

Researching surviving cancer and sexuality using visual methods: a reflection on research rationale and negotiating ethical issues.

This paper, grounded in our experience of conducting a qualitative study around the impact of cancer on sexual and relational wellbeing, offers an account of working with visual methods focusing on the methodological framework that guided our study. We conducted interviews with 12 leukaemia survivors and inspired by graphic medicine, where comics and graphic novels are used in patient care, artists transformed the data into visual representations of participant's narratives. In this paper, we discuss our methodological rationale, outlining how our study was guided by a research design grounded in feminist principles. We reflect on the tension between the flexibility that qualitative and visual methods require in contrast to the rigidity of NHS ethical frameworks. We hope to raise awareness of how the methodological framework can be used as a resource to guide the use of visual methods; the aim being to encourage others to push the boundaries of research using visual methods.

Introduction:

Despite an increase in attention, coupled with evidence which suggests that patients are willing to talk about sexual issues (see Katz, 2005), the sexual and relationship challenges cancer survivors experience remain an under researched area and one which is also under developed in clinical practice. Previous work suggests that sexual side effects, sexual dysfunction, lack of sexual confidence and attractiveness, dissatisfaction with intimate relationships and a reduced sense of masculinity and femininity are not uncommon occurrences (see Enzlin and De Clippeleir 2011; Gilbert *et al.*, 2012; Mercadante, 2010). These studies begin to reveal the profound impact cancer has on sexual wellbeing and relationships. Evidence also suggests that patients require additional support in addressing the sexual and intimate changes cancer brings (Horden and Street, 2007).

In Parallel, there is a growing body of literature that discusses the advantages of presenting health information in a graphic form (Kennedy, 2014; Lo-Fo-Wong *et al.*, 2013; McNicol, 2014; Green and Myers 2010; Williams, 2012). This work suggests that a visual approach to information presentation is attractive due to: the visual allure, the accessible methods of delivery and consumption, it enhances understanding, provides clarity and insight, increases the recall of health information, it requires only a short attention span therefore complex ideas can be quickly and easily digested, and the powerful visual messages can convey immediate visceral understanding in ways that conventional texts cannot. Furthermore, the literature claims that comics (sequential narrative art) in particular provide insight into the subjective experience of being ill, provide comfort for patients to know that they are not alone in their experiences, reduce isolation and provide support in more accessible and immediate ways than joining a self- help group or reading traditional text based patient leaflets. Graphic medicine approaches can also help patients and their families better understand what to expect of illness by relaying facts, such as the effects of treatment, as well

as the social issues around illness, and it may provide the opportunity to raise questions with health care provider that they had not considered or find hard to approach

It has been suggested that comics might have a role to play in the discussion of difficult, complex or ambiguous subject matter and they are non-threatening, personalizing and can universalize illness experience (Williams, 2014; McNicol, 2014: 49). The potential for humour in comics can mean unpalatable reality is easier to see (Al-Jawad, 2013). These properties make them potentially useful for providing information about sexuality. The multiple layers of comics make them a good way to explore the messy complexity of real life practice and as Green and Myers (2010) claim, the use of text and images allows the reader access to the world of both thoughts and words of the characters, this has the potential to generate empathy (see McNicol, 2014). The visual aspect can make the text more memorable if the two elements work together; the text may contain all the factual information necessary, but the images reinforce this understanding and help commit it to memory (McNicol, 2014: 54).

It can be argued that utilizing graphic medicine in a research study consists of using visual methods. How we define, conceptualize, use and analyse visual methods and the data they provide are key theoretical and methodological questions that are currently unclear (Russell, 2007). Visual methods are generally understood as “concerned with the production, organization and interpretation of imagery” (Prosser, 2007:13). The literature around visual methods is diverse and overlaps with other innovative methods. For example Parsons and Boydell suggest that “Arts-based research is grounded in the tradition of qualitative social science, and refers to the use of any art form(s) at any point in the research process, whether for generating, interpreting and/or communicating knowledge (Knowles & Cole, 2008)” (2012: 170). Thus, if a project utilizes drawing of some form, either to produce images by the participant, or for images to be produced by others for participants to comment, it can be seen that the boundary between the two is not fixed and instead there is fluidity. This lack of definitional clarity is beyond the scope of this discussion, but for the purpose of this paper and for clarity, we understand our study as a combination of visual methods and art based research. This paper is a description of the methodological framework that guided the project and rationale for using visual methods. We hope this account will offer an insight for other researchers into why we chose visual methods,, will demonstrate how this approach was appropriate for our study and will outline how we negotiated the NHS ethical review process.

The Research Process:

This study sought to explore the unmet sexual and relationship wellbeing needs of people who had survived cancer including if and how these needs could be better supported using visual and digital means. We recruited 12 participants who attended the hospital for a face-to-face interview with a member of the research team. One participant chose to take part via telephone for convenience. All participants provided written informed consent before the start of the interviews and all interviews were audio-recorded and transcribed. The transcripts were analysed using a thematic approach providing 4 main themes titled: relationships, information and awareness, normal and visual. These themes had a number of sub themes and provided a

guide for the visual materials. We worked with six graphic artists whom we sent details of the main and sub-themes. Artists then chose which sub/theme(s) they wished to work with and quotes from the transcripts were provided. The developed art was hosted on a website that the research team had built specifically for the project. To evaluate these images, we initially thought a focus group would be the best option. However, we experienced challenges organising a suitable time and a number of participants did not wish to take part. To address this we conducted the evaluation online. Only 3 of the 12 participants provided feedback about the art and website, which is a limitation to the study.

Rationale: feminist research principles

As Prosser and Loxley (2008) suggest, the first question visual researchers should address should not be ‘how’ and ‘when’, but ‘if’ and ‘why’ visual methods are appropriate for the project and the research design. As a key aim to our study was to explore, develop and evaluate the use of visual materials in supporting cancer survivors, the use of visual methods of some sort was already given. As the development of visual materials was essential to this study, in many ways our project differs from others which use visual methods to only illicit or represent data. This is not to say that Prosser and Loxley’s ‘if’ and ‘why’ were not important, in fact these guided our methodological framework and our methods choices. Our study was guided by a feminist methodological framework. There is not scope to explore the feminist methodological literature (see Ramazanoglu and Holland, 2002; Reinharz and Holland, 1992; Stanley 2013), however, there are a number of key points about research that is grounded in feminist principles. It is argued that such work gives a voice to the marginalised aiming for social transformations to improve the lives of those who are marginalised. Such research is thought to act against oppression, address inequalities and to challenge experts. Feminist research rejects the traditional researcher/ participant hierarchy and attempts to provide participants with more power and calls for a reflexive approach. Feminist research is open to innovative methods. We address these principles below.

Working with marginalised groups, challenging experts and improving lives:

There is evidence to suggest that cancer survivors experience social isolation, economic inequality and a range of side effects from treatment and ongoing health issues as outlined above (Foster et al 2009; Glaser et al., 2013; Short et al., 2005). Those who have experienced cancer report feeling stigmatised and a sense of powerlessness about the decisions that are made about their treatment, their body and their life (Chapple et al., 2004; Short et al., 2005). The dominance of the biomedical model which privileges doctors and health care professionals over patient’s experiences, further increases the marginalisation of cancer survivors (see Nettleton 2013). Kennedy et al. who have conducted work on the self-management of diabetes using cartoons, claim that whilst it is acknowledged that patients should be consulted to ensure that graphic representations are meaningful and not used in a way which is counter-productive, there is little guidance for how cartoons can be developed in a collective and reciprocal way to encourage engagement with self-management support (2014: 3). They go on to claim that generally ideas originate in clinicians and researchers who work with artists and there is a lack of clarity where, or if, patients voices are included . We placed participants, as cancer survivors, as experts in cancer survivorship, thus a goal of

this project was to describe life worlds “from the inside out”, from the point of view of those who participate (Flick et al., 2004: 3), to explore surviving cancer from the perspective of survivors themselves.

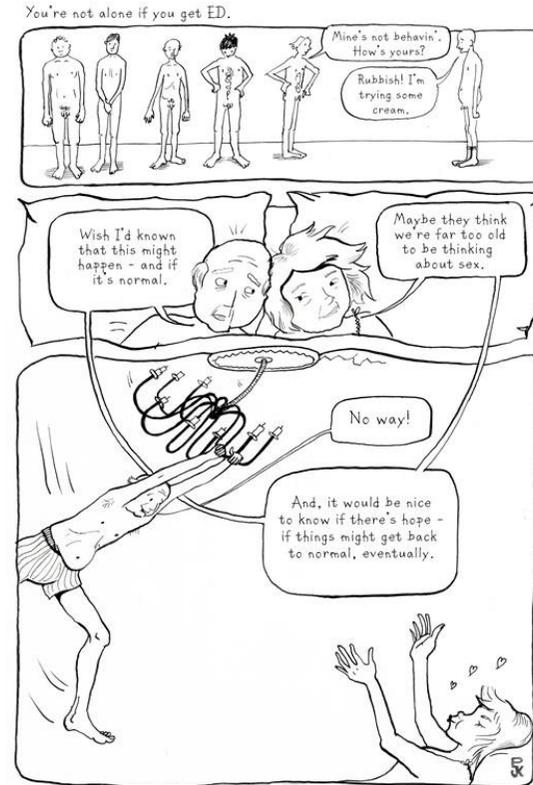
By gathering cancer survivor's subjective experiences, it is necessary to generate what Geertz (1973) calls “thick description”. So instead of simply describing the changes and challenges those who suffer from cancer experience, this approach allows the meaning of experiences, such as bodily and relationship changes, to be understood from a survivors perspective. Whilst qualitative interviews could be seen as invasive or intrusive, refusing to speak of sexuality and relationships further serves to stigmatise and silence the challenges cancer survivors may face in these areas of their lives. Therefore, semi-structured interviews were the best method of gaining the information required allowing us to formulate interpretations and thus understand the meaning of participants’ experiences, as opposed to simply documenting that they exist (Warren, 2002).

Holden and Street (2010) suggest that there is a mismatch between patients and doctors perceptions of issues surrounding sexuality and cancer. By taking a feminist inspired approach, we sought to challenge the passivity, silencing and subordination of this marginalised group. The use of qualitative interviews with cancer survivors was the first step in this process. Following other feminist framed work, by focusing on cancer survivors we directly sought to challenge the medical ‘expert’ view on what was important to survivors. It was the second step, the development and evaluation of the visual materials of participant’s narratives that have the potential to lead to change.. By transforming key themes from the narratives¹ into comic style and other alternative visual forms, we sought to improve the lives of people who had survived cancer by producing materials that could, for example, address questions that cancer survivors may have around sexuality and also offer a sense of comfort in that patients were not alone in experiencing sexual difficulties. Figure 1 represents the work of one of the artists we commissioned²:

1 It is beyond the scope of this paper to discuss the findings and evaluation of the artist’s interpretation of participant’s narratives.

2 Website and art available to view here <http://isrg.shef.ac.uk/joomla/>

Figure 1: Normal by Paula Knight³.



3 <http://paulaknight.wordpress.com/>

Innovative methods:

Feminist methodologies grew out of feminist concerns about mainstream social science methods and purposes, amongst other issues (Gorelick, 1991). The key goal of addressing inequalities necessitates methods which are flexible, collaborative, participatory and more innovative than traditional approaches (Liamputtong, 2007). In addition, feminist inspired research has generally been open to innovative methods which can be particularly appropriate for exploring sensitive topics such as sexuality (Liamputtong, 2007). Being creative requires flexibility and we had a number of ideas of how we could work collaboratively with patients to capture their experiences and how to transform these into visual representations. For example, we discussed having an artist sit in during interviews, listening to the discussion or taking part where appropriate. We thought artists could draw during interviews to portray participant's stories as they were told, or, produce the images after reflection at a later date. We also discussed participant generated images. However, ethically a number of issues were raised such as would participants have the artistic literacy to produce visual images of their stories? . Would it be ethical to let artists sit in on interviews and how could this affect the dynamic of the interview and knowledge generated At the start of the project, we were excited about experimenting with these different formats, however, the requirements for NHS ethical approval hampered this innovation and experimentation.

Wiles *et al.* found visual researchers tend to avoid NHS ethics committees as they were seen as “highly bureaucratic and standardised, allowing little room for variation from the norm of consent forms and anonymisation, and as being less sympathetic to qualitative research and visual methods” (2012: 3.6). This bureaucracy and shift towards standardisation is part of a wider trend of the expansion of audit and inspection procedures in all fields of life, but specifically the public sector and the NHS; it is argued the ethical regulation of research is part of this wider growth in the audit culture (Rustin, 2010). We found we had to be incredibly specific about the research design with little room for creativity and flexibility and it quickly became apparent to gain NHS ethical approval, there was little space for creative and innovative experimentation within the research process. This was a 12 month project, so there was little time and money to undertake preliminary work which could have been beneficial.⁴ We met once with a local cancer survivor group to explore how such a project could be valuable, and if more time was available we could have approached members of the local cancer or graphic medicine community to discuss the project in more depth and to have explored alternative ways of working. However, we were aware of the lengthy delays in gaining NHS ethical approval (see Pollock, 2010) which has been blamed on increased bureaucracy, thus we sought to submit our application as quickly as possible after we were awarded our grant. We had to make rapid methodological and ethical decisions but we also had to make sure that we were granted ethical approval; we did not want to be rejected nor did we want to go through several rounds of amendments. So whilst we were guided by feminist principles, the use of innovative methods presented ethical challenges that we had to negotiate within a bureaucratic and standardised system.

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As Wiles et al. (2010) discuss, the researchers they interviewed did not feel that there had been any impact on the day-to-day running of their project due to ethical constraints. Similarly, we did not experience this and we received no complaints about our use of visual methods. Other queries about recruitment, the support offered by NHS services including how consent would be broken and other minor administrative issues were raised⁵. We were however warned that any changes would require a major amendment for further ethical approval from the board. Upon reflection it is apparent that we took the ‘safe option’; whereas at the start we wished to embrace innovation within our research design, we instead opted for the design we hoped would obtain ethical approval in the most efficient manner. Processes based on audit regimes only seek compliance and those being audited “develop strategies to cope with being audited” (Power, 1997: 12). Our perception that anything that could breach traditional notions of confidentiality could be potentially problematic for ethical approval and to ensure that the study was as minimally intrusive as possible, we opted for no patient contact with the artists and that of no patient produced images; we developed a way of “working with the system” (Wiles, et al. 2012: 4.3). Hillman et al. (2013) argue that concerns about potential untoward events disrupt the provision of care in acute hospital settings generating a culture of restriction and limitation. Similarly, concerns around the potential for risks resulted in us restricting and limiting the methodological innovation within our study. We were not prevented from using visual methods in our study; however, due to our own perceptions of NHS ethical review processes we limited the methodological innovation we had initially discussed using. Had we not been so constrained by time or funding, we may have submitted a more innovative research design for ethical approval that took more risks. From our experience, ethical review process may have the “unintended consequences of curtailing innovative (visual) research practice” (Wiles et al., 4.5). The real and anticipated difficulties of negotiating regulatory process which are intended to protect participants may stifle and censor research, limiting and directing what and how research is done (Pollock, 2012). As Pollock argues this misplaced protectionism may constitute harm rather than benefit. However, our experiences also demonstrate that NHS ethical review boards are open to innovative methods and different ways of working; the challenge becomes in how to further advance the use of innovative methods that require flexibility throughout the research process within such bureaucratic and rigid ethical review procedures at a time when much research is undertaken under increased resource constraints.

Conclusion:

This paper has provided the rationale for the use of visual methods in our study around cancer survivorship and sexuality. Responding to Boydell et al.’s (2012) statement that researchers are not explicit in why they choose a particular art genre, we have explained our use of graphic medicine and comics as the choice of art work. We have outlined how we were guided by a feminist methodological framework and how this framework grounded in principles of working with marginalised group, challenging the privileging of medical knowledge, a desire to promote social change and innovation necessitated the complimentary use of interviews and visual methods. We have described how our use of the feminist framework and visual methods was challenged by NHS ethical processes, but we have

⁵ We did find the process beneficial and it helped us to clarify certain aspects of our project.

outlined how these challenges were negotiated and how by ‘playing it safe’, we complied and compromised to ensure we were granted ethical approval for the use of visual methods that represented the needs of those who have survived cancer. In laying out our rationale and some of our experiences we hope it can encourage other healthcare researchers to engage with alternative methods and help to offer improvements to patient care. By considering the lessons learned from our study we hope this assists fellow researchers in negotiating ethical procedures and applying visual methods effectively. Overall, we have demonstrated that despite the challenges we have faced, the use of visual methods in research presents an interesting and exciting addition to the researcher’s tool kit.

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