

Article

“I Just Don’t Think There’s Any Other Image That Tells The Story Like [This] Picture Does”: Researcher and Participant Reflections on the Use of Participant-Employed Photography in Social Research

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Abstract

The incorporation of visual forms of expression has become common in qualitative research over the past two decades, with participant-employed photography being most prevalent. Visual methods such as photovoice have been used in community-based studies and with individuals to explore their lived experiences, particularly because of their participatory nature. Despite widespread support for visual approaches in existing research, there has been insufficient attention paid to how photography can enhance understanding of the phenomenon under study. Additionally, the existing literature is somewhat bereft of discussion of what individuals think about their participation in studies that incorporate participant-employed photography, or researchers’ perspectives of carrying out this type of research. In this article, we describe a photovoice study carried out with young adult women affected by serious illness and provide examples of participants’ photographs to illustrate how participant-employed photography can enhance the depth of research data. Specifically, the examples highlight how the photographs enriched participants’ verbal descriptions of their lived experiences, which generated a better understanding of their personal embodied realities. We also discuss the young adult women’s inclusion of previously taken photographs and reflections on their participation in the study. Finally, we examine the need to consider the intended audience of photographs, and specific ethical and methodological considerations for researchers contemplating the incorporation of participant-employed photography. In doing so, we provide insight into the advantages and challenges of photo-

methods, which can inform other researchers contemplating the incorporation of participant-employed photography into social research.

Keywords: illness experiences, photography, photovoice, research participation, qualitative research, young adults

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There is a growing trend toward the inclusion of images in qualitative research, which has largely been driven by approaches involving participant-employed photography. One such approach is photovoice, a visual methodology and method grounded in theories of empowerment and inclusion that “uses the immediacy of the visual image to furnish evidence and to promote an effective, participatory means of sharing expertise and knowledge” (Wang & Burris, 1997, p. 369). With photovoice, participants are involved in the research process through their use of cameras to generate images that capture what their lives are like. Next, the meaning of the photographs is explained by participants in interviews or focus groups. Photovoice has primarily been utilized as a means for health promotion within communities (e.g., Carlson, Engebretson, & Chamberlain, 2006; Castleden, Garvin, & Huu-ay-aht First Nation, 2008; Wang, Burris, & Ping, 1996), but it has also been incorporated into research on individuals’ lived experiences of certain phenomena (e.g., Drew, Duncan, & Sawyer, 2010; López, Eng, Randall-David, & Robinson, 2005; Poudrier & Thomas-MacLean, 2009; Thompson et al., 2008). While photovoice has been used with a variety of populations, such an approach is frequently incorporated into health research, which is likely a reflection of the need for alternative ways of communicating about health and illness that go beyond dominant linguistic resources to capture the more personal and complex aspects of individuals’ experiences. For example, Guillemin and Drew (2010) have proposed that images have the ability to “express the unsayable” (p. 178). Furthermore, researchers frequently aim to decrease power differentials in the research process and empower research participants through photovoice (e.g., Foster-Fishman, Nowell, Deacon, Nievar, & McCann, 2005; Packard, 2008), which aligns with empowerment models that are becoming increasingly advocated by health care providers (Zoffman & Kirkevold, 2012).

Although some scholars have focused on the benefits of photovoice and similar methods involving participant-employed photography (Foster-Fishman et al., 2005; Oliffe & Bottorff, 2007; Wang & Burris, 1997), further evidence is required of exactly how the inclusion of photographs enhances understanding of certain phenomena. In addition, there is a need to further examine possible methodological limitations and individuals’ perspectives of their participation in such research because little of the existing literature has explored practical considerations and the complex emotions raised by the photographic process (e.g., Baker & Wang, 2006; Packard, 2008). In this article, we describe a photovoice study carried out with young adult women affected by serious illness and provide examples of how photographs enriched participants’ verbal descriptions. In doing so, we demonstrate how participant-employed photography offered greater insight into participants’ embodied experiences of illness. In addition, we explore their reflections on their involvement in the photovoice study. Last, based on participants’ reflections and our experiences as researchers, we discuss the use of participant-employed photography in research on sensitive topics such as illness experiences.

Visual Approaches to Qualitative Research

Researchers adopting visual approaches utilize images, such as photographs or drawings, as data. In some cases, visual methods are the main source of data generation, while at other times images are incorporated as an additional layer that allows for triangulation with other data (Stanczak, 2007). Despite previous utilization of visual data by sociologists and anthropologists based on its perceived objectivity, many researchers now recognize that visual data is subjective in nature (Hansen-Ketchum & Myrick, 2008; Phillips & Belanger, 2011; Prosser & Schwartz, 1998); specifically, the subject and meaning of an image depends on the context from which it has emerged. Therefore, contemporary visual approaches are often based on a relativist position that visual data are not reflections of reality, but instead have meanings that are constructed by the producer of the image and those who view it (Harper, 1998; Phillips & Belanger, 2011). Accordingly, contemporary visual methodologies are founded on the recognition that visual data

will be interpreted differently by individuals with varying social backgrounds and also within different settings (Harper, 1998). Thus, visual approaches have shifted from a past association with realist research to fit within the relativist or constructivist paradigm.

Although there are numerous motivations and means for incorporating visual methods into social research, many researchers are looking to make the research process more participatory by adopting such methods. Participant-employed photography is one example of a participatory visual method in that participants have the opportunity to choose the focus of their photographs and explain their meanings (Packard, 2008), which in turn influences the direction of the research. Furthermore, Davidson (2002) has contended that visual data offer an effective means of including participants in data interpretation in participatory research (as cited in Castleden et al., 2008, p. 1395) because researchers can elicit interpretations of visual data from participants regarding the content and meaning of photographs. Images can therefore be “both a form of data and a conduit for the elicitation of interview data—thereby revealing more and greater details than other methods alone would have generated” (Shaw, 2005, p. 239). Consequently, visual approaches are thought to yield richer data and more insightful findings in comparison to interviews or focus groups alone.

A common visual approach is photovoice, a methodology that incorporates participant-employed photography as a means to explore individuals’ and/or communities’ experiences of social phenomena with the intent of bringing about awareness and social change. Drawing on principles from feminist theory and critiques of documentary photography, as well as Freire’s work on education for critical consciousness (Wang, 1999), photovoice as a methodological approach has a variety of goals. First, photovoice is rooted in feminist theories advocating for research “by and with women instead of on women in ways that honour women’s intelligence and value knowledge grounded in experience” (Wang, 1999, pp. 185–156). Accordingly, photovoice is based on participatory and feminist principles, including efforts to involve participants in the research process, value their experiences and knowledge, promote change, and advocate for participants (Wang, 1999).

The photovoice approach also emerged from a shift in social research that sought to ameliorate the power differences inherent in documentary photography by having participants rather than researchers employ cameras. Wang and Burris (1997) stated that giving cameras to marginalized individuals allows them to share their experiences from their point of view, rather than being “passive subjects of other people’s intentions and images” (p. 371). Participants can influence the focus of the research by taking photographs that reflect their social realities and sharing the meanings they attribute to their photographs as well as stories they evoke about their lives. Thus, another goal of this approach is to promote participation in the research process through the photographic component, which can potentially decrease the power differential between researcher and participant (e.g., Packard, 2008). The participatory nature also promotes the aim to use participants’ photographs and their meanings to raise awareness of the issues that they face and to advocate for relevant improvements in programs or policies (Wang, 1999). Furthermore, participants’ photographs can “interrogate and disrupt the dominant visual terrain” (Poudrier & Thomas-MacLean, 2009, p. 306), therefore serving as a means to challenge pre-existing beliefs about a social phenomenon.

Photovoice methodology is underpinned by Freire’s (1970, 1973) work on education for critical consciousness in which he sought to address power differences and empower individuals to make change in their lives (Wang & Burris, 1997). According to Freire, participatory strategies attempt to shift power dynamics to create an egalitarian approach among teacher and learner that provides opportunities for individuals to reflect on and feel responsible for their learning (as cited in

Carlson et al., 2006). In turn, valuing participants' experiences and emphasizing that they are experts on their own lives elevates their status within the research study. Moreover, the opportunity to choose the subject of photographs and influence the focus of the research affirms the value of participant-led prioritization of issues (Castleden et al., 2008). Therefore, the involvement of participants in photovoice studies contributes to the goals of fostering trust among researchers and participants, generating meaning and a sense of ownership in the research process for participants, increasing participants' self-reflection and awareness of their social environment, and prompting social change (Castleden et al., 2008; Drew et al., 2010; Foster-Fishman et al., 2005). In addition, some participants have reported therapeutic benefits of participant-employed photography (e.g., Oliffe & Bottorff, 2007; Yi & Zebrack, 2010). As such, participation in the research process is viewed as beneficial both to the individuals involved and the overall success of the research.

In addition to offering a means for accessing subjective experiences and engaging participants, photovoice and similar approaches have several potential benefits for research. Foremost is the facility to elicit new perspectives and information because participants determine what is photographed and discussed (Clark-Ibanez, 2007; Guillemin & Drew, 2010; Hurworth, 2003; Packard, 2008; Samuels, 2007), thereby influencing the research agenda. Consequently, such research can generate greater understanding of participants' lives, as well as empathy in viewers of photographs (Thompson et al., 2008). In addition, photographs provide a focus for discussion, which can help to promote rapport and dialogue, and trigger memories for participants (Drew et al., 2010; Hurworth, 2003; Samuels, 2007). Another advantage of this method is that photography can be useful for expressing complex thoughts and experiences that can elude verbalization (Guillemin & Drew, 2010). Therefore, photographs can elicit details and stories with potentially greater richness than what is typically generated in a traditional interview (Clark-Ibanez, 2007; Samuels, 2007; Shaw, 2005).

Potential limitations of photovoice and similar visual approaches should also be acknowledged. For example, the inclusion of participant-employed photography requires participants to have some degree of technical proficiency, which some populations may lack (Packard, 2008). In addition, some individuals might have difficulty with portraying intangible ideas and issues in photographic form (Clark-Ibanez, 2007; Drew et al., 2010) or capturing their ideas in what is directly observable (Castleden et al., 2008). The possibility also exists for participants to forget the meaning of photographs between the time that they were taken and the time of the interview (Thompson et al., 2008), or for the meanings of photographs to be misinterpreted by researchers or other audiences (Stanczak, 2007). The inclusion of photographs in research also raises a number of ethical issues, particularly because cameras can be intrusive and might subject participants to greater vulnerability than other research methods (Harper, 1998). Consequently, efforts must be made to maintain the privacy of participants and anyone appearing in the photographs.

Finally, there are many ways to incorporate visual methods in social research. Although specific steps for conducting photovoice research are given by its developers, researchers can adapt photovoice to the particular participants, goals, and research area under investigation (Wang, 1999; Wang & Burris, 1997). Accordingly, some researchers have blended photovoice with other methodologies, such as phenomenology or grounded theory (e.g., Burles & Thomas, 2012; López et al., 2005). In this article, we discuss a qualitative study of young adult women's experiences of serious illness that incorporated a modified version of photovoice, similar to approaches adopted by other researchers to study experiences of health and illness (e.g., Brooks, Poudrier, & Thomas-MacLean, 2008; Drew et al., 2010; Thompson et al., 2008). The modified approach involved engaging participants in the qualitative interviews and photovoice project on an individual basis,

rather than as a community. We next outline the methodological approach and research process, before exploring the contribution of participant-employed photography to the study and participants' reflections on their participation.

Methodology and Methods

In carrying out this study, we adopted an interpretive phenomenological approach that sought to understand what it is like to be seriously ill during young adulthood. Our approach aimed to gain an in-depth understanding of participants' "lived experiences" (van Manen, 1990) through a focus on how illness affected the taken-for-granted nature of the body and time (Schutz, 1967). We chose to blend phenomenology with a modified version of photovoice (Wang & Burris, 1997) in hopes that the interviews and photographs would access specific examples of participants' everyday lives with serious illness and offer insight into how they gave meaning to them. In addition, our blended approach aimed to account for the embodied and social nature of illness by enabling exploration of the physical, psychological, and social aspects of experience through images and words.

Recruitment and Participant Characteristics

Participants were recruited from a Western Canadian province to participate in the phenomenological interviews and photovoice project. Following ethics approval from a university's behavioural research ethics board, we used a snowball sampling approach that involved the distribution of advertisements through a university's online bulletin board and local support organizations, as well as through word-of-mouth. Recruitment materials provided a brief explanation of what participation would entail, including a description of the photovoice component. We decided that to be eligible for the study participants must have been diagnosed with a serious illness within the previous three years and be between the ages of 19 and 39 years. Determining the age range for inclusion began with a review of existing literature, which revealed a lack of consensus regarding the specific ages of "young adults." Specifically, other research includes individuals as young as 15 years and as old as 49 years (Burles, 2010). However, it was decided to exclude teenagers and individuals in their 40s because of perceived differences in their roles and responsibilities, with those in their 20s and 30s being more likely to be concerned with education, employment, intimate partnerships, and starting a family, among other activities.

Prior to commencing the study, we proposed to focus on the experiences of 10 young adults to ensure the feasibility of data collection and analysis, and to aim for depth rather than breadth (Rossman & Rallis, 2012). Specifically, a sample size of 10 allowed us to obtain an in-depth understanding of each participant's experience through multiple interviews and the photovoice project, but also to make meaningful comparisons across participants' experiences (Mason, 2002). We deemed the sample size appropriate following data generation with 10 participants because of the diversity of experiences that were captured and the insight gained into what it was like to be seriously ill during young adulthood. Recruitment advertisements yielded 22 inquiries from interested individuals. Of these, some did not meet the age or time-since-diagnosis criteria, and thus were ineligible to participate. A few other individuals decided that despite their interest in participating the time commitment was too great or their diagnosis too recent to discuss.

Based on response and established criteria, our sample was composed of 10 young women ranging in age from 20 to 37 years who had been diagnosed with a serious illness in the preceding three years. Whereas all 10 participants completed a phenomenological style interview about their illness experiences, only nine completed the photovoice project because time constraints impeded one participant from doing so despite her intentions. This participant, however, consented for her

initial interview to be included in the study, and her data is a part of the findings reported elsewhere (Burles & Thomas, 2012). Here, to illuminate the photographic process, we focus on interview and photograph data generated by the nine participants who completed the photovoice project.

Each participant had received a diagnosis of some type of serious illness, including life-threatening, chronic, and mental illnesses. Three participants were married, one with two children and two without children. Two participants had boyfriends at the time of the interviews, and five did not indicate being in an intimate relationship at that time. One participant resided in a rural community, one in a small community near a city, and eight in one of two urban centres. Information about socio-economic status or education level was not solicited, but all of the young women discussed attending university and some were involved in graduate studies. None of the participants reported experiencing severe financial difficulties.

Research Process and Ethical Considerations

As each participant was recruited, the first author arranged an initial meeting to discuss what her participation would entail. During the initial meeting, the participant was informed of the purpose of the research and given details about the photovoice component. Specifically, she was given information about the consent process and photograph release forms for anyone appearing in the photographs, as well as suggestions of how many photographs to take (10-12) and potential topics that could be explored (diagnosis, everyday activities, family, support, relationships, education, employment, etc.). Despite these guidelines, it was emphasized that participants could complete the photovoice project as they saw fit. Participants were offered a digital camera to use, although only one participant borrowed the camera while the rest used their own digital cameras. Once any questions were answered, participants could choose whether to complete one or two interviews. Most participants opted to be interviewed at the first meeting, and then participated in a second interview once the photovoice project had been completed a few weeks to two months later. One participant chose to combine these two interviews at a later date.

The initial interview included open-ended questions about participants' lived experiences of illness; topics discussed were often determined by each participant, but interview questions focused on their experiences of the onset of illness, diagnosis, and treatment, in addition to its impact on their everyday lives and goals for the future. In the second interview (or the second half of the interview for one participant), the focus was on the photographs taken by the participant and the meanings attributed to them. The sharing of photographs was led by the participant, who selected the order in which they were viewed and discussed. Participants typically began with an explanation of the subject of the photograph and how it related to the illness experience. In some cases, the interviewer asked for elaboration or clarification from the participant to obtain a more in-depth understanding of what the photograph depicted and meant. These questions often led to participants telling stories related to the photograph content. The young women were able to discuss all of the photographs that they had taken, with the number of images ranging from 4 to 22.

Following discussion of the photographs, any other queries regarding participants' experiences were posed, and then feedback on the photovoice project was solicited, even if the individual had previously shared comments about the photographic component. In particular, each young woman was asked: "How did you find the experience of taking photographs?" Also, if participants had not previously broached the issue of photographs not taken, they were also asked: "When you were taking photographs, were there any ideas that you could not communicate with a photograph?" In total, 18 interviews were completed with 10 participants,

ranging from 45 minutes to 2 hours in duration. Additionally, nine of the participants generated 111 photographs.

Prior to each interview, written consent was gained. Given the sensitive nature of the research and additional complexity of incorporating photography, steps were taken to avoid harm and ensure the privacy of participants. First, open-ended questions enabled participants to guide the interviews and share as much or as little information as they wished. Second, although personal information was largely removed from the data, participants could determine via a graduated consent form the degree of anonymity they desired; specifically, they could choose whether their real name (first name only) or a pseudonym would accompany their data, because some participatory research participants might want to be recognized as co-researchers and associated with data that they generate, particularly when personal images are included. Participants could also decide whether images of themselves were included as they appeared or were de-identified (blurred) to avoid identification. All human subjects appearing in photographs were asked to sign a photograph release form authorizing their use in the study. If a photograph depicting an individual was not accompanied by a photograph release form, the image was not disseminated. The methodological focus of this article influenced our choice not to include real or fabricated names or images that could reveal participants' identities.

Data Analysis

All of the interviews were transcribed verbatim, after which transcripts and photographs were returned to each participant for verification. Participants returned any revisions to their transcripts along with signed release forms authorizing the inclusion of their interview and photographic data in our analysis. Transcripts and photographs were then analyzed in accordance with the phenomenological focus on the embodied, temporal, and relational aspects of experience (van Manen, 1990). Specifically, data were analyzed for what they revealed about participants' lived experiences of serious illness during young adulthood. Transcripts were analysed holistically and cross-sectionally with the qualitative analysis program ATLAS.ti. Holistic analysis involved looking at individual cases within the data set in order to understand the "particular in context," while cross-sectional analysis refers to the application of a consistent set of categories to the entire set of data which allows for the identification of similarities and differences (Mason, 2002, p. 165). By performing both holistic and cross-sectional analyses, we reached a comprehensive understanding of each participant's experience of serious illness, and identified common themes across the young women. Photographs were analyzed with respect to their content and the meanings assigned to them by participants during interviews.

By analysing participants' accounts of illness and their photographs, we sought to connect lived experiences to broader social structures (Richardson, 1997) and social understandings of illness and the life course. We report elsewhere our findings that relate young women's experiences to socio-cultural ideals regarding the life course (Burles & Thomas, 2012). In this article, we focus on the photographic component of the research and what it revealed about participants' embodied experiences, as well as their reflections on participation.

Findings

Telling the Story of Young Women's Experiences of Serious Illness

Having already participated in phenomenological style interviews, participants had recounted a chronology of illness-related events and highlighted significant points in their experience prior to sharing their photographs. However, through the taking and sharing of photographs within an

interview format, participants reflected on their experiences and drew attention to the issues they faced because of illness. For some, the photographs were a way to broach issues not raised previously and to tell stories about the impact of illness on the body, identity, roles, and relationships. The following examples demonstrate how greater insight into participants' embodied experiences was elicited by their photographs, and how the photographs often became the medium through which they broached the complexities of negotiating serious illness during young adulthood.

Gaining insight into the illness experience.

The sharing of photographs during the interview generated significant insight into participants' lived experiences. For example, one participant described disruptions experienced because of having to incorporate medication and vitamins into her daily routine due to her endometriosis, and she specifically mentioned the difficulties she faced in deciding when to take blood-clotting medication prescribed to treat heavy bleeding. To illustrate her experience, this participant shared two photographs (Figures 1 and 2) showing the variation in her day-to-day life:

So that's the number of pills that I take on a good day, just the three multi-vitamins. . . . Just to kind of give you a contrast of that, a good day versus a bad day, how many pills that I take. . . . those are the hemophiliac pills [in the second photograph], the blood clotting pills. . . . So yeah! That's my little pile of pills. . . . [and] I do take a tiny little hormone tablet [as well] but I didn't want to take it out of the package . . . but that's added into my little cocktail.



Figure 1. A Good Day



Figure 2. A Bad Day

Thus, she used these images to sum up a good day as one in which she only takes vitamins, and a bad day as one that requires numerous pills for blood clotting and pain management, in addition to vitamins and an oral contraceptive. The participant also identified other concerns related to medication and the treatment of endometriosis in relation to these images, including disruptions to her education and employment and negative interactions with health care providers. Accordingly, through these photographs and her explanation of them, the participant provided significant insight into her struggle to cope with illness on a day-to-day basis.

Five participants out of the nine who completed the photovoice project took photographs of medication, and some included several. The number of such photographs might have been because medication offered a concrete and simple object to photograph (easy to access and explain). Medication also provided a specific example of how participants' lives had been changed by illness (the need to incorporate medication into daily routines). However, participants also seemed to have had complex and personal reasons for photographing medications. For

example, images of medication reflected: disruptions to everyday life, tension with health care providers regarding the treatment of certain illnesses, impact on the body and changes in body composition, and uncertainty about fertility due to medication. Therefore, participants' photographs of medication depicted a number of themes, both tangible and intangible, and provided an accessible visual translation of issues of concern at the time of participation in the study. Consequently, these examples demonstrate how photographs were used to raise important aspects of participants' illness experiences and their specific meanings, thereby eliciting a layer of data supplementary to the initial interviews.

Transcending verbal expression.

Photography also offered participants a chance to be creative and express themselves differently than with words alone. Specifically, some participants captured through photographs feelings and moods that might not have been communicated otherwise. A striking example of this was one participant's use of the black-and-white setting on her camera by which she sought to convey the emotions surrounding her experience of depression. The photograph (Figure 3) depicts a painting by this participant, which she described by saying:

I thought of what photos to take, 'cause that was definitely common to come home and crawl in and roll up in bed and just kind of think, but not want to go out. And isolation, so that's kind of the grey around her, there's just this big fog and mist, and you don't know.

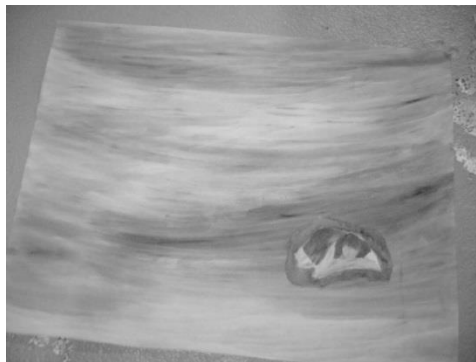


Figure 3. Depression

Her explanation emphasizes her feelings while depressed, which are conveyed through the use of black-and-white photography that illustrates the lack of joy and hope in her life at that time.

This participant then used another photograph (Figure 4) in juxtaposition to depict the healing process; the photograph shows the same painting but with a small figurine standing on it, and the photograph is taken in color. She explained:

This particular [figurine] I got for my graduation [from my aunt] . . . so I put these in contrast 'cause I think this [curled up person] is more what I felt like . . . earlier in the depression. But then when I put this [figurine] back there, I was like "You know what? I like that." Because it almost feels like a guardian angel appearing, or like it's watching over [me] and overshadowing [depression] even.



Figure 4. Recovery

Through the sharing of images that she associated with depression, this participant effectively communicated the emotions surrounding two phases of her illness experience: the first photograph speaks to the isolation experienced during the acute phase of depression, and the second photograph captures a renewal of hope that emerged through the healing process. The use of photography therefore offered her another dimension for sharing her story of illness that employed both colour and its absence. The images also provide understanding into her embodied experience of depression as one of being withdrawn and closed in, while recovery involved opening up, both physically and socially. Thus, both the subject of a photograph and how the subject is depicted convey meaning and offer insight into experience that might otherwise not be available.

Inclusion of previously taken photographs.

Although we asked participants to generate photographs about their experiences of illness, some participants included previously taken photographs or those taken during the time of the photovoice project for other purposes. For example, one participant included images of her house before and after renovation, her wedding day, and a recent gathering with her siblings and their families. Another participant included a photograph previously taken of her parents who did not live in the same country as her, and a third participant included previously taken family photographs as well as some taken, not solely for the purpose of the research, on a recent family vacation. Despite being taken for a different audience, it is important to consider why participants chose to include previously taken photographs. For example, practical reasons such as not having access to certain individuals or locations sometimes figured in such decisions.

However, participants also had more nuanced reasons to include such photographs. For instance, one participant indicated in relation to a previously taken photograph of her children that she wanted to show “the things that we were dealing with at the time [of my breast cancer diagnosis] with [my daughter] being on oxygen and [a] little munchkin, and [my son] being quite little himself too.” The inclusion of this photograph enabled the participant to highlight what was happening in her life at the time of her diagnosis as a caregiver to two small children, including one who was born premature just before her diagnosis. Thus, through the photograph, viewers are able to see the young age of her children and the fragile state of her daughter at the time, and can likely imagine how difficult it would be to cope with a life-threatening illness while simultaneously caring for very young, vulnerable children. With respect to a photograph taken of her healthy family of four on a recent vacation, this participant reflected on how far her family had come since her diagnosis and her determination to spend more time together as a family because of her illness experience. For this participant, the photographs in juxtaposition evoked an understanding of how much time had passed since her diagnosis and how resilient she and her

family turned out to be. Without these visuals, this participant might not have been able to contemplate and capture this trajectory in such a powerful way.

Capturing the embodied nature of illness.

Another example of the power of images to evoke immediate, multifaceted understanding is the following photograph of a participant's mastectomy site (Figure 5). With respect to this image, the participant stated: "I just don't think there's any other image that tells the story like [this] picture does." In sharing this photograph, she enables viewers to see her daily reality following breast cancer treatment, and the striking contrast between her healthy breast and the mastectomy scar. She also captured the struggle with her changed appearance and the daily reminder of cancer that summons the possibility of recurrence and death, two issues that continue to plague her at the present. This participant also shared photographs of her bras and bathing suits "before-and-after" breast cancer to emphasize the impact of her mastectomy on her everyday life because she now has a prosthetic breast and can no longer wear styles she previously did. Strikingly, the photographs offer visual evidence of her embodied experience and survivorship of cancer that went beyond a verbal description of her mastectomy site to enable viewers to comprehend the ongoing implications of breast cancer that she must face.



Figure 5. Mastectomy Site

In addition to providing participants with an alternative way to communicate about their experiences, the inclusion of photography in the research process enabled them to choose how their story was told. Taking photographs involved selecting which images to capture and which to include in the research. As such, participants were able to use photographs to determine the aspects of their experience that would be discussed, which contributed to the first level of data analysis in the study. In this way, participant-employed photography enables individuals to participate in the research process in various ways that affect the outcome, which can enhance the meaningfulness of the research to participants.

Our above examples demonstrate the potential of participant-generated photography for research on social phenomena, such as young women's experiences of illness. Taking and sharing photographs can: prompt participants to reflect on their experiences, elicit stories about what an experience has been like to give it meaning, illuminate emotions and moods that might not be fully captured by words alone, and provide greater insight to researchers and other audiences. The photographic process, and the potential inclusion of previously taken photographs, can therefore lead to a deeper understanding of participants' experiences by tapping into additional data that might not emerge through purely verbal research methods. Our examples also reveal how photographs provided a window into participants' embodied experiences that generated understanding of what it was like for them to be seriously ill during young adulthood; we literally

could envision what they were talking about, which enhanced our understanding of their experiences. Furthermore, through their photographs, participants often captured specifics surrounding certain issues that had not been described in the initial interviews. Accordingly, we agree with the conclusion of other researchers that visual approaches can generate richer data than qualitative interviews or focus groups alone (Clark-Ibanez, 2007; Samuels, 2007; Shaw, 2005). However, it is also necessary to consider participants' perspectives on such approaches to research, which we do in the following section.

Young Women's Reflections on Photovoice Participation

Although photovoice has been utilized in a variety of settings, less attention has been paid to perspectives on its use from participants themselves. Accordingly, we examine the comments made regarding this approach by the nine young women who completed the photovoice project about their illness experiences. Comments from participants emerged spontaneously during the interviews and in response to a specific question about photovoice that was asked at the conclusion of the photograph-sharing interview even if they had previously discussed their perceptions of taking photographs. In examining participants' reflections on their participation in the photovoice project, we seek to understand the benefits and challenges of adopting a photovoice approach in social research, particularly in relation to the study of illness experiences or other sensitive topics. We conclude this section with a discussion of participants' verbal descriptions of photographs that they did not take despite wanting to, which adheres to the assertion by Hodgetts, Chamberlain, and Radley (2007) that photographs not taken also exemplify important issues in the lives of participants.

Valuable and challenging aspects of participant-employed photography.

While sharing photographs, several participants indicated that they saw value in the photovoice project. Specifically, participants suggested that the incorporation of photographs into the research made it more personal, human, and emotionally evocative than words alone. For example, one participant stated, "I think [the photographs] make [illness experiences] real too, you know? If you listen to the presentation [about this study], it's not just all facts and figures and theories and things. It's real people with real flaws in their lives." A similar sentiment was echoed by another participant who said, "I wanted to show that there is so much more than just the diagnosis involved. There's family, there's friends, there's a person that you're treating, not [only] the illness." As such, photovoice was viewed by many of the young women as a useful and meaningful way to communicate to others, including health care providers, what it is like to have a serious illness during young adulthood.

Some participants also commented positively on the reflection and self-dialogue prompted by participation in the photovoice project. In particular, it was suggested that taking photographs required reflection on their experiences, which often led them to realize the more positive attributes that came out of being ill, such as resiliency and coping ability. However, the need to reflect on their experiences to generate photographs was also challenging for some participants. The following two quotations from one participant sum up the tension that she experienced during the photovoice project:

I found that when I took the pictures it caused a lot of like self-dialogue. I thought a lot about it, I did a lot of thinking about it after, but it was way harder than I thought it would be . . . to put myself in that position again and probably feel a bunch of things that I've kind of shut out – to feel vulnerable again.

I think it helped me actually. I think it definitely gave me time to think about it and kind of force me [to], 'cause I've got to take these pictures and I'm going to have to talk about them. So I think it really did help me kind of, maybe go through some things that I hadn't thought about in a while, so I found it helpful.

This participant's comments emphasize both the challenging and therapeutic aspects of her photovoice participation. Although contemplating the sudden change in her health and implications of an epilepsy diagnosis was difficult for her, the photovoice project caused her to confront feelings that she had been avoiding and make realizations about her coping ability.

Although many of the participants appreciated the opportunity to be creative and choose the focus of their photographs, they also noted that it was difficult to translate experiences and emotions into photographs. In particular, a few commented on their perceived lack of creativity as they discussed photographs of family members and everyday objects. Despite that one participant was initially attracted to the study by the photovoice project, she recalled her struggle with taking photographs: "It was harder than I thought it would be just because [endometriosis] is kind of invisible. But it was really nice though because I got to think about [my experiences] and be creative about it, and then actually do it." As such, capturing illness experiences visually was sometimes challenging.

The above comments also speak to photographs taken by other participants who appeared to have an easier time choosing photograph subjects when there were physical signs or evidence of illness. For instance, several photographs taken by one participant highlighted changes in appearance resulting from breast cancer, as shown by images of her bathing suits and bras before and after surgery, and the mastectomy site. Some of another participant's photographs also addressed the physical components of her anorexia experience, with photographs of exercise equipment and a grocery store reflecting her compulsive exercising and under-eating. These examples, along with the above-quoted comment, suggest that it might be less complicated for participants to share illness experiences through photography when there are concrete signs of illness, whereas psychosocial experiences and illnesses that affect internal processes are more elusive to visual depiction.

Practical considerations for participant-employed photography.

Participants also raised practical considerations related to photovoice that are important to note. For instance, some indicated that their photograph-taking was challenged by issues such as: weather, time, access to certain people, and the absence of a camera during photograph-worthy moments. Thus, participants were not always able to capture the desired image. Another practical consideration was the difficulty encountered when trying to capture experiences retrospectively because some participants were a few years past their diagnosis. For example, one participant suggested that if she had been taking photographs during chemotherapy treatments she would have included a photograph of herself with no hair; however, because two years had passed and her hair had grown back some time ago, taking photographs required greater reflection on the lasting changes and what she wished to share about her experiences.

In some cases, participants overcame issues of not being able to access subjects retrospectively or because of geography by including photographs taken previously. As described above, four participants included one or more previously taken photographs to highlight important issues or demonstrate changes that had occurred since their diagnosis. None of these participants asked if the inclusion of such photographs was appropriate, and other participants would have likely done so if that possibility had been explicitly suggested. The incorporation of previously taken

photographs into photovoice projects has not been raised in the existing literature on photovoice, despite being one means for participants to access and share lived experiences.

Photographs not taken.

Another aspect of the photovoice project that was discussed by several participants was photographs not taken, with a variety of explanations being given for why this was the case. For example, five participants were unable to access certain individuals or otherwise encountered barriers to taking the photographs envisioned, such as weather or time constraints. In addition, a few participants indicated that thinking about certain ideas for photographs brought up challenging emotions that stopped them from taking the pictures. One participant described two photographs that she never took:

I wanted to take a picture of an ambulance and I wanted to take a picture of [my former workplace] where [the seizure] happened, and I found it too painful. I couldn't go there and take a picture of that 'cause it just reminded me of everything that happened that day.

Another participant also shared anxiety over an idea for a photograph, one of her scars from her mastectomy and reconstruction surgeries. Although she never took this photograph, in talking about this potential image she raised an important issue, that her surgical scars are a reminder of breast cancer and the possibility of recurrence, which is similar to what was expressed by the participant cited earlier. She also discussed ongoing discomfort with her appearance because of the scars and her husband's efforts to reassure her that she remained beautiful. Thus, in talking about this photograph not taken, the participant highlighted two prominent illness-related issues that she faced. This example affirms Hodgetts et al.'s (2007) proposition that photographs not taken should be analysed, in addition to those that have been taken, because in discussing the absent photograph participants "invoke places, relationships, and identities and point to the essence of what is important to [them]" (p. 275).

Discussion

Photovoice and similar visual methods have been employed in a variety of research, yet there has not been substantial effort made to explicate how participants share stories through photographs and what participants themselves think about such approaches. As such, we offer examples from our research with young adult women affected by serious illness to illuminate the role of photography in the investigation of their lived experiences. First, we examined how the incorporation of photographs into the research elicited stories and provided alternative means for participants to communicate their experiences. Our analysis revealed that the visual data generated additional insight into participants' experiences that went beyond their verbal descriptions to show how they constructed being seriously ill during young adulthood. This finding echoes the claims of other researchers that photographic approaches can generate richer data than interviews alone (e.g., Clark-Ibanez, 2007; Samuels, 2007; Shaw, 2005). The photographs depicted in the first section of this article provide a visual representation of the variations in our participants' lives that they attributed to illness. Although their verbal explanation of the photographs reveal the specific meanings they associate with the images, it is the combination of words and images that more vividly conveys their stories; specifically, through the juxtaposition of two photographs or the absence or presence of colour a deeper understanding of issues faced because of illness can be gained. Accordingly, these examples reinforce the claim that visual approaches can add depth to research data.

Although photographs do not have innate meaning, the images that participants shared drew attention to issues of significance, even if these issues diverged from the subject of the photograph and their initial aim in sharing the image. As discussed earlier, photographs of medication highlighted various aspects of the young women's experiences and had varied meanings for them. Although images of medication represented a definitive change that had occurred in their everyday lives since being diagnosed with a serious illness, participants also used them as a launching point for talking about communication problems and relationships with health care providers, family members, and friends, among other concerns. A single image often represented a multitude of concerns and elicited stories regarding significant events; thus, specific aspects of participants' lived experiences of illness were accessible through the photographs.

Additionally, many participants emphasized the value of incorporating participant-employed photography into research in their comments regarding its potential for depicting a more personal and human side of illness. The examples offered suggest that participants appreciated the opportunity to communicate their experiences in a way that allowed them to determine the focus. Specifically, the photography project prompted reflection on their experiences and enabled participants to tell their story as they chose, which provided an opportunity for the young women to actively construct the meaning of their lived experiences. This engagement was particularly empowering for some, who chose to focus on positive attributes that had emerged from the illness experience. Thus, the photography component made the research more meaningful to participants because it offered an opportunity to be creative and to have (at least some) control over the research process and how their experiences were constructed. Participants also indicated that the research was more evocative because their photographs could better tell their stories than words alone, and thus would have a greater impact on the audience. These reflections from the young women are similar to what is reported elsewhere regarding research on illness involving photography (Olfiffe & Bottorff, 2007; Yi & Zebrack, 2010), which emphasizes the potentially therapeutic and empowering nature of participant-employed photography.

Despite having a number of clear benefits for the richness of qualitative research, the use of participant-employed photography also needs to be considered with respect to ethics. In particular, we believe it is necessary to move beyond issues of privacy in ethical discussions regarding photovoice to address the impact of participation on those involved in such studies. For instance, as Guillemin and Drew (2010) have suggested, researchers must be aware that visual methods can generate complex feelings regarding difficult experiences, which have the potential to be emotionally harmful. Furthermore, some individuals might be hesitant to share emotional experiences with others (Baker & Wang, 2006). Although participants in this photovoice study generally conveyed positive sentiments regarding their experience, some participants also discussed the emotionally challenging aspects of participation. Specifically, reflecting on their experiences to determine the subject of the photographs was difficult for some because it brought up emotional memories and/or led them to confront losses resulting from illness.

Notwithstanding that such reflections contribute to the depth of the research data, researchers incorporating participant-employed photography to study sensitive topics must consider the potential for challenging emotional responses to the project when the researcher is not present. This is a different context than face-to-face interviews when information about support services can be provided. Consequently, we recommend that researchers prepare for such possibilities by providing information about appropriate support services to participants along with instructions for taking photographs at the beginning of their participation. Furthermore, those participants with recent diagnoses expressed more complex emotions in relation to the photography project than those who had been diagnosed more than one year prior. As such, the use of photovoice and similar approaches in research on sensitive topics might be better suited to individuals for whom

some time has passed since the event being studied to ensure that coping resources have been identified.

Nonetheless, we believe that researchers considering the use of participant-employed photography should not shy away from doing so purely because of ethical complexities; potential for positive outcomes of participation in such research also exist. In particular, reflecting on lived experiences can facilitate the meaning making process, which can be valuable for coping with illness or other traumatic events. The participatory nature of photovoice and similar approaches can also facilitate the construction of experience according to participants' viewpoints, thus photovoice has the potential to challenge or go beyond dominant social constructions, as suggested by Poudrier and Thomas-MacLean (2009). Additionally, an aim of photovoice research is to empower individuals and prompt the development of critical consciousness that fortifies the ability to initiate change (Carlson et al., 2006). As such, participation in photovoice studies can be the catalyst for personal as well as community growth. A sense of empowerment can also arise from sharing one's experiences, which can improve understanding and influence policy and services positively; therefore, participants might be empowered to know that they are helping others facing similar issues.

There are also important methodological considerations for researchers who are considering incorporation of participant-employed photography into research. As Harrison (2002) pointed out, the intended audience for photographs has gone unassessed. Following Harrison's lead, Guillemin and Drew (2010) suggested the need to reflect on the intended audience of visual images and the role of the researcher; specifically, they have contended that images are produced for the participants themselves, as well as for researchers and others. Therefore, it is worth questioning why an image was selected by a participant in terms of its impact on (which) audience and what they are seeking to accomplish with it, whether explicitly or implicitly.

In the context of this research on young women affected by serious illness, considerations of the audience and the intended purpose of the photographs are important, particularly because illness was often experienced as inconsistent with participants' life stages and expectations for young adulthood (as described in Burles & Thomas, 2012). Thus, at least two participants may have included specific photographs to emphasize their resiliency and ability to overcome illness-related challenges or move past illness. Four other participants also incorporated photographs that conveyed themselves in a positive way or highlighted their resiliency with respect to illness. In this sense, these participants may have used the photography component of the research to downplay the impact of illness on their lives and well-being, as self-motivation, or to not appear weak to others; for example, see Hay (2010) for a discussion of the emphasis placed on productivity by individuals affected by chronic illness. Therefore, researchers should recognize that photographs can be constructed in certain ways to create a particular impression, or to allow a participant to revise their own thoughts about illness (Oliffe & Bottorff, 2007).

Conclusion

Our examples from research data generated by young adult women affected by serious illness provide insight into their lived experiences, and illustrate the value of photography for generating in-depth understanding. Namely, the generation of photographs added depth to qualitative interviews because this process encouraged reflection, allowed participants to share their experiences in a format that went beyond language, and elicited stories that might have otherwise gone unheard. In this sense, photographs acted as the medium through which individuals shared their experiences and identified what they believed was important. In addition, the photographs offered significant understanding of the embodied nature of participants' experiences by drawing

attention to bodily experiences, changes to function and appearance, and the emotions introduced by illness.

In addition, participants' reflections on participating in a photovoice project highlight a number of benefits and challenges resulting from the incorporation of participant-employed photography into psychosocial research on illness. For instance, the young women who participated in this study appreciated the photographic process because it added a creative and personal aspect to the research, and prompted reflection and self-dialogue. However, it was also challenging for participants to translate experiences into photographs and confront emotions opened up by revisiting their illness experiences. Both emotional and practical reasons contributed to some participants not taking photographs that they had planned to shoot, although some participants included previously taken photographs to overcome certain practical issues. In conclusion, our experience as researchers adopting a modified photovoice approach in the study of serious illness during young adulthood demonstrates that such visual methods can significantly enrich qualitative interviews. Although there are ethical and methodological issues that must be considered when deciding whether to incorporate such an approach into social research, we believe that photovoice and other visual approaches have potential to complement and enhance the depth of understanding obtained through qualitative interviews.

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