Involving young people with life-limiting conditions in research on sex: The intersections of taboo and vulnerability

Key words

Sensitive-research, sex, relationships, life- limiting/ life threatening conditions, young adults.

Abstract

There is a growing literature that seeks to explore what is ‘sensitive’ about ‘sensitive’ research. In order to problematise and interrogate the concept of what may or may not be considered ‘sensitive’ research, this paper draws on four related projects exploring sex, intimacy and relationships for young people, over 16 years, who have life-limiting or life-threatening conditions (LLTCs). The authors focus on how, when and why these projects are regarded as ‘sensitive’ and consider who defines them as such. Drawing on the notion of methodological performativity, a mixture of complex phenomena that explores the relational aspects in interprofessional team practices, the authors examine aspects of the process of doing ‘sensitive’ research, exploring how research methods and techniques are employed because the research has already been defined (by others and the authors) as ‘sensitive,’ while simultaneously serving to (re)construct and (re)enforce the ‘sensitive’ nature of it.

Introduction

This paper outlines four projects that are at the heart of our work. We describe the perfect storm of intersecting taboos and vulnerabilities of sensitive research about sexuality and disability. Any project on sex that involves young and disabled, seriously ill people whose lives are shortened, is highly likely to be regarded as ‘sensitive’. We argue that enacting this research as indisputably ‘sensitive’ (re)frames the potential agency for both the researcher and those being researched. We also acknowledge the inevitability of methodological performativity.

While there is no agreement among researchers on how to define ‘sensitive’ research, it generally encompasses a wide range of issues, undertaken across a variety of disciplines and settings, using a range of methods (Dickson-Swift, James & Liamputtong, 2008). Sensitive topics, Lee (1993) argues are those which pose a substantial threat to those involved in the work, including the researcher.

In order to problematise and interrogate the concept of sensitive research within this special issue, this paper draws on four related projects exploring sex, intimacy and relationships for people, over 16 years, who have life-limiting or life-threatening conditions (LLTCs). In particular, we focus on how, when and why these projects were regarded as 'sensitive' and consider who defined them as such. Drawing on the notion of methodological performativity, whereby methods are seen to 'bring into being what they also discover' (Law & Urry, 2003, p.3), we examine aspects of the process of doing 'sensitive' research. We explore how research methods and techniques are employed because the research has already been defined (by others and by us) as 'sensitive' while simultaneously serving to (re)construct and (re)enforce the 'sensitive' nature of it.

Methodologies

All four projects focus on sex, intimacy and relationships for people whose life course maybe uncertain and shortened. They were carried out by individuals or members of The Open University Sexuality Alliance; a trans-disciplinary, multi-professional and inter-sectoral consortium of individuals, co-researchers and organisations with expertise in working with, supporting, or researching people with LLTCs. The research participants were aged between 16-39 and we refer to them as 'young people' because this is how they describe themselves and how they prefer to be referred to. Nevertheless, we acknowledge it is a problematic term; it speaks to the infantilization of disabled people by society in general, and to the continued infantilization of people who live beyond original expectations.

Project One is an action-research project that engaged with young people to develop guidance and standards on sex, intimacy and relationships for professionals (see Blackburn, Chambers & Earle, 2017; Earle & Blackburn, 2020). Previously professionals had identified the issue of sex as a problem and felt uncertain on how best to support people. Young people said that care professionals did not always appreciate how and why sex and sexuality were important for those with LLTCs. Often this was due to the professional's lack of confidence, knowledge, understanding and access to support and guidance in how to approach and talk about sex with young people (Open Learn, 2019). Via hospice organisations, four focus groups were held in England and Scotland in 2014 and 2015 with both young men and women with LLTCs, ages 16-28 years. A charity provided additional questionnaire contributions from two parents and one young person. Separately, six hospice trustees participated in a group interview. In total, 31 people participated in this project .

Project Two explored the sexuality, relationships, intimacy and reproductive choices of young people with LLTCs (Blackburn, 2018). Adopting a broadly interpretive approach, the project used guided in-depth interviews and focus group discussions (n=13), age 16-39 years, partners (n=2), parents (n=10) and health care professionals (n=10). The 35 participants, both young men and women, were recruited via two hospices in England and the fieldwork was conducted between 2014 and 2015.

Project Three was an interpretive, qualitative project involving 20 young women and men, age 16-25 years, living within LLTCs. The focus was on exploring the significance of sex, intimacy and relationships for emotional wellbeing and happiness (Blackburn, Cooke and Earle, 2017). Recruitment was via our existing network of organisations and contacts; five focus groups were held at five separate locations in England and Scotland in 2017, with 20 people participating in total.

Project Four involves inclusive action-research to support the transition of young people, age 16-30 years, in the UK who have LLTCs, by developing their confidence in talking about sex, intimacy and relationships (see Together for Short Lives, 2018). It was developed in collaboration with AdversiTeam, a group of co-researchers whom have LLTCs, to generate open educational resources (see: https://www.open.edu/openlearn/health-sports-psychology/health/intimate-not-intimidated-its-time-talk-about-sex-and-disability).

A perfect storm: Intersections of taboo and vulnerability

By exploring sex, intimacy and relationships for young people who have LLTCs, four major intersecting issues come together to be defined as ‘sensitive’: sex as taboo; the taboo of death; the vulnerability of youth; and, vulnerabilities of disabled people.

The first two issues relate to the issue of taboo. Taboo refers to that which is forbidden or prohibited either by law or custom or, at least, to that which should not be referred to in conversation (Walter, 1991). We argue that both sex and death can be understood as taboo. Sontag (1969) argues that in Western cultures, sex is a ‘special case’ in that it consistently invokes inconsistent attitudes and beliefs. On the one hand, sex is dirty and unmentionable, whereas on the other it is considered to be a core part of the modern self. In modern Western cultures death is equally taboo (Walter, 1991). Similarly, while we are indirectly bombarded by death on a daily basis – for example, in the news – it is also something that is feared and often hidden (see Fisher, 1973).

The perceived vulnerabilities of this group of research participants further intersect with the taboos of sex and death. The participants are considered vulnerable because they are young. Children are regarded as ‘incomplete, irrational, unproductive and asexual whereas adults are seen to be complete, rational, productive and sexual (Liddiard & Slater, 2017). Young people are in what Lesko (2012) describes as the ‘border zone’ between child and adult, thus perceived as requiring special attention. The research participants are also considered vulnerable because they are disabled and seriously ill. There is a considerable body of work that has already discussed the ways in which disabled people are marginalised, infantilised and perceived as asexual (see Shakespeare, Gillespie-Sells and Davies 1996). Disabled people, but particularly, young disabled people whose lives are limited and uncertain, are perceived as generally vulnerable in many ways. For example, young people with LLTCs were often perceived as being at greater risk of abuse and harm (Blackburn, 2018). They were also considered ‘hypersexual’, sometimes requiring containment (Liddiard, 2018). Participants in all four projects had been told throughout their lives that they were going to die soon and often found this deeply frustrating. In reality, they preferred to savour every moment, ‘living life to the fullest’ (Liddiard et al, 2018).

What makes this type of research ‘sensitive’ is the perfect storm of taboo and vulnerability. Below we explore how they intersect during distinct elements of the research process. We highlight the difficulties we encountered and discuss the ways we sought to manage them, successfully or not.

Project start up: Managing funding, ethics and risk

Securing funding and obtaining ethical approval for projects that focus on sex is notoriously difficult; securing funding and obtaining ethical approval for projects that focus on sex with young and disabled people whose lives are shortened is even more challenging. In spite of the project team’s desire to normalise sex and intimacy for young disabled people and work inclusively, it has been impossible for us to move away from narratives of ‘sensitivity’. We deal with two specific issues here. Firstly, the dilemma in how we must present our work as ‘sensitive’ to others in order to secure funding and ethical approval. Secondly, the risk management strategies that we employed within the project team in order to address the realities of working with disabled young people who are seriously ill.

We encountered many examples of ‘sex-negativity’ during the research process. Sex-negativity refers to the way in which sexuality is defined as a deficiency, rather than a resource, and as something that can be regarded as dangerous and damaging from which people need to be protected (Egan & Hawkes, 2008). We encountered funders, parents, professional staff and organisations that were concerned with the notion of safeguarding and the actions that we should put into place to protect participants and disabled co-researchers. For example, in response to very robust questioning during a funder interview as to the nature of our plans for safeguarding, in Project Four, and in collaboration with the young adult co-researchers, we nominated an external ‘Safeguarding Lead’ responsible for safeguarding issues. In all four projects, the intersections of vulnerability and taboo raise ethical issues around the tension between protecting young people who might be considered to be vulnerable to abuse, with avoiding overprotective ‘bubble wrapping’ and respecting the individual’s rights to take acceptable risks (de Than, 2014). As researchers we challenge the idea that young disabled people are vulnerable and in need of protection while, at the same time, want to appease funders and ethics committees that appropriate plans were in place to contain risks. Sometimes this meant that we felt the need to modify the language we used to talk about sex to avoid language that regarded as more 'explicit' (and, therefore, more sensitive), in favour of language that was less explicit and more euphemistic. When communicating with individuals and organisations which seemed more conservative, we avoided drawing on a rights-based discourse that promotes sex-positivity and sexual pleasure, in favour of a more medicalised biopsychosocial discourse which stresses the importance of sex and intimacy for health and wellbeing. So, in this sense, while not wanting to frame this area of work as de facto sensitive, we reframed the research in order to achieve success with funders and ethics committees.

All of the four projects are collaborative in nature but Project Four is the only project that is fully inclusive and led by young people themselves. Managing an inclusive research team is sensitive work and, in this instance, death and dying come to the fore. It is difficult, and awkward, to openly acknowledge that some members of your team have a higher than average probability of being very unwell or even dying during the project, while simultaneously writing this into your risk management plan. It *feels* awkward because as a society many regard death as taboo and would rather not have to raise the subject and, thus, we enact the research as sensitive. Equally, we recognise that contemporary social science literature questions for whom death is, or might be a taboo subject (Walters, 2017; Tradii & Robert, 2017). It is often those close to the dying person who struggle in talking about death, rather than the person who is close to death (Walters, 2017). The young people in these four projects repeatedly told us that they wanted 'to live life to the full' and that uncertainty about their life-course should not exclude them from having open and frank discussions about death.

When working with young disabled and seriously ill young people, the problems young people can encounter with travel and health can mean that face-to-face project meetings must be replaced with online meetings. This is a practical solution usually works well and has many advantage but may miss more nuanced face-to-face communication where you can sometimes gauge whether someone is well, or unwell without it being explicit. Striking the right balance between courteous enquiries about health and wellbeing which may be intrusive, and not ignoring silence, which could be detrimental to the project, is difficult. Contingencies for when co-researchers with LLTCs are unwell need to be in place at the project's outset. For example, we put into place clear protocols as to when individuals – or someone on their behalf - should advise that they were ill or in hospital and unable to work. We also introduced a system of deputies for specific project roles so that project activities could continue if someone became ill or died.

Talking about sex: Asking questions about sex, intimacy and relationships

As others have noted (Liddiard et al, 2018; Liddiard, 2018), it is not easy to carry out research on sex. Indeed, not everyone wanted to participate in our projects. For example, in Projects Two and Three, a number of potential participants declined to take part in the study because they felt too uncomfortable talking about sex. However, for many of the participants , it was often the very first time that they had ever discussed it (Blackburn, 2018). We wondered whether this fact, in itself, makes our research sensitive? Plummer (1995) argues that the way in which we talk about sex is historically and culturally rooted, and that there must be ‘social worlds waiting to hear’ (p. 34). Our projects created an opportunity to talk about sex for this group of young people and a social world that would be interested in what they had to say.

Hollomotz (2018) argues that research about sexuality is more successful where plain language is used, and participants are consulted and can agree language in advance of the research. In Project Two, we conducted a pilot study to ascertain the preferred sexual vocabulary. Participants requested the use of plain terms and the avoidance of over-medicalised jargon. In Project Four, disabled co-researchers determined the language used.

The project team didn’t always agree on how we should talk about sex but following discussions, usually reached consensus. In Project One, we developed a set of standards and guidance for those working with young people with LLTCs as part of a large multi-disciplinary, multi-professional team, recognising the different language requirements of various members. Young people with LLTCs asked for condition-specific, practical solutions, written or communicated in plain English. Practitioners argued for coherent governance and compliance measures. While academics wanted to address issues such as gender identity and sexual citizenship, and, lawyers argued for clear, jargon-free legislation. The ultimate and shared goal was developing a useful resource by The Open University Sexuality Alliance, 2019 while challenging the taboos of sex and death.

Some members of the team believed in more direct approaches and explicit language, whereas others preferred a less direct approach. We viewed this through our own normative lens of what would make the research less ‘sensitive’ for participants. In Project Two, interviews began with general questions rather than questions that directly focused on sex and intimacy. We initially disagreed on this approach, but the interviewer felt that, as most of the young people had not previously discussed sex with anyone, and had been informed that they were exceptionally shy, that they would welcome initial ‘rapport building discussions’ before talking with strangers explicitly about sex. This raises questions as to whether ‘sex’ is a ‘sensitive’ topic for participants, or whether researchers can sometimes find it difficult to ask questions about sex too thereby enacting sensitivities where there may actually be none. There was clear evidence of methodological performativity in the data that we generated using this interviewing technique. For example, a proportion of the data generated in the project did not focus entirely on sex and intimacy, instead it focused on wider contextual and background health and social care issues related to their LLTC – a direct result of the way in which interviews were organised, what questions were asked, and in what order.

After projects end: The issue of posthumous consent

Informed consent is an essential component of responsible research practice. In our case – because many of the participants were at risk of dying either during or after the end of a project – we needed to secure posthumous consent to include their data. The literature on posthumous consent primarily relates to reproduction and the ethical and legal issues on the use of sperm and egg donation after death (Tremellen & Savulescu, 2015; Collins, 2005). There is an absence of literature addressing participants' choices about the use of their data following death, especially for young adults where family may usually feel involved in decision-making.

Securing posthumous consent in this research field is particularly important because we recognised that some participants may die during the project. This was relevant for Project Two. Because the participants were young and disabled, other people, particularly family, were likely to be intimately involved in their lives – more so than other people who are not life-limited. This, and the focus on sex, means that there can be difficulties with data use following death, if posthumous consent is not clearly secured and documented at outset or, during the project.

The practice of securing posthumous consent feels uncomfortable. Most of the participants involved were more interested in living and making the most of their lives; asking about posthumous consent meant that the issue of death needed to be brought to the fore. It may be difficult to predict how data will be used in future, particularly if a participant dies during the course of the research. During the consent process in Project Two, one young man enquired 'What will happen to my data if I die during or following your research?' to which the researcher replied, 'What would you like to happen?' The young man responded that he wanted his interview data to be used following his death to provide a 'living legacy' of his contribution about relationships, intimacy and sex. He did not set any time limits on its usage. Together, the young man and researcher included an additional sentence within his consent form, reflecting his request. The young man signed a revised consent form before his interview and died during the project.

Following his death, the young man's parents contacted us and requested that their son's data was not used in subsequent publications as they were uncomfortable about the subject matter of the project (sex). We subsequently met with the parents, explaining the purpose and intentions of the research and followed this up with a letter. The parents ultimately, although uneasily, respected their son's request to use his interview data posthumously.

Due to the intersections of taboo and vulnerability, we argue for the importance of discussing and recording the different phases of consent and assent, recognising participants nearing the end of life might die before the research is completed or published. As noted here, parents and/or care practitioners sometimes answered for and acted as gatekeepers, on behalf of the young people, both during their lives and after death. This raises issues about seeking, renewing and addressing posthumous assent or consent before death.

Concluding remarks

In this paper we have explored the sensitivities of conducting research on sex, intimacy and relationships with young people whose lives are threatened. We reflected on the learning from the process and offered suggestions as to how these might be relevant to other researchers in the future. We have focused on three elements of the process, drawing on pertinent issues that are present at project start up, our preparations for talking about sex with participants, and what we needed to consider after projects ended. There are many other issues, but we have focused on the issues that, as a project team, we either disagreed on the most or we found more challenging to address.

We have shown how we have simultaneously both rejected and embraced the definition of our research as ‘sensitive’ at different times during the research process, recognising that the positioning of this research as sensitive frames the process. The project team adopted a predominantly rights-based, sex-positive approach to the subject area which seeks to define sex as normal and every day, and therefore, ‘not sensitive’. However, in order to secure funding, ethical approval and posthumous data rights we found ourselves drawing more on approaches that favoured safeguarding and biopsychosocial models of health, rather than a rights-based discourse. Adopting the notion of methodological performativity, we have illustrated how the defining of research as ‘sensitive’ by others can shape the nature of a research project, including the use of different research methods and techniques. As researchers, we have also enacted the research process as a sensitive one although we sometimes also wanted to reject this definition and didn’t always agree on how to go about things. In conclusion, we agree with Sparrman (2014) who argues that research on ‘sensitive’ topics can be a ‘messy’ business and that tried and tested experiences should continue to be published.

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