

## RESEARCH METHODOLOGY: DISCUSSION PAPER – METHODOLOGY

### A review of the issues and challenges involved in using participant-produced photographs in nursing research

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#### Abstract

**Aims.** To discuss the issues and challenges that may occur when using participant-produced photographs in nursing research.

**Background.** The place of visual representation in society is increasingly being recognized and there is a growing discussion on the advantages of implementing visual methods, such as photography, in health and illness research. Integrating photographs has much potential for both nurse researchers and participants but it remains a novel method of gathering qualitative data and many aspects have had little consideration in the nursing and medical literature. This paper presents a discussion of some of the issues that may arise when using photographs as data. It draws on examples of the insights and experiences we had when we asked study participants to produce photographs to complement their interviews designed to explore their experience of living after cancer.

**Design.** Discussion paper

**Data sources.** This paper is based on our own experiences and supported by literature and theory.

**Implications for nursing.** Disseminating this research has prompted much interest from nurses and clinical staff. This paper should highlight some of the factors that may need to be addressed before employing such a novel method, thus ensuring the research process is positive and the outcome relevant for all parties.

**Conclusion.** Examples are used here to illustrate practical, ethical and philosophical issues around the research plan, creating and interpreting photographic data, confidentiality and copyright and analysing and disseminating photographs produced for research.

**Keywords:** cancer, ethics, interpretation, nursing research, participatory research, photography, research methods

#### Why is this review needed?

- There appears to be much potential and interest in using participant-produced photographs to gather qualitative data in nursing research.
- There is little discussion in the published nursing literature about using participant-produced photographs.

#### What are the key findings?

- There are practical, ethical and philosophical issues that should be considered before integrating participant-produced photographs into health research.
- Examples from our own research are offered to illustrate and explain some of the aspects to consider if this research method is used.

#### How should the findings be used to influence research?

- This paper is intended to offer a guide to some of the challenges nurses and clinical staff who employ participant-produced photographs in their research may wish to consider.
- This paper highlights the potential for both participants and researchers of using participant-produced photographs and suggests ways to negotiate the issues peculiar to this novel research method.

## Introduction

Photography and visual images are central in representing phenomena in our culture (Rose 2007). Without calling on imagery, it is difficult for people to describe their work, social lives, conversations, identities, hopes or history (Pink 2007) and everyday maxims such as ‘seeing is believing’ or ‘I saw it with my own eyes’ indicate that it is given certainty and trust (Baldwin *et al.* 1999). However, despite a history of using photographs to capture, record and express the social world and to promote understanding in nursing, more creative uses of photography and visual media have largely been disregarded by nurse researchers (Riley & Manias 2004). Instead, research observations have tended to be translated into impartial words and numbers, leaving images to be associated with subjectivity and persuasion (Harrison 2002, Frith *et al.* 2005) and nursing has been criticized for subordinating vision as a means of perception and communication (Riley & Manias 2004). Furthermore, concerns about the ethics, consent and anonymity of using photographs in health and illness research have confounded the development of methods (Close 2007, Woodhouse 2012). Nevertheless, perhaps influenced by the adoption of critical theory and cultural studies in philosophies of health and nursing where visual representations are recognized as

important information sources (Harrison 2002, Rose 2007) and the promotion of participatory methods and consumer-led research (Close 2007), arts-based research and visual methods are becoming increasingly employed in health and illness research (Guillemin 2004, Riley & Manias 2004, Wiles *et al.* 2008).

We recently conducted a study with the aim of exploring the experiences of living after a cancer diagnosis with an expected poor prognosis. This was approached from a symbolic interactionist perspective and contextualized in the social and cultural representation of cancer in contemporary UK society (Balmer *et al.* 2014). Our concern was that many published examples of experiential research of people diagnosed with cancer recruited from populations with better prognostic cancers (e.g. breast) and this might dominate understanding in cancer care, whereas people with poorer prognostic cancers might have diverse experiences and distinct concerns which required different services.

## Choosing an appropriate research method

Being aware that many in this population were living with the legacy of a difficult diagnosis and intensive treatment (Macmillan Cancer Support 2013), we realized that some participants may have been physically or emotionally unable to verbalize all their experiences and perspectives. For instance, all head and neck cancer treatments arguably have some effect on speech and/or swallowing (Logemann *et al.* 1997) which can vary from hoarseness to total removal of the tongue or voice box (Radford *et al.* 2004). Even an intelligible but hoarse voice can make long interviews difficult and painful. Furthermore, people with speech concerns are much more likely to avoid social activities (Fingeret *et al.* 2013). It is not known how this affects research recruitment but it seems likely that some of the interview-based studies that have explored the perceptions of people with head and neck cancer will have somewhat skewed results because the opinions of people with significant speech difficulties may not be fully represented. Similar distortions may be apparent in other cancer sites. We wished to avoid these as much as possible and therefore sought an inclusive research method that did not wholly rely on in-depth interviews so that we were able to encourage recruitment and data collection from as wide a group of such cancer survivors as possible.

We considered many participatory ways to gather qualitative health data, such as diary-keeping (Välimäki *et al.* 2007), drawing (Guillemin 2004) and video-making (Jewitt 2012) but discounted each as we felt they might be too demanding in terms of time, cost or learning new skills for

both ourselves and the participants. However, reviewing literature made us aware that participant-produced photographs are increasingly being used to complement qualitative data (Boydell *et al.* 2012). Arguably, photography is now a very accessible and egalitarian medium and one many people feel comfortable using (Sontag 1979, Guillemin & Drew 2010, Mitchell 2011). It has recently been used to include groups sometimes omitted from interview-based research in the past, such as children and young people (Epstein *et al.* 2006, Drew *et al.* 2010). Although we had concerns that photography and this methodology may have required particularly skills not held by all potential participants, we were reassured by the good quality and descriptive photographs produced by participants in a pilot study, including one who had never used a digital camera before.

The potential benefits of using participant-produced photographs in health and illness research have been described by many authors and include:

- Assisting the communication of things that are difficult to ‘put into words’ e.g. pain, sexuality
- Allowing participants to opt in or out of direct personal association
- Empowering participants by putting the data collection tool (camera) directly in their hands and enabling them to set or veer the research agenda
- Facilitating a sensory and emotional recreation of events/perceptions
- Accessing personal spaces where identities are often made (or undone) and generating important data about the self and everyday experience
- Supporting stake-holder participation in research
- ‘Building bridges’ and aiding dialogue between the participants and researcher

(Harrison 2002, Kristiansen *et al.* 2010)

Additionally, the rapid growth in digital technology and home computing have enhanced the capacity to create, share and display photographs which has become an accepted and even expected part of contemporary social events and everyday life (Guillemin & Drew 2010, Mitchell 2011).

Our study proved successful at exploring experience for this previously under researched group (Balmer *et al.* 2014) and the method has created much interest from nurses and other healthcare professionals. However, while conducting it, we were made aware of some of the potential obstacles of using such a novel method. Here, we review the issues and challenges that nurses may face by including participant-produced photographs in research,

drawing on examples from our study. This has been called for in the nursing literature, so that photographic methods may become more rigorous in the nursing community (Riley & Manias 2004).

## Data sources

This discussion paper is based on our own experiences and supported by literature and theory.

## Discussion

### Planning the research

Despite the proliferation of photographic technology, which has made cameras commonplace and accepted (e.g. on mobile phones), taking photographs to illustrate and explain experience is novel and there are certain practicalities that should be considered (Tinkler 2013). These include:

- How many photographs are required for the study?
- How long should participants be given to produce the photographs?
- What cameras and equipment are available
- How will photographs be viewed and shared?
- How do you motivate people to take pictures?

Our research involved interviewing each participant, then asking him or her to produce photographs they were willing to share with us and which illustrated and represented ‘living with and beyond cancer’ for them. At this point, we interviewed participants again, specifically about their photographs. Feasibility work with two people indicated that enthusiastic participants take many photographs! Based on this, we limited the number of photographs shared by each participant for research purposes to a maximum of ten. This was a greater number than in the few other studies that have discussed this but allowed participants to depict a large number of aspects and perspectives of their lives without the dataset becoming too unmanageable for researchers. More than 250 usable images were eventually shared with us. We also wanted to allow people enough time to take photographs comfortably and unhurriedly but within a suitable timeframe that did not allow the process to stall. We therefore revisited participants approximately 2 or 3 weeks after their first interview. However, investigating a phenomenon that changes over time, such as following participants through treatment or exploring recovery, may require longer.

We bought some basic digital cameras but all participants had their own and only one chose to borrow ours. All were

able to produce good quality images that effectively illustrated issues and allowed us to explore phenomena with them further. We used digital cameras to make image transfer easier and allow participants to immediately view and delete photographs they did not want to share. We felt that this was ethically appropriate for this population; however, it has been argued that this may mean interesting images are lost or less thought and value is given to subject matter as it is easy to obtain or alter multiple images. Furthermore, digital technology may be culturally inappropriate in some environments (e.g. where possession may make participants more likely to encounter crime), making disposable cameras more appropriate (Photovoice 2007).

We were very keen not to 'prompt' participants with examples of images they might include. However, we were aware that participants would be unfamiliar with the process and may find it difficult to find suitable subject matter chosen for its literal or metaphorical representation, rather than aestheticism. After one researcher (CB) attended a training session held by the charity Photovoice (<http://www.photovoice.org/uk>) where this was discussed, we prepared advice to overcome it (see Table 1). Other studies have reported the necessity of similar coaching methods and encouragement (Baker & Wang 2006, Drew *et al.* 2010) but the majority of our participants did not require this.

### Creating and interpreting photographic data

Although it is generally agreed that participatory photographic methods are 'enabling' to both researchers and participants, their newness means there are many theoretical issues about both the process of image production and the

resulting images that have not yet been fully addressed (Close 2007, Guillemin & Drew 2010). For instance, there is a commonly held (mis)conception that 'the camera never lies' (Sontag 1979, Baldwin *et al.* 1999, Oliffe *et al.* 2008). Photographs, being automatically produced, are often seen as authoritative and unrestricted by the cultural constraints and intentions that are recognized in other forms of representation (Lister 2003). Although, photographs are candid in terms of the mechanical, chemical or electronic processes involved, the human eye and brain composing the image and the complex processes of interpretation make an image no more truthful than any other form of communication (Rose 2007, Spencer 2011). Furthermore, what participants choose to include and exclude from their photographs become important factors in the 'reality' the image conveys (Frith *et al.* 2005). This may be a conscious act, such as deliberately setting a scene or using software to alter a photograph, or less conscious, for example class, gender and ethnicity may influence the choice of visual image or the representation of self (Pink 2007, Wiles *et al.* 2008). Photographs are created and viewed in particular social, political and historical contexts and are influenced by both the researcher and participant.

In our study, there were many instances when people only wanted to share photographs of themselves indicating how well they looked and therefore how far they had come since their cancer diagnoses and treatment. Many did not want to share pictures showing surgical scars, alopecia or other visual signs of illness. This has been noted previously in health research drawing on participant-produced photographs. For example, Guillemin and Drew (2010) describe a young participant who talked about the physical, emotional

**Table 1** Advice prepared to coach the process of producing photographs.

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#### Photographing a morning

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If you find it difficult to find appropriate images to photograph, you may find it helpful to try this exercise one day which 'photographs your morning':

- What is the 1st thing you do in the morning? Perhaps you turn the alarm off or brush your teeth? *Take a photo to illustrate this*
- Do you take a long time having breakfast and getting ready or do you rush out of the door with a piece of toast in your hand? *Take a photo to illustrate this*
- Do you walk, take the bus, jump in the car or get on your bike? *Take a photo to illustrate this*
- Do you see anything interesting on your journey? *Take a photo to illustrate this*
- Where do you go? Perhaps to work, school or the shops? *Take a photo to illustrate this*
- What is the weather like? *Take a photo to illustrate this*
- Are you a 'morning person' or does it take you a while to wake up in the morning? *Take a photo to illustrate this*
- Do you stop for a break mid-morning? What do you do? *Take a photo to illustrate this*

By now you will have a series of photographs which illustrate and represent 'your morning'. They may seem like unusual photographic subjects but you can use them to help you describe and talk about the morning.

Now try to find images to illustrate and represent 'living with and beyond cancer' for you. Please take photographs that will help you show and describe aspects of your experience.

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and isolating struggle of living with chronic fatigue syndrome but would only share what they call 'happy snaps' of herself dressed up for social outings and special occasions.

There are certain conventions involved in taking personal photographs that should be recognized as they may have the potential to influence the subject matter of photographs created (Van Dijk 2008, Pink 2011, Van House 2011). For example, dominant subjects for personal photographs include family members and friends (Sontag 1979, Van House 2011). This has been replicated in participant-produced photography studies that have been analysed quantitatively by content (Einarsdottir 2005, Lassetter *et al.* 2007). For example, 78% of the photographs taken by the siblings of children with Down's Syndrome in Rampton *et al.*'s (2007) study were of people and 85% of these were of family members. A large proportion of the photographs shared by participants in our study also contained images of family members, even though these people had often not been mentioned to us in interviews held before the photographs were created. Careful interviewing then had to explore the reason which may have been unrelated to significance in their experience. For example, one participant said: 'taking a picture of people...felt like saying a little sort of thank you to them and that was very nice'.

Those viewing photographs will also have their own creative vision, which will inform the meanings they give to them (Pink 2007). A viewer will decode the features of a photograph through associations with their existing cultural references and subjective experiences (Spencer 2011). According to Barthes (2003), photographs have both an 'obvious' and 'obscure' meaning. The obvious meaning (in itself, culturally and contextually constrained) represents the commonly recognized elements in a photograph, whereas the obscure meaning is often personal and emotional and may disrupt an apparently unequivocal reading. We found it to be extremely important to recognize this when interpreting photographs. For instance, five participants each shared a photograph of their male partner with us. The photograph construction and content were extremely similar. However, although the photographs 'looked' as though they depicted the same thing, interviews with the participants revealed that each signified very different aspects of living after cancer, namely the expectations and reality of support, body image alterations and changes to sexuality, communication difficulties, relationship breakdown and guilt about the impact of cancer on others.

Although photographs can be used as an alternative to verbal communication, the majority of research employing them, including our study, also involves interviewing participants about the images they have taken and why. This

combination of both visual and verbal data has the potential to enable a more extensive and holistic understanding of a situation (Frith *et al.* 2005). Photography may allow a sensory and emotive recreation of the participants' worlds thus creating a unique and specific understanding of a previously indescribable experience. This may be particularly helpful when exploring 'new' phenomena such as those that are becoming evident in the wake of increasing cancer survival. In our study, this included returning to work after diagnosis and treatment, forming new relationships or getting older with long-term treatment side-effects. Furthermore, more creative approaches permit people to communicate experiences or perspectives that may otherwise be overlooked and allow different aspects, perspectives and realities to be conveyed (Frith *et al.* 2005, Rapport *et al.* 2005). Sharing photographs often produced very emotional responses for study participants, which also highlighted the significance of phenomena for both them and us. We also discovered that photographs allowed us to explore phenomena that may have remained 'hidden' in an interview only. When sharing photographs with participants in our study, we were taken into homes, gardens, workplaces, hospitals and other important environments where identity and roles were constructed and disrupted. According to Pink (2007), this creates important data about everyday experience and personal space and may prompt participants to express their identity and experience more readily. For example, one participant had been very positive about his experience in an interview but had taken all his photographs in one area of his house. When we queried this with him, we discovered that he had experienced many body image problems and feelings of stigma, which had made him feel unable to leave his house and left him very lonely and isolated. We believe this is unlikely to have become evident in an interview alone.

It is also important to note that photography and the sharing of images is altering with technological innovation, market forces and sociological and cultural changes. Van Dijk (2008) argues that, allied with cultural shifts involving individuality, communication and distribution, photographs are becoming tools to converse, communicate everyday experience and foster peer groups. As such, there may be differences in the subjects, representation and purpose of photographs produced by different ages of participants involved in such studies.

### Ethical and legal considerations

Due to its novelty, the use of participant-produced photographs in health research lacks a history of ethical practice.

Issues are frequently omitted from research articles and reports, even though the use of visual images demands complex ethical consideration (Riley & Manias 2004, Pink 2007, Boydell *et al.* 2012). For instance, confidentiality is a central principle of both nursing and ethical research but it may be impractical or even impossible to maintain anonymity and therefore confidentiality if visual methods are employed and control is handed to participants (Wang & Burris 1997, Harrison 2002, Wiles *et al.* 2008). Participants may be keen for identification, especially when they argue for their right to be visible, for example, if they are disabled or physically different (Wiles *et al.* 2008, Guillemin & Drew 2010). As Prosser *et al.* (2008) discuss, one of the main aims of participatory visual research is to empower individuals and marginalized groups but if such individuals and groups are anonymized against their wishes, important questions are raised about power relationships and control in the research.

Obscuring identity, such as pixilation, may be employed in photographs but concealing features may not completely anonymize an image. For instance, people may be recognized by the environment they are photographed in (Prosser *et al.* 2008). Such concealment is also contentious and has been criticized by researchers who question whether 'sanitizing' images impacts the integrity of the data (Close 2007). Wiles and her colleagues (2008) discuss how obscuring features affects the interpretation of visual images because faces may explain physical, psychological, social and emotional aspects. They also argue that blurring or obscuring faces objectifies people and removes their identity. Oliffe and Bottorff (2007), whose participants depicted their prostate cancer experience through photographs, argue that ethical considerations of non-visual research may actually be greater than those they had to address because their participants held the exclusive rights to what images were taken, seen and shared. We offered anonymization of all or parts of photographs to participants but all requested that the photographs they shared were used as produced.

Although professional codes of practice and a regulated system of independent review by ethics committees/review boards should guide nurses and researchers and reassure participants, there remains little consensus among both ethics committees and researchers themselves about standard practice and acceptable guidelines. This inconsistency has been criticized as limiting research (Murphy & Dingwall 2007, Prosser *et al.* 2008, Wiles *et al.* 2008, WHO 2014). As Prosser and colleagues argue, guidance about good ethical practice is 'contested, contextual and dynamic' (Prosser *et al.* 2008, p. 3). They say that decisions about confidentiality in photographs should be informed by an understanding of and

engagement with ethical theory and in the context of a framework that accommodates the researcher's moral outlook and professional guidelines. For instance, different ethical issues may emerge depending on who takes a photograph and for what purpose it is taken.

Legal considerations and restrictions also exist concerning photography, mainly in relation to what may be photographed and the ownership of images. These need to be addressed by researchers and made clear to participants. Such limitations differ slightly from country to country and may alter over time, for example if there is perceived to be a threat to security (Wiles *et al.* 2008, BBC 2009). Our study was governed by UK law which does not restrict photography in public places or of specific groups of people. However, both the definition of a public place and the inadvertent photographing of someone who does not consent may be problematic as photographing someone in a place where they would expect a reasonable amount of privacy may be considered an invasion of that privacy (Henderson 2003, Wiles *et al.* 2008, McPherson 2009). This might be particularly relevant when photographing in some healthcare environments. For example, Frith and Harcourt had no opposition from a research ethics committee to their study proposal of women taking photographs of their breast cancer chemotherapy experience, whereas Radley and Taylor had to take photographs with their participants who were recovering after surgery and were refused permission to allow any photos depicting individuals (Radley & Taylor 2003, Frith & Harcourt 2007). This may have been because Radley and Taylor's participants were hospital inpatients as opposed to Frith and Harcourt's whose emphasis was not necessarily on the hospital experience (informal discussion with researchers). However, implications about confidentiality, well-being and consent of individuals photographed for the two studies were arguably the same.

Ownership of photographic data produced for research is determined by copyright law. In many countries, including the UK, a photograph is considered to be an 'artistic work' and, as such, may be copyrighted by the photographer and only used if he or she gives explicit permission (Prosser *et al.* 2008, Wiles *et al.* 2008). We advised participants about the legal implications of photography in our study's participant information leaflet and obtained written consent to use each photograph in educational and non-profit making publications and presentations arising from the study. We also asked all participants if they wanted reproduced photographs to be copyrighted, thus removing complete anonymity but preventing anybody else using their images and about half requested this.

### Analysis and dissemination of photographs

Despite a history of analysing photographic content and visual images in disciplines such as cultural studies and published literature about analyses of existing images or photographs produced by researchers (Van Leeuwen & Jewitt 2001, Spencer 2011), there has been little written to date about the qualitative analysis of participant-produced photographs specifically for research (Pink 2007, Rose 2007). Some researchers have explicitly avoided analysing such photographs for epistemological reasons, arguing that the photographer's interpretation has the most important, if not absolute, meaning (Oliffe *et al.* 2008). Those who have discussed a method have usually based it on a 'grounded theory' approach, which emphasizes gaining understanding from phenomena that are grounded in the visual data itself and involves the constant comparison of this data with emerging categories to capitalize on the similarities and differences (Glaser & Strauss 1967, Close 2007, Drew *et al.* 2010, Liebenberg *et al.* 2012).

Jenkings *et al.* (2008) and Kolb (2008) suggest that the discussion of photographs that takes place between researcher and participant makes such analysis more participatory and interactive than most methods of analysis. The specific type of photography method followed also drives the degree of participation in analysis. For example, Caroline Wang and Mary Burris developed 'photovoice' in the 1990s specifically as a method to empower participants to influence the health policies that affected them. Photovoice involves recruiting a group of participants who come together as a group to create photographs and then select the significant ones to illustrate pertinent issues collectively. This naturally demands participatory analysis (Wang & Burris 1997, Wang 1998, Catalani & Minkler 2010). However, the need to modify photovoice to incorporate people's physical or travel limitations and the impracticality of attending group sessions, particularly when they are ill or disabled, has been recognized and it is more usual for photographs to be created and shared on a one-to-one basis in health research (Baker & Wang 2006, Catalani & Minkler 2010).

Radley and Taylor (2003) and Rose (2007) recommend that researchers consider their analytical approach carefully so that photographs do not simply become illustrations of their accompanying interviews. One of the few analytical frameworks that have been outlined for participant-produced photography is known as 'layered analysis' (Dowdall & Golden 1989, Oliffe *et al.* 2008) and this is the one we chose to analyse our data. Layered analysis was originally developed by Dowdall and Golden (1989) as a tool with


which to examine a historical collection of photographs depicting life in a hospital for people with in the United States. This approach was then adapted by Oliffe *et al.* (2008) to analyse the participant-produced photographs and associated interview data they collected for their ethnographic study about new fathers and their perspectives on their own smoking habits. Layered analysis aims to prioritize photographic data and can arguably expand what is both said about and interpreted through, photographs (Oliffe *et al.* 2008). An illustration of how we analysed the interviews and photographs is given in Table 2.

Data from participant-produced photographs can be disseminated in a variety of ways, making it arguably more directly accessible to patient and care groups, professional groups and health policy-makers. For instance, studies can be published via traditional channels, such as conference presentations, journal articles or textbooks. However, photographs can also be easily disseminated via exhibitions, books and digital media (Alsop *et al.* 2006, Fleming *et al.* 2009). The mode of dissemination presents different ethical implications in relation to anonymization and identification that should be considered carefully and discussed with participants (Prosser *et al.* 2008). For example, the Internet offers significant opportunities for global dissemination but may allow images to be copied and reproduced out of the context where they were obtained. Pink (2007) suggests that representation should not simply reflect the willingness of participants to allow their photos to be published but should also take account of the social, political and cultural contexts where published images will be viewed and interpreted.

### The impact of using photographs in our research

Our study revealed that living with and beyond the diagnosis of a poor prognostic cancer was persistently disruptive and continued for a long time after the usual 'follow-up' period for our participants. This ongoing phenomenon prevented participants completely returning to 'normal' and defining themselves as 'survivors'. Furthermore, society's stigmatizing perception of cancer gave them specific responsibilities and obligations. Our initial purpose for using participant-produced photographs was to make the research as inclusive as possible considering the physical and emotional effects of living with cancer. However, as argued elsewhere (Balmer *et al.* 2014), we found that this was a straightforward and useful method and photographs gave depth of the interviews, added richness to the data, revealed more than would have emerged from interviews alone and produced a broader understanding of relevant issues. Furthermore, we

**Table 2** Example of how we analysed interviews and photographs using layered analysis (Balmer *et al.* 2014).

Example extract from 1st interviews	Example extract from 2nd interviews	Associated photograph	Examples of related memos made during analysis	Theme	Code reached through iterative process
<p><i>I don't think I fully appreciated that I would have effects that would last the rest of my life. Like one of the doctors said to me, 'Swallowing will never be the same for you again and you'll have a dry mouth forever' and I thought, well that doesn't seem so bad, I'll eat soft foods then but when you're living with those kinds of affects they are more real</i></p>	<p><i>We tend to eat by about 7 and if we're invited anywhere I have to stop eating really at half 8 to let it all go down before I go to bed and what people don't understand is the implications of it. After that then I'll go but I won't eat... you haven't got the freedom or spontaneity to do something late, so that's the significance of the clock</i></p>	 <p>© M Haynes</p>	<p>Day-to-day reminders of living with cancer. Ever present side-effects, physical limitations and related items e.g. aids carried in bags. Often invisible to others – difficult explanations sometimes needed e.g. when travelling.</p>	<p>Side-effects and limitations caused by cancer</p>	<p>Constant reminders of living with cancer</p>



have found that presenting study data in the form of photographs has offered a powerful and relevant way of exhibiting and communicating experience to various professional and lay groups and has the potential to reach a far greater and more diverse audience (Balmer *et al.* 2014).

The experience of taking photographs has also been reported as being therapeutic and having a positive effect on making sense and giving meaning to those living with ill-health and disability (Newbury 1996, Radley 2010, Stuckey & Tisdell 2010, Boydell *et al.* 2012). It has been argued that involvement in the creative process itself allows participants to gain self-awareness and an understanding of their own identities. For example, none of the participants in Stuckey and Tisdell's (2010) study of women with diabetes had thought about how it 'felt' to have diabetes but gathering data through photography and visual images created a new avenue of expression and served as a catalyst to making meaning. It was an unexpected but positive consequence that all our participants said they had enjoyed the process of creating photographs and the majority had found them helpful in being able to explain issues and experiences with the researchers. Several also explained that viewing the photographs had reassured them about, for example, the progress they had made over time, how much better they looked now or the support they were receiving. This has been explored by others (e.g. Photovoice 2010) and possible reasons for its therapeutic value are reproduced in Table 3.

## Implications for nursing and research

As described throughout this article, methods incorporating participant-produced photographs offer much potential to nurses undertaking research and participants. They allow and encourage a greater number of participants from more diverse populations to contribute to research from which some may be excluded and have the promise to gather more rich and complete data. Via images shared, nurse researchers are able to access patients' social environments and meet their friends and families in a way that may be clearer than interviewing alone. In turn, this can produce a greater understanding of the social impact of illness. In early dissemination of this work at events and conferences attended by nursing and healthcare staff, there has been much interest in participant-produced photography. However, this is a new method and requires some unfamiliar consideration, such as issues around confidentiality and copyright, interpretation, analysis and dissemination. Our intention in sharing our experience is to provide a preliminary guide to nurses and healthcare staff who may wish to implement this potentially insightful and helpful method.

## Conclusion

Despite the significance of vision in contemporary culture, visual methodology and the use of visual methods (such as

**Table 3** The possible therapeutic value of participatory photography (after Photovoice 2010).

Action	Potential value
Exploration of self and identity	Discussing photographs provides participants with opportunities to explore and reflect who they are, what has happened to them and where they are now
Creation of a distraction	'Patients' become 'photographers' and taking photographs can be a respite from symptoms and a distraction from problems
Establishment of order	The photographic process encourages participants to think about what they want to photograph and why which can create a structure and offer a way to take control when things seem chaotic
Maintenance of distance and containment	Photography objectifies and can create a more distant or safe perspective of difficult or sensitive issues. Distance can be created by focussing on the image or process of photography rather than direct emotions. Traumatic or distressing phenomena are detached.
Encouragement of sharing, storytelling and dialogue	Photography is a narrative medium and telling and sharing stories enables participants to explore meanings, memories and significance which can be cathartic. Photographing people participants care about and sharing the image with them can strengthen relationships.
Provision of fun opportunities	Photographs allow participants to create new realities which may provide a sense of freedom, inventiveness and creativity.
Boost to confidence and self esteem	Photography allows participants to be involved with a creative process and feel proud of the work they produce. Mastering a skill is often a rewarding and confidence-building experience. Presenting photographs to an audience can be affirming and validating for participants.
Opportunities to overcome social isolation	Social exclusion can affect people living with and after cancer but photography can provide a focus and reason to get out, connect with a locality/community or explore new environments.

participant-produced photographs), still represent a new and developing way to approach research into health and illness. Potentially it has the ability to benefit both researchers and participants. Researchers may obtain more rich, holistic, profound and multifaceted data from a greater population base. Participants may be more empowered in the process, more able to take part in research and more competent at effectively explaining their experience. However, the relative originality of such methods means that certain processes and considerations have not yet been thoroughly tried and tested. For example, formal methods of analysis remain in their infancy and there is still much debate about ethics and the confidentiality of visual data. Furthermore, philosophical and contextual issues about the creation and consumption of images need to be addressed when employing such techniques in research.

Notwithstanding these considerations, we found that the integration of participant-produced photographs in our study exploring the experience of living after the diagnosis a poor prognostic cancer was a straightforward means of data collection for participants and an effective method that appeared to add to the depth and context of the interviews. We believe it revealed more data than would have emerged from interviews alone and produced a broader understanding of relevant issues. We have presented participant-produced photographs and related interview text together in publications and presentations and have found that this has offered a powerful and relevant way of exhibiting and communicating experience to various professional and lay groups and has the potential to reach a far greater and more diverse audience.

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## Conflict of interest

No conflict of interest has been declared by the authors.

## Author contributions

All authors have agreed on the final version and meet at least one of the following criteria [recommended by the IC-MJE ([http://www.icmje.org/ethical\\_1author.html](http://www.icmje.org/ethical_1author.html))]:

- substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;
- drafting the article or revising it critically for important intellectual content.

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