Article

Qualitative Social Work
12(5) 671–688

DOI: 10.1177/1473325012450484
qsw.sagepub.com

‘But they’re happening to you at the wrong time’: Exploring young adult women’s reflections on serious illness through photovoice

Meridith Burles
University of Saskatchewan, Canada

Roanne Thomas
University of Ottawa, Canada

Abstract

Although serious illness is often associated with aging, many young adults are affected by various life-threatening and chronic illnesses, and thus have experiences that do not correspond to socio-cultural expectations for young adulthood. In this article, we describe a qualitative study exploring young adult women’s experiences of serious illness. Ten participants diagnosed with a life-threatening or chronic illness in the previous three years participated in phenomenological interviews and photovoice project that focused on what it is like to be seriously ill during young adulthood. Our analysis reveals that participants experienced serious illness with respect to their position in the life course; specifically, participants perceived ill health as being inconsistent with young adulthood. This finding is illustrated by three inter-related themes: feeling abnormal and ‘off time,’ realizing vulnerabilities, and renegotiating expectations for young adulthood and the future. We propose that these themes offer evidence of how illness is experienced within the broader socio-cultural context of individuals’ lives. We conclude that social workers involved in supporting this population are well positioned to address life course disruptions brought about by illness and aid in negotiating ill health with respect to expectations for young adulthood.

Keywords

Constructionism, health, phenomenology, photovoice, psychosocial, young people

---

Corresponding author:
Meridith Burles, Postdoctoral Fellow, College of Nursing, University of Saskatchewan, 107 Wiggins Road, Saskatoon, SK S7N 5E5, Canada.
Email: meridith.burles@usask.ca

Introduction

Developments in science and medical practices, along with improved hygiene, housing, nutrition, and income, have contributed to increased longevity for individuals living in contemporary Western society (Lupton, 2003; Moseley, 2004, cited in Kellehear, 2007: 201). Consequently, there is widespread expectation that individuals will live into their 70s, 80s, and even 90s (Bury and Wadsworth, 2003; Kellehear, 2007). Such expectations regarding the life course significantly influence the way that individuals envision the trajectory of their lives. Although the life course is universally anchored by biological events – birth and death – it is a socially constructed concept; specifically, age reflects common meanings arising from the social practices of a society (Matthews, 1979, cited in Holstein and Gubrium, 2007: 338), and the categorization of age into life stages provides members of a society with prescriptions for when expected life events should or should not occur. While biological markers are frequently used to demarcate the transition between different stages in the life course, Hockey and James (2003) emphasize that meanings associated with such markers are what affect their incorporation into socio-cultural understandings of the life course. Therefore, as Bury and Wadsworth (2003: 111) propose, 'health and ageing take on distinct features that cannot readily be reduced to biology.' Adopting a social constructionist perspective enables conceptualization of the life course as a set of expectations for individuals' progression through time that powerfully influences how individuals understand themselves and experience the social world (Hockey and James, 2003).

Yet, there are no guarantees how life will unfold. One event perceived as contrary to life course expectations in contemporary Western society is the diagnosis of serious illness prior to old age. Such a diagnosis can be especially problematic because it contradicts widespread assumptions about youth, health and longevity in contemporary Western society (Exley and Letherby, 2001; Hilton et al., 2009), and because younger individuals may not yet have established themselves with respect to employment, intimate relationships, and identity outside their family of origin (Petersen et al., 2003). Thus, serious illness can threaten young adults' ability to fulfil goals commonly achieved during young adulthood, and contribute to feeling different from what is considered 'normal.' Compounding these issues is the potential for young adults to experience illness as 'premature aging' (Singer, 1972, cited in Bury, 1982), which is difficult given that aging is generally devalued and undesired in contemporary Western society. Younger individuals may experience 'biographical disruption' following the diagnosis of a serious illness because it disturbs everyday life and requires the re-examination of expectations for the future (Bury, 1982). Therefore, life stage can influence how individuals experience and make sense of illness.

Although research has described disruptions experienced by middle-aged adults due to illness, less attention has been given to the experiences of young adults. Some existing studies have focused on young adults with cancer, which offer a preliminary understanding of what it is like to be ill during young adulthood. Research indicates that cancer can cause young adults to feel isolated and different than their peers (Dunn and Steginga, 2000; Odo and Potter, 2009), which can be detrimental to their well-being and self worth (Grant and Roberts, 1998, cited in Grinyer, 2007: 75; Lee, 2001). Additionally, cancer can threaten the sense of invincibility often possessed by young adults, and independence may be put in jeopardy because illness and treatment can lead to a 'retrograde step' or shift back to dependence (Grinyer, 2007; Miedema et al., 2007; Odo and Potter, 2009). Although illness can result in loss of independence for individuals of all ages, dependency on others may be particularly difficult to manage during young adulthood because independence is often newly established and highly valued (Kyngas et al., 2001), and because young adults are engaged in the process of constructing an adult identity (Odo and Potter, 2009). Young adults also experience setbacks related to education, employment, financial well-being, and relationships due to cancer (Lynam, 1995; Odo and Potter, 2009). As well, issues related to fertility and having children are prominent in research on young women with breast cancer (Coyne and Borbasi, 2006-7; Dunn and Steginga, 2000), and young adults with cancer in general (Grinyer, 2007; Halliday and Boughton 2011; Lynam, 1995; Odo and Potter, 2009). Overall, existing research provides evidence that the physical and psychosocial effects of cancer can be uniquely experienced by young adults.

However, further research is needed with young adults affected by serious illnesses other than cancer, as few studies have explored the experiences of young adults with chronic illnesses (e.g. schizophrenia (McCann and Clarke, 2004); epilepsy (Raty et al., 2007)). Furthermore, effort has not been made to identify similarities in experience across young adults with different types of serious illness, nor have young adults' experiences been examined with respect to socio-cultural expectations for the life course. Consequently, we performed a qualitative study of ten young women's experiences of having a life-threatening or chronic illness in order to better understand the role of life stage in serious illness experiences. Participants were engaged in phenomenological interviews and photovoice project that explored what it is like to be seriously ill during young adulthood. The photovoice project was based on a modified version of Wang's (1999: 186) photovoice, a visual approach that involves participants in research by using photography to 'express, reflect and communicate their everyday lives.' In this article, we describe themes regarding participants' feelings of *being abnormal and 'off time'* (Williams, 2004) and their *realization of vulnerabilities* as a result of illness. These themes illuminate another, interrelated theme regarding participants' re-examination of their *expectations for young adulthood and the future*. Our findings offer an understanding of the life course disruptions experienced by young women affected by serious illness, knowledge of which can assist social workers in supporting this population with negotiating the implications of illness.

Methods

Setting, participants and recruitment

Participants from a Western Canadian province were recruited through a snowball sampling approach, following ethics approval from a university's Behavioural Research Ethics Board. Recruitment involved distributing advertisements through local support organizations, a university online bulletin board, and word of mouth. The majority of responses to recruitment were from women; however, two men contacted the researchers about participation, but did not fit the inclusion criteria. Participants were ten young women between 20 and 37 years old who had been diagnosed with a life-threatening or chronic illness within the previous three years. Illnesses by which participants were affected included: anorexia, breast cancer, depression, endometriosis, epilepsy, multiple sclerosis, primary hypoadrenalism and secondary hypothyroidism, and a malignant brain tumour.

One participant was married with two children, two were married without children, two were dating, and five were single at the time of the interviews. Most participants resided in one of two urban centres, although one participant lived in a town outside an urban centre and one participant lived in a rural community. Participants were not asked about socio-economic status, although all indicated having some university education, including some with graduate-level education. None discussed severe financial hardships, despite some financial ramifications of illness, suggesting that participants had similar socio-economic backgrounds. None identified as a minority based on racial/ethnic identity or sexual orientation.

Methodological approach

Interpretive, hermeneutic phenomenological and photovoice methodologies informed our efforts to learn about participants' 'lived experiences' and better understand the 'essence' or meaning of being seriously ill during young adulthood in contemporary Western society (van Manen, 1990). Specifically, we sought to examine how illness led participants to question 'taken-for-granted' aspects of their lives, including shared understandings about time, or 'lived social time' (Schutz, 1967). The phenomenological interviews aimed to elicit stories about illness from participants, and broad questions were used to prompt participants to talk about the impact of illness. The development of interview questions was guided by the four existentials – spatiality, corporeality, temporality, and relationality – that phenomenologists believe compose an individual's lifeworld (van Manen, 1990).

The photovoice project involved participants taking photographs that captured aspects of their illness experiences. Photovoice is a visual methodology and method developed by Wang and Burris (1997: 369) that is rooted in feminist and empowerment theories, and 'uses the immediacy of the visual image to furnish evidence and to promote an effective, participatory means of sharing expertise and knowledge.'

Accordingly, participants control the photographic process and determine the subject of the photographs, which can be empowering (Wang, 1999). Images also offer a means for understanding what it is like to live under certain conditions, which can generate empathy and self-reflection in those viewing the images (Lorenz, 2011; Phillips and Bellinger, 2011).

Originally developed for community-based health research with marginalized populations, photovoice can be adapted to fit with different groups and fulfil various research objectives (Wang and Burris, 1997). We used a modified version because the population was not a unified community residing in the same geographic area and, similar to other studies, individuals joined at different points over several months (e.g. Brooks et al., 2008; Drew et al., 2010; Thompson et al., 2008). Although a photograph sharing session would have been ideal, it became evident that this would be challenging given participants' diverse experiences and variance in how they were coping with illness. For instance, participants who suffered from illnesses that were not well publicized, such as endometriosis, suggested that certain illnesses were less problematic because of greater public awareness and availability of health care and support services; these participants resented having a 'marginalized' illness and felt different than those affected by more well-known illnesses. Furthermore, a sharing session would have been burdensome to some participants because of the additional time required. Upon completion of the study, participants' photographs and explanations were disseminated in academic and lay settings with researchers, health care professionals, and the public.

Participants chose between participating in two interviews, one phenomenological and one photovoice interview, or a combined interview. Eight participants chose to complete two interviews each, while one participant opted for one combined interview following completion of the photovoice project. Another participant completed the phenomenological interview but not the photovoice project because of time constraints resulting from education, employment, and medical appointments. All interviews were conducted in person by the first author and audio-recorded.

At each initial meeting with a participant, guidelines were provided for the photovoice project, which included: suggestions about how many photographs to take (10 to 12), broad topics that they might focus on (diagnosis, treatment, family, everyday activities, social support, relationships, education, employment), and explanations of the consent process and photograph release form that photographic subjects were required to sign. Additionally, participants were encouraged to interpret the photovoice project in their own way, and take as many or few photographs as deemed necessary. Participants were offered a digital camera, although all except one chose to use their own digital camera instead. Once photographs had been generated, an interview was conducted with each participant to discuss their photographs and meanings. In these interviews, participants offered insightful stories while describing how the content of the photographs illustrated their illness experience. In total, 18 interviews were completed, lasting between 45 and 120 minutes, and 111 photographs were provided by participants.

Prior to analysis, interview transcripts were reviewed by participants for accuracy and to fill in missing information. Our analysis was guided by van Manen's (1990) hermeneutic phenomenological approach, with particular attention to how participants experienced illness with respect to their embodiment, relationships, sense of time and space. Given our focus on young adulthood, we were particularly interested in temporality, the subjective experience of time, and how illness affected participants' 'perspective on life to come' (van Manen, 1990: 104). Accordingly, the findings discussed in this article constitute one major theme from our analysis focusing on temporality and shifts in participants' thinking about the life course due to serious illness, and the implications for their embodiment and relationships. Participants' photographs were analysed according to the meanings assigned to them during interviews and the insight they offered into their illness experiences.

Holistic and cross-sectional data analysis was conducted by the first author in consultation with the second author. Holistic analysis involves looking at individual cases within the data set in order to understand the 'particular in context' (Mason, 2002: 165). Cross-sectional analysis refers to the application of consistent categories to an entire data set, which enables identification of similarities and differences (Mason, 2002). By using both holistic and cross-sectional approaches to data analysis, we sought a comprehensive understanding of each participant's experiences of serious illness, and to identify common experiences among participants. Several close readings of the transcripts contributed to a preliminary sense of the interviews and identification of thematic categories. Further readings were then performed to refine these categories. Once broad themes and sub-themes were determined, the qualitative software program *Atlas.ti* was used to code and organize the data, which allowed for further refinement of the themes.

Results

Our analysis of the young women's stories revealed that a disjuncture existed between the experience of illness during young adulthood and how the participants envisioned their current position in the life course and the future. The following inter-related themes illustrate different aspects of this disjuncture and how the young women sought to reconcile their current reality with their hopes for the future.

Feeling abnormal and 'off time'

Several participants talked about how having a serious illness made them feel different than others their age. Specifically, illness brought about changes in their lives and sense of identity that made them feel abnormal or 'off time' with respect to socio-cultural expectations for young adulthood. The concept of being 'off time' emerges from Williams' (2004) study of terminally ill cancer patients from low socio-economic backgrounds in the United States, and refers to a belief that the timing of an individual's illness and/or death is atypical with respect to their position in the life course. Similar to the participants in Williams' (2004) study, the

Figure 1. My medication.

young women perceived their experiences as inconsistent with an expected life course trajectory in contemporary Western society.

Foremost, many participants talked about how having to negotiate medication and/or limitations imposed by illness diminished the carefree lifestyle associated with young adulthood. For example, Nicole, who had been diagnosed with epilepsy, and Aurelie, who had a malignant brain tumour, both felt that they were unable to enjoy a night out with friends because of fatigue, risk of having a seizure, mobility issues, and/or potential interaction between alcohol and medications. Nicole discussed the disruptions to her social life with respect to this photograph (Figure 1):

> I feel really limited being [an] age that a lot of people do go out to the bar and, um, drinking's a big thing for them . . . Even if I did want to go out to the bar, I know that I wouldn't stay very long because I'd feel sick and it's just, it's exhausting for me . . . I just feel a little bit left out sometimes.

She viewed her bodily state as limiting and inconsistent with what is typical for her age. Similar to Nicole and Aurelie, other participants expressed resentment toward illness-related limitations because they made everyday life more complicated and left them feeling abnormal.

Side effects of treatment also caused some participants to perceive their body as 'off time.' For example, Stacey and Laura each experienced menopausal symptoms due to breast cancer treatment, which Stacey described:

> It's like forcing a thirty year old, or I guess a thirty three year old at that time, to live in their mother's body because suddenly you've got, um, you know, hot flashes, more

> peach fuzz on your face, like just, you know, the things that happen to an older woman but they're happening to you at the wrong time.

Stacey emphasized her view of menopausal symptoms as inconsistent with being a young woman, particularly because menopause was perceived as a bodily experience common for women of her mother's age. Additionally, she described her bodily state as unfamiliar and unnatural, which threatened her sense of identity as a young adult and plans for the future. Nancy expressed a similar sentiment regarding the possibility of chemically-induced menopause as treatment for endometriosis, sarcastically exclaiming: 'Whoa! Okay, yeah! Menopause in my 20 s, cool. Like, that's awesome.' In saying this, Nancy communicated her discontent with facing a bodily experience that is typically associated with older women, particularly because she thought it would negatively impact her well-being and make her feel 'off time' with her peers. Such comments highlight an important issue raised by several participants: the physical implications of serious illness contributed to an inconsistency between their current embodied state and perceived position in the life course.

In addition to feeling different than others their age, some participants also indicated that they did not relate to others affected by the same illness because they were at different points in the life course. For example, Laura, diagnosed at age 29, emphasized that she felt unique in comparison to other women with breast cancer:

> I actually did join [an exercise group for women affected by breast cancer] because I'm interested in being physically active and things like that. But again, I feel like I don't fit with them either because I think the person closest to my age is in their 40s or something like that . . . I mean still, we've had this same experience and get to talk . . . But, I also feel like 'Well, I don't have kids, and I don't have grandkids.' And I just have a hard time connecting really with them.

The lack of other young women in the exercise group reinforced Laura's feelings of being different and 'off time,' and reminded her that she might not have opportunities to do things that older women had prior to having breast cancer.

Realizing vulnerabilities

Along with feeling 'off time,' participants discussed how illness prompted the realization of vulnerabilities. For some participants, illness created uncertainty and threatened their sense of invincibility and perceived control over life. Uncertainty led several of the young women to confront their mortality and consider that their life could be shorter than expected, which resulted in a changed relationship with their body and different perspective of the present and future. Particularly, these participants questioned their future and sought to adapt to the possibility that life would unfold differently than previously imagined.

One example of how illness prompted the realization of vulnerabilities was evident in 21-year-old Elizabeth's discussion of the lasting impact that depression had on her identity. Specifically, she indicated that depression had changed how she viewed herself as a young adult, saying: 'I think [depression has] taken away my sense of, you know, my invincibility, especially being a youth ... Just like the mentality: "I can handle things fine on my own. I don't need your help."' Her comment highlights the challenge that depression posed to Elizabeth's identity and her recently established independence from her family of origin; specifically, her experiences contributed to the realization that she was more vulnerable than formerly believed and could not handle every challenge on her own. Illness thus challenged perceptions of invincibility and her sense of independence.

Illness also caused participants to realize that they lacked control over their body and the future. For example, discussions about illness aetiology led some participants to conclude that, despite leading a healthy lifestyle, their health was outside their control. Other participants highlighted the perceived loss of control resulting from illness in discussions of the unpredictability of symptoms and side effects of treatment. For example, Nancy expressed uncertainty regarding the future impact of endometriosis on everyday life because her symptoms varied immensely and were sometimes debilitating: 'I've just kind of, like, been hoping that [endometriosis] doesn't become a work issue, but I mean it's always going to be I think. Well, it's kind of like a life-interrupting issue. It's like you can't really control it.' Uncertainty generated feelings of vulnerability and helplessness, despite that Nancy remained hopeful that treatment would alleviate her symptoms.

Sandra also described uncertainty related to a multiple sclerosis (MS) diagnosis in her early 30 s:

> Every time I get sick, I immediately wonder if it's an MS attack. Everything, every time I feel odd. So it's weird to have it always there, always present, you can't avoid that ... it's always at the back of my mind ... All the decisions I make, all the thoughts I have, all the choices I make are peppered with it, because there's a lot of 'what-ifs' because that's the nature of the disease, um, you don't know what's going to happen and your mind always jumps to worst-case scenario ... It's never not there.

Recognizing that MS can have an unpredictable trajectory, Sandra was uncertain how quickly it might progress or what limitations she might face. In relation to this photograph (Figure 2), she described one preparation that had been made in case the MS progressed:

> [MS] was a driving force for us to get this [fireplace] done. It was so much work and it cost so much money and it took so much time, and it seems like the underlying excuse always was my disease – so 'just-in-case, just-in-case.' And so finally we got it done, and I do love it in ways that I can't explain or I don't feel do it justice enough. Like the peace of mind that comes with hearing it and smelling it and being warmed by it I find so beneficial that, um ... it seems like an important part of my life.

Figure 2. The fireplace.

In describing this preparation for the 'worst-case scenario,' Sandra drew attention to the disruption that illness had caused to her envisioned future; particularly, she had not foreseen becoming ill, and now questioned what her quality of life would be like if the MS progressed.

Illness led other participants to reflect on their future, and those affected by cancer were especially cognizant of their mortality. Despite wanting to resume their lives following breast cancer diagnoses and treatment, Melanie and Laura both addressed the possibility of recurrence several times during their interviews. Stacey poignantly shared her hopes for the future, while also recognizing that her life could be shorter than previously expected. With respect to this photograph (Figure 3), Stacey said:

> What going through the cancer journey has done is forced me to confront some of those things or to say to myself, you know, 'Maybe you're not going to be here as long as you thought you were, so maybe you need to seize the opportunities instead of wishing you had done something and then just wishing and never doing it.' And so, um, part of what's in this photo is the store that we purchased, which was one of the scariest things I have ever done . . . but it's [also] been good.

Stacey experienced this realization of her mortality as a need to revise her envisioned life course, and feel a greater urgency to realize her goals and dreams. Similarly, Aurelie expressed an awareness that she might not live to be as old as previously expected, saying: 'You think "When I am 70 . . . " but maybe I won't be 70 at all. That's difficult because you don't know, your life, is it long or short? It's very uncertain.' Aurelie voiced the realization of her mortality that resulted from

Figure 3. Our ‘carpe diem’ store.

having a malignant brain tumour that could affect her longevity. Several of the photographs that Aurelie shared highlighted the uncertainty that she faced and her efforts to reconstruct her identity to account for the possibility that her life might not follow a typical, albeit socially constructed, life course.

Revising expectations for young adulthood and the future

Part of the ongoing process of managing illness-related disruptions to participants’ envisioned life course involved renegotiating expectations for young adulthood and the future. Revising expectations in light of actual and potential implications of illness was often difficult for participants because this involved coming to terms with uncertainty and losses resulting from illness. Thus, participants struggled to reconcile their present and uncertain future with their past expectations.

Stacey, who had three breast cancer occurrences over approximately seven years, articulated the ways that her expectations for young adulthood had been disrupted. She described a rupture between her expectations for her 30 s and how they had been:

> I feel like [my husband and I have] fallen behind, and maybe that’s ridiculous, but when I entered my 30s I remember sort of what my unwritten list of goals were. You know, by the time I’m 40 these are the things that I’m hoping we’ve accomplished: I wanna have the mortgage paid off, we will have kids...

She also explained how such goals were not yet fulfilled because she had put life on ‘pause’ due to breast cancer treatment. Her comments and the photographs that she shared highlight her awareness of certain life events typically associated with young adulthood, including establishing a career and financial stability, setting up a home, and having children. Laura discussed similar issues in relation to several of her photographs, noting that her breast cancer diagnosis caused setbacks in completing her education, obtaining a full time job, and buying a home with her partner, all of which had financial ramifications. Consequently, like others, these participants negotiated their current situation with respect to expectations for young adulthood.

Several participants also talked specifically about their desire to have children during young adulthood and how illness could alter this plan, specifically because the physical ability to bear children was potentially compromised by illness or treatment. For example, Nicole described how the anti-seizure medication that she took might jeopardize her plans:

> The last time I saw [the doctors], they said ‘Well, we’ll have to see, but you’ll probably have to take [the medication] for a couple more years.’ and I’m like ‘No, I just don’t want to have to take it for the rest of my life.’ . . . They don’t know about birth defects, or what effects [it could have], and I don’t really want to take it much longer ’cause I do want to get married in the next couple of years and start my family.

Laura shared the experience of not knowing if she would be able to have children, which she discussed in relation to this photograph (Figure 4) of her hormone replacement medication. Recognizing this potential loss, she said: ‘I don’t know, I don’t think I’ve dealt with it fully yet because I don’t know yet if, which way it’s going to go, but it’s kind of just trying to prepare myself for both eventualities.’

Both Nicole and Laura’s comments highlight how their hopes for the future were threatened by the possibility that treatment would negate their opportunity to have children. Other participants, including Nancy, Leanne and Sandra, shared similar thoughts regarding possible complications with fertility and pregnancy resulting from illness, while Stacey expressed feeling ‘left behind’ because of not being able to have children. Illness was therefore experienced as a threat to participants’ expectations and hopes, which resulted in a sense of loss of the future that could have been. Although the majority of participants discussed concerns regarding fertility and pregnancy, two participants did not raise this topic, and one indicated that she had never wanted to have children.

Participants also reflected on the impact of being ill on their education and employment goals. In some cases, illness forced participants to take time off from university or hindered their ability to secure desired employment. In relation to a photograph of her computer, Leanne discussed having to take a leave from her education once hospitalized for anorexia. She indicated that this disruption required her to adjust her expectations for herself: ‘[Before] I was the person that was gonna have their Master’s by 25 . . . like I was gonna be done. But now I’m like “I’ll be done when I’m done.”’ Consequently, Leanne came to have a more

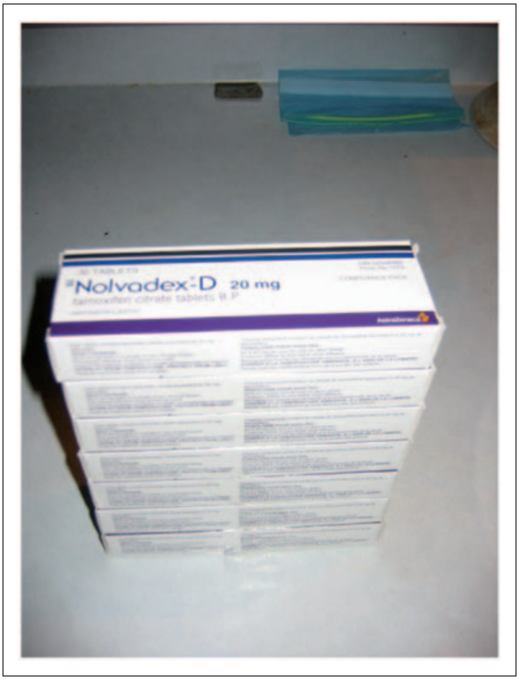

Figure 4. A lot of pills.

balanced approach to her education, and sought to accept that life could turn out differently than previously envisioned.

Similarly, Melissa described how she had different expectations for herself since becoming ill with primary hypoadrenalism and secondary hypothyroidism:

> It's just a matter of making adjustments, you know? At first I thought 'Oh maybe I'll do an Honours program.' and then I realized that I don't need to push myself or force myself into getting those grades that I know would be achievable if I wasn't sick. But I can only do what I can do right now and I don't want to put my life on hold any longer... The best thing I can do is not put pressure on myself and not worry... I don't put any expectations on myself.

Melissa's comments capture the shift in her expectations due to illness, which reflects an observation from Charmaz's (1991: 21) extensive research on chronically ill individuals that 'illness and disability force lowering expectations of self – at least for awhile.' Accordingly, some participants described attempts to adjust to limitations and re-envision a future including their changed health status. Thus, illness prompted participants to renegotiate their expectations for young adulthood, particularly when being ill hindered education or employment. However, despite the likelihood that certain goals would go unachieved or delayed, many participants expressed a desire to persist in their efforts to achieve certain goals or pursue them in partial ways. Although participants' specific goals often differed, each young woman spoke about the need to revise their expectations in some way.

Discussion

Participants' stories of serious illness told through their words and photographs call attention to how illness was experienced in terms of the disruptions caused to their life course position. Our analysis reveals that illness resulted in: feelings of being abnormal and 'off time' (Williams, 2004), realizations of vulnerabilities, and the renegotiation of expectations for young adulthood and the future. Participants struggled with illness-related disruptions to education, employment, leisure activities, and relationships, and viewed illness as being inconsistent with young adulthood because it made them feel different from their peers and out of synch with an expected life course. Consequently, participants experienced illness in the context of socio-cultural expectations for the life course, with little recognition that the life course is socially constructed and that many individuals do not pursue or achieve certain tasks associated with young adulthood. The influence of socio-cultural expectations on participants' illness experiences suggests that social workers could help this population by encouraging the examination of presuppositions for time and the life course as a means for coping with illness-related disruptions. Re-envisioning a fulfilling life course along a variety of trajectories could lessen feelings of difference and the mourning of lost opportunities. However, revising expectations surrounding the life course to account for diversity cannot ameliorate all of the potential losses that young women face due to illness because some goals are linked to structural or biological conditions, such as educational or reproduction opportunities. Therefore, social workers can provide crucial support to seriously ill young women with reconciling their current reality with former expectations and making adjustments to accommodate illness-related limitations, particularly those affecting their embodied self and unfulfilled dreams.

Participants' realizations of vulnerabilities because of illness also contributed to an altered relationship with their body. Specifically, feelings of invincibility were challenged by illness-related limitations, and participants recognized that their life course could diverge from that previously imagined. Thus, the illness experience shook participants' sense of security and control over their life and body. Realizing vulnerabilities also involved becoming cognizant of their mortality. Although serious illness can bring about the realization of mortality for individuals of any age, the resulting vulnerability was amplified for participants because it involved the recognition that their life course could diverge from their expectations and that thought to be typical in contemporary Western society. Consequently, participants struggled with how to integrate uncertainties related to illness into their identity and to accept potential losses. Illness-related threats also had positive ramifications for some, as realizing their mortality led to a greater sense of urgency to pursue dreams in case their life course was shorter than expected. Awareness of participants' lived experiences can benefit social workers working in a variety of practice settings in their efforts to facilitate the development of coping strategies for managing uncertainty and vulnerability.

Feelings and realizations emerging from the illness experience caused participants to re-examine their expectations and sense of identity as young women. Despite wanting to move forward and regain a sense of 'normalcy' (Miedema et al., 2007) in their lives through the assumption of former or new roles, the illness experience generated lasting disruptions that required participants to reconsider previous goals for education and employment. Additionally, several participants expressed concerns regarding their capacity to become pregnant, and struggled with the possibility of not being able to have children. Thus, illness initiated a complex process of revisioning for participants that involved acknowledging potential losses and negotiating past expectations for young adulthood and the future. The findings emphasize the need for individualized support that focuses on young women's specific struggles when faced with a life-threatening or chronic illness.

This research also highlights the value of the photographic process as a means for making sense of and communicating about illness. First, deciding what to photograph required participants to reflect on their experiences and feelings, which contributed to the process of making sense of illness. Additionally, participants' photographs often focused on issues currently being dealt with, thus providing insight into what they were coping with. Third, the photographic process helped some participants acknowledge positive outcomes of illness and their resilience. Finally, as researchers, we were better able to understand and empathize with participants by viewing their photographs and learning about their experiences. These observations underscore the potential of the photographic process for future social work practice and research.

Conclusion

Serious illness was experienced by participants as inconsistent with their 'aged identities' (Hockey and James, 2003) and happening at the wrong time. Specifically, the implications of illness were perceived as conflicting with common characteristics of young adulthood. Illness also introduced uncertainty and prompted the realization of mortality for many participants, who came to perceive time as more fragile than before. Accordingly, illness threatened participants' previous beliefs that they had many more years to achieve their aspirations. Thus, the experience of serious illness during young adulthood constituted an upheaval of the taken-for-granted and altered participants' everyday lives and outlook on the future.

The themes discussed illuminate how serious illness during young adulthood was disruptive to the life course, leading participants to recognize that life might be significantly different than expected. Consequently, participants faced potential losses due to illness that required the renegotiation of their expectations for young adulthood and the future. Although participants often had concerns pertinent to seriously ill individuals of any age, such as feeling vulnerable and dependent, they understood these concerns with respect to their inconsistency with socio-cultural prescriptions for young adulthood. Furthermore, the illness experience had a lasting impact on participants' relationship with their body, social roles, and envisioned future because it required them to revise current roles and expectations for the future in light of illness-related limitations and losses. These findings illuminate potential issues affecting seriously ill young women that could be managed with support from social workers.

Our analysis reveals that there are commonalities between young women affected by cancer and other types of serious illness related to disruptions caused by illness to everyday life and the life course. Accordingly, the findings emphasize that illness is experienced within the broader social context of individuals' lives and, in particular, with respect to socio-cultural expectations for the life course. Therefore, it is critical to address life stage concerns in the delivery of health care and support services to young adults affected by illness. Furthermore, the findings suggest a need for life stage specific information and innovative support interventions, such as the use of participant-employed photography, that facilitate coping and making sense of illness.

Funding

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

References

Brooks C, Poudrier J and Thomas-MacLean R (2008) Creating collaborative visions with aboriginal women: A photovoice project. In: Liamputtong P (ed) *Doing Cross-Cultural Research: Ethical and Methodological Perspectives*. New York, NY: Springer, pp. 193–211.

Bury M (1982) Chronic illness as biographical disruption. *Sociology of Health & Illness* 4(2): 167–182.

Bury M and Wadsworth M (2003) The 'biological clock'?: Ageing, health and the body across the lifecourse. In: Williams SJ, Birke L and Bendelow GA (eds) *Debating Biology: Sociological Reflections on Health, Medicine and Society*. New York, NY: Routledge, pp. 109–122.

Charmaz K (1991) *Good Days, Bad Days: The Self in Chronic Illness and Time*. New Brunswick, NJ: Rutgers University Press.

Coyne E and Borbasi S (2006–2007) Holding it all together: Breast cancer and its impact on life for younger women. *Contemporary Nursing* 23(2): 157–169.

Drew SE, Duncan RE and Sawyer SM (2010) Visual storytelling: A beneficial but challenging method for health research with young people. *Qualitative Health Research* 20(12): 1677–1688.

Dunn J and Steginga SK (2000) Young women's experience of breast cancer: Defining young and identifying concerns. *Psycho-Oncology* 9(2): 137–146.

Exley C and Letherby G (2001) Managing a disrupted lifecourse: Issues of identity and emotion work. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine* 5(1): 112–132.

Grinyer A (2007) *Young People Living With Cancer: Implications for Policy and Practice*. New York, NY: Open University Press.

Halliday LE and Boughton MA (2011) Exploring the concept of uncertain fertility, reproduction and motherhood after cancer in young adult women. *Nursing Inquiry* 18(2): 135–142.

Hilton S, Emslie C, Hunt K, Chapple A and Ziebland S (2009) Disclosing a cancer diagnosis to friends and family: A gendered analysis of young men's and women's experiences. *Qualitative Health Research* 19(6): 744–754.

Hockey J and James A (2003) *Social Identities Across the Life Course*. New York, NY: Palgrave Macmillan.

Holstein JA and Gubrium JF (2007) Constructionist perspectives on the life course. *Sociology Compass* 1(1): 335–352.

Kellehear A (2007) *A Social History of Dying*. New York, NY: Cambridge University Press.

Kyngas H, Mikkonen R, Nousiainen EM, Rytilahti M, Seppanen P, Vaattovaara R and Jamsa T (2001) Coping with the onset of cancer: Coping strategies and resources of young people with cancer. *European Journal of Cancer Care* 10(1): 6–11.

Lee CS (2001) The use of narrative in understanding how cancer affects development: The stories of one cancer survivor. *Journal of Health Psychology* 6(3): 283–293.

Lorenz LS (2011) A way into empathy: A 'case' of photo-elicitation in illness research. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine* 15(3): 259–275.

Lupton D (2003) *Medicine as Culture: Illness, Disease, and the Body in Western Societies*, 2nd edn. Thousand Oaks, CA: SAGE Publications.

Lynam MJ (1995) Supporting one another: The nature of family work when a young adult has cancer. *Journal of Advanced Nursing* 22(1): 116–125.

McCann TV and Clarke E (2004) Embodiment of severe and enduring mental illness: Finding meaning in schizophrenia. *Issues in Mental Health Nursing* 25(8): 783–798.

Mason J (2002) *Qualitative Researching*, 2nd edn. Thousand Oaks, CA: SAGE Publications.

Miedema B, Hamilton R and Easley J (2007) From 'invincibility' to 'normalcy': Coping strategies of young adults during the cancer journey. *Palliative and Supportive Care* 5(1): 41–49.

Odo R and Potter C (2009) Understanding the needs of young adult cancer survivors: A clinical perspective. *Oncology* 23(11): 23–28.

Petersen L, Kruezek T and Shaffner A (2003) Gender roles and the family life cycle: The case of women with cancer. *Journal of Feminist Family Therapy* 15(2/3): 99–119.

Phillips C and Bellinger A (2011) Feeling the cut: Exploring the use of photography in social work education. *Qualitative Social Work* 10(1): 86–105.

Raty LKA, Soderfeldt BA and Larsson BMW (2007) Daily life in epilepsy: Patients' experiences described by emotions. *Epilepsy & Behavior* 10(3): 389–396.

Schutz A (1967) *The Phenomenology of the Social World* (translated by Walsh G and Lehnert F). Evanston, IL: Northwestern University Press.

Thompson NC, Hunter EE, Murray L, Ninci L, Rolfs EM and Pallikkathayil L (2008) The experience of living with chronic mental illness: A photovoice study. *Perspectives in Psychiatric Care* 44(1): 14–24.

van Manen M (1990) *Researching Lived Experience: Human Science for an Action Sensitive Pedagogy*. London, ON: Althouse Press.

Wang C (1999) Photovoice: A participatory action research strategy applied to women's health. *Journal of Women's Health* 8(2): 185–192.

Wang C and Burris MA (1997) Photovoice: Concept, methodology, and use for participatory needs assessment. *Health Education & Behavior* 24(3): 369–387.

Williams BR (2004) Dying young, dying poor: A sociological examination of existential suffering among low socio-economic status patients. *Journal of Palliative Medicine* 7(1): 27–37.