

# Complex abdominal wall hernias as a barrier to quality of life in cancer survivors

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**Background:** Many cancer survivors live with postoperative complex abdominal wall hernias (CAWHs). However, the impact of CAWHs on their quality of life is unknown, and few descriptions of patient experiences exist. We performed a qualitative study to explore cancer survivors' experience with CAWHs before and after repair.

**Methods:** Patients waiting to undergo CAWH repair or who had completed the surgery in the previous 18 months were identified from a single surgeon's practice in CAWH at a tertiary care centre. Clinical and demographic data were extracted from the electronic patient record. An in-depth semistructured interview guide was developed by experts in CAWH and qualitative methodology. Interviews were conducted in March 2013. We used comparative analysis techniques and coding strategies to identify themes.

**Results:** Ten preoperative and 12 postoperative participants were interviewed. The average age of the participants was 64 years in both groups, with an even sex distribution. The most frequently diagnosed cancer in both groups was colorectal cancer. Participants' views were organized into 5 themes: 1) unable to return to normal life, 2) sense of abandonment, 3) experiencing fear and distress, 4) preoperative: desperate for help and 5) postoperative: "getting my life back."

**Conclusions:** Our findings show the all-encompassing impact of a CAWH on the life of cancer survivors. They strongly suggest that hernia management should be viewed as an integral part in the continuum of cancer treatment to improve the quality of life of cancer survivors with hernias.

**Contexte :** De nombreux survivants du cancer vivent avec des hernies postopératoires complexes de la paroi abdominale (HCPA). Or, on ignore quel en est l'impact sur la qualité de vie, et peu de descriptions existent quant à l'expérience des patients. Nous avons procédé à une étude qualitative pour analyser l'expérience des survivants du cancer présentant des HCPA, avant et après une cure de hernie.

**Méthodes :** Les patients attendant une cure d'HCPA ou ayant subi une telle chirurgie dans les 18 mois précédents ont été identifiés à partir de la clientèle d'un seul chirurgien pratiquant la cure d'HCPA dans un centre de soins tertiaires. Des données cliniques et démographiques ont été extraites des dossiers électroniques des patients et un guide d'entrevue semi-structurée a été conçu par des experts de la cure d'HCPA et de méthodologie qualitative. Les entrevues ont été réalisées en mars 2013. Nous avons utilisé des techniques d'analyse comparative et des stratégies de codage pour cerner les thèmes.

**Résultats :** Dix participants ont été interrogés en période préopératoire et 12 en postopératoire. L'âge moyen était de 64 ans dans les 2 groupes et il y avait autant d'hommes que de femmes. Le cancer le plus souvent diagnostiqué dans les 2 groupes était le cancer colorectal. Les perceptions des participants ont été organisées autour de 5 thèmes : 1) incapacité de retourner à la vie normale, 2) sentiment d'abandon, 3) sentiment de peur et de détresse, 4) préopératoire : immense besoin d'aide et 5) postopératoire : « retrouver sa vie ».

**Conclusion :** Nos observations font la lumière sur l'impact global de l'HCPA sur la vie des survivants de cancer. Elles suggèrent fortement que la cure de hernie devrait faire partie intégrante du continuum thérapeutique en oncologie pour améliorer la qualité de vie des survivants du cancer porteurs de hernies.

Patients with cancer are achieving improved long-term survival as a result of advances in early detection and multimodal, complex therapeutic regimens.<sup>1</sup> As of 2017, an estimated 60% of Canadians with cancer will survive at least 5 years.<sup>2</sup> Improvement in survival has been accompanied by a myriad of novel issues of survivorship.<sup>3</sup> Furthermore, it is well established that patients with cancer frequently do not return to normal health once they have completed treatment.<sup>4</sup> Many patients experience serious rehabilitation problems in the domains of physical, psychosocial, sexual, medical interaction and marital relationships.<sup>4,5</sup> New research and policy directions are thus focusing attention on survivorship care as a distinct chronic phase of cancer care, with an intense focus on quality of life.

The number of cancer survivors with postoperative incisional hernias, particularly complex abdominal wall hernias (CAWHs), has increased, and this condition now occurs in 11%–30% of patients.<sup>6</sup> Examples of CAWHs include recurrent hernias, hernias with an associated bowel fistula or the need for concomitant bowel surgery, hernias involving a synthetic mesh infection from an initial attempt to repair the hernia and very large hernias with loss of domain issues. Complex abdominal wall hernias can be challenging to manage owing to their large size and larger incisions, the presence of temporary and/or permanent stomas, the potential for multiple/staged operations, increased wound complications caused by chemotherapy and/or radiation, and postoperative complications, such as hospital-acquired infections.<sup>7,8</sup>

Hernias, specifically CAWHs, are known to have major physical, social and emotional repercussions on patients.<sup>9–13</sup> Despite important advances in abdominal wall reconstruction (AWR) surgery, several barriers to effective and efficient treatment continue to exist, including lack of surgical expertise and cost. Many patients continue to undergo failed surgical repairs<sup>14</sup> or are told that operative repair is not an option. Against the backdrop of a dearth of treatment options, many are forced to live with hernias that have a devastating impact on quality of life.

Previous studies have shown that hernia repair leads to marked improvement in quality of life measures.<sup>10,11,14</sup> To our knowledge, however, there are no studies that qualitatively investigate the impact of CAWHs on cancer survivors' lives from their perspective. A qualitative study design allows us to gain in-depth insight into experiential phenomena<sup>15</sup> by capturing patient-centred experiences. Qualitative research is increasingly used as a valid form of scientific inquiry. The strength of qualitative research is that it provides complex and rich descriptions of a patient's lived experience. Qualitative methods are effective in identifying how the broader social context, such as social norms, socioeconomic status and social supports, affect one's experience and health outcomes. Qualitative research can help us better understand the

complex reality of a given situation and interpret more meaningful implications of quantitative data.

Given the frequency of postoperative incisional hernias and the associated policy and practice implications, the impact of hernia repair or not repairing it warrants further exploration. The purpose of this study was to qualitatively explore cancer survivors' experience with CAWHs before and after repair. Our primary goal was to offer insight into the impact of CAWHs on the quality of life of cancer survivors with the view to identifying and addressing gaps in cancer survivorship care to inform policy and practice for this patient population.

## METHODS

### *Participants*

Patients with a CAWH were identified from a single surgeon's practice at a tertiary care centre. Clinical and demographic data including age, sex, type of original cancer and mean duration of follow-up were extracted from the electronic patient record. Research ethics board approval was obtained before the beginning of the study.

We used purposive sampling to interview patients who were awaiting surgery or who had completed surgery by a single surgeon using the same operative techniques for all participants as described in Appendix 1 (available at [canjsurg.ca/014917-a1](http://canjsurg.ca/014917-a1)). Postoperative participants had undergone repair for their CAWH following cancer surgery between September 2011 and July 2012. Purposive sampling is determined on the basis of theoretical saturation, the point at which data collection no longer yields new insights. The primary surgeon (F.B.) contacted patients by telephone to ask for their permission for another author (C.B.) to contact them to introduce them to the study and formally recruit them to participate in the research study. Preoperative participants on the existing surgical waiting list for CAWH surgical repair were contacted in chronological order. Participants provided written or verbal consent in advance of their participation.

### *Data collection*

Data were collected through in-depth semistructured one-on-one interviews, an optimal method for collecting data on people's personal histories, perspectives and experiences.<sup>15</sup> Participants were interviewed in person or by telephone in March 2013. An interview guide (Appendix 2, available at [canjsurg.ca/014917-a2](http://canjsurg.ca/014917-a2)) was developed by identifying domains of inquiry from a literature review and from discussions among the research team (R.N., C.B., A.J.S., F.B.). Interviews were recorded electronically, transcribed verbatim and verified for accuracy of transcription. Sample size was determined by thematic saturation, the point at which no new concepts emerge from successive interviews.

## Data analysis

Data analysis proceeded simultaneously with data collection by way of the constant comparative method<sup>16</sup> in that we began identifying emerging themes after the first interview, which informed subsequent interviews. The analysis was completed through 3 phases of coding by 2 members of the research team (R.N., C.B.). The first phase, open coding, consisted of reviewing transcripts with the view to dividing text into distinct ideas or concepts. The second phase, axial coding, consisted of comparing for consistency within and between transcripts via a combination of inductive and deductive reasoning to create a basic frame of overarching themes and conceptual supporting categories. The third phase, selective coding, consisted of further developing central themes by iteration to eliminate redundancy.<sup>17</sup> The data analysts conducted the analysis independently to confirm the accuracy of the coding scheme, ensuring that categories were comprehensive and reducing the influence of experience and preconception in the final framework. To show rigour, the research team evaluated the study results based on agreed-on criteria that enhance the quality of qualitative research: width (that the data are comprehensive), coherence (that the different parts of data interpretation create a complete picture), credibility (the research team's interpretations resonate with patients and the surgical community) and transparency of the research process.<sup>17</sup>

## RESULTS

A total of 10 preoperative and 12 postoperative participants were interviewed. Table 1 outlines their demographic and clinical characteristics.

Participants' views were organized according to 5 overlapping themes: 1) unable to return to normal life, 2) sense

of abandonment, 3) experiencing fear and distress, 4) preoperative: desperate for help and 5) postoperative: "getting my life back."

## Themes

### 1: Unable to return to normal life

Without exception, participants expressed the inability to return to their normal life owing to the presence of their hernia following cancer surgery. Descriptions of life as "restricted," "interrupted," "on hold" and "hell" were ever-present as participants recounted being unable or struggling to return to normal day-to-day activities, including bathing, walking, gardening and cycling. Furthermore, many were unable to return to work. Participants consistently reported that their hernias contributed to frequent pain and discomfort.

### 2: Sense of abandonment

Participants had an overwhelming sense of abandonment. They felt there was little or no support from their health care providers or from the health care system as a whole. Frequently, the only treatment option allotted was in the form of an intermediary support (abdominal binder), which did little to alleviate the impact of the hernia on their overall life. Until their assessment for CAWH surgical repair, many participants thought there were limited or simply no options for a permanent solution. Many had been told their hernia was inoperable or that the risk of repeat surgery was too high (in 1 case, the patient was told it would almost certainly result in death). Most were referred forward only when they had serious complications, such as multiple episodes of obstruction or incarceration, sometimes years after the first occurrence of complications (in 1 case, nearly 10 years). Many participants felt a strong sense of guilt over what could be perceived as complaining, even as they felt abandoned. Participants expressed that they were grateful for surviving their cancer treatment and thought that their postoperative hernia was something they "just had to live with" despite its severely limiting impact on their capacity to return to normal life.

### 3: Experiencing fear and distress

Both pre- and postoperative participants experienced substantial fear and distress around the potential complications of their hernia. Although many were not given the option to repair the hernia, they had been informed of potential hernia complications such as incarceration, strangulation or perforation. The constant fear of complications further limited their lives — many described limiting travel in case there was an episode of obstruction or incarceration. Some lived in fear of requiring unplanned, emergency, high-risk surgery, and others described living in fear of death from complications of their hernia. Overall,

**Table 1. Patient demographic and clinical characteristics**

Characteristic	Group; no. (%) of patients*	
	Preoperative n = 10	Postoperative n = 12
Age, yr, mean ± SD	64 ± 8	64 ± 10
Sex		
Male	5 (50)	6 (50)
Female	5 (50)	6 (50)
Length of follow-up, mo, mean ± SD	NA	12.4 ± 2.5
Type of original cancer		
Colorectal	7 (70)	6 (50)
Neuroendocrine tumour	0 (0)	1 (8)
Pancreatic	0 (0)	1 (8)
Ampullary	1 (10)	0 (0)
Bladder	0 (0)	2 (17)
Endometrial	1 (10)	2 (17)
Prostate	1 (10)	0 (0)

NA = not applicable; SD = standard deviation.  
\*Except where noted otherwise.

participants desperately wanted to stop living with the constant fear of a recurrence of the complications they had been experiencing. Even following repair, several participants continued to live in fear, specifically the fear of hernia recurrence, particularly those who had experienced debilitating complications before surgery.

#### 4: Preoperative: desperate for help

Participants clearly expressed that they were desperate for help. They desperately wanted to return to some level of normalcy in their lives. Many described feeling hopeless about their situation while being hopeful for substantially improving their quality of life once their hernia was repaired surgically.

#### Postoperative: “getting my life back”

Patients reported a substantial improvement in their overall quality of life after undergoing AWR surgery to repair their hernia. They recounted the different ways it had positively affected their lives, such as an improved body image and a renewed sense of confidence. Furthermore, although they did not necessarily return to the lives they had had before their cancer diagnosis, they felt they were able to establish a “new” normal. Many were able to return to work and to the activities that gave meaning to their lives before their cancer treatment. Several participants stated explicitly that the surgery to repair their hernia “[got] my life back.”

Illustrative quotes by theme are presented in Table 2.

## DISCUSSION

Assessing quality of life in cancer survivors is challenging. Most surgical studies examining quality of life involve quantitative measures such as the 36-Item Short Form Health Survey to develop cancer-specific quality of life measures.<sup>3,4,18,19</sup> These measures, however, evaluate only cancer-specific quality of life immediately after treatment or in long-term cancer survivors. We sought to explore the impact of CAWHs as an experience distinct from cancer treatment.

Traditional outcome measures following hernia surgery have centred around recurrence rates, resource use, hospital length of stay and physician-assigned patient outcomes. We suggest that patients’ self-reported outcomes are extremely important and offer an in-depth view of the patient experience around AWR surgery. The results of our qualitative study summarize the challenges facing this group of patients and, we believe, further underline the need for ongoing care, including that of CAWHs, in cancer survivors.

We found that the impact of a CAWH on the life of a cancer survivor is likely both substantial and underestimated. Our participants had considerable morbidity, with limitations in nearly every aspect of their lives, including

physical (decreased to no activity), psychological (decreased self-esteem and loss of confidence), social and sexual constraints. In addition, patients who underwent AWR had a dramatic improvement in how they rated their quality of life.

Patients with CAWHs that were previously considered impossible to repair can now be helped with AWR surgery. Although surgical repair with synthetic mesh is the current standard of care for uncomplicated hernias, advanced new surgical techniques that involve separation and medialization of abdominal wall musculofascial components to close the hernia defect have changed the way complex ventral abdominal wall hernias are managed.<sup>20,21</sup> These advanced reconstruction techniques may be further reinforced with a biologic tissue matrix or an absorbable synthetic mesh in complex hernias, where synthetic mesh may be contraindicated owing to the high risk of wound and synthetic mesh infection.<sup>22</sup>

Despite these advances, and although patients are frequently highly symptomatic, our participants reported that there was often a prolonged delay and hesitation regarding surgical management of a CAWH. As a whole, surgical repair of CAWHs is often restricted to surgeons with expertise in AWR surgery. Constant changes in available technology and long, challenging procedures have led to a dearth of surgeons competent in complex AWR.<sup>23</sup> Moreover, AWR cases are expensive procedures, with high tissue matrix or mesh costs and a longer hospital stay compared to uncomplicated hernia repair.<sup>24</sup> Our findings suggest that these barriers to surgery are frequently present among cancer survivors. To counter the notion that AWR is a costly endeavour, a recent cost analysis showed that repair of a CAWH, even with the addition of synthetic mesh, is cost-effective when one considers average quality-adjusted life-years.<sup>25</sup> To our knowledge, there is no literature evaluating the cost-effectiveness of hernia repair surgery in cancer survivors. However, we speculate from our findings that this patient population would also benefit from hernia repair, especially if AWR is done at the right time following cancer treatment to prevent costly long-term complications. As a case in point, a recent study highlights the economic burden of adult cancer survivors in the United States owing to increasingly complex survivorship issues.<sup>26</sup>

More fundamentally, the current study identifies an additional need for the cancer survivor. Advances in cancer care have greatly decreased overall mortality rates, which has necessitated management of long-term morbidity.<sup>27</sup> Most patients who receive a cancer diagnosis will not die from their cancer but, rather, from noncancer comorbidities.<sup>28</sup> Furthermore, there is evidence that cancer survivors have an increased likelihood of not receiving recommended care across a broad range of chronic medical conditions.<sup>29</sup> However, major oncology groups and survivor groups have not made non-cancer-related health concerns

Table 2. Illustrative quotes by theme

Theme	Illustrative quote
1. Unable to return to normal life	<p>"It [the hernia] totally changes your life. [choking up] Well, the whole thing changed our lives. Pardon me, I'm very emotional."</p> <p>"There are a lot of emotional adjustments that you have to make as an individual. ... That's really the hidden secret for anybody [who] has a serious operation, it changes things, and you can't get back to normal again."</p> <p>"What it looked like was not what bothered me the most, it was that I couldn't do normal activities."</p> <p>"As soon as the chemo was over and [the doctor] said 'This is it,' I had a bulge, and he said 'You've got a hernia,' so it was like it was non-stop ... I had no chance to recuperate one after the other, it just followed."</p> <p>"So I had been a ... 61-year-old healthy as a horse, strong as a moose to ... a 7-year-old kid, because I had no strength, I couldn't do anything, and I'm not used to having people do things for me, and I had to have people do things for me, which didn't really make me really happy. So that's where my quality of life was at that time."</p>
2. Sense of abandonment	<p>"Things have gone disastrously wrong, and you just can't help wondering if the system has just sort of abandoned you, like, 'We'll push him over here because we don't see any positive outcome here.' Those are the kinds of things that go through your head when you're left in limbo, that you're just ... you're buried somewhere in a corner of the system, a file that ... just happened ... doesn't get opened again."</p> <p>"I almost felt at times that maybe there was something wrong with me, that this was my imagination and 'get over it.'"</p> <p>"I went everywhere and I was getting absolutely nowhere."</p> <p>"I try not to complain about it because people don't want to hear it. I try not to think about it and just kind of manage it."</p> <p>"As the doctor would say, 'Well, at least you're alive.'"</p>
3. Experiencing fear and distress	<p>"My biggest fear was strangulation of the intestines, which I'd already had the experience with, and I wouldn't ... I don't want to have that feeling again."</p> <p>"I lived in fear of what was going to be happening, and again not wanting to go away anywhere, and every little bit of discomfort I thought 'Maybe it's going to do it [incarcerate] again.' So it was an awful feeling of living in fear as to whether the next time would mean another surgery on an emergency basis."</p>
4. Preoperative: desperate for help	<p>"But I take that [surgical] risk instead of living the way I live now. That's not living. I'd rather take that risk for the operation."</p> <p>"I [was] hopeful that the surgery could be done but also almost certain [the doctor] wouldn't agree to do it, so I think I minimized most things of what I felt — I just didn't want to make a big deal about it. But then ... I realized there was hope here, and so I really would love to have it done."</p> <p>"Well, this is how I think, honest to God it would make me a different man. I'd look at life totally different. I'd have more inspiration."</p> <p>"I think it's going to make a tremendous difference to how I feel, also to how I look, and to activities."</p> <p>"Just the simple fact that there was acknowledgement that there was an issue was positive."</p>
5. Postoperative: "getting my life back"	<p>"[The surgery] was like a miracle — I have my body back."</p> <p>"The benefits are I have no more pain in my stomach, I feel much better physically and certainly mentally."</p> <p>"The normalcy of my life right now is ... exciting."</p> <p>"I've been living my life on hold for 6½ years, on hold 'til they found the cancer, on hold after the cancer while it healed ... on hold waiting for this surgery. .... I'm not on hold for the first time in 6½ years. That's huge!"</p> <p>"As far as I'm concerned, my life starts now."</p> <p>"It's a whole different life now, a whole ... a second chance, and that's ... you don't often get that, and I think people should know that there is hope. I think some people probably don't know about all these wonderful things, these new procedures, and they don't believe that they can change their lives and become back to normal if not better."</p> <p>"It's given me my life back."</p>

a priority.<sup>29</sup> Our study further elaborates on this, showing that cancer survivors experience a sense of abandonment with respect to their CAWH and often note that they are desperate for help. It is evident from the literature that cancer survivors are a vulnerable population. As Roland and Bellizzi<sup>1</sup> noted, although a patient may be told that he or she is "disease-free," often survivors are not truly free of

their disease. Specifically, cancer survivors face lifelong challenges relating to both the emotional and physical turmoil of potential recurrence of their disease.<sup>30,31</sup> As such, cancer continues to affect all aspects of a survivor's life.<sup>1</sup> As our findings show, patients require help "negotiating the lengthy cancer experience" that will last the rest of their lives.

## Limitations

This study has limitations. We recruited patients from the referral base of a specialized surgeon at a tertiary centre, which may have led to selection bias and may also limit the generalizability of our findings. Given the nature of the referral base, the study likely captured patients who were on the higher end of the spectrum of complexity of abdominal wall hernias. These patients with complex hernias tend to be referred to surgeons with additional expertise in AWR, but, more and more in Ontario, general surgeons are gaining expertise and experience in managing these patients, thus increasing the generalizability of our findings. The study included participants with several different cancer diagnoses, with or without stomas, and of varying sizes or symptoms. As such, we believe it is reasonable to posit that our results are generalizable to this patient population. A further limitation is that participants were interviewed at only 1 point in time, which may not have captured the long-term effects of living with a CAWH and/or undergoing repair. Finally, the majority of our participants underwent their initial operation for colorectal cancer. Laparoscopic colorectal surgery continues to evolve, and many complex cancer cases are now approached and completed laparoscopically. Hernia rates have been shown to be lower in patients who undergo laparoscopic resection,<sup>32,33</sup> and the uptake of this technique may also decrease the number of patients with CAWHs.

## CONCLUSION

The current study makes a substantive contribution to clinical practice by enhancing our understanding of cancer survivors' lived experience, allowing us to better understand the implications and opportunities for clinical care. We believe the study shows that CAWHs have a substantial impact on the quality of life of these patients and that hernia management should be viewed as an integral part in the continuum of cancer treatment. Future longitudinal studies should examine the long-term effects of surgical repair on quality of life to see whether the impact our study describes is sustainable in the longer term. Furthermore, studies need to be done to identify current barriers to offering/receiving appropriate CAWH management on both the physician and the patient level. Our findings suggest that clinicians, surgeons and patient groups need to advocate for the development of and access to CAWH surgical options, which are currently limited by variable access. Furthermore, this study adds to the current growing body of literature that survivorship care should be a distinct chronic phase of cancer care.

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**Contributors:** All authors designed the study. R. Nenshi and C. Bensimon acquired and analyzed the data, which T. Wood and F. Wright also analyzed. R. Nenshi, C. Bensimon and T. Wood wrote the article, which all authors reviewed. All authors approved the final version to be published and can certify that no other individuals not listed as authors have made substantial contributions to the paper.

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