

**Unpacking sensitivity:
Methodological challenges of
undertaking sexuality research with
young adults with life-limiting
and/or life-threatening conditions**

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Aims



Present and discuss methodological dilemmas of conducting sexuality research with young adults with LLTCs, age 16-40, based on my doctoral thesis:

“Sexuality, relationships and reproductive choices in young adults with life-limiting and /or life threatening conditions”

Consider the intersection of multiple ‘sensitivities’ and reflect on how and why certain taboos were foregrounded in this PhD research with young adults the LLTCs in relation to sexuality, disability, death, dying and end-of-life

Present examples from interview data



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The research participants

- 13 young adults aged 16-40 years, nine males, four females, with some, but not all, life-limiting or life-threatening conditions, mean average age.
- People with Cystic Fibrosis, Duchenne Muscular Dystrophy, other progressive neuromuscular and rare conditions, certain cancers and other genetic conditions.
- Explored the views and contributions of family supporters. Two non-disabled partners, ten parents and ten care practitioners.
- 35 participants, one focus group. Some participants interviewed on more than one occasion.
- In-depth semi-structured f-to-f interviews. Thematic analysis
- Lifecourse approach.



Participant	Participant type	Sex	Age Group	Country of Birth	Education Level	Faith	Household	Medical Condition(s)	Occupation
<i>Alfa Romeo</i>	YA	Male	30 up to 40	UK	Special College	Christian	Lives with parent(s)	DMD	Volunteer
<i>Austin</i>	YA	Male	20 up to 30	UK	University	Christian	Lives with parent(s)	Benign recurring brain tumour	Volunteer
<i>Diamond</i>	as a Young Adult	Female	30 up to 40	UK	Mainstream College	Christian	Lives with partner	Leukaemia	Mixed
<i>Fiat</i>	YA	Male	20 up to 30	UK	Special College	Christian	Lives with parent(s)	DMD	Not working
<i>Jaguar</i>	YA	Male	20 up to 30	UK	Special School	Christian	Lives with parent(s)	DMD	Volunteer
<i>Jane</i>	YA	Female	10 up to 20	UK	Mainstream School	Other	Lives with partner	Rare life-limiting condition	Volunteer
<i>Lamborghini</i>	YA	Male	20 up to 30	UK	Special College	Christian	Lives with family	DMD	Not working
<i>Lily</i>	YA	Female	20 up to 30	UK	Mainstream School	Christian	Lives with family	Rare life-limiting condition	Volunteer
<i>Marmaduke</i>	YA	Female	20 up to 30	South Africa	Special College	Unassigned	Lives with parent(s)	Rare life-limiting condition	Special college
<i>Maserati</i>	YA	Male	20 up to 30	UK	University	Unassigned	Lives with parent(s)	Brain tumour- cancer	Volunteer
<i>Mini</i>	YA	Male	20 up to 30	UK	Special College	Christian	shared parent scheme	DMD	Special college
<i>Morris</i>	YA	Male	20 up to 30	UK	Special College	Jewish	Lives with parent(s)	Adrenoleukodystrophy	Not working
<i>Vincent</i>	YA	Male	20 up to 30	UK	University	Jewish	Lives with partner	Cystic Fibrosis	Postgraduate Student
<i>Dee</i>	Partner	Male	40 up to 50	UK	Mainstream School	Unassigned	Lives with Jane	N/A	In full time employment
<i>Smidge</i>	Partner	Female	20 up to 30	UK	University	Christian	Lives with Vincent	N/A	In full time employment
<i>Daisy</i>	Parent	Female	30 up to 40	UK	University	Unassigned	Unassigned	N/A	In part time employment
<i>Emerald</i>	Parent	Female	40 up to 50	Jamaica	University	Episcoplian	Lives with family	N/A	In part time employment
<i>Goldie</i>	Parent	Female	30 up to 40	UK	University	Episcopalian	Lives with partner	N/A	In part time employment
<i>Liliana</i>	Parent	Female	40 up to 50	UK	Mainstream College	Christian	Unassigned	N/A	Main Carer
<i>Pear</i>	Parent	Female	40 up to 50	South Africa	Mainstream College	Christian	Lives with family	N/A	Main Carer
<i>Precious</i>	Parent	Female	30 up to 40	UK	Mainstream College	Christian	Lives with partner	Leukaemia	CNS
<i>Primrose</i>	Parent	Female	40 up to 50	UK	University	Christian	Lives with family	N/A	Care assistant
<i>Ruby</i>	Parent	Female	40 up to 50	UK	Mainstream College	Christian	Lives with family	N/A	In part time employment
<i>Diamond</i>	as a Parent	Female	30 up to 40	UK	Nursing School	Christian	Lives with family	Leukaemia	In part time employment
<i>Topaz</i>	Parent	Female	40 up to 50	UK	University	Jewish	Other residential care	N/A	Main Carer
<i>Millie</i>	Social Worker	Female	50 up to 60	UK	Mainstream College	Christian	Lives with husband	N/A	Social Worker
<i>Peach</i>	Med Student	Female	20 up to 30	UK	Medical School	Roman Catholic	Unassigned	N/A	At University
<i>Oak</i>	GP	Female	30 up to 40	UK	Medical School	Unassigned	Unassigned	N/A	Doctor
<i>Ellie</i>	GP	Female	40 up to 50	UK	Medical School	Unassigned	Unassigned	N/A	Doctor
<i>Apple</i>	Carer	Female	20 up to 30	UK	Mainstream College	Christian	Lives with partner	N/A	Main Carer
<i>Cherry</i>	Care Practitioner	Female	40 up to 50	Ireland	Nursing College	Christian	Lives with family	N/A	Full time employment
<i>Elm</i>	Care Practitioner	Female	30 up to 40	UK	Mainstream College	Unassigned	Unassigned	N/A	Youth Leader
<i>Spruce</i>	Care Practitioner	Female	40 up to 50	UK	Nursing College	Unassigned	Unassigned	N/A	CNS
<i>Walnut</i>	Care Practitioner	Female	40 up to 50	UK	Nursing College	Unassigned	Unassigned	N/A	CNS
<i>Pine</i>	Care Practitioner	Female	40 up to 50	UK	Nursing College	Unassigned	Unassigned	N/A	Main Carer
<i>Focus group</i>	YA	Male	20 up to 30	UK	Various	Various	Various	Multiple life-limiting conditions	Various

What is sensitive research?

Many definitions:

- Joan Sieber and Liz Stanley (1988:49) 'socially sensitive' research as, *'studies in which there are potential consequences or implications, either directly for the participants in the research or for the class of individuals represented by the research'*.
- Renzetti and Lee (1993) acknowledge that all research has the potential to be sensitive, so sensitivity should not be used to describe only particular groups or approaches to research
- Some research may be more sensitive than other research
- Some definitions do not capture the reality and meanings of 'sensitive' where multiple sensitivities interact.

Literature on sensitive research

- De Laine, M. (2000). *Fieldwork, Participation and Practice: Ethics and Dilemmas in Qualitative Research*. London: Sage Publications.
- Lee, R. M. (1993). *Doing Research on Sensitive Topics*. London: Sage Publications.
- Lee, R. and Renzetti, C. (1990). 'The problems of researching sensitive topics: an overview and introduction', *American Behavioral Scientist*, 33:510-28.
- Newton, V. (2016) 'It's good to be able to talk': An exploration of the complexities of participant and researcher relationships when conducting sensitive research', *Women's Studies International Forum*, March–April, vol. 61, pp. 93–99.
- Tomkins, S. (1995) *Shame, Humiliation and Contempt-Disgust* p133-178 in *Shame and its Sisters* Edited by Sedgwick, E. and Frank, A. London: Duke University Press
- Valentine, G. (2007) Theorising and researching intersectionality: a challenge for feminist geography, online at <http://doi.org/10.1111/j.1467927200587> , accessed 4 November 2016.

Four intersecting areas of sensitive research

- Researching Sexuality
- Researching Disability
- Researching uncertainty along the lifecourse
- Researching Death, Dying, End of Life
- *(The sex researcher, the death researcher, the disabled researcher).*

Sensitive research

SO

- Why are these areas sensitive?
- For whom are they sensitive?
- The participant, the researcher, or both?



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The researcher

- The individual researcher may not consciously perceive a topic as sensitive
- *Fears over the sensitivity of the research topic may lead researchers to 'edit' themselves out of the research (Valentine, 2007)*
- The fear of enacting harm through the intervention of the interview may cause the researcher 'to disappear' in pursuing elusive objectivity (Lee, 1993).
- The political and ethical problems inherent in the relationship between the researcher and the researched, and in the analysis, data management, dissemination and publication of research (*Lee and Renzetti, 1990*).
- Hierarchy of the taboos, notions of the mundane and the exotic?
- How the research should be planned, carried out, analysed.

The research Ethics Committees (HRECS)

- **The topic:** sex and sexuality – taboo
- **The language:** intercourse, ‘making love’, ‘having sex’, ‘bonking’, ‘f*cking’ (*Abbott, D. W. F., Jepson, M. and Hastie, J. (2016)*)
- **The researcher:** who does it, where is it done, how long will it last?
- **Is it safe?**
- **HREC an individual Hospice RECS:** do their views differ?
- Undertaking qualitative research raises a variety of ethical issues on sensitive subjects, such as death and dying, sexuality, homelessness, HIV/AIDS or cancer (*Dickson-Swift et al., 2008; Newton, 2017*).

The participants

- Reciprocity in research does not always amount to equal exchange with participants, particularly in relation to receiving data (Rubin and Rubin, 1995) *but it should...*
- Do researchers assume participants may be shy about the **death**, **sex** and **disability** words?
- **Chapter 4: contextual data chapter (ice breaker, building rapport)**
Maddie: “Tell me a bit about yourself, your condition?”

Posthumous Consent

Mini: What happens if I die during this research, what will happen to what we've talked about together. Will my interview be shared?

Maddie: What would you like to happen?

Mini: I want you to use whatever you wish from my interview. It will be my living legacy and means my contribution will not be wasted. I want people to know what I feel about sex....

(Mini died whilst I was writing up. His discussions regarding sex, death and dying, end-of-life are included in the thesis. His parents contacted me, following his death regarding his data)

- GDPR issues. Obtaining consent to use data before death

Gatekeeping issues



Conclusion

- Multiple taboos and ‘sensitivities’ are encountered when researching sex with young people with LLTCs who may or may not be approaching death.
- Unexpected, unanticipated and unimagined ‘sensitive’ encounters on the research journey, such as access and gatekeeping, posthumous consent.
- Certain taboos viewed as ‘sensitive’ by both participants and researchers and may be more prominent on different stages of the research journey.



