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COMMENTARY

Seeing the bigger picture: Qualitative research in the Zoom® age

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Participants in clinical trials for new haemophilia treatments are routinely asked to complete quality of life (QoL) questionnaires using validated and disease-specific instruments. Yet too often in clinical research we know very little about the life stories of individuals, making it difficult to know how they have been affected by a new therapy and what exactly has changed for the better – or for the worse. In my own research, I wanted to understand the differences that new treatments are really making to people's everyday lives. While traditional QoL instruments can be helpful, using a qualitative approach that involves speaking directly with people with haemophilia (PwH) and their family members has enabled me find out what has really been going on their lives, including impacts on the wider family. The Covid pandemic and the need to maintain social distancing changed the way in which my research has been carried out, but in fact provided an opportunity to see an even bigger picture. I believe that using videoconferencing platforms to conduct interviews and focus groups has both allowed me to see more of the world in which the participants live and has enabled participants to be more relaxed and open in their conversations, resulting in a potentially richer dataset. While this approach to qualitative QoL research should not replace interviews and focus groups, the use of videoconferencing should be considered as another methodology researchers can and should use to enable them to glean the richest data possible. Qualitative interviews offer an important complementary addition to the validated QoL measures used in clinical trials, enabling us to hear more about where improvements have occurred, where further improvements can be made, and the real-life impact of a new treatment for PwH and their families.

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Qualitative research provides an opportunity to understand more about the real-life impact of new treatments for people with haemophilia – and using videoconferencing may enable the gathering of even richer data

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As a research nurse based at a comprehensive care centre in the United Kingdom, I've been involved in clinical research in haemophilia for about nine years. Much of this has involved people with haemophilia (PwH) who are taking part in trials of novel therapies. Participants in such trials are routinely asked to complete quality of life (QoL) questionnaires for regulatory purposes using instruments such as the EQ-5D, Haemo-Qol and, more recently, PROBE. Results using these instruments are often positive but can be poorly or inadequately reported. Consequently, we rarely know what effect any stated improvement means to individual people.

The World Health Organization defines quality of life as "individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" [1]. As such, quality of life refers to subjective evaluations that are embedded in cultural, social and environmental contexts and norms.

Yet too often in clinical research we know very little about the life stories of individuals, making it difficult to know how they have been affected by a new therapy and what exactly has changed for the better – or, indeed, for the worse. This prompted me to consider a qualitative research approach when I decided to pursue a PhD by published works. I wanted to understand the differences that new treatments were really making to people's everyday lives.

Traditional QoL instruments can be helpful and sufficiently sensitive to describe changes in an individual's experiences of a disease or condition, especially if administered when they attend their care centre for clinical visits. There are, however, some inherent flaws in their design and application which can mean they can be inaccurate or misleading [2,3]. There is also a tendency to lose the individual in the aggregated scores. Many tools also focus on the presence or severity of the functional aspects of a condition but fail to take account societal attitudes, or issues of healthcare access, which may have a deeper impact on the lives of PwH [4]. It has been suggested that respondent-generated tools could help overcome this and also enable the capture of data on what really matters to individuals in terms of their QoL [5].

Rather than relying on these traditional QoL assessment tools, the research projects on which my PhD is based have involved speaking with PwH and their family members directly [6,7,8,9]. The aim has been to find out what has really been going on in their lives – what their thought processes were when they decided to go into a clinical trial, why they remained in that trial, what they gained from it, what improvements did it make to their lives, whether it had it made life worse in any way, and whether or not their expectations had been met. I'm interested to know both what has gone well and what hasn't gone as well as it might have done. The very act of listening to an individual narrative of lived experience has multiple benefits including increasing our understanding of a given patient group [10]. In the context of haemophilia care, it acknowledges the voices and experiences of PwH as they navigate a changing treatment landscape and enables them to be heard. And it allows us, as caregivers, to empathise – a process associated with improved patient outcomes [8,11,12].

My research has used a mixed methods approach that includes both focus groups and individual interviews. These different approaches to collecting qualitative data offer different benefits, but ultimately work together to build a rich picture [13,14]. An individual interview offers the opportunity to really focus, explore and probe each element of that person's story, while in a focus group participants will bounce off one another, the tale of one person's experience bringing up an idea with someone else. Within a focus group there is always a risk that one individual will be more vocal than the others. The focus groups in my studies have been small (five participants at most), making it easier to ensure that quieter participants join the conversation. It is also easier to avoid 'groupthink', and to employ strategies such as playing devil's advocate [15].

Those in clinical practice know that haemophilia and its management impacts both the affected individual as well as their wider family, and any change in QoL, whether for better or worse, will also affect others within the family. So in my research I always knew that it would be important to interview family members alongside those who have participated in clinical trials. While the ultimate decisions around joining a gene therapy trial may rest with the individual, I wanted to understand their decision-making process and what part their family played in it. I have heard, for instance, from some wives and partners of PwH who have had gene therapy that while they would never have disagreed with their partner's decision they had concerns about the process which they felt unable to discuss with them. It is important for us to hear and understand what impact any decision has on a family because as health care professionals we may not ordinarily see the wives, children and/or parents of the individuals we treat. But my research gives the opportunity to see and understand more about their lives and experiences – what is going on within the family, whether there are concerns among their children about their condition, what the family as a whole understands about it. There is a whole family behind each individual who walks through the door of the haemophilia centre and being able to hear from them enables us to see more of the bigger picture.

The Covid pandemic and the need to maintain social distancing practices has changed the way everyone in healthcare has had to work. It has also changed the way in which research has been carried out – the traditional methods of face-to-face interviews and large focus groups have had to be curtailed. Despite this, in some ways, these enforced changes have allowed me to see a bigger picture than I might have expected. My original plan had been to visit people's homes to interview them, or to find a venue where we could hold a conversation or conduct a focus group. When the pandemic struck, I had to radically rethink what was possible – and like so many others began using videoconferencing platforms. What could have been seen as a second-best option has in fact, I believe, given a richer data set as I've been able to see more of the world in which the participants live. Because I used a videoconferencing platform to carry out the interviews and focus groups, I have interviewed people in their kitchens while they were cooking or eating their tea; I have interviewed people cosied up for the evening in their loungewear; I have seen how they interact with other members of their family as they've momentarily stepped into the interview. Most importantly, though, I think they have been more relaxed in their conversations. The fact that there has been a computer screen between them and me seems to have somehow enabled them to be more open – perhaps because although I was there, I was not completely in their space.

Discussions about remote interviewing and the use of videoconferencing platforms for qualitative interview studies are increasing [16,17,18], and as we come out of the pandemic I think this is a trend that is only likely to increase. Videoconferencing is not an infallible technique – technical issues can occur, sound can drop out as interviewees move away from the microphone, or there can be issues with internet connections. Awareness of these issues, though, mean they can be mitigated if they occur.

My approach to analysing the study data has remained the same as it would have been if I had interviewed research participants in person. After each interview or focus group, I wrote up my field notes, identifying elements of the interview that struck me as immediately important, interesting or relevant, as well as personal comments about how I felt at the time or how some of the comments made me feel. While the notes were never formally analysed, they have provided a useful tool and guide when analysing the interviews, providing important contextual reminders. All of the interviews and focus group recordings have been transcribed, and I have gone through the transcripts line by line to identify common themes. I have often gone back to the recordings too, to listen to what an individual has said and the way in which it has been said. I want to know if a particular issue is raised by just one person, or whether it is something that is more commonly experienced. And if it is more commonly experienced, I want to know how people are describing it, whether they are describing it in the same way or differently. It is an ongoing and iterative process: having heard something in an earlier interview or focus group I have been able to introduce it into later groups so that it can be further explored. Again, this analysis helps to build a bigger picture.

Although familiarising myself with the technology and gaining proficiency in its use was initially a challenge, I personally feel there are few, if any, downsides to using videoconferencing platforms to conduct qualitative research: indeed, from what I have seen to date their use has been a positive experience. Face-to-face interviews and focus groups will always remain the dominant methodologies, but if we are to glean the richest data possible then researchers should use all available methodologies.

With respect to new treatments for haemophilia, I now believe that qualitative interviews offer an important complementary addition to the validated QoL measures used in clinical trials and that, as such, both regulatory authorities and the pharmaceutical companies should seek to incorporate them into future clinical studies. Without them, we may simply miss hearing about the improvements that have occurred and, more importantly, where further improvements can be made.

Undertaking this research has certainly given me a new view of my own role. Clinical research is very process-driven and too often researchers remain unaware of the real-life impact of a new treatment for PwH and their families. Qualitative interview-based research enables us to see and understand this – and it can be a joyous and rewarding experience.

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