



# The Experiential Learning Pathway of Cancer Survivors as They Recover Their Lives Post-Treatment: A Qualitative Study

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## Le parcours d'apprentissage expérientiel des survivants du cancer qui reprennent leur vie après la fin des traitements: Une étude qualitative

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### Abstract

For many cancer survivors, post-treatment challenges are predominantly related to their personal and social lives. These challenges are part of an experiential learning process linked to a survivor's identity, their desire to preserve independence, their social roles, and responsibilities along with a return to their normal lives. We used interpretive description to describe the experiential learning process of cancer survivors as they recover post-treatment. Data from five group discussions with 27 participants were combined with data from 9 in-depth individual interviews that examined post-treatment challenges. Through an iterative qualitative analysis, we uncovered 3 experiential learning pathways. Narrative vignettes are used to portray and highlight learning involved in accepting loss, asking for help, and rebuilding authentic social networks. Experiential learning shares recognizable features among individuals identified as milestones. These lead to a greater understanding of how cancer survivors acquire a new sense of self and recover their lives post-treatment.

### Résumé

Pour de nombreux survivants du cancer, les défis post-traitement sont principalement associés à leur vie personnelle et sociale. Ces défis liés entre autres à l'identité du survivant, à son désir de préserver son indépendance, à ses rôles et responsabilités sociales ainsi qu'au retour à une vie normale font partie d'un processus d'apprentissage expérientiel. À l'aide de l'approche de description interprétative, le processus d'apprentissage expérientiel de survivants du cancer lors de leur rétablissement après la fin des traitements a été décrit. Au total, 27 participants ont pris part à des groupes de discussions ( $n = 6$ ) et des entrevues individuelles ( $n = 9$ ). À la suite d'une analyse qualitative itérative des données, trois parcours d'apprentissage expérientiel ont été dévoilés. Des vignettes narratives ont été utilisées pour dépeindre et mettre en évidence l'apprentissage lié à l'acceptation de la perte, à la demande d'aide et à la reconstruction de réseaux sociaux authentiques. L'apprentissage expérientiel partage des

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caractéristiques similaires parmi les individus pouvant être identifiés comme des jalons de ce parcours d'apprentissage. Ces derniers permettent de mieux comprendre comment les survivants du cancer acquièrent une nouvelle conscience de soi-même et se réapproprient leur vie après les traitements.

### Keywords

cancer survivorship, post-treatment challenges, experiential learning, vignettes, qualitative, Canada

### Mots clés

survie au cancer, défis post-traitement, apprentissage expérientiel, vignettes, qualitatif, Canada

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## Introduction

One in two people in industrialized countries will be diagnosed with cancer in their lifetime (Canadian Cancer Statistics Advisory Committee, 2021). Of this number, it is estimated that over 65% will be alive five years after diagnosis, in large part due to advances in health care (Canadian Cancer Statistics Advisory Committee, 2021). These people can be referred to as cancer survivors and this term applies as soon as the diagnosis is announced (National Cancer Institute, 2019). Surviving cancer brings about many changes. A large pan-Canadian survey confirms that the post-treatment period carries the most difficult cancer-related experiences (Canadian Partnership Against Cancer, 2018). Notably, at the end of cancer treatment, there are numerous collateral impacts of cancer on lifestyle and significant changes on physical (e.g., fatigue), emotional and psychosocial levels (e.g., altered social and family relationships, inability to return to work, and limited access to financial assistance) (Arndt et al., 2017; Jagsi et al., 2014; Mehnert & Koch, 2013; Recklitis & Syrjala, 2017; Reilly et al., 2013). Despite these challenges, many cancer survivors learn to regain a so-called “normal” life, by learning to live with a chronic illness (Bilodeau et al., 2021).

People living with a chronic illness develop unique strategies to competently manage the consequences of their disease (Lawn et al., 2011). Patient learning, based on experience gained during self-management situations (Jouet et al., 2010), leads to an accumulation of experiential knowledge acquired from observing their bodies and their reactions to the disease or treatments (Vinette & Bilodeau, 2021). Over time, patients develop a solid expertise about living with the disease and about available therapies (Boudier et al., 2012).

The inherent challenges of post-cancer life offer important opportunities for experiential learning. This synergistic effect between challenges and learning relate to the cancer survivor's identity, their desire to maintain autonomy and independence, their social roles and responsibilities, and their intent to resume a normal life (Bilodeau et al., 2021). Rich and profound perspectives about personal struggles and breakthroughs are often embedded in the experiential learning of cancer survivors. A better understanding of this learning would allow nurses and other health care professionals to refine and develop meaningful educational interventions, including follow-up

care. In what follows, we present work stemming from a broader project that identified and described certain elements of experiential learning among cancer survivors across different age groups (Bilodeau et al., 2021). These findings demonstrated that learning to live with a chronic disease was similar across age groups, but the elements of this learning were experienced differently according to age. Here, we focus on the process of experiential learning as these survivors returned to their “normal” lives after treatment by asking the research question: how do those who have completed treatment for cancer learn to recover a normal life?

## Theoretical Underpinning

The experiential learning framework proposed by Kolb (2014) defines learning as a dynamic process grounded in the transformation of experience into knowledge. This framework identifies four stages in the experiential learning process that may not necessarily occur in a linear sequence: concrete learning, reflective observation, abstract conceptualization, and active experimentation. A basic tenet is that learning is continuous, and results are unique to the learner in that they reflect individual adjustments to personal life circumstances. During the concrete learning stage, learning is acquired through new experiences. Reflective observations by the learner reveal features of their experience and discrepancies with what they already know. Once these discrepancies become clearer, the learner generates new ideas about the situation which propel new actions. In the active experimentation stage, the learner “applies” the new ideas and “tests” the results, which may lead to a new concrete learning stage. With Kolb's framework as our foundation, we present the experiences of cancer that may lie behind the daily challenges survivors face after completing treatment. These challenges were interpreted as visceral experiences from which knowledge is gained.

## Methods

We adopted a qualitative methodology and approached the data using interpretive description. As proposed in Thorne (2016), interpretive description is appropriate to answer research questions raised from clinical practice and allows various data collection methods (e.g., interview, focus group)

**Table 1.** Participant characteristics.

Participant characteristics	N = 27
<i>Socio-demographic characteristics</i>	
Age, yrs.	
15–18	5
19–29	4
30–44	6
45–59	7
60 +	5
Gender	
Women	21
Men	6
Highest educational level	
High school	7
College	5
University	15
<i>Occupational characteristics</i>	
Work status before the diagnosis	
Permanent – full-time	12
Permanent – part-time	2
Self-employed	2
Unemployed	2
Disability leave	2
Retirement	4
Attending school	
Yes	7
<i>Clinical characteristics</i>	
Cancer diagnosis	
Breast cancer	10
Hematological cancer	6
Endocrine cancer	2
Female reproductive cancer	3
Male reproductive cancer	2
Other	6
Multiple diagnosis or recurrence	6
Type of cancer treatment	
Surgery	20
Radiation therapy	13
Chemotherapy	20
Transplant/ graft	2
Oral medication	16
Hormone therapy	9
Time since last diagnosis	
6–11 months	1
1 year	5
2 years	5
3 years	6
4 years	5
5 years	5

to reveal experiential and subjective knowledge. This approach allows for a reference framework to structure research (e.g., Kolb's experiential learning framework (2014)). We used a constructivist epistemology that is subjective and transactional. In this way, researchers and participants engage in a process of

knowledge creation (Guba, 1990). Our data collection had several phases and results were co-constructed among researchers and participants. In addition, we adopted patient-oriented research principles that encourage multidisciplinary research teams whom actively seek patient partner involvement (Canadian Institutes of Health Research, 2015). Our patient partner (Lynda Piché), collaborator on this project, was involved in all team meetings, workgroups, and discussions regarding data analysis and conclusions. She was introduced to our research team by a volunteer organization and had no “patient/professional” relationship with any team member or participant.

### Sample

A convenience sample was selected based on the following inclusion criteria: participants had to be French speaking, aged 15 years or older at the time of diagnosis, must have completed cancer treatment at least 6 months before and less than 5 years prior. Six months was considered a minimum length of time to have started to make preliminary adjustments in their lives, and 5 years was the limit for events to be sufficiently fresh in their minds. Twenty-seven participants were recruited via Facebook pages linked to the research center as well as associations and foundations dedicated to patients living with cancer in Quebec (Canada) (Table 1). A nominal financial incentive was offered for their participation.

### Data collection

Data collection involved three stages (Table 2): (1) focus groups stratified by age; (2) focus group to discuss preliminary results without age preference; (3) individual interviews. First, five focus groups were held with cancer survivors ( $N = 27$ ) stratified by age: (15–18, 19–34, 35–44, 45–59,  $\geq 60$ ). Each group comprised four to seven participants (Krueger & Casey, 2009). During the focus groups, participants were invited to describe their personal experience of learning to manage their life after cancer and discuss new or unexpected situations that led to new learnings. Secondly, voluntary participants took part in a focus group (without age preference) to discuss the preliminary findings (themes, sub-themes) gleaned from the previous focus groups and to identify specific situations that triggered learning. Thirdly, nine participants from the existing sample were invited to a 60-minute individual interview to discuss findings associated with experiential learning. We selected volunteer participants from each age group (15–18 ( $n = 2$ ); 19–34 ( $n = 2$ ); 35–44 ( $n = 2$ ); 45–59 ( $n = 2$ ),  $\geq 60$  ( $n = 1$ )) to discuss how they experienced four major challenges highlighted during group discussions (Bilodeau et al., 2021). The individual interview questions were oriented to explore the feelings, thoughts and strategies that were used to overcome individual challenges. Each participant completed a socio-demographic questionnaire. Data were transcribed *verbatim* by a professional transcriber.

**Table 2:** Data Collection stages.

Stage number	Aim	Participants	Data collection method
1	Describe their personal experience of learning to manage their life after cancer and discuss new or unexpected situations that led to new learnings	5 age groups 15–18 19–34 35–44 45–59 ≥60)	5 homogeneous focus groups (90 minutes)
2	Discuss preliminary findings (themes, sub-themes) from the previous focus groups and identify and prioritize situations which triggered learning	No age preference	1 heterogeneous focus group (90 minutes)
3	Discuss findings associated with experiential learning situations	Nine ( $n = 9$ ) participants from the existing sample of each age group 15–18 ( $n = 2$ ) 19–34 ( $n = 2$ ) 35–44 ( $n = 2$ ) 45–59 ( $n = 2$ ) ≥60 ( $n = 1$ )	60-minute individual interviews

### Data analysis

Interviews and focus group transcripts were processed separately. We approached the transcribed data using inductive content analysis in an iterative process of data condensation, data display, and development and verification of conclusions (Miles et al., 2014). Three successive coding cycles were conducted. First, an initial inductive coding cycle was performed to identify challenges, emotions, questions, and strategies used by participants to overcome challenges. A second coding cycle was used on grouped data sets to identify patterns/milestones in the experiential learning process using Kolb's experiential learning stages as a guide. Subthemes emerging from this cycle were organized into tables and summaries. Finally, to illustrate and convey the uniqueness of experiential learning processes, we developed a series of narrative vignettes which aptly illustrate our team members' common interpretations and the emerging themes (Erickson, 1986; 2012; Merriam & Tisdell, 2015). QDA Miner v.5.0.19 was used for data management (Miles et al., 2014).

Procedures recommended by Miles, Huberman and Saldana (2014) were followed to ensure rigor as per confirmability, reliability, credibility, and transferability. The procedures were: (1) a logbook documented data collection along with notes on methodology and interpretation; (2) transcripts were validated against the digital audiotapes and some data were validated by participants during the heterogeneous focus group (stage 2) and interviews (member checking); (3) conclusions were validated through feedback with the co-investigators and the research professional, as well as by rereading transcripts and field notes; and (4) detailed descriptions of the study's context were carefully collected.

### Data Presentation

We chose narrative vignettes as described by Erickson (1986, 2012) to present our data. Vignettes are akin to composite portrayals of pathways of a fictitious persona. They convey a broader sense of what it is like to experience an event as opposed to a factual and impersonal account of events lived and told by a single individual. The results are composite sketches that incorporate the narrative our study participants shared with us. This is an innovative approach to present data to answer our research question. We present three narrative vignettes to illustrate the experiential learning process undertaken by cancer survivors as they recover their lives after treatment. This will allow a deeper exploration of the main features of each experience, as well as key insights gained about experiential learning among cancer survivors.

### Ethical Considerations

This study was approved by the Hospital Research Ethics Board affiliated to the Université de Montréal (ref. number MP-02-2019-7889). All participants signed consent forms, of which they received a copy, and were informed that the data would remain non-identifiable.

### Results

Twenty-seven cancer survivors participated in this study (Table 1). Most participants identified as female ( $n = 21$ ), 10 of whom had survived breast cancer. Twenty ( $n = 20$ ) participants held a college or university degree and 12 occupied full-time employment at the time of diagnosis. It was a diverse sample in the type of diagnosis and length of time since

**Table 3.** Learning Pathway Milestones Inspired by Kolb's Stages of Experiential Learning.

Milestones of the experiential learning pathway	Description	Examples
Post-treatment challenges	Post-treatment challenges were more acute in the social and personal realms. They stemmed from a perceived gulf between the individual's previous life, before cancer, and life after treatments	<ul style="list-style-type: none"> <li>- Wanting to return to a normal life</li> <li>- Realizing that I need help to take care of myself</li> <li>- Adapting relationships with loved ones</li> <li>- Coping with sick and cancer survivor identities</li> </ul>
Triggers	Triggers tended to intensify the challenges, and this led to the activation of internal resources by the individual	<ul style="list-style-type: none"> <li>- End of treatments/follow-up</li> <li>- Recurrence of side effects of cancer or treatments</li> <li>- Attitudes/comments from others about cancer being a thing of the past</li> </ul>
Reflections	Faced with the challenges, the individual reflects deeply and critically about their aspirations, their capabilities and what they want	<ul style="list-style-type: none"> <li>- What is my new identity?</li> <li>- How will I live now? in the next years?</li> <li>- How much time will it take before I am able to recover some capabilities?</li> <li>- Am I able to take care of myself?</li> <li>- Have I overstepped my limits?</li> <li>- Can I assume the same responsibilities (loved ones, children, family)?</li> </ul>
Learning/actions	The individual undertakes actions or activates resources to overcome the challenges. These actions arise from accumulated life experiences dealing with previous challenges including the recent cancer episode	<ul style="list-style-type: none"> <li>- Acceptance of self in a new body/health condition</li> <li>- Review of priorities</li> <li>- Fixing small objectives/steps</li> <li>- Recognizing side effects patterns</li> <li>- Accepting the new limits of the body</li> <li>- Asking for help</li> <li>- Identifying needs</li> <li>- Learning to take care of oneself</li> <li>- Speaking out</li> <li>- Maintaining genuine relationships</li> <li>- Assuming roles at your own pace and capabilities</li> </ul>

the last diagnosis. Notably, six participants had had more than one cancer diagnosis or had experienced a recurrence of cancer.

We identified four key milestones in the experiential learning pathway among participants: *post-treatment challenges*, *the presence of triggers*, *individual reflections* about post-treatment challenges, and *actions to overcome the challenges*. Table 3 describes these milestones and provides examples for each. Overwhelmingly, *post-treatment challenges* were more acute in the social and personal realms of participants. Challenges stemmed from a perceived gulf between the individual's previous life, before cancer, and life after treatment. *Triggers* tended to intensify the challenges leading to the activation of internal resources by the individual. The trigger destabilizes the individual setting them off on a unique learning pathway in which they *reflect* deeply and critically about their aspirations, their capabilities and what they want. Subsequently, the individual undertakes *actions or activates resources to overcome the challenges*. These actions

can vary from one individual to another, and our results suggest that they arise from accumulated life experiences dealing with previous challenges including the recent cancer episode. The notion of time appears to acquire greater saliency for cancer survivors and plays a defining role in the learning pathway. Awareness of passing time leads the individual to be proactive when confronting post-cancer challenges by recognizing triggers, reflecting, and accepting trial and error as a learning mechanism. Learning to recover after cancer treatment requires time.

Some of our results highlight a somewhat disheartening observation for health care professionals: participants revealed that their learning rarely came from the instruction or teachings of health care professionals. For example, one participant told us:

When they take charge of us in chemotherapy, they don't tell us everything. They don't talk about the symptoms, the impacts: yes, you'll be nauseated, you'll be tired. But, Ok. You never speak of the other stuff, all the symptoms...(FG W3)



The three narrative vignettes below represent composite examples of learning pathways as they unfold on a timeline: *Learning to deal with losses*, *Learning to ask for help*, *Learning to rebuild social relationships*. The vignettes were written in such a way as to highlight post-treatment challenges, to illustrate how triggers occur and convey individual reflections about post-treatment challenges and, finally to describe concrete actions taken to overcome challenges.

### Vignette 1: Learning to Deal with Loss

This first vignette (Box 1) presents the challenges raised by the post-treatment period in terms of the aspirations of a young adult. Notably, the particularities related to this stage of life are the desire for independence, the establishment of social networks (friends, colleagues, and intimate relationships), and career choice. This vignette highlights the impact of triggers such as the “end of treatment/follow-up” and the “recurrence of side effects” which bring tension to the experience. The underlying question that leads to reflection is: How much time will it take before I am able to recover my physical abilities? As a result, the vignette shows how a person can act to manage their symptoms, such as fatigue. The vignette also illustrates the extent to which learning, and acceptance take time (e.g., managing fatigue).

Ethan’s story deals with mourning for one’s old life, as it is manifested by his intent to return to a normal life, as it was before. The underlying post-cancer challenge is that of wanting to reclaim a normal life. Our participants explained that the end of treatment accentuates the desire to resume past activities such as sports, leisure, work, or school. Yet, they reported being fully aware that life after cancer would be different. Many past aspirations and previous plans no longer seem possible: the unforeseen fork in the road of their initial life path leads them to learn about loss and grief. A participant shared:

Grieving, clearly. [Silence] Yes, it’s bereavement. There are projects, loss of career, loss of family ... Because in my situation, I was in a moment in my life where I was well into my career, I

started my family, I was there. So, it happens all of a sudden, and then you go back to treatment, and then all that... It makes you mourn for your career, maybe giving up having a child or having more children, depending on the person. There are many losses that you have to go through. (FG M1)

Participants also mentioned that post-cancer challenges emerge gradually, and their impact can take months to be felt. One participant explained:

Right after the treatment sessions, I thought, “That’s it, let’s move on!” I went to work, I got on with my business, and I was aware that life was different, but I didn’t want any down time. I didn’t feel the need to do it gradually. I was ready. Then it was after a few months of getting back to normal that it seemed like it caught up with me, that: ah, well... finally, maybe I would need to talk to someone. I might need help with the side effects of my medication. It took a few months...a few months after it was over, that’s when it started to show up, the need to adjust to life after cancer, well! I need a little help. (FG W2)

Ethan’s story illustrates how recurring side effects act as powerful triggers for learning. Participants in our study reported becoming rapidly aware of recurring cancer symptoms and greater physical limitations. This awareness leads to new reflection and can bring up difficult feelings such as anxiety, frustration, and even guilt. One participant explains:

For me to do my triathlon and cross that line [the end of treatment] was the most significant thing for me, to say, OK. It’s in the past and now, I’m back to life. Except that soon after, I started to work and then I crashed... because my energy was no longer there. I emptied everything; I gave it all in my triathlon. I was very happy, but I crashed. And that’s when I realized that... my life will never be the same. (...) I live with guilt. I’m very hard on myself because I say to myself: well, I’m lazy! (FG W3)

Ethan’s story and this quote provide insight into how individuals learn to accept a new level of endurance and adapt

#### Box 1. Ethan’s story.

Ethan, 31, was diagnosed with cancer. He has undergone surgery and chemotherapy. The end of treatment is important to Ethan because he can leave the disease behind. He wants to get back to practicing judo, to activities with his friends and life-partner and to return to work. He feels like he has no time to waste. He also feels tired, but he tells himself that it will pass. The important thing for him is to stay active. It’s been *three months* since the end of Ethan’s treatment, and he realizes that he must deal with his “new health.” He can’t work out like he used to, he can’t go out several times a week with his friends, and he must reduce his workload. Through trial and error, he has learned that his body remains fatigued. He feels shaken by a sense of loss and wonders how long it will take to regain his physical abilities. *A year after completing treatment*, Ethan has adjusted his lifestyle. He now carefully plans his energy expenditure and chooses activities which require less effort or energy. He has invited his friends to plan activities in advance, as he needs to plan his day accordingly (e.g., nap, rest time). *It has been 2 years since* Ethan completed treatment. He and his partner are thinking about having children. They have decided to make long-term plans. They are aware of the uncertainty surrounding Ethan’s health, but they want to move forward. Ethan remains careful with his schedule to manage his energy level. He remembers how he and his partner used to tell each other that life would get back to normal. Unfortunately, that hasn’t happened yet.

their activities to curb fatigue. The focus on their bodies led participants to learn when different symptoms appear and their patterns, forcing participants to implement solutions or adaptive actions to bring immediate relief. For example, many participants were able to assess their energy level and the tasks or activities which caused the most fatigue. They undertook specific actions to adapt their daily lives. One participant explained:

Time management, managing my agenda, going out...Even at work, I don't book more than one or two meetings in a day because I can never get back on track, both in terms of energy and neurological intellectual capacity. And it's the same thing in my private life: two evenings a week maximum for an outing with friends or every other weekend. (FG W4)

Ethan's story presents an excerpt from a journey which lasted over 2 years. In the months and years following the end of treatment, our data suggest that survivors intuitively integrate these learnings into their daily lives. Over time, they also realize that it will be impossible to return to the life and physical condition they held before cancer. Learning to grieve their old life becomes more apparent. One participant shared:

The first time, me and my girlfriend made the mistake of saying to each other: "We'll give it a year. Then after a year... OK, it's going to get better. I'm still not like I was before or like I'd like to be. [...] Society expects us to return to a normality fairly quickly. Then at some point you say to yourself, 'maybe it's never going to happen.'"(FG M5)

Ethan's story and the participants' quotes illustrate how learning to deal with loss facilitates an acceptance about the need to adapt to new circumstances. Individuals learn to assess their symptoms and adapt their daily lives, accordingly. Overall, we observed that time constitutes an independent variable in this process—time is required but it is impossible to predict how much.

## Box 2. Kate's Story.

Kate, 55, has completed her cancer treatment and has had multiple surgeries. Kate lives alone and is self-employed. Treatment and surgery were difficult for her, and she feels the need to recuperate. She is in a lot of pain and must take narcotics. The pain and fatigue prevent her from taking optimal care of herself. Kate feels incapable of doing housework, of going shopping or preparing meals. After a few weeks, Kate had to resign herself and ask for help from those around her. She realized that she could not provide the right conditions for her recovery. Asking for help has been very difficult. Kate sees herself as independent and she feels embarrassed that she needs help to take care of herself. She realized that she had to put her pride aside and accept her limitations. Usually, it was others who asked her for help, not the other way around. Fortunately, she was able to express her needs to her friends and family. They willingly ran errands for her and brought her meals.

Kate has regained energy over the last few months. She has been thinking about the right conditions for recovery. She realized that her friends were happy to help her. Her feelings of embarrassment have dissipated. She realizes that she needs them and that they are there for her, as she was for them.

Over the past year, Kate has developed good habits. She takes a cab to run errands, has her groceries delivered, and has even hired someone to help with the housework. She has decided to make her life easier by adapting her life to accommodate her abilities and remain independent

## Vignette 2: Learning to Ask for Help

The second vignette (Box 2) presents a learning pathway for Kate, a late middle-aged cancer survivor dealing with the challenges inherent in recovering from treatment. Kate's story is an example of how recurring side effects act as a trigger which interfere with a person's efforts to maintain autonomy. The vignette illustrates the difficulty of asking for help. The underlying question that leads to reflection is: Am I able to take care of myself? Kate's story presents someone who has decided to facilitate their recovery. The vignette shows that learning, namely asking for and accepting help, take time and can be difficult to achieve.

Kate's story illustrates how survivors may confront their pride and accept needing help. This is a crucial post-treatment challenge. Surviving treatment is a source of pride in and of itself, but survivors may struggle to reconcile their pride with the revelation that they need help with daily tasks. This is a fundamental lesson that participants, in multiple ways, shared with us.

Kate's story highlights how fatigue and pain act as powerful triggers in forcing an individual to certain realizations: in this case she cannot rely solely on herself. Indeed, participants reported that side effects from treatment interfered with their ability to take care of themselves and adopt or maintain a healthy lifestyle. The shock can be brutal for some. One participant recounted:

I woke up one morning, I wasn't able ... I looked at my apartment, it had been a month since I had cleaned, there were dishes and clothes everywhere. I realized too late that I was not saving my energy and that I had let myself go for three or four weeks, and my place was a bit of a mess. I realized that all I was eating was cheese sandwiches and canned soup. That morning I thought, "I don't think this is the best way to take care of myself." (INT W4)

Kate's story and the above quote illustrate the thought process that leads an individual to link the awareness of

altered limitations and abilities with a new, and often unexpected, sense of vulnerability. There may be factors that mitigate this effect, such as the presence of a spouse that naturally “picks up the slack” (e.g., meals, cleaning, taking care of the children). For many participants, the sudden need to recognize themselves as a person in need of help comes with difficulty. One participant described it this way, alluding to alterations in self-identity:

I became [the care receiver] instead of the person who is the caregiver. I’m a very generous person, but I would have had to accept being in the position of [person in need of help]—to accept the generosity of others and then it’s true that it was a disruption in my role that I had no choice to change. (INT W4)

Kate’s story underlines the tension between the sudden and unavoidable need to accept care from others with the need to alter an individual’s perception of self. This clearly generates learning on a level that may be associated with personal growth and gaining new perspectives about relationships with others. With the passage of time, we see the effects of that shift, participants said they needed help from family and friends or professionals. Some had to seek help from their parents, an event that once might have felt like a failure. One participant recounts:

I realized that I couldn’t take care of myself to the extent I thought I was supposed to. Then it was a call to my parents “hello mom, hello dad” (laughter) because they were the only people who were able to take me in at that time (sob). So, I went to spend a little over a year at my parents’ house sleeping 12–15 hours a day, having my coffee and my breakfast brought to my bed by my dad. I was treated like a guest at a 5-star hotel. For me, it was a relief, but at the same time a huge loss of autonomy. Everything I thought I had put in place to survive those three years of chemotherapy definitely did not work. So, I felt a little bit like a failure, but it was also the best thing that could have happened to me at that point. I think if I had waited two more weeks, nothing

bad would have happened, but I think it would have been harder to get back on track. (INT W4)

Kate’s story and the above quotes show how learning becomes visible as the individual learns to make efficient use of available resources (e.g. help with groceries, cabs, parents, and spouse). These lessons learned during recovery can also be transferred to other challenges such as returning to work. One participant recounts:

I was very proud at the beginning and then I told myself, “I will get through it.” But I couldn’t. I decided to order groceries online or to buy them at the store and have them delivered, which I had never done in my life. So, that’s the kind of thing that I would say makes my daily life more comfortable. I would say that I have kept certain reflexes, because sometimes I say to myself, well, this will make my life easier today, it will be easier for me (...) small accommodations, but which make life much more comfortable. (INT W6)

In sum, Kate’s story highlights changes which occur at a deeper level, forcing an individual to accept the need for help, that help is available and that they are entitled to it. Most of our participants described learning which included confronting their fears while, at the same time, relinquishing control over their lives, that had once made them so proud. Thus, asking for and accepting help requires time and is a learning process for cancer survivors.

### Vignette 3: Learning to Rebuild Social Relationships

The third vignette (Box 3) presents additional challenges of recovery from cancer treatment for an early middle-aged person. The initial trigger of this learning is the apprehension of “attitudes/comments from others.” This creates tension as the cancer survivor becomes aware that their identity is changing. The underlying question is: What is my new identity? In Marilyn’s story, we present a process of learning

#### Box 3. Marilyn’s story.

Marilyn, 41, has completed cancer treatment. She is the mother of two young children. Her partner helped her a lot during treatment. Marilyn is in shock: She feels like she is not the same person she was before her diagnosis. She feels old and does not recognize herself physically. She feels uneasy and destabilized

It has been *six months* since the end of her treatment. Marilyn’s family and friends are asking when she will return to work. Marilyn feels pressured by those close to her to rapidly return to a “normal” life. When she talks about cancer or the side effects, those around her prefer to change the subject. Marilyn feels alone and isolated. She feels like everyone wants her to move on, but her life has changed so much, and she is not sure how to move forward

After *9 months*, Marilyn felt ready and went back to work. Her co-workers were very welcoming and quickly forgot that she had been on sick leave for cancer for over a year. She says they forgot about her cancer episode because she no longer looks sick and because her hair has grown back. Her colleagues even tell her that she looks great! Inwardly, Marilyn feels disconnected between the image she projects and the way she feels

Over *the past year*, Marilyn has begun to better communicate her needs to those around her. She told her loved ones that cancer had changed her. Additionally, she decided to put her social life in order. Marilyn gave up certain friendships and focuses on relationships that are healthy for her. It was very difficult, but she felt she had to do it to respect who she is now



how to communicate anxiety about resuming one's place in a social environment.

Marilyn's story illustrates how shifts in self-perception (identity) have an impact on social relations outside the immediate family setting and is a major post-treatment challenge. Surviving cancer does not necessarily preclude the need to rebuild existing relationships with friends and work colleagues. The impending sense of "the elephant in the room" makes conversations tricky with people who try to avoid the subject of cancer, while others make it easy to re-establish authentic and healthy social relations with cancer survivors.

The last vignette illustrates that the apprehension of "Attitudes/comments from others" is a trigger which broadens the challenge of facing one's loneliness and the need to forge a new sense of self. Many participants expressed that cancer survivors do not look sick (e.g., their hair has grown back) and this helps to ease social relations. They reported that looking good physically meant that all problems related to cancer were over. Comments from family and friends urged the person to put the cancer experience behind them. In contrast, many participants had a strong sense that their identity had changed. One participant shared some of the discourse held by those around him:

My circle of friends is like, "Well, when will you go back to work? It's going to be good for you!" Then it seems like it's kind of... It's going to make them feel safer if I go back to work. So, he mustn't be so sick anymore. I'm kind of in that dynamic. (FG M1)

Some participants may have trouble talking about these challenges to those close to them. They experience tension between not wanting to worry others and not wanting others to feel like they are playing the victim. This reflection leads to a sense of isolation for many. One participant reported:

The isolation, at some point, you feel it much more when you don't die because people say to themselves, "Well, she's okay now." (...) But it's a feeling that happens when you heal that makes it isolating because you're okay, since you're not dead! [Laughs] That's a weird thing to say. (INT W8)

The last vignette also illustrates the impact of the cancer experience on the individual's sense of self. Changes in physical appearance, as one participant revealed, can lead to a new physical identity:

The first challenge was to discover my new physical identity (...) That was quite disturbing. Now, when I see myself, I find it hard to recognize the person I was before. I had long hair and then I lost it and now it's grown back. It's hard to recognize myself (INT W7)

Several participants reported questioning their priorities or the importance of certain relationships. These thoughts can be anxiety-provoking as one participant shared:

So, after all this time, I questioned myself a lot. (...) "Do I go back to what I was doing before?" Which was very stressful or "Do I decide to make a new life for myself?" So, I had to ask myself these questions. (...) I ended up making a decision... It was very anxiety-provoking. (INT W8)

Marilyn's story illustrates how a person can learn to communicate what they are experiencing and identify their emotions. Several participants expressed that it was difficult to talk about what they were experiencing with their loved ones. When they tried, it took time and patience. They also chose who they could confide in. Several participants shared that they had ended friendships. The most common reason given was a lack of reciprocity in the relationship or a lack of understanding of their experiences. Although this type of experiential learning is challenging, many participants felt it was necessary and even welcomed it. One participant commented on their experience:

To tell people what's wrong in certain relationships, to name things and to be ready to take the blame for it, to assume the consequences that this may have afterwards. So, I would say that yes, there are things that have been put in place, that I have finally been able to take my place and been able to assume the consequences that come with that. (INT W6)

Marilyn's story reminds us there are multiple facets to a person's social persona which undergo important shifts among cancer survivors. It also illustrates the impact of physical changes on social relationships as well as discovering how the feeling of solitude becomes a mediator of social identity. The discovery of the intertwined identities post-treatment can lead the survivor to adjust their social interactions. Our data reflects the learning process underpinning these adjustments.

## Discussion

This paper described the experiential learning processes involved in recovering from cancer. The originality of this study lies in the developmental approach to the data, highlighting change over time. Although Kolb's framework was our theoretical starting point, the learning that we discovered indicates a deeper transformative process as patients recover. The four milestones in the learning pathways of cancer survivors that emerged: (1) initial experience of a post-treatment challenge that is (2) amplified by an internal trigger (e.g., experiencing recurrent effects of cancer) or an external trigger (e.g., comments from others), that ultimately (3) initiates reflection and learning that lead to (4) new attitudes and actions point to refinement of the Kolb model. Experiential learning is multifaceted and affects several aspects of a person's life (physical, personal, social). Furthermore, it takes time, months, even years to unfold. The three narrative vignettes and the accompanying interview

data provide a rich portrait of what survivors go through post-treatment and the adaptations they are forced to undertake. The points of tension experienced by the survivor between life before and life after treatment, the subsequent shock and adaptations required all illustrate that post-treatment experience is more than overcoming and managing symptoms. It entails deep reflection about one's life, a reappraisal of social relationships and enhanced self-awareness. In this vein, the learning that stems from such an experience is transformative in that its sole purpose is to adapt to a new normal. At times, this may be neither easy, nor pleasant.

Indeed, self-management journeys have been described as difficult (Dunne et al., 2019). Such journeys evolve across levels of patient engagement and development (Larsen et al., 2021; Saeidzadeh et al., 2021; Vinette & Bilodeau, 2021). Most studies or reviews list the needs, skills, or strategies required for self-management in the face of chronic illness (Howell et al., 2017; Howell, 2018; Kim et al., 2020; Larsen et al., 2021). Others have demonstrated that advice from health care professionals is difficult to integrate into daily life because the strategies deployed by patients are highly personal (Boland et al., 2018; van Dongen et al., 2020). Our results describe individual processes of learning self-management strategies thus contributing to a broader understanding of cancer recovery. To our knowledge, ours is the first study to describe experiential learning among adults living with a chronic illness in such detail.

The vignettes underscore three themes of survivor's lives post-treatment: loss and acceptance, a sense of shifting identity and the reconstruction of social relations. Our results point out key elements of the experiential learning process through these common themes of survivorship. Notably, psychosocial concerns related to changes in relationships (e.g., family, friends, and colleagues) may have precedence over recurrent or long-term effects from treatment (e.g., cognitive impairment) (Fitch et al., 2019). Our results show that recurrent side-effects act more like triggers that enhance learning in the psychosocial sphere. This observation underscores the complexity of life post-treatment and the specific nature of the experiential learning required to return to a satisfactory way of life.

Our findings highlight the challenges of reconciling multiple identities for the cancer survivor. Some authors speak of an identity that vacillates between the pre- and post-illness state (Avdi & Koutri, 2016; Cavers et al., 2019). Cancer brings a constant renegotiation of the person's identity and of the components of their daily life and aspirations (Trusson et al., 2016). Tensions arise with the realization that the previous state is unattainable which contributes to a sense of loss of self, of ability and of autonomy (Avdi & Koutri, 2016). Among our study participants, the loss of the former self was a major concern. Clearly, this has unexpected consequences and leads to multiple experiential learning about letting go and about how to channel pride into the right things. In many ways, this leads survivors to accept their

vulnerability and to overcome the challenge impeding them to seek help, which is what the second vignette focused on. Indeed, accepting one's vulnerability due to a loss of self creates tensions that lead to new experiential learning. Namely, coming to terms with a former self-awareness as an independent, self-reliant person and asking for help—sometimes even returning to the safety of being a child at home. Reaching this threshold becomes a sign that acceptance of one's new circumstances is possible.

Our results also show that the gaze of others affects the cancer survivor's self-perception. This gaze can be confronting and destabilizing. It is a trigger for a learning process. Public discourse suggests that cancer survivors are better after completing treatment, which is in opposition to the person's inner feelings (Raque-Bogdan et al., 2019). The latter may experience psychological and social changes that may be exacerbated by societal expectations implying that one should regain a certain level of well-being (McGannon et al., 2016; Powers et al., 2016; Trusson & Pilnick, 2017). In our study, participants revealed mixed feelings about how their cancer experience might affect social relationships outside the family environment. They worried about what other people might think of their new physical appearance and how they would figure out whether or not to discuss the cancer episode. In essence, participants learned to choose people to include in their social circle given their new identity as a cancer survivor.

Our study, showcasing experiential learning about surviving cancer, can lead to new and practical insights for nurses and other health care professionals. Greater awareness of the difficulties in asking for help, for instance, can lead to a careful review and adaptation of discharge and follow-up procedures. Additionally, awareness of the discrepancies between a person's outer appearance and the emotional turmoil kept inside warrants alternative ways to listen to patients as they describe their experiences. The raised awareness of a sense of self, coupled with new learnings about the body, symptoms and the long-term effects of cancer can all act as sources of knowledge that can buttress nurses and other healthcare professionals' competencies leading to greater quality of care. In addition, appreciating patients' unique learning can lead to their empowerment as their voice becomes recognized and heard during treatment and care.

Finally, the use of Kolb's experiential learning framework as a starting point helped us to understand that a patient's visceral experiences following the end of cancer treatment led to transformative learning, that is, that of adapting to a new normal. Our results reveal the unique expertise acquired by patients as they transform their lives to cope with the recurrent side effects of cancer. This leads us to question Kolb's implicit assumption that learning is propelled by the individual's natural rational curiosity, described as a shift from a reflective observation to abstract conceptualization. Our results speak forcefully about the learning triggered by the experiences of recovering from cancer. These lead the destabilized

individual to engage in more than critical thinking; they acknowledge profound changes in their identity, a steep curtailment of their autonomy and a redefinition of their social status. Linking experiential learning to such changes allows health professionals to gain a greater understanding of their patients' experiences and needs, leading to new ways to help them. Furthermore, many authors have noted the social relevance of experiential knowledge, encouraging further exploration to understand how (1) this knowledge makes sense to its owner, (2) how experience is transformed into knowledge and invested into action, and (3) how to delineate the limits of experiential knowledge (Blume, 2017; Boardman, 2017; Mazanderani et al., 2012).

### Strengths/Limitations

The use of an adult education perspective is an innovative approach in exploring the post-cancer experience. It places greater value on the person's learning as affected by the disease rather than their inability to cope with problematic situations. Our approach focuses on the person's ability and potential to act and provides practical guidance to both survivors and health care professionals. Notably, data collected in the study came from multiple sources (interviews and focus groups), and once validated by participants, were rigorously analyzed. The presentation of data in a vignette format allowed for a rich and nuanced description of experiential learning after cancer treatment. The sampling selection of participants contributed to the richness of the data. However, this variability (age, diagnosis, and length of time since last diagnosis) may make the transferability of certain findings difficult, especially for younger clients (under 30 years old). Additionally, using focus groups to collect data limits the revelation of individual experience because they aim to explore and confront multiple perspectives among members. It was during the interviews that the individual experiences of surviving cancer were explored in greater depth. Research on the experiential knowledge held by cancer survivors is emerging and methodological avenues such as narrative approaches are being increasingly used. Furthermore, most of our participants were Caucasian, well-educated, and identified as women. Further studies would be beneficial to explore the influences of gender, education, or culture in the experiential learning pathways of cancer survivors. Finally, results should be interpreted in their specific context.

### Conclusion

The experiential learning pathway of cancer survivors as they recover their lives post-treatment is unique and fraught with tensions that arise from a powerful sense of loss, accepting help from others, and rebuilding an authentic social network. Recovering a sense of normalcy post-treatment is complex, evolves over time and can lead to profound personal changes. This requires experiential learning that is difficult, highly personal and cannot be taught: that is, it must be experienced

and then told to someone who understands. As we have shown, experiential learning shares recognizable features among individuals that we have identified as milestones defining a learning pathway. These milestones lead to a greater understanding of how cancer survivors recover a new sense of self and piece back together their lives. We believe that the way nurses and healthcare professionals accompany cancer survivors could be more personalized and humanistic by basing our "teachable moments" and our practice on the practical and human aspects narrated by the very patients we help. Finally, sharing this experiential knowledge among patients can lead to greater peer support and improve the experience of recovering from cancer. The question then becomes how to make experiential learning meaningful to cancer survivors and healthcare professionals alike so that it can be leveraged to build innovative approaches to patient care.

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