughter to events and managing the household. In the beginning, her husband helped with the baby, while she focused on her care. “The homecare nurses who visited post-surgery were amazing, offering care, guidance, and an ostomy booklet”. Despite challenges, Kendra remained fiercely independent. She managed her stoma, navigated public bathrooms with meticulous care, and took comfort in the small joys of life. Her loyal girlfriends were her stay in difficult times, and her connection to church provided the community support she needed.

CHANGE IN EMPLOYMENT

Participants described employment and financial changes due to health.

Emma described working as a house cleaner saying, “I do this for cash, nothing else, just cash to make ends meet. Keeping active and walking has probably saved my life. I walk to the grocery store, the pharmacy and any place I want to go. Though I started to feel tired, just tired, not depressed, just tired. So I take the bus, taxi or my boyfriend drives with me. This is so kind.” Emma says she went back to work in the service industry for 12 months after the ostomy was created. “I lifted boxes and managed a clothing section of a big store, I did not lift all the time, but I guess from walking so much I was strong and did not have hernia problems.”

Grace worked in an administrative role alongside her husband for many years. Her husband continues to work and has benefits that cover some of her medications and ostomy supplies, but some are not covered and are very expensive. **William** asked: "Why are these essential UC meds not covered?" **Alex** said he "continues to work full time after retirement as a dispatcher for a trucking team for funds" (*Field note, 2023*). **Patsy** had been very ill with UC for six years before surgery. She describes missing up to two days of work a week and was not paid on those days. Her husband works full time. Since the surgery she has been able to work full-time. "Having a supportive boss mattered, they were very supportive to get back to full-time with my ostomy benefits" (*Field note, 2023*). **Martha** described herself as fortunate as she had sick-time benefits. As an educator she was able to have her sick leave paid, and she is now back at work full time.

FINANCES AND ACCESS TO SUPPLIES

Participants expressed distress over the lack of secure funding for ostomy supplies and they had limited knowledge of tax credits available to them. Many seniors (over 65 years) on the Pharmacare program shared that coverage often didn't fully address the costs of medications and ostomy supplies. Participants described running out of benefit funds, using personal savings, and going to thrift stores or food banks to stretch their budgets.

Emma voiced frustration over the financial burden of a stoma. She explained her budgeting priorities, including subsidised rent, phone and television, and food costs that had risen dramatically post-pandemic. "My meds and ostomy supplies are most important—I don't have a choice. I didn't ask for this." She advocated for full coverage of medications related to her condition, emphasising the unfairness of the situation. "If you have to poop in a bag for the rest of your life, your meds should be covered." Despite these challenges, she maintained her resilience, adapting to her circumstances while advocating for systemic changes.

Grace highlighted the importance of her community pharmacist in managing her supply budget. "I trust the pharmacist in a community; it is accessible. I order my supplies through one trusted site; this is central to my ability to maintain my ostomy supplies reliably and affordably."

Alex found creative ways to manage costs, utilising stoma company flyers to request product samples and test new options. "Everyone with a stoma should be connected this way." While traveling as a truck driver, he carries pre-cut pouches/flanges for emergencies and relies on pharmacies in various locations to restock supplies. He credits his coping to being resilient and resourceful. He values his relationship with pharmacists, which allowed him to plan effectively during his frequent travels.

Kendra reflected on financial challenges, particularly during her maternity leave, when she earned only 55% of her salary. "It was extra stressful, but we managed," she said, crediting

her husband's unwavering support. She expressed a desire for better family education around ostomy care and finances. She also suggested developing a children's book to help families understand what to expect before and after surgery. "There should be better education for families, that is accessible and practical."

Martha shared she was in a good financial position for ostomy supplies due to her benefits. She pays for her supplies, and is later reimbursed, allowing her to manage her expenses effectively. "I go cheap and use plastic and paste—no fancy systems for me." Martha described her habit of organising her supplies at home, ensuring her family knew where to find them if needed. She wears her system for up to seven days, stretching her resources while maintaining comfort and reliability. Martha also praised her pharmacist and ostomy nurse "I drive 40 minutes to my pharmacy because I know my supplies will be there, and they're always correct."

PARTNER AND FAMILY SUPPORT ARE "SO IMPORTANT"

Emma described the importance of good friends: "I have a boyfriend; he has a car, like me he is a widow/er, and he is kind. We shop, visit, watch movies, go for coffee and meals, he is amazing. He knows and does not care about my ostomy." **William** said, "our friends are kind and know about my wife's stoma, they are loyal, kind and consistently visit, this matters in the long-term" (*Field note, 2023*). **Andrew** added the following:

The ostomy has been great, once I got used to it. It has been way better, now we can do things together, whereas before my wife had to be home due to frequent bowel movements. We can go out to eat anywhere and enjoy our food. We can go for longer drives, vacations; I finally have my wife back. My life was affected, yet I am less depressed as I can now take my wife out and go places without the added stress of having to explain to people why she was not attending. People don't understand the effects of UC. As well, I use Google, rely on the surgeons, doctors and nurses.

Patsy said: "Work friends are so good to me, and I am independent. I learned this from my mother and my illness. I drive where I want to go. To shop my son brings home heavy objects, otherwise I just manage." **Grace** said: "I really have a good group around me, my son and his wife. They get extra supplies if I am hospitalised and that happens a lot, I mean a lot. I worked with the ostomy nurse, and they are all reliable". **William** said, in hindsight: "I just kind of hovered after the multiple surgeries. I tried to be a good support. I work so I know we have money for everything she needs".

OSTOMY AND WEB-BASED SUPPORT GROUPS

In this study we specifically asked if participants were going to ostomy groups, and/or web-based supports. Participants shared the following.

Grace:

I did not really get connected to the ostomy support group though I knew it was there and got a call from the group. I

preferred to share my journey with a few trusted friends. I have good friends at church, my husband and family that are always kind.

Kendra:

The *Real Ostomy Support Group* online is my lifeline, you can post a question, ask the program to search for information, and you can also post. The interactivity is good. I do not go to the local ostomy support group, honestly, I was not given that information. I was surprised I was not given local resources. Are there others with stomas here, in my community? [she asked the researcher]. I would love to be more connected.

Patsy:

Well, I tried when I was about 34 or 35 years to go to the ostomy support group. I was not comfortable, so I went once or twice and never went back. I have good internet, but do not use it to read about stomas, well maybe sometimes, but no, not really. I am the type of person that would have benefited by having an ostomy visitor, maybe they offered, and I refused because I was so sick at times.

Andrew said “I read everything my wife brought home, I just read and read. I never was invited to go to a support group, in hindsight I might have gone” (*Field note, 2023*). **Emma** said: “I am learning how to use a tablet; I am not so good on a computer. I still use my phone or this great cell phone my daughter sent me. I used to have a flip phone, now I love my new phone, my kids are good to me. Between us we can look up anything we want.

Grace stated:

I do not use internet for ostomy information. I looked at ostomy sites few times and found the blogs too problem focused and not accurate, the sites did not seem to have an expert correcting some of the misinformation. Also, I do not like the complaining tone of the comments. I was surprised to see comments like this on a site that is meant to be supportive. These are demonstrations of poor coping skills; the poor comments and negativity will not help anyone adapt. They tell too much information, private information, every little thing that is not perfect is discussed. I do not use or recommend these to people.

Kendra described the importance of technology in the following comments:

Technology could be our best friend. We, as persons with ostomies, need easy access to a multidisciplinary care team, face-to-face or online. As I developed diabetes with my pregnancy with an ostomy, I was considered high risk, therefore I was referred to a speciality clinic. I was absolutely amazed, there was a dietician, physician, nurse practitioner, ostomy nurse. Though I only went once I had the understanding, they were a collaborative team. In my local site there is a surgeon, no dietician, and the ostomy

nurse. It was so different. I wanted to know I was part of a team that cared for me. I wanted a team that cared about my weight concerns, food and nutritional requirement for persons with an ostomy. I really would have benefited from good health information and referrals to credible websites to read and study especially to prevent complications. I really also needed a social worker (finances), psychologist (well-being), and ostomy nurse and pharmacist to help me and some of this could have been online.

EDUCATION RECOMMENDATIONS

In this study persons living with an ostomy and their partners described the need for local resources to be posted on the internet. **Emma** stated: “If and when I go online, I would like to see local, current information.” **Grace** requested: “I want to see better information about self-management skills and education materials that are current and relevant” **Patsy** requested: “I want education for men that you can still have intercourse with persons living with a stoma.” **William** stated: “I was just too quiet, I would have read more and studied the seriousness of the disease, we eventually figured out the intimacy thing”.

Andrew recommended:

Advocacy skills for the partner and encouragement to ask more questions. I wanted to make more informed contributions to the decisions we were undergoing. I wanted to be engaged and be able to find good education materials as well. Why is it just the person undergoing the surgery? I wanted to be educated to the fullest before any major decision.

DISCUSSION

In this study, we sought the voices of persons living in small communities. We systematically analysed the data seeking practical improvements.²⁶

We interviewed participants in a post-pandemic environment, and this may have had a bearing on the findings. Nevertheless, the stories collected contained rich findings and possible outcomes for the care of people living with an ostomy.

Connectedness between the patient and interprofessional team

The findings show participants strongly desired connection with an interprofessional ostomy team to improve support, health outcomes, finances and well-being.³¹ This need for connection was intertwined with themes of resilience and courage. Participants’ stories highlighted their ability to adapt despite challenges related to local food security, environmental and economic factors.^{32,33,34} Participants were resilient, adaptable and each engaged in a flexible response to multiple surgeries, procedures and testing. Yet they still wanted to know that they were connected to a team for urgent, non-urgent or complications-long term. Philips-Salimi et al. describe this concept as connectedness; this includes the importance of building trust-filled relationships between the care provider and patient.³⁵ Yet, the sense of being connected is not guaranteed, especially for people in small and rural

communities.¹⁹ Developing a sense of 'being connected' is richly intertwined with each individual's history, whether or not they want or need to be connected, their social and cultural influences, personality traits and ability to interact with others.³⁵

We believe that opportunities to connect could be facilitated through regular and relevant ostomy education for patients and partners. This could be developed by using robust websites, offering interprofessional web-based care, phone call support,¹⁵ and community-based educational opportunities for patients and partners. Long-term access to ostomy nurses is critical to facilitate this change, thereby promoting healthy patient outcomes and the prevention of complications.

The burden of the disease

Participants' quality of life with an ostomy was impacted by the chronic disease, surgeries, complications and the repeated nature of these events.^{5,37,38} Beyond the physical challenges, each surgery represents a significant life adjustment, affecting their daily routines, mental health, and the need to adapt each time. Of concern is the constant burden of finances for ostomy supplies and medication costs related to the underlying disease.³⁸ For this reason, ostomy teams need to include social workers and team members that can actively help with finances, reimbursement and be knowledgeable about any tax credit programs long-term.⁴⁰

Self-management and well-being

Finally, participants described the importance of developing effective self-management skills alongside team support.³⁸ As part of the team, participants wanted enriched support from a registered dietitian to help navigate meals, maintaining hydration and electrolyte balances.³⁸ This would help develop confidence and a sense of control over one's health, which is important for reducing anxiety, thereby improving well-being.^{38,39} Overall, the growing of one's self-efficacy is ongoing and would be enriched by interprofessional team supports.^{40,41,42}

IMPLICATIONS FOR PRACTICE

Similar studies in rural Canadian communities are needed to capture patient and partner experiences.¹⁹ These findings could enhance educational opportunities and highlight the value of relationships with ostomy nurses and the need for educational and financial supports for patients and their families.

CONCLUSION

Stories highlight the resilience and adaptability of individuals living with an ostomy, showing how life continues despite challenges. Though their paths are unique, the common thread is their determination to live fully, embrace independence and move forward with courage.

CONFLICT OF INTEREST

The authors declare no conflicts of interest.

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