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Young adults with life-limiting or life-threatening conditions: sexuality and relationships support

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ABSTRACT

Objectives: The research project addressed the need to support young adults with issues relating to sexuality and relationships through the development of guidance and standards for practice.

Methods: An action research project underpinned by an interpretivist qualitative framework. Participants were recruited to the project via three hospices in the UK. Data from four focus groups were analysed thematically using a process of constant comparison.

Results: Sixteen young adults with life-limiting or life-threatening conditions aged 21-33 years participated in the study. Three significant themes were identified: sexuality and the transition to adulthood; recognising the significance of sex and relationships; and, realising sexual rights.

Conclusion: Sexuality and relationships play an important role in the transition to adulthood for people with life-limiting or life-threatening conditions living in the UK. While young adults with these conditions may have considerable support needs, it is important to balance this with the freedom to exercise choice and make independent decisions. Sex negativity can have an adverse impact on the experiences of young adults and creates barriers. Improved ongoing access to sex education and the provision of enabling environments that afford privacy and safety are important to support young adults with sexuality and relationships.

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INTRODUCTION

Until relatively recently, children and young people with life-limiting and/or life-threatening conditions (LLTCs) were not expected to live into adulthood; these are defined as ‘diseases with no reasonable hope of cure that will ultimately be fatal’ (p.924).[1] In children and young people, the term ‘life-limiting condition’ encompasses malignant and non-malignant conditions and includes childhood cancers, cystic fibrosis, muscular dystrophies, neurological disorders and HIV.[2] Due to advancements in medical technologies and clinical treatments, a new population are now living past original expectations into early adulthood and sometimes beyond [3] and today there are approximately 55,000 people with a LLTC living in the UK.[1, 4-5]

Given that this population is relatively new, policy and research has focused on issues of transition to adulthood, including the need to support young people with sexuality and relationships.[6] Talking about sex and relationships can be difficult in so far as it is often considered personal, private and taboo.[7] For young adults with LLTCs, talking about this subject can be even more difficult because most individuals were not expected to live into adulthood, yet their life trajectory remains uncertain and shortened.[8-9] Previous research suggests that professionals, carers and parents find it challenging to discuss these issues.[9]

To date, limited empirical work on sexuality and relationships has been carried out with this population [10] and that which does exist has focused on specific conditions or diseases.[11-14] This paper draws on an action research project designed to support young adults living with LLTCs with sexuality and relationships in the transition to adulthood.

METHODS

Study design

This study addressed the need to support young adults with issues relating to sex, intimacy and relationships through the development of guidance and standards for practice.[15] Using action research, underpinned by a broadly interpretivist qualitative framework, this paper draws specifically on the data derived from focus groups with young adults involved in the development of the guidance and standards. The project used action research since our ultimate goal was to improve practice in order to enhance the support available to young adults. It is a useful approach when seeking to acquire information that has ‘practical application to the solution of specific problems’ (p.3).[16]

Recruitment to the study

Three hospices in the UK were involved in the recruitment of participants for the project. Using the participant information sheet designed by the all-female project team, individuals were approached by hospice care staff with responsibility for supporting young people in transition to explore whether they might like to participate (Table 1 details the inclusion/exclusion criteria). The hospice also determined whether individuals had the capacity to agree to participate in the research according to the requirements of the Mental Capacity Act.[17] Nineteen young adults were approached but three declined because they were not well enough to take part. Written or verbal consent (which was audio recorded) was sought from participants by a member of the research team prior to the research taking place.

Table 1: Inclusion and exclusion criteria

<p><i>Inclusion criteria</i></p> <ul style="list-style-type: none"> • a life-limiting or life-threatening condition • aged 18 or over • had the capacity to consent to participate in the project
<p><i>Exclusion criteria</i></p> <ul style="list-style-type: none"> • Individuals under the age of 18 • those not able to give consent to participate in the project

Participant characteristics

In total, 16 young adults with LLTCs participated in the research (see Table 2) as well as 9 parents. The focus of this paper is on the data from the young adults only. The range of LLTCs represented were muscular dystrophies (including Becker muscular dystrophy, Duchenne muscular dystrophy and Spinal muscular atrophies), neurological disorders (including brain tumours and cerebrovascular accidents (CVAs) and a number of other very rare conditions. Eleven of the young adult participants were male and five female. All identified as heterosexual and cisgender. The age of participants ranged from 21 to 33 years and their average age was 26 years. Participants self-identified as Black British, White British, White European and Asian. Not all participants spoke English as their first language although all were able to understand and communicate in English.

Table 2: General profile of research participants

Group	Setting	Age range	Gender
Focus Group 1	Organisation 1	21-27	1 female; 2 males
Focus Group 2	Organisation 2	22-33	4 males
Focus Group 3	Organisation 3	22-29	4 females
Focus Group 4	Organisation 2	21-33	5 males

Some LLTCs are extremely rare and can, potentially, identify individuals. As such, the data presented here are fully anonymised. To protect participants' anonymity, we have chosen not to identify individuals by condition and have deliberately not named any of the very rare conditions.

Generating data

Four focus groups with young adults were held at hospices between July 2014 and July 2015 in England and Scotland. Each focus group lasted for approximately 2 hours although this included time for regular breaks in order to rest and/or carry out medical treatments. Although there is some

disagreement within the social sciences about discussing sensitive topics in focus groups, many researchers would argue that a focus group is the perfect setting to discuss 'sensitive' issues such as sex and relationships.[18] With additional resources it would have been useful to also carry out some 1:1 interviews. However, given our action research approach, the use of focus groups aligned with the aims of objectives of the project. A number of topic prompts were used to guide the focus group discussions to assist the research team with the development of the guidance and standards for practice (see Supplemental File 1). These included: the significance of sexuality, intimacy and relationships; the impact of different settings on sexuality and relationships; transition issues; sex education needs; sexual health issues; sexual development; genetics, counselling and reproduction; and, perceptions of sexuality, intimacy and relationships.

The focus groups were drawn from existing groups that met regularly for health, social and other activities. Some participants were supported by carers or staff at the request of the young adult. We had not originally planned for this but made it very clear that individuals could choose to have someone with them, or not. Carers and staff that attended the focus groups were also asked to sign consent forms and were reminded that discussions were confidential. Not all participants were able to communicate orally or had significant difficulties with spoken communication. Communication difficulties can profoundly impact the ability of individuals to participate in research [19] so we used a range of methods (e.g. Makaton symbols and tablets) to facilitate the inclusion of all research participants. In a number of instances, carers assisted with the participants' communication needs. In other instances, the carer or staff member seemed to be providing reassurance and/or emotional support. We wanted to encourage participants to take part in the research even though – for some – it was the first time they had been asked to discuss the topic. Three focus groups were facilitated by author 2 and the fourth focus group by another member of the research team. Both focus group facilitators had previous experience of working with people with communication difficulties and with young adults with life-limiting and/or life-threatening conditions, but they were not known to the group prior to the focus group taking place.

Data analysis

The focus group discussions were digitally recorded and transcribed verbatim by Author 2. Handwritten research notes were produced after each focus group to capture additional information including non-verbal communication. Data were analysed by Authors 1 and 2 using thematic analysis[20], adopting an inductive and data-driven approach. Each author analysed the transcripts using inductive, open coding: the qualitative data analysis software package QSR NVivo (QSR International (UK) Ltd) was used to support this process. The codes were then compared and contrasted using a dynamic process that Lincoln and Guba describe as ‘going back and forth’ (p.342)[21] in order to produce a ‘code list’. At this point there was some replication of data coding to suggest that coding saturation had been reached. The authors then discussed and agreed the code list and used this to refine data analysis in order to generate main themes.

Research ethics

The project was approved by the Open University’s Human Research Ethics Committee. Ethical approval was also given by the research ethics committees of the participating organisations.

FINDINGS

Three main themes were identified and are discussed below: sexuality and the transition to adulthood; recognising the significance of sexuality and relationships; and, realising sexual rights.

Sexuality and the transition to adulthood

Participants were initially asked to discuss the issue of sex and sexuality in general terms and to explore if and why it was important to them. Many of the participants in this study spoke about the significance of sexuality in the context of living adult lives. Participant 1, for example, makes this point:

Participant 1: ‘Over 18s are classed as adults so we should be able to be treated like adults, you know, and we have to make our own choices in life. We will learn from our mistakes, you know.’ [spoken] (focus group 4, male)

Making independent choices can be challenging for people with LLTCs as many will require support in order to realise these choices. When people with LLTCs reach adulthood, they can begin to make choices about issues (such as sex and relationships) that they were never anticipated to make because they were expected to die. Another participant talks about how it can be awkward when he is dating because his mother constantly gets in touch to check that he is okay:

Participant 2: My Mum texts me ‘Where are you? Would you like me to come and pick you up? ‘Ah yeah, okay’ ‘Are you with somebody?’ and it’s like ‘Yeah, but I don’t know how to put it, I’m out with a lady’ It’s a bit hard to tell your Mum, do you know what I mean? [spoken] (focus group 2, male)

Participant 5 also talks about being restricted in what he wants to do. For example, he talked about wanting to go out (on a date) but not having the practical support he needed:

Participant 5: Unless you have got [support], it depends if you are going to certain places, and you are not too far away which could be-, you could want to go to town and you can’t go to town to meet someone [spoken] (focus group 2,male)

Getting out and about can be challenging for some people with LLTCs because it can require specialist support, transport and equipment; this can limit opportunities for socialising, establishing relationships and experiencing sex and intimacy. Participants discussed opportunities for this within settings such as hospices and residential care homes and concluded that safeguarding of activities was paramount but that there should be opportunities to form relationships and experience intimacy in the

context of living adult lives. Participant 5, for example, talks about the possibility of having a girlfriend stay overnight at a hospice:

Participant 5: Why shouldn't someone have the opportunity to have someone there? I think as long as they are respectful of the place and what they, how they go about it, I think then that's fine. [spoken] (focus group 2, male)

Chronologically, reaching 18 years of age appeared to be important; the data suggest that this marked the transition to adulthood and that being treated as an adult meant being able to realise sexual relationships. Levels of support were important; too little support meant that individuals were not able to socialise or date and too much support could be experienced as infantilising and oppressive.

Recognising the significance of sexuality and relationships

As noted above, sexuality was seen to be an important part of adult life. Participants in this study were very clear that the issue of sex and relationships was significant in their lives. As one participant said:

Participant 16: 'I want to live my life like others and get out, meet people, have fun, shop, and have relationships and stuff.' [spoken] (focus group 3, female)

The quote above seeks to normalise sex and relationships in the context everyday life, although there was not one homogenous view. In this study, sex and relationships meant different things to different people. Some participants valued close friendships, others wanted to date and experience sexual relationships, whereas others were thinking about the possibility of having children. For example, Participant 10 says:

Participant 10: 'To be honest I would rather just have a companionship type of relationship, and if anything else happens after that, that's just how things go, you know?' [spoken] (focus group 2, male)

Although participants were clear that sex and relationships were important, they also spoke about how important it was for others to recognise this. This was especially relevant since individuals were often reliant on others to facilitate their sexual agency. Participants spoke about being recognised as people with sexual needs, for example:

Participant 16: ‘... we are sexual beings with needs like everyone else, we might need some practical help to reach our goals but it does not make us any less human.’ [spoken] (focus group 3, female)

One participant spoke about how difficult it could be to make her sexual needs known when it was usually assumed that she would not be interested in, or capable of, having sexual relationships:

Participant 8: ‘... the challenge is to share your sexual needs when people seem to think we are not interested in sex or question our ability to have sexual relationships, in fact any meaningful relationship... [spoken] (focus group 3, female)

Participant 16 spoke about the challenge of being a sexual being in relation to medical encounters and discussions about fertility and childbearing. She believed that her sexuality and capacity for sexual relationships was questioned and, because her life would be limited – that these issues were deemed inconsequential:

Participant 16: ‘I get the feeling that some people – family and professionals – don’t feel I need to know about genetic information partly due to their perception that I am not sexually active so no need and also because I have a short life span and won’t need info as I won’t have children – go figure... [spoken] (female)

Participant 13: ‘Yes’ [one blink] (female)

Facilitator: Aleksy, do you agree with his view?

Participant 11: Yes, I do [spoken] (male) (all focus group 1)

The data highlight that people with LLTCs – whilst not sharing homogenous views – struggle to be seen as sexual beings with sexual needs, although participants were clear to articulate the significance of sex and relationships in their lives. Participants discussed the way that an uncertain and shortened life-expectancy curtailed their opportunities for sex and relationships because other people assumed that this issue was neither relevant nor appropriate.

Realising sexual rights

Research participants spoke about a range of other issues that were also important in realising their sexual rights including the need for life-long information and sex education, privacy and enabling environments.

Participants talked about the need for good quality information on sex and relationships and about having limited knowledge and minimal opportunities for sex education. When asked why information on sex and relationships was important, the comment from Participant 3 sums up the sentiments expressed by the majority of participants:

Participant 3: ‘information is crucial to live life!’ [spoken] (focus group 3, female)

For young adults with LLTCs, sex education may not have seemed relevant when individuals were not expected to live into adulthood. The participants in this study spoke about being ‘shut down’ when they wanted to find out more information about issues relating to sex and relationships:

Participant 8: ‘I am interested in how things work regarding carrier of condition, can it skip, will it skip etc. the few times I have tried to ask more the conversations have been shut down not really sure why?’ [spoken] (focus group 3, female)

Other participants mentioned no longer being able to find out information for themselves, for example, where their condition affected manual dexterity. One participant spoke about being reliant on others to find out information about sex because of being unable to use her hands:

Participant 15: ‘It is difficult when you have lost your ability to surf the net, I recognise that there is a lot of useful information out there but it can be challenging to ask for help if you need to look at sites with sexual stuff.’ [spoken] (focus group 3, female)

Privacy was also identified as important in enabling people with LLTCs to realise their sexual rights and make their own choices:

Participant 12: ‘I need privacy and respect for privacy as a sexual person... [typed on tablet] (male)

Participant 11: ‘Yes, I think it would be helpful.’ [spoken] (male)

Facilitator: ‘Do you understand? Do you think it is a good idea?’

Participant 13: ‘”Yes” [one blink] I understand and “Yes” [one blink...She also smiled] (female)

Participant 12: ‘People must be given the choices and respect to do what they want to do and what is safe.’ [typed on tablet] (male) (all focus group 1)

While privacy and respect for the individual are crucial to ensuring that rights can be realised, the data suggest there is a need to balance privacy with access to on-going support and information. This meant having access to enabling environments. Some participants discussed the difficulty of finding safe and confidential spaces that could be used to have conversations about sex and relationships. Involving parents in conversations about sex was not particularly welcomed and clinical environments were not seen as ideal places to talk about sex:

Participant 16: ‘People need to know that we do appreciate the chance to share our thoughts, but it’s a bit tricky to share thoughts around sexual things when you are at a clinic

appointment with a range of medics and your parent...’ [spoken] (focus group 3, female)

Participants were also asked to think about the issue of sex and relationships within different settings. Morag spoke about the different challenges of realising her sexual rights at home, in hospital and within a hospice environment:

Participant 16: ‘The problem [is] that all environments bring up their own challenges (no pun intended) home – parents can be tricky, taboo discussions plus recognition that I’m sexual developing – embarrassing for everyone....., hospital – well enough said clinical and very, very medical and hospice great place to chat, time for people to listen. But eh a hospice.... So good for information, discussions, peer support and answers to embarrassing questions but not the best location for the sexual act.’
[spoken] (focus group 3, female)

Although some constraints can be ameliorated, people with LLTCs can be constrained by the limitations of physical and cognitive impairments. Individuals often require practical support – relying on people or things to assist them – which adds an extra layer of constraint with respect to realising their sexual rights. Spatial, institutional and attitudinal barriers, as well as physical barriers, also constrain individual choice, including access to information, support and opportunity for sexual expression and exploration.

DISCUSSION AND CONCLUSION

The findings of our study highlight that sexuality and relationships are an important part of the transition to adulthood for people with LLTC. However, as previous research shows, disabled people are often infantilised, seen as asexual and/or requiring protection from abuse.[22-23] Young people with LLTCs are likely to require continued support and access to information into adulthood but our data indicate that young adults can perceive parental over-involvement as unsupportive.[24]

As discussed elsewhere [25, 9] the meaning and significance of sex can vary enormously but sexuality and relationships were significant to all of the young adults involved in our research project. Given that young adults with LLTC must often rely on others, participants emphasised the importance of other people's attitudes and beliefs. As Earle (p. 435)[26] has previously argued, 'sexuality is not seen as an integral part of the lives of disabled people. Disabled people are expected neither to reproduce nor be reproduced.' These attitudes create significant barriers to sexuality and relationships and form part of the sex negativity that can surround disabled people; sex negativity refers to the idea that sex is harmful, shameful or disgusting.[27]

Participants discussed the importance of realising their sexual rights and the tools that they needed to accomplish this. These included appropriate and life-long sex education and enabling environments that afforded privacy and safety. The literature suggests that talking about sex and relationships can often be difficult [7-9] and that disabled people are less likely to have received adequate sex education in comparison to their non-disabled peers.[28]

We acknowledge that there are some limitations to the study. The views of 16 people are represented and there is scope for a larger and more comprehensive project in the future. The findings of the study are thus not statistically generalisable although they are, arguably theoretically generalisable.[29] Of the 16 participants, eleven participants were male. It was harder to recruit women to participate in this study. We recognise that the views of women may be underrepresented although epidemiological research suggests that the overall prevalence of LLTCs in the UK is higher in the male population.[1] The views of people with cognitive impairments are also not represented here and there is scope to include them in future research. All of the participants identified as heterosexual and cisgender, this was not planned but future research should aim to include individuals who identify as LGBTQ+. It is also worth noting that carers and staff members attended some of the focus groups and their presence may have impacted on methodological rigour. It may, for example, have prevented some participants from discussing issues specifically related to their carers or to staff. However, in many instances we

noted that carers and members of staff – who knew the participants well – were very encouraging and prompted participants to talk about some difficult issues which may not have been raised otherwise. We did not plan to include carers and staff, but we did not want to exclude participants who could not take part without their assistance and support. To reduce methodological bias in the future, other research projects could consider other ways of supporting participants that do not rely on carers or staff known to them.

The data highlight a number of important implications for policy and practice. First, the data show that sex, intimacy and relationships are important issues for young adults with LLTCs; this needs to be recognised by all professional groups who work with this group, in addition to parents, carers and other family members. Second, the data highlight that people with LLTCs were expected to die young but are now reaching adulthood and beyond but that their requirements for adequate sex education, information and support are not yet being met. Service providers, commissioners and other organisations thus need to ensure that age-appropriate education, support and information is available to people with LLTCs from childhood and throughout the life course. Finally, the data highlight that people with LLTCs face a number of barriers that prevent them from realising their sexual rights. Practitioners require further training and development to raise awareness of the needs of people with LLTCs which highlights the importance of providing access to information and privacy. Moreover, training and development should also seek to counter the attitudinal barriers which infantilise and discount the sexual rights of people with LLTCs.

In conclusion, this paper highlights that although sex and relationships is considered important in the lives of people with LLTCs and a key marker of reaching adulthood, the opportunity to explore their sexuality is constrained by a number of significant barriers.

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COMPETING INTERESTS

There are no competing interests for any author.

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