Using Photographs to Capture Women’s Experiences of Chemotherapy: Reflecting on the Method

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This article examines the value of using the photo-elicitation method for generating health-related narratives. Drawing on research in which women kept a photographic record of their experiences of chemotherapy treatment for breast cancer, this research explored how this method (a) produced elaborate accounts of illness experiences through an exploration of the process of representing experiences and through an interrogation of the images themselves; (b) allowed an opportunity to capture experiences over time and a way of capturing the past, which can then be reexplored from the present; (c) enabled patients to retain control over their images of themselves and how they choose to represent their experiences; and (d) provided a window into the private, everyday experiences of patients away from a health care setting.

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**Visual methods.** Including the use of photographs, video recordings, drawings, and art, are increasingly used in the study of psychosocial aspects of health and well-being (see Harrison, 2002). In this article, we examine the strengths of using a photo-elicitation method by reflecting on our study that explored women’s experiences of having a changed appearance as a result of undergoing chemotherapy treatment for breast cancer. Photo-elicitation is a method in which photographs (taken by the researcher or by research participants) are used as a stimulus or guide to elicit rich accounts of psychosocial phenomena in subsequent interviews. We explore how asking patients to reflect on the process of creating a photographic record of this significant life event, as well as on the photographs themselves, can yield rich insights into the experience of health, illness, and medical treatment. The aim of this article is to examine the strengths of photo-elicitation for health researchers and to present our recommendations for its use. We begin by giving a brief overview of our study and the reasons why we chose to use the photoelicitation technique, before going on to discuss our reflections on this method.

**Background to the Study**

Our research explores the ways in which chemotherapy affects patients’ perceptions of their appearances, and it examines the psychological and personal impact of such changes, by listening to patients’ stories of their treatments. The diagnosis and treatment of disease can have a profound effect on patients’ appearance and body image; for example, the side effects of cancer treatment—including scarring, hair loss, altered weight, ulcers, and early onset of menopause—can all act as vivid, constant reminders of the disease (see Rumsey & Harcourt, 2005). Although the impact of cancer surgery on body image has received some attention, the impact of changes to appearance resulting from chemotherapy has remained relatively unexplored. Yet chemotherapy treatment can be especially distressing, with rapid alopecia and hair loss being one of the most feared and traumatic aspects of chemotherapy (see Batchelor, 2001; Münstedt, Manthey, Sachsse, & Vahrson, 1997). Developments such as patient-centered approaches (Bensing, 2000; Stewart, 1995) and narrative-based medicine (Greenhalgh & Hurwitz, 1998) suggest the importance of eliciting patients’ viewpoints on their illness and treatment. These approaches assert that hearing the personal stories of patients, including the life experiences, living situations, behaviors, and beliefs,
may enhance clinical diagnoses, therapeutic interventions, and understanding between patients and health care professionals. Photography, video recordings, and drawings have been used to elicit health-related stories (Guillernin, 2004; Hanna & Jacobs, 1993; Radley & Taylor, 2003a, 2003b; Rich, Patashnick, & Chaffen, 2002; Smith, Frost, Albayrak, & Sudhaker, 2006), and we anticipated that photography would provide a useful resource for exploring women’s stories of chemotherapy.

Participants

Nineteen women who were diagnosed with breast cancer and who were due to undergo chemotherapy in Bristol, England, volunteered to take part in a study to explore their experiences of chemotherapy. The following inclusion criteria applied: Patients needed to be at least 18 years old with a diagnosis of breast cancer, be English speaking, and be receiving adjuvant chemotherapy. The study was introduced to potential participants by their consultant. Patients who expressed an interest in the study were given a detailed information sheet and were then contacted by the researchers, who answered any questions and arranged an appointment for the initial interview.

During this initial interview, we obtained signed consent from participants. We do not know how many women were approached to take part in the study, but 19 women volunteered to be interviewed (one further woman was contacted by telephone but decided not to take part). Of these 19 women, 15 went on to provide all three sets of data (an initial interview, a set of photographs, and a second interview), and the other 4 provided an initial interview but were noncontactable or did not return telephone messages to arrange a second interview. The women were between 35 and 68 years old; all but one were in heterosexual relationships (12 were married), with the exception identifying herself as lesbian and in a relationship. Some had undergone surgery to remove some or all of the breast tissue; some were to undergo radiotherapy after the chemotherapy; and some were expecting to have surgery at a later date. For all but one of the women, this was their first experience of chemotherapy. We recognize that like all forms of research, this type of study would not appeal to all potential participants, and some chose not to participate when the study was first described to them. The participants in our study were clearly a motivated sample, receptive to the idea of taking photographs during their chemotherapy. In this respect, they may differ from other chemotherapy patients in general.

Procedure

This study had three stages. First, women were interviewed about their expectations and concerns regarding chemotherapy before commencing treatment, with a particular focus on appearance; for example, “Do you anticipate that the chemotherapy will change your physical appearance or your feelings about your body? How? In what ways?” Semistructured interviews were conducted in the participants’ homes (with the exception of two women, who preferred to be interviewed in a hospital setting); they were all tape-recorded, and each lasted approximately 1 hr.

Second, women were given a 27-exposure, single-use, disposable camera and asked to take photographs during the course of their chemotherapy that captured their experiences—in particular, those relating to how they felt about their appearances and bodies during this time. We contacted them toward the end of their treatment, provided an envelope for them to return the cameras, and sent them a set of the developed photographs. The photographs were used as a basis for the interview at the end of their chemotherapy treatment.

Finally, women were interviewed about their experiences after completing treatment, which included a discussion of the photographs that they had taken as well as a reflection on the process of taking them. Participants were asked to speak to each of their photographs in turn, explaining why it had been taken and what aspect of their experience it represented.

Why Use Photo-Elicitation?

Using photographs alongside interviews, or photo-elicitation, is not a new technique, and its development is often attributed to Collier in 1957 (see Harper, 2002, for a recent discussion). This technique is more widely used in ethnography and anthropology but is becoming increasingly popular in sociology and psychology. Photo-elicitation can involve the use of photographs produced by the researcher, which is especially useful for theory-driven research. Alternately, a more inductive approach involves asking participants to take their own photographs—sometimes called auto-driving (Heisley & Levy, 1991) or auto-driven photo-elicitation.
Capturing Detailed Accounts of Experience

We hoped that using photographs would elicit rich accounts that were grounded in the participants' everyday experiences and interactions. Interviews conducted in conjunction with photographs have been found to yield richer, more detailed, and more precise information than that generated by word-only interviews (Capello, 2005; Collier, 1957; Samuels, 2004). For example, in an ethnographic study of child monks in Sri Lanka, Samuels (2004) noted that in word-only interviews children listed only one or two abstract qualities when asked about their ideas of the perfect monk (e.g., one who serves others or protects his morality). But when asked the same question while looking at a photograph of “the perfect monk,” the children gave rich descriptions and concrete examples grounded in their everyday experiences (e.g., “When he teaches us, he shows interest in us and wants us to learn,” p. 1533). Similarly, we found that many of the images that the women in our study had taken were designed to capture a particular event or allow for the telling of a particular story. These stories were often poignant, vivid, and relayed with emotion.

By giving participants a relatively free reign in deciding what pictures to take, we were rewarded with a variety of images that were personally meaningful to each participant. We were not primarily interested in what participants chose to depict in their photographs; instead, we were interested in having participants speak to the photographs and explain what they had chosen to make visible and why (cf. Radley & Taylor, 2003a). In this way, we wanted to exploit this gap between the visual and the verbal by adopting a method that combines both. By allowing participants to take abstract and symbolic pictures (rather than insisting that they take photographs that simply document their altered appearance), we were able to capture a much wider range of experiences. These women were able to take photographs of objects that stood in for or represented a particular experience, without actually having to depict this experience or event. For example, when we first looked at one photograph of three model airplanes on a small table, we could not imagine what aspect of coping with an altered appearance this was meant to represent, but our respondent was keen to explain why it had been taken:

That one is [laughs], it was in the days when I was wearing my wig, well I was wearing a mixture of a wig and a bandana but mainly my wig, and we went to an air show with my son. We had a beautiful day, the only problem was it was very windy, and all day long I spent going like this [mimes holding down her wig], and I drove them nuts, I just drove them mad. I said when it blows the wrong way you can see the seam, and all day long I was conscious, and then it started to rain and I put my hood up and I felt better then because you couldn’t see my wig. In the end they got so cross with me, and so fed up with me fiddling, I said “Oh I’ve got a bandana in my bag.” And, I went over to the Port-a-loos, took my wig off and put my bandana on. I was alright then, and it was really from that day on I thought “I’m not wearing this any more” and I came home and I put it in the cupboard.

In this way, the photographs were a visual reminder used by participants to encapsulate a detailed story about a significant event that marked a turning point or development in their experience of chemotherapy. Others opted to take photographs that were symbolic representations of their feelings during their treatment:

That one I took on a particularly grey day, there’s this tree out there. There were these berries on it and they looked like they were hanging on and that’s how I felt. . . . Those berries are just me, and they’re like hanging on the branches, and one day I thought “I’m hanging on for dear life here” because I just felt so bad.

Some emotions, thoughts, feelings, and experiences are more easily or variously expressed in a visual rather than verbal form (see Gillies et al., 2005). Photographs can capture complex information about the different emotions, events, and relationships that have been
freeze-framed in the image. As such, these complexities can be teased out during the interview. For example, in the following extract, a participant describes the events surrounding one of her photographs:

Here we all are at the table I think, yes this is my hair falling out. My hair had begun to fall out that day and I’d been to [a shop] to get something in there, as I was walking down I remember putting my hand up and I could just pull out huge strands.

She went on to describe how one of her sons took the hair that had fallen out, created a picture of a face, and glued her hair onto the picture. She added, “For young children what they are drawing is often the best way of them expressing themselves.” Here the photograph captures not only the memory of her hair falling out and her thoughts and emotions around this, but also how those around her (in this case, her sons) reacted to this event and how she subsequently made sense of their reactions. These photographs and associated narratives are a rich source of information about the individuals’ experiences of chemotherapy because such images allow a range of experiences to be creatively represented in a variety of symbolic, abstract, and more concrete forms. In this way, visual methods such as photography may help health researchers to capture experiences that might otherwise be overlooked, difficult to articulate (Rapport, Wainwright, & Elwyn, 2005), or too abstract (Hurworth, Clark, Martin, & Thomsen, 2005).

Photographs are also rich sources of data because they are often treated as concrete and objective records of events that can be inspected, examined, and explored in the interview (Cronin, 1998). In turn, this opens up accounts to further exploration and comment. Patients in this study carefully selected photographs that they used to evidence and document their altered appearance, including changes to their hair, weight, nails, faces, and (as illustrated in the extract below) skin texture:

This is just a close up of yeah that sort of, the skin, you can see the effect on the skin, the hair, and sort of where the slightly haunted look, it’s partly the flash making me . . . but you know, I, I, it sounds dramatic but you look like something out of a concentration camp.

Although these details were not always readily visible from the photographs, the act of taking these images marked the event as a significant one to participants, and re-viewing the photographs in the interview provided an opportunity to draw attention to this part of their story. The detail captured in the photographs, some of which may not have been deliberately included in the image, allowed patients to pick out different aspects of the picture to further illustrate aspects of their experience. In the extract below, the patient has already given an account of why this photograph was taken but then goes on to make additional observations based on her re-viewing of the photograph during the interview:

The other thing about this picture [pointing to the photograph] is necklines. I’ve always had long hair and you get used to the way you look, how your T-shirts or whatever that you wear, look. And that used to be one of my favorite T-shirts and I put it on without hair and I just thought it looked . . . I didn’t like it.

Interviewers, too, can use details contained in the photographs to further explore participants’ stories. Continuing from the above extract, the interviewer notes that the woman was wearing a large necklace in the photograph, which she goes on to describe as “something to fill in the gap” left by her hair. She further explains how clothes that she had always worn and felt comfortable in suddenly became ones that she would “not feel happy about being seen wearing” once she lost her hair. Because photographs can be scrutinized, examined, and explored in the interview, they become a shared resource that can be used by both the researcher and the participant to produce elaborated accounts of health-related experiences (for a discussion of elaborated accounts in focus group research, see Frith, 2000; Wilkinson, 1998). Others have claimed that important health-related behaviors may be inadvertently included in patients’ photographs; for example, nutritionists have been able to estimate the size of food portions from photographs when this information was missing from patient logbooks (Williamson et al., 2003), and harmful practices excluded from written logs (such as those involving ashtrays and beer cans) have been identified in photographs produced by patients with type 2 diabetes (Frost & Smith, 2003). However, we argue that the value of this information is accessed only through an examination of patients’ understanding of these images, and it is inappropriate to assume that the images speak for themselves. For example, without understanding the context in which the pictures were taken and how patients interpret the images, it is not possible to know whether, for example, patients correctly estimate food portion sizes or whether the ashtrays and beer cans belong to the patient.
or represent resisted temptations. We caution against assuming that the meaning of experiences can be read from the photographs in any straightforward way.

One possible limitation of the photographic method is that people may forget to take photographs, the camera may not be available at the right time, and they may miss the moment. In our study, we asked participants about photographs that were missing from their collection because they had forgotten to take the camera, because a picture had failed to come out, or because taking the photograph was emotionally difficult. Participants were often able to identify a number of “missing” photographs:

After the first lot of steroids I came out in big boils on my neck, which to me they just felt like blind spots and I didn’t know what they were. . . . I talked to [the doctor], “What are these?” “Oh yes,” she said, “They’re boils, just a side effect of the steroids.” At least I now know what they are, but by this time they were already starting to go down and I thought, “oh well next time I’ll take a picture of them when they’re nice and big,” but they never came again.

This woman had not spoken about the boils or her skin—which she described as usually being “a bit spotty” but had been exceptionally clear once the boils disappeared—up until the point where we asked about missing photographs. She also mentioned a number of other photographs that were missing from her collection, including a photograph of “a pair of knickers because the hair on my head wasn’t the first to go,” a picture of a bedpan because using it was “humiliating,” and a photograph of friends who “used to send me flowers and phone me up, just to sort of keep me going.” When the product of the research is not the photographs themselves but rather the conversations around these photographs, then as the above examples illustrate, this information is not necessarily lost if participants are encouraged to reflect on the research process and on images that may be absent from their collection.

The myriad of ways in which photographs can be used to respond to the task of capturing experiences and the range of different kinds of events, symbols, and feelings that can be captured make it an ideal method for gathering information about patients’ experiences of health and illness and enabling them to share their health-related stories. By asking questions not only about the photographs but also about the process of representing their experiences in this way, the stories can develop through and beyond what is captured on film. The richness and complexity of information contained in photographs and the way in which this information can be scrutinized, evaluated, and elaborated on mean that these images are a rich resource for eliciting patients’ health-related stories.

Capturing Experiences Over Time

Most photo-elicitation studies ask participants to take photographs over a relatively short period, typically no longer than a week or two, and sometimes photographs are taken while the researcher is present (see Radley & Taylor, 2003b). We wanted to explore whether it would be possible to use this technique over a much longer period because chemotherapy typically takes place over several months. The experience of chemotherapy is not contained during the period in which treatment is being received nor within the walls of the hospital in which it is administered. The treatment and its side effects are often fearfully anticipated before the treatment starts (see Frith, Harcourt, & Fussell, 2007), are experienced over a prolonged time, and continue to be incorporated (or not) into a sense of self long after treatment has ceased. We hoped that the photographic record would provide a way of capturing the evolving experience of chemotherapy without requiring constant intrusion from the researchers. We were pleased that so many photographs were taken (the 15 participants who returned their cameras produced an average of 17.6 photographs) and that despite the relatively long time between first and second interviews, only 4 participants dropped out of the study. This indicates that a photographic task may be a good way of capturing the interest of research participants and keeping them involved in the study over a relatively long period. As such, this may be a good technique to use when there are relatively long periods between hospital appointments or when an illness is chronic and ongoing.

Photographs are often treated as if they are a record of a particular event or occasion (Cronin, 1998), providing a concrete point of reference for interviewees and capturing the immediacy of events as they unfold. The interviews were presented to participants as an opportunity to remember and recount their experiences of chemotherapy, and the photographs were presented as a resource to assist in this recall. We found that the photographs were used to tell a chronological story and represent the journey that each participant had taken over the course of her treatment. Like many stories, the volunteers’ stories had distinct beginnings, middles, and ends, and they included milestones (e.g., losing hair, wearing a wig, hair regrowth, and last treatment).
that took place over several months. Most participants took photographs throughout their treatment, although some took several photographs on one day and then none for several weeks. Several women took photographs of themselves before their treatment had started or before they noticed any physical changes (particularly, hair loss). They wanted to capture and retain an image of their normal selves: “That was just the start, before I’d lost my hair. . . . It reminded me of what I should have looked like.” Photographs were also taken to mark the end of treatment or when hair started to regrow: “I started to realize that my hair was starting to grow back and that I thought ‘I’ll take a photograph of that’ because it’s a really important thing to remember.” In this way, the use of photography over an extended period enables the researcher to explore the process of an illness and treatment and so capture the development of an illness and the changing use of coping strategies. Because the researcher is not required to be physically present to collect data at all points, this is a relatively unobtrusive, inexpensive technique that is not labor intensive.

Photography, then, was presented as a medium for capturing the past and was treated as such by participants. We are not suggesting that the photographs act as triggers for preexisting, internally held, and relatively fixed memories, but rather that talking about the photographs is a form of collective remembering, a form of social action in which the past is remade and becomes the basis for future reminiscence (Edwards & Middleton, 1990). Nevertheless, rhetorically, photographs are often treated by patients and researchers alike as if they capture events and hold memories that can be reactivated during an interview. Reexamining and accounting for the photographs in the interview was an invitation for participants to relive their experiences. Women noted that the pictures “took me back” or “brought all those things back to me.” One woman said, “I started to realize that my hair was starting to grow back and that I thought ‘I’ll take a photograph of that’ because it’s a really important thing to remember.” In this way, the use of photography over an extended period enables the researcher to explore the process of an illness and treatment and so capture the development of an illness and the changing use of coping strategies. Because the researcher is not required to be physically present to collect data at all points, this is a relatively unobtrusive, inexpensive technique that is not labor intensive.

One of the things that I’ve been aware of is the fact that over a period of a couple of months I put on quite a lot of weight when I was having my chemo, and I can see from the start of the chemo to the end, that I actually found quite upsetting.

I feel I look so much older and looking at those photographs and when I see photographs of myself just a couple of months before, or even after I’d had the operation before I lost my hair, I feel like I’ve aged a lot. . . . I mean I always had lines on my forehead but I used to, my fringe used to cover them, do you know what I mean, in a sense I used to hide a bit behind my longer hair and now I can’t.

The cumulative picture built up through the gradual changes documented in the photographs can reveal evidence of changes to appearance that had gone unnoticed. The changes, when viewed in the present, can be a source of distress. For some, the photographs provoked a confrontation with the seriousness of their illness and perhaps their own mortality:

I found that was probably the most harrowing photograph for me, I really, when I looked at that I thought “oh God” you know. Yeah I think I look really ill in that photograph. . . . I think I look really awful it doesn’t look anything like me.

The juxtaposition of before, during, and after pictures (or past, present, and future selves) allowed for the new and often painful reevaluation of selves and appearance. Being able to capture appearance over an extended period enabled these changes to become visible and noticeable. However, the photographs can also act as a reminder about how much better the participants feel or think that they looked at the end of their treatment:

Looking back on it now, and I think its not really that long since I finished my chemotherapy and yet I feel amazingly so much better, I know I don’t feel as well as I did before hand, but I feel so much better.
Photographic records are an exciting and vibrant way of enabling patients to tell their health-related stories because they allow participants to capture events, changes, and feelings over time and because they allow for stories to be recounted by reliving the past and by reviewing the past from the perspective of the present. As Radley and Taylor (2003b) observed, we need to access accounts that provide a telling of the experience as it occurs, as well as retrospective retellings of the experience, if we are to appreciate “how the temporal unfolding of experience occurs and what its significance for understanding recovery might be” (p. 130).

Enabling Participant Control

Because we were interested in visual appearance, it seemed appropriate to use a data collection method that would at least allow for the possibility that women would photograph changes to their appearance. However, because we recognized that women might find taking photographs of themselves difficult at the time, we wanted to allow for the possibility that they would represent their experiences in different ways. For this reason, we emphasized that they did not have to include photographs of themselves or use the cameras to document actual changes to their appearance but could instead include pictures that represented their experiences without actually showing these changes. We wanted to encourage women to feel control over the images that were produced and how they would be represented. They responded to the task of representing experiences of chemotherapy in a variety of often-creative ways. Although some participants took pictures of themselves that had a documentary or show-and-tell quality, others were keen to do something different:

I was very conscious, I didn’t want a load of pictures of me, this is me in my wig, this is me without my wig, this is me in a bandana. I was very conscious that I didn’t want photographs like that. I wanted to try, you said all along that you wanted to find out how this chemotherapy affected me, and I thought “well if I try to take photographs of other subjects besides me,” do you know what I mean? I didn’t just want it to be a pictorial of me going through chemotherapy.

We also recognized that patients often feel fatigued, distressed, and unwell during treatment and might be unable or unwilling to engage in other, perhaps more demanding, forms of data collection (e.g., keeping a diary, taking part in an interview). We were keen to be as sensitive and noninvasive as possible. At a time when women feel that they lack control over their appearance, privacy, and everyday activities (see Brennan, 2004; Harcourt & Frith, 2007), we believed that it was important to give women control over what pictures to take, how many to take, and when to take them. This meant that women controlled what kinds of representations of themselves were available. For example, women decided what not to photograph: “I don’t take a photograph of my mini-boob because I don’t like being photographed like that” and “The only thing missing is me with a bald head, but you’re not going to get that, I couldn’t have done that.” Some wanted to be able to control what images of themselves were available to others: “I didn’t want any photographs taken of me during the whole time. . . . If there’s no photographic evidence then your memory fades, but if you’ve got photographs they don’t, they’re permanent, and I don’t want that.”

For some women, it was not always easy to depict their experiences photographically. Sometimes, strong feelings, emotions, and experiences could not be encapsulated in a visual image. For example, one woman, in talking about her experience of panic attacks, said, “But you can’t see that in the photographs, you can’t, it doesn’t sort of, I don’t think they show how I felt inside they show how you look on the outside.” Another woman had similar difficulties in visually representing her feelings: “Everything I looked at or thought about didn’t sum it up. . . . To me it just seemed to take a picture was not showing what I was really feeling.” In addition, women sometimes felt too ill or too fed up to take photographs: “I didn’t take photos of the most painful times, because it was sometimes so all consuming” and “I was sometimes feeling so bad that sometimes I didn’t have the energy and inclination to get the camera out.” For researchers who are keen to using visual methods, the realization that participants may find it difficult to capture some of their experiences in this way may sound a cautionary note. However, by exploiting the gap between the visual and the verbal and by focusing on the conversations around the photographs (rather than on the photographs), we were able to access the planning, deliberating, and problems that surrounded taking the photographs, which was often as enlightening as the actual images. For some participants, understanding why they could not or would not represent particular aspects of their experience may be just as important as talking about the pictures that they did take. This is particularly important given that many illness experiences are disturbing, distressing, and traumatic.
We saw creating a photographic record as an individual task that the women would engage in, producing a representation of their individual, unique experience. However, we have noted the tendency for others to become involved in taking photographs. For example, in a study of students in two American schools, Clark-Ibáñez (2004) found that parents and siblings were keen to be present during the interviews (some parents had rearranged work shifts so that they could attend), and far from being shy about sharing their photographs, the children were wont to include their families. For many of the participants in our study, taking the photographs became a collective task that involved others—typically partners, friends, and children. This involvement was essential to be able to capture some of the most significant events that the women experienced. Many wanted to include photographs of themselves when they tried on wigs, shaved off their hair, and got dressed up to go out, which could not be captured by women’s operating the cameras themselves. Creating the photographic record became a joint project that could be shared with family and friends, and it provided a different way of interacting with the treatment and its effects. For example, one participant talked about shaving her hair off with her daughters and taking photographs of the process. This turned into an event in which they had a lot of fun and experimented with different hairstyles before removing the hair completely. We cannot know whether this event would have been treated in the same way if the camera had not been a part of the experience, but we do suggest that documenting the process photographically may have given the process a different kind of meaning (a memorable event), which made it easier to bear. In addition, some patients found the process of taking the photographs beneficial because doing so was a “distraction” and “gave me something else to focus on.” One woman said, “Even though maybe I wasn’t taking photos I was thinking about it, so it was a good coping mechanism for me, you know, to have that project in my head.”

Although it may have some benefits, others’ involvement can mean that participants lose control over the photographic process. One woman remarked, “I’m not entirely sure about these two photographs, apart from the fact that I think my husband would very often come in and say, ‘It’s a week since we took the last photograph, we ought to take another one.’” She went on to say,

He kept the camera on the coffee table in the lounge so it was a constant reminder, but he would often say if I didn’t say, he’d often say, you know if ten days had gone by, “you ought to take another photograph.” And sometimes I’d say to him “well today I don’t want you to, but take one tomorrow because I’m going to do this, or I’m going to do that.”

Under pressure to take pictures, these women sometimes had to be firm in retaining control over when and where photographs were taken. Although we had not intended for others to be involved in the research process, we came to realize that there may be some advantages to involving caregivers and family members in producing photographic records in some health research settings. There can be a tension, then, between patient control over the images produced and the productive involvement of family and friends in the process of creating these images.

We provided the participants with a set of their photographs for them to keep so that they would have the opportunity to see the photographs before the second interview, so that they would retain some control over the photographs, and so that we could give something back for their involvement in the study. Although they sometimes found it hard to take photographs, and sometimes even harder to look at them, many were glad that they had taken them, and many were keen to keep this record of their experiences. For some, it was important to have a permanent record of what was a significant event in their lives, and it was clear that the photographs were meaningful:

We take photographs to remind ourselves of things in our life and this is a hugely significant part of my life and... I think it would be important to remember, to have these because I think I may want to look at them at different times of my life.

The photographs were seen as an important point of reference, a reminder of what has gone before and, important for some, what had been achieved and survived. For many, the photographs have a life beyond the scope of the research, and alongside the private and personal photographs collected in family albums, they become “part of the complex network of memories and meanings with which they make sense of their everyday lives” (Holland, 2000, p. 121). Enabling women to have control over the images produced may be important at a time when they feel in control of very little in their lives; however, researchers can also consider whether using photography as a tool for accessing co-constructed narratives within families or communities might be useful for health-related research (for a discussion of the use of photo-voice in...
community action research, see Wang, 1999; for a discussion of different forms of photo-interviewing, see Hurworth et al., 2005).

Capturing Private Experiences

One advantage of asking participants to take their own photographs is that it allows the researcher to be relatively unobtrusive and to access spaces, places, and events that might otherwise be difficult or unethical for them to enter. For example, the Kampala street children in Young and Barrett’s study (2001) took photographs of the rooftop area that they frequented, which was the location for illegal activities such as drug taking and gambling. The authors argue that the presence of researchers in this space may have made it more conspicuous and visible to the streets below, potentially putting these children at risk. We hoped that using a photographic record would allow the private worlds of the participants, their everyday lives and environments, to be made visible to us as researchers in a way that would not be possible through interviews alone. It would not be feasible for us to be with our participants to observe their experiences over such a long period and in such intimate areas of their lives. Instead, we relied on our participants to make these private moments visually available to us—and they did. For example, one woman included a photograph of herself sitting on the bed with a plastic bowl on her knee, into which she had been vomiting. She describes the photograph in the following way:

This is when I still had my hair, I think this was the first cycle ever, and this was when I had that uncontrollable vomiting. I didn’t know what to expect, it’s quite frightening really, because you just don’t know what’s going to happen, how your body is going to react. So I was just hanging on to that sick bowl and feeling shit.

This private moment powerfully captures the participant’s experience. Although we might have anticipated that women would talk about feelings of nausea and vomiting, the photographs allowed these feelings to be fully described, and they gave us access into women’s everyday experiences that are not readily accessible to health care professionals. It was notable, for example, that few of the photographs were taken in medical settings. Although patients can feel as though their lives are organized around hospital visits and treatment appointments, much of their experience of chemotherapy takes place away from the hospital. This photographic method helped to capture these broader aspects of their treatment-related experiences.

Despite the fact that participants took a number of photographs and that many of these were accompanied by vivid and moving accounts of their experiences, some struggled with the process of taking the photographs. Sometimes they struggled to find inspiration, to “find the subject matter.” One woman noted,

I didn’t find it difficult to take them, sometimes I was concerned that it wasn’t going to be interesting enough and that maybe there were other things that I could photograph. I did racking, I did really give a great deal of thought about what I could photograph that would give an indication of how I was feeling at the time.

Participants were sometimes concerned that their photographs might be boring and uninteresting, not meaningful to anyone but themselves, and despite our reassurances that the photographs need not be artistic or “good” pictures, the volunteers were concerned about their abilities as photographers. When we first looked at the photographs, we were, much as Radley and Taylor (2003a) were in their research on recovery on a surgical ward, initially disappointed by the apparent banality of some of the images. But we, too, came to recognize that these pictures represented an important aspect of what was one of the most significant and distressing life events for the women involved. For example, one woman took a photograph of the unremarkable view from her sofa. Although this might be either mistaken for a picture that has been taken accidentally or dismissed as not a good photograph, this view was important because it captured her incapacitated state. She spent much of her time lying on this sofa feeling too ill or too weak to do much else. This view is one that she came to loathe, and it captured well the fatigue and repetitiveness associated with chemotherapy. These apparently boring and meaningless photographs gave us a useful insight into the women’s experiences even when the participants themselves could not see their value. Although participants may feel under pressure to take “interesting” photographs, for the researcher, these apparently dull images are just as important as those that can be considered more dramatic.

Photo-elicitation in which participants create a photographic record of their health-related experiences can help to provide a window into the private and inaccessible worlds of patients. As such, these photos can provide insight into the routine, day-to-day activities of patients when they are away from the hospital environment. Facilitating patients in telling the everyday stories of their illness experience allows
health care providers to gain greater insight into their patients’ experiences, and it encourages greater reflection on the larger context within which the patient experiences health, illness, and treatment (Hatem & Rider, 2004).

Conclusion

In this article, we explore the ways in which photo-elicitation can be a useful tool for generating health-related narratives. For researchers who are interested in using photographs within interviews, there are a number of key issues that we have found useful to remember in our study, which we summarize below.

First, encourage participants to be creative in using photographs to represent their experiences, to allow a variety of experience to be captured. Photographs can be used in the following ways:

- as documentary, to accurately record events, activities, and actions;
- as symbolism for feelings; for example, berries hanging on a tree to represent feelings of just hanging on; and
- as symbolism for relationships; for example, a picture of a gift given by a loved one.

Second, the conversation that takes place around the photographs is as important as the photographs themselves. By asking patients how they approached the task of representing their experiences, what they chose to make visible and why, and by interrogating the images themselves, researchers have access to a rich source of information and experience. The photographs provide opportunities to ask patients about their experiences in different ways. Ask about

- the process of deciding which photographs to take and about creating a photographic record,
- the photographs that are “missing” from the collection, the stories and events that are represented in the photographs, and
- what it is like to view the photographs as a collective from the present.

Third, photo-elicitation can be useful for capturing events over time because

- as a familiar and potentially fun activity, it can keep participants engaged in the research process, even with little interaction with the research team;
- they can help people to remember key events and help them to relive their experiences during an interview that can take place several months after the event has occurred;
- they can capture the process of responding to the development of an illness and the recovery from illness, and the process of coping with and managing treatment regimes; and
- they can be viewed as a collective and images can be compared and contrasted to allow new insights to emerge.

Fourth, photo-elicitation allows participants to retain control over how and when they engage in the research. This aspect may be a useful resource for acquiring rich and complex data without making excessive demands on patients. It may also be particularly important for those who feel disempowered by their illness experience and for those who experience varying levels of energy, strength, and mobility as a result of the illness and the associated treatment. In addition, photo-elicitation allows patients to control how they and their experiences are represented and captured. This point may be particularly important for cancer patients who feel as though they have lost control over many areas of their lives and for whom changes to their appearance mean that they are sensitive about what images of themselves are made permanent. As such,

- they can retain control over when, how, and how often they engage with the research; and
- they can control what images of themselves and their experiences are generated.

Finally, photo-elicitation can provide access to the private, everyday worlds of patients who are away from the hospital environment. This aspect allows for greater reflection on the larger context within which the patient experiences health, illness, and treatment.

By exploiting the interplay between the visual and the verbal, photo-elicitation provides a novel and stimulating technique for accessing patients’ health- and illness-related narratives by providing a varied means for representing, exploring, and recounting experiences. The women in our study valued the photographic records that they had created, which they believed captured a significant and vivid experience in their lives, and many wanted to keep the photographs to be able to remember how they felt at the time. These women are engaged in a project that goes beyond the life of the research, which is to make sense of their lives throughout their illness and related treatment.
References


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