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# *It's bittersweet, it's uncomfortable, yes, but it's necessary.* Methodological reflections on the experiences of young adults with life-shortening conditions on being involved in inclusive qualitative research

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Research in palliative care is regarded as ethically challenging although there is increasing recognition that such research is important. Young adults with life-shortening conditions were not expected to reach adulthood but this population is growing and there is limited research that focuses on their lives or their experiences of engaging in research. The study explored the unintended consequences of pandemic control measures on the lives of young adults living with life-shortening conditions in the United Kingdom. This paper focuses on some of the methodological issues arising from this study, drawing on data that explores participants' experiences of taking part. This is an interpretivist and inclusive qualitative study co-produced with three experts by experience using constructivist Grounded Theory method conducted during the first wave of the Coronavirus pandemic. In-depth interviews using a topic guide were transcribed *verbatim* and analysed iteratively until the point of data saturation. Twenty-six young adults aged 22–40 (17 female; 9 male), reporting a wide range of life-limiting and/or life-threatening conditions including rare and undiagnosed conditions and co-morbidities. Through analysis we identify four key themes focusing on participants' experiences of taking part in the research: helping others and influencing change; reciprocity and support; therapeutic value; and (in)visibility and legacy. This paper offers methodological reflections on research in palliative care drawing on qualitative co-produced research involving young adults with life-shortening conditions. Our findings indicate that although participating in research can feel uncomfortable, this is outweighed by the perceived benefits of contributing to research.

**Keywords:** Chronic conditions, Grounded theory, Interview, Methodology, Palliative care, Research ethics, Terminally ill, Young adult

## Introduction

Research in palliative care is often regarded as challenging 'due to the vulnerability of the population and other peculiarities'.<sup>1,p.75</sup> These peculiarities include overzealous gatekeeping as well as wide-ranging practical and ethical issues such as difficulties with gaining informed consent and the perceived burden, or potential harm, of research.<sup>2,3</sup> Research within this field is considered sensitive and more difficult than other types of research.<sup>4,5</sup>

Van der Steen et al.<sup>6,p.5</sup> challenge assumptions that those who are dying or receiving palliative care are universally 'vulnerable' and that research on these populations is 'improper and unethical'. They also argue that greater attention be paid to methodology; the cornerstone of rigorous evidence-based practice. In this paper, we draw on data from a research study<sup>7</sup> that explored the unintended consequences of pandemic control on the experiences of young adults with life-shortening conditions during the first wave of the Coronavirus (COVID-19) pandemic in the United Kingdom (UK).

Young adults with life-shortening conditions were typically not expected to live but due to advances in

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medical treatment and care they are now living longer.<sup>8,9</sup> It is an extremely heterogenous group including those with conditions that are life-limiting and where there is no reasonable hope of cure (e.g. Duchenne muscular dystrophy) or life-threatening, where curative treatment may exist, but could fail (e.g. cancer).<sup>10</sup> This population is growing<sup>11,12</sup> but there is relatively limited research on their experiences or their views of being involved in research. This paper offers methodological reflections on the experiences of young adults on being interviewed during a time of crisis. It draws principally on some of the questions asked toward the end of each interview which enabled participants to reflect on their involvement in research.

## Method

### Design

This paper is based on a qualitative research study co-produced by a multi-disciplinary team that included: three 'experts by experience' (young adults with a life-shortening condition; 2 female; 1 gender non-binary), seven female academic researchers (four of whom had practice experience) and a policy expert. It is part of a larger study including family members but whose data are not reported here. Drawing on an interpretive philosophical framework<sup>13</sup> the study is informed by constructivist Grounded Theory Methodology (cGTM) which assumes that data are generated through reflexive co-creation.<sup>14,15</sup> We have followed the consolidated criteria for reporting qualitative studies (COREQ) guidelines.<sup>16</sup>

### Participants

The participants included young adults aged 18–40 years with a life-shortening condition living in the UK.

### Sampling and recruitment

In accordance with cGTM, purposive and theoretical sampling<sup>17</sup> were used in participant recruitment (between June–December 2020) using inclusion/exclusion criteria (Table 1). Methods included advertising in the newsletters of the study's partner organisations

**Table 1** Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Aged 18–40 years	< 18 or > 40 years of age
Have a life-shortening condition	Did not have a life-shortening condition
Able to communicate in English	Not able to communicate in English
Able to give consent to participate	Not able to give consent to participate
Able to participate remotely	Not able to participate remotely
Agree to be audio-recorded	Not agree to be audio-recorded
Living in the UK	Not living in the UK

(*Hospice UK, International Children's Palliative Care Network and Together for Short Lives*), social media and the professional, academic, and social networks of the research team.

### Data generation and analysis

Data were generated using in-depth interviews<sup>18</sup> informed by a topic guide (see Table 2).<sup>14,18</sup> Online interviews were held between July and December 2020; they were audio-recorded and transcribed verbatim. Four participants were interviewed with a parent or sibling (who also participated in the research). Two participants, who were not able to communicate orally, participated in an 'email interview'.<sup>19</sup> Length of interviews varied between 59 and 75 minutes and some participants were interviewed twice to allow for their health needs.

**Table 2** Interview topic guide

At start of interview	introductions; purpose of research; format and approach to interview; recap on consent process; opportunity for interviewee to ask questions before interview start
About the interviewee	basic demographic information, everyday life before lockdown; impact of condition; typical care and support needs
Experiences of lockdown and shielding	shielding decisions; government guidance; risk taking; change from everyday life
Coping with feelings	overall emotional wellbeing during lockdown and shielding; managing emotions; support with emotions; supporting others emotionally; changes to emotional wellbeing
Health and care needs	experiences of COVID including testing, avoiding or acquiring virus; managing health care needs (e.g. health advice, appointments, medication and, equipment); managing care needs (e.g. role of carers, agencies and, family); managing illness; changes to health and/or social care needs during lockdown and shielding
Feelings of safety and vulnerability	keeping safe/keeping others safe; managing risks; support needs; clinical vulnerability (receiving shielding letter); vulnerability and disability; self-identity; changes to self or behaviours.
Issues of death, dying and bereavement	impact of COVID on end-of-life planning; advance care planning and COVID; funerals and bereavement; dealing with grief; changes to plans or ideas about death, dying and bereavement
Everyday life	impact of COVID on other aspects of everyday life not already addressed (e.g. work, hobbies and shopping); living arrangements; staying in touch with others; role of technologies; changes (if any) during lockdown and shielding
Relationships	impact of COVID on intimate or romantic relationships; impact on other significant relationships (e.g. friendships, family relations, colleagues)
At close of interview	looking back/looking forward; experience of interview; opportunity for interviewee to raise other issues; project next steps.

Six members of the study team took part in interviewing; four of the researchers (SE, MB, HM, LOD), one of whom had a policy and practice background, and two of the experts by experience (LW, SW). Interviewers sometimes worked in pairs either because they were not experienced researchers (the experts by experience) or had not previously carried out research with this population group (two of the four academic researchers).

Data were analysed inductively using the constant comparative method by all team members<sup>20</sup>; data analysis and theoretical sampling were carried out iteratively using line-by-line coding and memoing with the assistance of QSR NVivo 12. Coding was further analysed to generate themes, and some form the basis of this paper. Although it is sometimes difficult to determine when theoretical saturation has been reached<sup>21</sup> we stopped interviewing when key themes were saturated.

### Ethical issues and informed consent

Approval for the study was given by The Open University Human Research Ethics Committee (#EARLE3595, June 2020). Participants completed an online consent form prior to participation and verbal consent was taken informally during the interview, in acknowledgement that informed consent is constantly negotiated.<sup>22</sup> All participants were followed up by email within 24 hours post-interview and sent supportive information. Culturally appropriate pseudonyms have been used to protect participant anonymity. Participants were offered an honorarium (£40 gift voucher) as a thanks for their time.

## Findings

Twenty-six young adults aged 22–40 years were recruited to the study. Participants reported a wide

**Table 3** Characteristics of research participants

	Participants (n = 26)
<i>Age (years)</i>	
<25	6
25–29	9
30–35	5
36–40	6
<i>Sex/Gender</i>	
Female	17
Male	9
<i>Ethnicity</i>	
White British/White Other	18
British Asian	3
Black British	2
Mixed Race	2
Latin American	1
<i>Location</i>	
England	21
Scotland	2
Wales	2
N. Ireland	1

range of life-shortening conditions including autoimmune disorders, cancers, fatal respiratory disorders, multiple organ failure, neurodegenerative conditions, genetic conditions of the connective tissues or bones, and undiagnosed complex diseases known to be progressive and assumed fatal. Some participants reported very rare conditions or multiple co-morbidities. Table 3 describes their main demographic characteristics.

Four main themes were identified which address participants' experiences of being interviewed: (i) helping others and influencing change; (ii) reciprocity and support (iii) therapeutic value; and (iv) (in)visibility and legacy. Table 4 provides an illustrative example of analysis.

### Helping others and influencing change

Participants fundamentally believed that the study was worthwhile; they often described the research as *a good thing* and said that it was *important*. Wanting to help others was frequently cited as a reason for agreeing to be interviewed.

I want to help other people . . . . Thank you for picking me for this because I really do like helping people. (Aesha)

For some participants, taking part in the interview process appeared to be *really enjoyable* and *easy*. Of course, this was not the case for everyone and even those who found the interviews mostly enjoyable found some questions difficult.

Taking part in the interviews was sometimes described as *challenging* or *uncomfortable* but participants placed this discomfort into context by saying that it was *worth it* if they were able to help others by sharing their experiences. Indeed, they frequently thanked the interviewer for inviting them to take part in the study and often expressed gratitude for the opportunity. Some of the participants voiced surprise when they were told they would receive a small honorarium and usually said there was *no need* and *would have done it for free*.

Participants also acknowledged an understanding of the role of research in influencing future change,

**Table 4** Illustration of relationship between coding and themes (therapeutic value)

Examples of initial codes	Focused codes	Theme
going crazy	Emotion	Therapeutic value
hiding feelings	management	
just getting on	Respecting	Validating feelings
managing emotions	boundaries	
opening up	Validating feelings	
opportunities to talk		
upsetting others		

and how taking part in research could contribute to this.

... I just think it's a good thing, and I think hopefully there'll be something of value that comes out of it, and maybe it'll influence some change down the line. (Bashir)

Several participants expressed an interest in whether we were recruiting successfully to the study. Some participants then went on to pass on our details to other people known to them so that they, too, could participate in the research.

Overall, participants regarded the research study as worthy, important, and vital, and they wanted to be a part of it by sharing their views and experiences. Participants were also motivated by a strong sense of altruism; they wanted to help others and influence change through their contributions to research.

### *Reciprocity and support*

Helping others was an important reason for getting involved in the research, but sometimes participants acknowledged reciprocal benefit too. That is, while they had originally agreed to be interviewed to help with the research, towards the end of the interview process they sometimes reflected on its personal value.

... although I'm doing this for the research I'm learning something about myself. So it's not only benefiting the project, but it's benefiting me as a person. (Megan)

Some of the research questions also prompted participants to think about practical solutions to pandemic-related problems and uncertainties. These included matters such as timely access to vital medications, the threat of acquiring the virus and dealing with COVID-related travel restrictions. Participants described how the interviews had *made them think* and *opened their eyes*.

Some of the interviews were very conversational, especially when questions were being asked by the experts with experience or the interviewer with a practice background. Occasionally this meant that the interviewer offered suggestions on how to deal with a prevailing situation or problem. This tended to happen when the interviewer had either personal experience of the issue or was concerned about the welfare of the participant and felt that they should offer support.

Your suggestions about respite, hospice care ... .  
I wouldn't have necessarily had that bravery, but I found it really useful. (Jasmine)

Participants often thanked the interviewers for their support and said they felt *appreciative* of any suggestions.

Reciprocity was an unanticipated but welcome benefit of taking part in the research. Research questions sometimes provided an opportunity for further pandemic preparedness, and, in some circumstances, participants received more direct support that focused on solving immediate practical issues.

### *Therapeutic value*

Taking part in the research study seemed to offer some participants therapeutic benefits, particularly when it gave them the opportunity to talk about difficult subjects. A participant describes how his experiences of lockdown and shielding led him to attempt suicide. At the time of interview, the participant had only shared this with one other person:

It was hard to admit that I thought about doing myself in. ... my mum's got her own mental health issues and I don't want to add to what she's got to deal with ... And my dad just doesn't understand any of it. (Sammy)

It was very common for participants to protect family members by not discussing difficult topics with them. Respecting other people's boundaries was also discussed as a reason for curtailing opportunities for sharing feelings. Discussing end-of-life was a particularly difficult subject to raise within the family, especially with parents.

*My mum finds it quite hard to talk about [end-of-life], so sometimes we'll have a conversation, and my mum will go, 'no can we talk about it another day?' (Megan)*

In some interviews, participants spoke about *just getting on with things*. This referred to getting on with living, trying not to dwell on difficult feelings or situations and not thinking about death. However, participants acknowledged that talking about issues they would normally avoid was no *bad thing* and that it sometimes *needed to be done*. Participating in the interview process could also sometimes offer a fresh perspective, enabling participants to *think differently*.

In some instances, taking part in the research also served to validate participants' feelings and experiences. It allowed them to place their worries into a wider context, and this appeared to have some therapeutic value, as the following exchange highlights:

You obviously can't tell me what other people have been saying but is it similar to what I've been saying? That other people have been worrying about? Making sure I'm not going crazy! (laughs)

(Interviewer) You're not going crazy. (Willow)

A minority of participants spoke about being in therapy or receiving counselling prior to the pandemic, and about their lack of access to talking therapies during lockdown. They sometimes directly likened their experience of being interviewed with their experience of therapy, describing the interview as an opportunity to *open up*, which made them *feel better*.

Taking part in the interview process gave respondents the opportunity to talk about sensitive issues they seldom discussed, only discussed superficially or avoided.

### *(In)Visibility and legacy*

Most research participants spoke about their feelings of invisibility and abandonment during the pandemic. In some instances, participants felt let down by their friends but, mostly, this sense of abandonment was derived from the belief in a pejorative public discourse that positioned the clinically vulnerable as dispensable. Taking part in the research meant that participants felt less invisible.

The Prime Minister didn't even mention the shielded community in any of his speeches! After the first couple, we were forgotten about. Who cares about them?! They're probably all dying off anyway! ... It's nice this is happening [the interview] and I hope people are going to read it ... (Willow)

Some participants had participated in other research studies or similar activities previously and expressed a commitment to continue doing so as long as possible, if it meant that their needs and priorities could be more visible to others. For example:

If I can be of any help answering questionnaires or doing interviews ... then I'll keep doing them, because I think it's important to get as much out there in the community and in the world. (Kellie)

As already highlighted, being interviewed was not always easy; some participants felt that the process was uncomfortable. However, participants accepted that momentary discomfort was necessary if it meant leaving a legacy after death.

I would say it's bittersweet ... It's uncomfortable, yes, but it's necessary ... at the end of the day that is all I can do with my life. I can try and make sure that when I do leave this world things are a little bit better for the next generation. (Chrissie)

For some of the participants, taking part in the research meant that they were able to be seen at a time when, literally and figuratively, they were hidden from sight while in lockdown and shielding.

Although taking part was not always easy for everyone, contributing to the research was seen as doing something worthwhile which would endure posthumously.

### Discussion

This paper offers insights into the experiences of young adults with life-shortening conditions on being interviewed at a time of global crisis and uncertainty. The findings indicate that participants were strongly motivated by wanting to help others and influence change, even at a time when they were experiencing feelings of deep unease or distress. This supports the conclusions of previous research which highlight how altruism is a common theme in the views of palliative care patients towards research.<sup>1,23,24</sup> Indeed, others have suggested that there is 'untapped altruism'<sup>25,p.759</sup> within the palliative care population but that there is a disconnect between people's willingness to take part in research, and the views of gatekeepers.

The role of patient and public involvement in palliative care research is increasingly recognised<sup>26</sup> and considered a prerequisite for high-quality health and social care research in the UK.<sup>27</sup> Our research was undertaken by a multi-disciplinary team which included policy and practice experts, and experts by experience. Our findings highlight how participants benefited from self-reflection, reciprocity and support, opportunities that were afforded by our methodological approach and the inclusive nature of the team. Indeed, the orientation of research teams has been shown to have an important role in participants' experiences of research.<sup>28</sup>

There is considerable literature on the emotional burden to palliative care patients on taking part in research and the ethical challenges of including them.<sup>29</sup> However, evidence increasingly suggests that this burden is over-estimated<sup>30</sup> and researchers point to the right for people's suffering to contribute to research.<sup>1</sup> The participants in our study felt that the interview process gave them the chance to talk and reflect on emotional issues. While we do not argue that research is therapy, there is a body of literature that deconstructs this notion, highlighting the therapeutic benefits of research participation.<sup>31</sup>

It is recognised that children, young people and adults with life-shortening conditions experience considerable isolation and loneliness<sup>32</sup> and several studies have highlighted the 'hidden lives' of families who care for children and young people with a life-shortening condition.<sup>33,34</sup> Scholars have also drawn attention to the phenomenon of social death – a process whereby society turns away from those who are ill and dying.<sup>2,35,36</sup> As the findings of our study show, taking part in research can be a way of resisting

social death through increased visibility, even at a time of acute isolation. Legacy-making – which has received considerable attention in palliative care<sup>37–39</sup> – was also considered important by some participants and this was also part of their interview experience.

### Strengths and limitations

This research study has generated rich data on an under-researched topic and, to our knowledge, is the only in-depth UK study of the experiences of young adults with life-shortening conditions during the pandemic. At a time of global crisis and uncertainty, we brought together a committed multi-disciplinary team to bear witness to the experiences of 26 participants, many of whom were isolated, anxious or fearful, but enthusiastic about making a difference through their involvement. However, all studies have strengths and limitations. For example, we sought to include a diversity of participants, but they were predominantly white, and female.

The multi-disciplinarity of the team strengthened the research; the involvement of experts by experience particularly enhanced people's willingness to take part in the research and enabled successful recruitment. However, the heterogeneity of the team led to differences between interviews and, potentially, to experiences of being interviewed. A positivist framing – which places high value on 'objectivity' and standardisation – would automatically regard these differences as problematic.<sup>40</sup> Of course, this is at odds with our interpretivist approach,<sup>13</sup> and the use of cGTM, which recognises the co-creation of research<sup>15,18</sup> and the values of subjectivity and reflexivity.

The data for this paper were generated by asking participants to talk about their experience of taking part in the research. Participants may have censored their responses to please the interviewer, and this bias has been discussed elsewhere.<sup>29</sup> That said, while some participants described being interviewed as *easy* or *enjoyable*, others admitted that parts of the interview were *difficult*, *hard going* or *uncomfortable*, reflecting a diversity of experiences.

Data generated through grounded theory research is situational and this is a potential limitation of this paper. However, as proponents of grounded theory we argue that the opposite is true and that cGT studies provide richly-contextual original findings that are credible, resonant and – most importantly – transferable to other similar research problems or fields.<sup>41</sup>

### Conclusion

This research highlights the wide-ranging potential benefits of being involved in ethically challenging research, even for participants typically labelled as

vulnerable. Our findings offer useful insights for gatekeepers and other researchers.

### Implications for future research

Aside from the ethical approvals process, we did not rely on gatekeepers to carry out our research, but gatekeeping has been identified as an important barrier to palliative care research.<sup>1–3,30</sup> The benefit of participating in research should be recognised by those in gatekeeping roles so that those who are dying or receiving palliative care are not denied the opportunity to participate.

Previous researchers have avoided the potential of reciprocity within research.<sup>42</sup> However, they may want to consider its potential more carefully, critically exploring the value of multi-disciplinary research teams – including the role of experts by experience – in creating a reciprocally meaningful research experience for participants. As others have highlighted, while standard approaches to research are necessary, it is important to consider how innovative approaches can contribute to effectiveness and inclusion.<sup>4</sup>

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### Data sharing

Data can be obtained from the lead author on request.

### Disclaimer statements

**Contributors** All authors made substantial contributions to the conception and design of the study, including securing ethical approval. Participant recruitment was supported by SE, MB, LC, KF, JH, HM, LW and SW. Data were generated by SE, MB, HM, LO, LW and SW. Data analysis was led by SE with input from all authors. The manuscript was drafted by SE and was revised for important intellectual content by MB, JD, KF, HM and LO. All authors approved the final manuscript.

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**Ethics approval** Ethical approval to conduct the study was secured. Participants provided informed written consent prior to participation in the study.

### Notes on contributors

**Professor Sarah Earle** is a medical sociologist with a qualitative research background and extensive experience of in-depth interviewing and focus

groups, grounded theory methods, thematic analysis and narrative synthesis. Her particular areas of expertise are: inclusive research with groups often labelled as vulnerable and/or marginalised, and research in fields that are considered sensitive or taboo. She has worked inclusively on research with young people and adults with life-limiting and life-threatening conditions.

**Dr Maddie Blackburn** is a (semi-retired) qualified lawyer, senior health professional, clinician and lecturer with extensive background in policy development, research, management, law, and performance auditing and inspection. Her particular expertise includes academic, policy research and management related to young people with life-limiting and/or life-threatening conditions, high level reviews and regulatory inspections of health, social care and youth offending institutions and health care law and ethics.

**Lizzie Chambers** is Director of Programmes and Professional engagement for the national charity Together for Short Lives. Lizzie leads their work with professionals, supporting the sharing of good practice and supporting the development of research in the children's palliative care sector. She has worked in the sector for over 20 years and has written a number of key resources such as the Guide to the Development of Children's Palliative Care Services and the series of Care Pathways.

**Professor Julia Downing** is an experienced palliative care nurse, educationalist and researcher. She has extensive experience in global palliative care, research and education, and is on the editorial board of *ecancer*, *APM* and the *IJPN*. She has both a qualitative and quantitative research background, with extensive experience of in-depth interviewing, focus group discussions, thematic analysis, statistics, tool development and working with children. Her particular area of research expertise is palliative care, health systems strengthening, and research with children and young people with life-limiting or life-threatening conditions.

**Professor Kate Flemming** is a highly experienced academic, internationally known for her leading research and service innovation in palliative care nursing. Kate's research programme focuses on complex interventions including patient and carer experience of palliative care across different service models, disease types and morbidities, including motor neurone disease. This work is closely integrated with her methodological expertise in qualitative evidence synthesis.

**James Hale** is a policy expert focusing on health policy and disabled people, with research experience in small group interviews (leading focus groups during development of Equality Act 2010), surveys

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**Dr Hannah Marston** is a societal technologist with mixed methods expertise. Her areas of expertise include: Digital Games, Gamification, e-Health, Mobile Health Apps. She is particularly experienced in gerontology, societal and health research. She has led several journal special issues, edited a book and is currently writing a book focusing on the impact of technology on different societal cohorts with colleagues from Ireland, UK and Age Northern Ireland.

**Professor Lindsay O'Dell** is an applied developmental psychologist with expertise in qualitative research methods. Her research has focused on children, young people and families who are seen to be, or who see themselves, as in some way 'different'. This has included young carers and language brokers; children with disabilities including autism, ADHD and neurological difference more broadly; children with health conditions including sickle cell anaemia and facial disfigurement.

**Dr Valerie Sinason** is a (semi-retired) Consultant Child Psychotherapist and Adult Psychoanalyst, qualified secondary school teacher, national and international teacher, lecturer and supervisor and prolific writer with over 200 published papers and chapter and 17 solo or co-edited books. She is an international clinical research expert on intellectual disability, abuse and trauma.

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