Hear my voice: a community-based participatory study gathering the lived experiences of people with disabilities and older people in Tanzania

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This study provides evidence on the specific nature and experiences of people with disabilities and older people from their own perspectives in rural and urban settings in Tanzania. Its aim was to better inform efforts to provide services for and improve the lives of people living in those regions. A community-based participatory approach was used, involving collaboration with the community. Peer researchers and research partners collected and analysed interviews with people with disabilities and older people, leading to policy and advocacy recommendations and early stage plans. Findings were framed in terms of experiences of participation and inclusion as impacted by physical, social and attitudinal factors, as well presented at individual, interpersonal and societal levels. They demonstrate how lack of access to healthcare and education, social limitations and powerful community attitudes were interwoven and exacerbated poverty in these contexts. Policy recommendations cover issues such as halting persecution and killings of people with albinism, support and guidance for families of children with disabilities, national policy on ageing legislation, and implementing and monitoring the UN Convention on the Rights of Persons with Disabilities.

Keywords: disability; older people; community-based participatory research; Tanzania; policy; albinism; UN Convention on the Rights of Persons with Disabilities; Sightsavers

Introduction

Sightsavers is a UK-based international non-governmental organisation (NGO) that works in more than 30 countries to eliminate avoidable blindness and support people with visual impairments to live independently. Sightsavers works with partners in developing countries to treat and prevent avoidable blindness, and promote equality for people with visual impairments and other disabilities. It is based in Haywards Heath, with branches in Sweden, Norway, India, Italy, Ireland, the United Arab Emirates, and the USA. In its 66 year history, Sightsavers has distributed treatment to protect more than 295 million people against river blindness (onchocerciasis), carried out 6.1 million sight-restoring cataract operations and

treated 43 million people with antibiotics to combat the potentially blinding infection trachoma (Sightsavers 2016). High quality research is considered as critical for the successful delivery of its strategy and programmes. Gathering and disseminating sound research evidence ensures that programmes are demonstrating scalable and cost-effective approaches that are meeting the needs of the people they are designed to serve. Research evidence is also a strong tool for advocating with governments and policy makers for improved policies and environments that lead to elimination of avoidable visual impairment and allow people with disabilities equal opportunities for participation within society (Sightsavers 2016).

In 2015, Sightsavers began a one-year research study gathering stories on the lived experiences of people with disabilities and older people in Tanzania. It was a collaboration led by its policy and research teams, partnering with the Ifakara Health Institute in Dar es Salaam, ADD International, HelpAge International and a team of peer researchers, most of whom were people with disabilities and older people. Its aim was to better inform efforts to provide services for and improve the lives of people with disabilities and older people in Tanzania and create a body of evidence that can be drawn upon by stakeholders in Tanzania and beyond. This stemmed from the understanding that strong and inclusive policies, based on evidence formed in collaboration with people with disabilities and older people, enable informed implementation of the 2030 Agenda (UN 2015) and the UN Convention on the Rights of Persons with Disabilities (UN 2006). Community-based participatory research (CBPR) is seen as one collaborative approach for the co-creation of evidence with local people.

This paper seeks to contribute to understanding the lived experiences of people with disabilities and older people in Tanzania, in this case as captured and expressed by them. By presenting the findings and discussion it is also a vehicle for informing efforts to improve their lives. Further, it aims to demonstrate how CBPR can be adopted as a methodology in relation to social inclusion research in the global South. The paper begins by introducing CBPR, its advantages and potential pitfalls. It then describes the research project in detail, explaining ethical principles adhered to, data collection and analysis methods. Findings are presented and a discussion of these follows. Reflections of study design are shared, with the conclusion considering the overall methodology and local, national and global policy and advocacy plans emerging from the study.

Community-based participatory research

CBPR involves respectful collaboration with the community. Its features include non-hierarchical, mutual dialogue and understanding, shared decision-making and ownership, and members of the community being actively involved in planning, data collection, analysis and dissemination (Levine-Rasky 2015; Kemmis & McTaggart 2005). Community members, organisational representatives and researchers contribute expertise within an orientation to

research that recognises the unique strengths that each brings. CBPR has a critical and emancipatory nature that seeks to break down social injustice and the structural constraints that produce inequities of power (Levine-Rasky 2015). It demands a rethinking of positionality, with vigilance towards one's own power (Pain, Kindon, & Kesby 2007). The overall aim of CBPR is to increase knowledge and understanding of the situation being studied together, to construct meaning together and integrate this with interventions and policy change to improve the quality of life for the community.

There are numerous advantages of adopting a CBPR approach (CSJCA & NCCPE 2012; McDonald & Stack 2016). The Centre for Social Justice and Community Action (CSJCA) and National Co-ordinating Centre for Public Engagement (NCCPE) highlight an increase in quality and validity of research, joining partners with diverse expertise to address complex problems, improving intervention design and implementation by facilitating participant recruitment and enhancing the relevance and use of data. It also describes increasing trust and bridging cultural gaps between partners, providing resources for the communities involved, benefiting the community and researchers alike through the knowledge gained and actions taken and the potential to translate research findings to guide the development of further interventions and policy change. Specific to the context of this research, the principles of CBPR fit well with those of disability rights, which emphasise full inclusion and opportunities. People with disabilities and older people can contribute to the research which may itself help nurture equity. Resulting research focuses on topics important to community members and generates increased feelings of respect and trust, thereby promoting greater research participation and more representative knowledge (McDonald & Raymaker 2013). CBPR projects can also serve as an effective model for the inclusion of people with disabilities in science and society (McDonald & Stack 2016).

However, as undertaking CBPR with people with disabilities and older people is innovative, there are few models to build on for the Global South context, though similar disability research in high income countries can be drawn upon (e.g. Walmsley 2004; Nind & Seale 2009; Stalker 1998 focus on the U.K.). Further, previous research focussing on the Global South reported difficulties adhering fully to CBPR principles and challenges in identifying and maintaining accommodations for participants, missed meetings due to transport challenges, and times of uncertainty with roles and responsibilities (McDonald & Stack 2016).

The research project in Tanzania

The 2008 National Disability Survey estimated that 8% of the Tanzanian population is affected by some form of disability and that 20% of people with disabilities encounter barriers when accessing health services (NBS 2008), with disadvantage clearly broader than

this one aspect (Myamba et al. 2015; Njelsani, Couto & Cameron 2011). Some 6% of the Tanzanian population is estimated to be aged 60 years old and above, and this is expected to triple between 2020 and 2050 (United Nations Population Fund (UNFPA) & HelpAge International 2012). As older people experience disproportionate levels of poverty and marginalisation (Burns & Oswald 2014), the government is likely to face increasing pressure to design interventions to reduce poverty among older people (Mboghoina & Osberg 2011). Therefore, understanding the lived experiences of people with disabilities and older people is an important foundation for moving forward. Within this understanding, it is important to note the overlap between disability and older people, as older people can develop some form of disability and people with disabilities age (WHO & World Bank, 2011).

The study provides evidence on the specific nature and experiences of people with disabilities and older people from their own perspectives in the rural setting of Nachingwea and urban setting of Kibaha Urban Municipal Council. Both districts contain projects supported by Sightsavers, HelpAge and ADD International, allowing in-depth understanding from this study to strengthen current and future work. The study design builds on a 2012-13 pilot study in Bangladesh, where Sightsavers, HelpAge International, ADD International and Alzheimer's Disease International worked together with the Institute of Development Studies, University of Sussex, UK, and a group of peer researchers to bring the perspectives of people with disabilities and older people into post-2015 policy making (Burns & Oswald 2014). The study followed the ethical principles recommended for CBPR by the British Centre for Social Justice and Community Action and National Co-ordinating Centre for Public Engagement (CSJCA & NCCPE 2012):

- Mutual respect: for example, being prepared to listen to the voices of others, accepting that there are diverse perspectives;
- Equality and inclusion: for example, seeking actively to include people whose voices are often ignored, challenging discriminatory attitudes and behaviours and ensuring information, venues and formats for meetings are accessible;
- Democratic participation: for example, acknowledging and discussing differences in the status and power of research participants, working towards sharing power more equally, using language everyone can understand;
- Active learning: for example, ensuring time to identify and reflect on learning and sharing responsibility for interpreting the research findings and their implications for practice;
- Making a difference: for example, debating what counts as positive change and building it in as a goal;
- Collective action: for example, agreed visions and goals that meet partners' differing needs for the research and for how to share knowledge and power more equitably;
- Personal integrity: for example, accurate and honest analysis and reporting of research, being open to challenge and change, and prepared to work with conflict.

Although peer researchers actively participated in data collection, analysis, interpretation and identifying priority sectors, they were not actively part of conception and design, as this study was building on learning from a pilot study. The focus was on incorporating research and reflection in order to affect change in the project districts. Funding was not provided to support actions resulting from the study, but there are plans for global and national policy and advocacy work, both within Sightsavers, HelpAge International and ADD International, and by partners based in Tanzania.

Ethical approval for the study was sought from the Ethical Committee of Ifakara Health Institute and National Health Research Ethics Review Sub-Committee (NatHREC) of the Tanzania National Institute for Medical Research (NIMR). A total of 106 interviews were conducted: 76 from people with disabilities and older people, and 30 from Tanzanian non-governmental organisations (NGOs) working with people with disabilities and older people. In terms of location, 36 interviews took place in Nachingwea and 40 in Kibaha Urban Municipal Council, and all 30 NGO interviews were undertaken in Dar es Salaam. There was a fairly even gender ratio (57 male to 49 female) and older-age-to-disability ratio (44:32), with all types of disability represented. Some of those working within NGOs had disabilities as did some older people, which was taken into account in relation to ratios and analysis, hence the initial lower ratio of disability to older age.

Interviews were collected by 29 peer researchers, after training: 19 community members spread evenly from both districts and 10 Tanzanian NGO staff members working in these communities. There was an even gender ratio and older-age-to-disability-ratio in the peer researcher group, partly made so by involving the NGO staff members. The peer researchers were recruited from a range of localities in the study areas to reflect diversity, and care was taken to invite those people with least influence. Partnering organisations made suggestions as to who to approach. Adaptions were made during peer research training, data collection, group analysis and dissemination events for peer researchers with a range of impairments, including using accessible buildings, a sign language interpreter for hearing impairments and large print documents or readers for those with visual impairments.

Interviews were transcribed verbatim and anonymised. Peer researchers were brought together and, with support, asked to identify the main issues in all 106 interviews, why they thought they happened and how they were connected. During the same workshop they were asked to identify priority sectors or categories on which to focus policy and advocacy efforts. This activity drew on their cultural and contextual experience. As this analysis included peer researchers' opinions on what they considered to be main issues, the peer researcher analysis was then triangulated by researchers who coded a selection of interviews from the original 106, asking the research question: *How did participants experience ageing and disability?* A total of 36 interviews were selected for coding to cover a balance of location, gender,

disability and older age. The sample included 10 interviews with key people from NGOs to gain their insight of working locally in the field of disability or older age. A grounded theory approach was adopted, using open, axial and selective coding. The aim was not only to use the Sightsavers research team to code this data, but to use the activity to invite policy, advocacy, programme and evaluation team members from partnering organisations to learn the process of qualitative coding and be immersed in each story through analysis workshops. Had findings from the coding produced very different results than those found by the first analysis, further interviews would have been coded. The findings from this coded analysis were shared with the community members in person for their consideration and in order to bring the two sets of findings together.

Findings

The peer researchers identified eight priority sectors or categories on which to focus policy and advocacy efforts. These priority sectors were identified based on their opinions and experiences of the recurring issues raised in all 106 interviews.

1. Access to education: peer researchers reported that the government has not invested much in this sector, especially for people with disabilities. They explained that this is a key contributing factor as to why families with children with disabilities have kept them at home and not sent them to school. Teachers are not well trained to teach children with disabilities while school infrastructures are not user-friendly. An example that was highlighted from the transcripts was of an eighteen-year-old with a hearing impairment: 'I was bright but started to struggle in class … I left school because I couldn't hear what was being taught.'

2. Access to health services: peer researchers underlined that a lack of medical equipment and supplies at health facilities is among the major challenges faced by the health system in Tanzania. People with National Health Insurance (NHI) cards can pre-pay for their services, but shortage of medicines was a clear problem for study participants. Alongside this, health care providers have not been adequately trained in making their care inclusive – for example, offering sign language to communicate with people with hearing loss.

3. NGO financing and resource constraints: peer researchers highlighted that NGOs budgets depend mostly on donor support and limited funding from the government. They drew on interview data such as lacking equipment to provide to members, learning materials relevant to schools and permanent offices. Unsurprisingly, during interviews NGOs reported needing greater financial resources when supporting people with disabilities and older people. One NGO reported a loss of premises: 'We had our own buildings at Sinza which were built by donors for us, but the government took them from us.'

4. Poverty relating to income and dependence: they highlighted that many older participants and those with disabilities described limited support from the both the government and the community. There was little opportunity available for income generating activities. As a result, some participants worried: 'When I look ahead, I can't sleep during at night…I can see that I'll face difficulties later because I have no savings in the bank and little pension. It's painful as I'm supposed to get treatment at the referral hospital but I can't afford it.' (Older person, Nachingwea.)

5. Attitudes towards witchcraft and albinism: they explained that organs and limbs of people with albinism are used in witchcraft activities, often sold in goldmines and outside the country.

6. Relationship difficulties and marriage breakdowns: the peer researchers highlighted relationship difficulties within the transcripts through examples such as parents deciding who they would marry and others' apathy and aggression in relation to disability.

7. Sexual violence and gender issues: alongside drawing on examples from transcripts, peer researchers discussed a growing understanding that women with disabilities are being sexually exploited, threatened and mistreated. They explained that men who marry women with disabilities are often convinced by their friends to leave them.

8. Poor treatment from family: they cited issues from the transcripts ranging from lack of support to ignoring practical needs, relatives looting participants' properties, abandonment and, for participants with albinism, attempted murder. There were regular stories such as this one told by a 32-year-old deaf participant from Kibaha: 'I stayed at home because they said that a deaf person is like a patient, and shouldn't be engaged in any activity.'

These eight priority sectors or categories were then triangulated by analysing the data from 36 purposively selected interviews using a three-tier coding approach: open, axial and selective coding. At the end of the third stage of coding - selective coding - there were a number of themes or codes that could be grouped and presented in more than one way, depending on the perspective from which they were considered. Therefore, two frameworks were used, to offer multiple perspectives on the emerging data, as described below.

The findings from the three-tier coding process were loosely framed by the International Classification of Functioning, Disability and Health (ICF) (World Health Organization 2001), which is the World Health Organization framework for measuring health and disability at both individual and population levels. This framing of the findings was chosen because it shows participants' experiences of participation and inclusion as impacted by environmental factors: physical, social and attitudinal. Alongside this, the findings from the three-tier coding were also framed in terms of individual, interpersonal and societal experiences in order to

make connections between small and large scale community barriers and impacts. Together, these two lenses through which to consider and present the findings offer a three-dimensional view of the findings, without fixing them from one perspective. It is worth noting that the sharp delineation between individual, interpersonal and societal had its limitations. However helpful both frameworks were in offering lenses through which to see the findings, it remains that the domains within any framework are artificial, in a constant state of flux and overlap.

Within the ICF physical domain, both people with disabilities and older people experienced multiple illnesses, sometimes causing or exacerbating each other. They also described details of their impairments or the effects on their bodies due to older age. Transport issues were raised and injuries from domestic abuse described. Both demographics of participants also described the physical effect of the lack of available medication or ability to afford it.

In the ICF social domain, participants described a high exposure to death due to age or illness. Exclusion from social and religious activities was common due to physical impairment but also due to others' attitudes. Some participants in each demographic cited a lack of young people to help practically, though these were mainly older people. Many also had one-off positive stories of community support. Various barriers to accessing human rights were raised, particularly in relation to health systems, but also relating to access to toilets and privacy once there for those with disabilities. Stories of good access to health systems often showed NGOs as instrumental. Access to school might have been available to participants with disabilities but learning was limited due to lack of resources and training and so participation often ceased. This had a knock-on effect on work opportunities, with work places also creating their own limitations.

In the ICF attitudinal domain, complexities surrounding domestic abuse emerged, as did extreme persecution of people with albinism. Specific to albinism, two killing attempts were cited, along with others' fear and rejection of albinism, and general discrimination. One participant with albinism expressed that '…it is better for somebody to kill you than to cut off your body parts because you will become even poorer. We are already poor; when you lose your limbs you will end up in extreme poverty and you know your parents then can't work.' More generally, people with disabilities often experienced mistrust in their capacity and resentment from those helping them when help was required. One participant with disabilities was hindered from progressing in politics due to others' attitudes, and a significant number of participants from both demographics spoke about being overlooked; it felt as if they were being made invisible. Older people expressed experiencing neglect. There were several examples of self-empowerment and help-seeking behaviour, showing a strong sense of value. One person with disabilities self-identified as 'a one-person army'. Bad experiences led a few people with disabilities to forge an independent life and find their own value. Families and spouses' attitudes led to breakdowns in relationships for people with disabilities, but there

were a few stories revealing a strong and positive marital experience, often in spite of community opposition.

Through the second chosen framework, experiences at an individual level (and with significant crossover to physical experiences in the previous framework) included: having multiple illnesses, sometimes with one instigating another; negative self-perception; stress; a high exposure to death, be it due to old age or because of a health complication leading from a disability; and sharing emotional memories of being young. The emotions expressed during interviews that were linked to these experiences – feeling overwhelmed, hopeless, fearful, joyful and insecure – had not been seen by peer researchers as important evidence when considering priorities for action. Interviewees, although able express their feelings, also seemed to not expect them to be prioritised by others based on their interview comments.

Experiences at an interpersonal level included: stories of domestic abuse and sexual fear; being respected for their skills; receiving assistance from the church, mosque and neighbours; receiving support from police, work place, peers and family; enjoying good relationships with neighbours; being prevented from joining social activities; being taunted, when young, about a parent's disability; exclusion from religious activities; old age being viewed as a sickness; and fear of persecution and violence relating to albinism. Another experience recounted by several interviewees involved arranged marriages or sexual activity by persons with disabilities. An NGO interviewee described one such incident: 'We met a girl with disabilities living comfortably with her parents in the village. But what we learnt whilst visiting her was that, although the girl could have chosen a fiancée, the parents informed her that they would bring an older man to take care of her sexual desire.' Again the emotions that resulted from these and other interpersonal experiences were often glossed over by interviewees and not highlighted in peer researcher discussions.

At a societal level, interviewees described experiences including political barriers, education discrimination, lack of work opportunities or appropriate transport, and opportunities and barriers to access to healthcare and support from social services. The interviewees working for NGOs cited numerous financing and resource constraints as impediments to effectively address these issues. One older participant explained: 'Older people are not well treated. The government says that the treatment of older people, children and pregnant women is free of charge but this is not the case. If you go to the hospital, the doctor tells you that your prescribed drugs are not available. You can go and purchase the drugs in the drug shop…this is unjust…and it pains me.' Participants seemed to find talking about their experiences at a societal level easy, and (to some extent) share feelings about. These experiences relating to society as a whole were generally viewed by peer researchers in their analyses as more important evidence than individual experiences.

Central to the findings framed by both lenses was that participants' experiences, whether physical, social or attitudinal, individual, interpersonal or societal, often worsened their levels of poverty, which in turn worsened their experiences. This led to a cycle that was difficult to break. For the participants and those in their lives, relationships to and experiences of traditional African medicine tended to influence this cycle. The World Health Organisation (WHO) defines traditional medicine as 'the sum total of the knowledge, skills, and practices based on the theories, beliefs, and experiences indigenous to different cultures, whether explicable or not, used in the maintenance of health as well as in the prevention, diagnosis, improvement or treatment of physical and mental illness' (as quoted in Abdullah, 2011), with traditional African medicine specifically reflecting African history and culture (Abdullah, 2011). Engagement with traditional African medicine influenced all three ICF domains and the individual, interpersonal and societal experiences, both positively in terms of receiving a holistic approach, and negatively in a variety of ways. Examples of negative experiences were recounted by interviewees with albinism, whose body parts are believed to transmit magical powers and are ingredients in rituals and medicine created by witch doctors, leaving them at great risk. This issue was not often acknowledged by others, as witchcraft is still a taboo subject to be discussed in communities. Other interviewees reported worsening symptoms after families administered traditional African medicine to them or mistrusted and avoided traditional Western biomedical health services.

Discussion

By exploring different dimensions of the lives of people with disabilities and older people in Tanzania, the study has helped to improve understanding of how and why it is difficult for these groups to break free from experiences that worsen their poverty, which in turn worsens their experiences. Issues around NGO service delivery, poverty, income, dependence, witchcraft, albinism, family difficulties, marriage break ups, sexual violence, gender, access to education and health, as well as poor treatment from family, permeate these 106 stories of empowerment, despair and hope. The constraints experienced by participants cut across sectors, though the health sector features heavily. Consistent with other studies in resource-poor settings (United Republic of Tanzania 2004), findings suggest that people with disabilities and older people have a number of challenges related to poverty, income and dependence which in turn add to the problem of health care access.

In terms of health, the government through the Prime Minister's Office – Regional Administrative and Local Government (PMO – RALG) has also mandated that people with disabilities and older people be exempt from fees at any government health facilities. The reality from the participants' stories, however, is that people with disabilities and older people are asked to pay for services such as consultation fees and medicines. The implementation of

this mandate will require advocacy to introduce legislation as a way of enforcement, so that people with disabilities and older people can benefit from free health services.

Lack of employment is a clear challenge for people with disabilities (Yeo and Moore 2003; Wan 2003; Mitra et al. 2013). The National Employment Policy (United Republic of Tanzania 2008) states that the government and associations of people with disabilities, in collaboration with other stakeholders, must undertake affirmative action to enhance employability of people with disabilities , yet the implementation of the policy has been extremely slow, if not completely stalled. During the participatory analysis workshop, peer researchers observed that older people are not involved in the different social development issues in their respective localities. The implication is that their expertise is not readily utilised in government-related activities at the village level regardless of the post they may have served in prior to retiring from government service.

Findings related to education revealed significant barriers for children with disabilities to access quality education. Participants' stories indicate that many families of children with disabilities have not paid serious attention to their education. Moreover, a significant proportion of teachers are not well trained to teach children with disabilities, and this is further complicated by poor school infrastructure to support children with disabilities. For instance, one participant with visual impairment recalled, 'When I was in primary school, I would tell the teacher that I can't see. I would ask "Can you please read for me?" But the teacher would say, "If you can't see, why do you come to school?"' To add to this, while a free education policy for children with disabilities is in place in Tanzania (United Republic of Tanzania 2014), data suggests that children with disabilities have had to pay school fees along with other classmates.

Interviews with people with albinism raised already well-documented human rights issues. People with albinism are exposed to stigma all over the world, including the United States (Wan 2003) and Africa (Brocco 2015). In Tanzania, like other countries, the killing of people with albinism has created fear among this particular group in society. Labelling of people with albinism using undesired names is also reported (Green 2007; Brocco 2015). This study found complex cultural beliefs about the relationship between people with albinism, their organs and good fortune. These beliefs complicate the process of inclusion and acceptance of people with albinism in their communities (Wan 2003; Brocco 2015). In Tanzania, people with albinism have had little platform to tell their difficult stories, and the results of this study may help to bridge this gap. More research is needed to establish a deeper truth on the source of killings of people with albinism and the market for their organs. Furthermore, some children with albinism have abandoned education and this has exacerbated their marginalisation.

The findings found through systematic coding reflect the eight priority sectors or categories initially raised by peer researchers. However, the systematic coding analysis also highlighted

that, although emotional distress was apparent throughout the interviews, interviewees and peer researchers did not seem to expect emotions to count towards, or be viable evidence in the fight for change for older people and people with disabilities in the Tanzanian context. This needs further research, particularly in relation to participants feeling invisible, but indicates that there is a need for government and partnering organisations to better support people with disabilities and older people emotionally, regarding their past, present and future challenges.

In addition to providing evidence to inform policy and advocacy efforts, the study also highlighted ways of making CBPR more inclusive in relation to disability and older age by including peer researchers with disabilities in the research design; through their involvement rich data has been collected and there has been clear ownership of findings by the peer researchers. Participants' needs were also well considered in relation to transport and accommodations relating to disability and older age.

On reflection, it would have improved the analysis to incorporate the open, axial and selective process of coding and the mapping of the emerging codes to the two chosen frameworks (ICF domains relating to environmental factors and individual, interpersonal and societal domains) into the analysis workshops in Tanzania, so that peer researchers were part of the triangulation process. Bringing the peer researchers' lived experience when considering key issues together with the systematic coding approach would have further strengthened the collaborative analysis process rather than separating it and bring it back together as this project did. For large amounts of data, this may involve analysing data inductively with NVivo software, then peer researchers analysing some of the data deductively in groups with the core research team. For smaller amounts of data, the peer researchers could inductively code together in a workshop setting.

As all peer researchers were literate, their perceptions of what the greatest issues were in the stories will have reflected this. Efforts had been made to include those less literate within the research design, but the design itself could have been built with this inclusion more in mind. Also, issues surrounding sexual abuse were extremely sensitive and it is very likely that some stories were not shared, with those that were, triggering unseen emotional turmoil. Similarly, some of the participants with albinism may have been emotionally affected by sharing their stories. Study planning had not placed emphasis on aftercare, such as explicitly linking them with local practitioners for support. Finally, there was also some initial uncertainty with understanding each other's roles and relationships, which improved as stakeholders better understood and embodied the methodology.

Conclusion

This study has informed efforts to provide services for and improve the lives of people with disabilities and older people in Tanzania and created evidence that can be drawn upon by stakeholders in Tanzania and beyond. It has contributed to building ways of engaging with CBPR in the context of social inclusion and disability. Actively involving people with disabilities and older people as peer researchers, including their perspectives as participants in research and generating evidence to inform policy development has proved extremely valuable within this study. Joining partners with diverse expertise required a great deal of planning and diplomacy, but it was essential to generate local ownership of the findings and facilitate the translation of knowledge into a catalyst for real policy change.

Local, national and global policy and advocacy plans are currently being developed based on the study. How programme partners and peer researchers build the recommendations into their work or community will be followed up by study partners. The recommendations will need to be taken on board by community leaders and policy-makers in order to address the issues raised in the study and respect, protect and fulfil the rights of people with disabilities and older people in Tanzania more generally.

So far, peer researchers have realised that they have an active role to play in raising awareness of the situation of people with disabilities and older people in their communities. For instance, they decided to speak up during village meetings and actively engage with local authorities to implement the National Disability Policy of 2004, and provide better support and provision of services to families of people with disabilities and older people. They also decided to provide sexual education to communities involved in the study. Peer researchers have also highlighted the need for government to reinforce the law and stop the persecution and the killing of people with albinism in Tanzania. Alongside this, they resolved the government should provide counsel to parents of children with disabilities, giving better support and guidance to families. Finally, they want to see policy-makers legislate the national policy on ageing so that there is a binding legal framework under the new Ministry of Health, Social Development, Gender, Older People and Children.

Globally, it is clear that the UNCPRD (UN 2006) must be ratified by all UN Member States in order to be implemented and monitored. There are also increasing calls for a UN Convention on the Rights of Persons of Older People to strengthen older people's human rights, inform policy development and prevent further marginalisation. These actions need to be accompanied by systematic and inclusive data gathering and analysis mechanisms to comply with the UNCRPD (UN 2006) and the 2030 Agenda (UN 2015). This study showcases the importance of involving different stakeholders, especially people with disabilities and older people, who are key players and voices in laying the foundation for an effective policy and advocacy strategy to uphold the articles of the UNCRPD (UN 2006) and in developing greater rights for older people. The high level of ambition seen in the 2030

Agenda (UN 2015) with the ultimate objective of 'leaving no one behind' will be better achieved if people with disabilities and older people are participating in local, national and global research and policy making. In the short term, civil society needs to continue raising awareness about the experiences of people with disabilities and older people to actively reduce stigma and discrimination.

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