

## Enabling the authentic voice

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# Enabling the Authentic Voice: Generating Ethnographies of Women with Cerebral Palsy

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## RESEARCH



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## ABSTRACT

Historically, research has been undertaken using methods that have restricted the participation of disabled women with speech impairments. Metaphorically and literally, their voices have not been heard. Facing barriers to speak for themselves makes it difficult for women to challenge disabling narratives, including those of asexuality. The result is increased marginalisation, inequality and simultaneous oppression across different spheres of public and private life. In this paper, we reflect on our experiences of undertaking two qualitative studies that explored experiences of sexual and reproductive healthcare for women with cerebral palsy (CP), using internet-based methods such as Facebook and email. We offer reflective insights regarding the core issues for researchers when conducting research about sensitive topics with women with CP in particular, and disabled women in general. Specifically: 1) An enabling research environment; 2) Interpersonal relationships and identity. Overall, we argue that using digital and flexible research approaches not only enables disabled women to be involved in research about issues that concern them, but also provides an enabling context in which their authentic voices can be heard.

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Disabled women are often positioned as ‘other’ or ‘different’ in the various social spaces in which they participate across their lives (Linton, 2007). Discourses in relation to disabled women are reported to be constructed through an ableist medicalised lens, conceiving disabled women’s bodies as asexual, non-normative and dysfunctional (Hocaloski et al., 2016; MacKeigan, 2020). The social narratives told about disabled women—as opposed to with or by them—can influence how disabled women see themselves and are seen by others in both public and private spaces, and marginalise them from systems and structures that grant them sexual citizenship (MacKeigan, 2020). Such narratives can create barriers to attaining equity in society for disabled women, especially those with embodied speech impairments, as is the case for some women with cerebral palsy (CP). These women may not be able to make their needs, choices and rights understood in the conventional way—the reason we focus particularly on women with CP in this paper.

Limitations in knowledge and understanding about CP in adulthood inevitably create challenges for women with CP to present their perspectives in spaces where they have frequently been overlooked, such as healthcare (Turk, 2001). This could potentially restrict timely preventative healthcare, placing women with CP at a higher risk of developing debilitating or life-threatening conditions (Poulos et al., 2006). It is paramount that disability perspectives are equally represented in health and social research, so as not to limit the application of research findings (Rios et al., 2016). To do so calls for an inclusive research design to ensure women with CP can participate in research opportunities and in doing so contribute to the advancement of accessible healthcare, especially sexual and reproductive healthcare, for disabled women.

Authors such as Rios et al. (2016) and Ison (2009) point out that the adoption of overly rigid recruitment and data collection instruments could exclude some disabled people from becoming active research participants. Their work shows that time and resource constraints, and limitations in researcher knowledge and flexibility can deter researchers from involving disabled people, including those with associated speech impairments, in health and social care research. However, as Law et al. (2011) argue, methods have a social life, and the creation of new methods can be motivated by the desire to generate new results from specific populations. This includes using internet-based methods, either instead of or in combination with more conventional face-to-face research methods, to involve disabled people in research in different ways, such as participants or advisors. Increasingly, funders of health (i.e., National Institute for Health Research; Burdett Trust for Nursing) and social (i.e., ESRC) research are looking for evidence of patient and public involvement and societal impact, therefore it seems particularly important for researchers to consider different ways of achieving this (Rios et al., 2016). Moreover, it is inherently good practice to ensure that meaningful patient and public involvement is embedded within every research design.

Researchers have suggested how internet-based methods offer flexibility to participants in terms of time and space, enabling their involvement across different geographical locations without the practical barriers incurred by face-to-face research methods (James, 2016). These internet text-based methods provide an anonymous distance between researchers and participants, so the latter are more likely to feel comfortable to disclose private and sensitive narratives (Pearce et al., 2014). Designing research to include the use of digital-based methods can provide opportunities for disabled participants to complete a research-related task (such as responding to recruitment materials or completing a consent form), which may be difficult or impossible with non-digital methods, and thus limit them from participating in research on an equal basis to others (Harniss, et al., 2007). Williams and Moore (2011) suggest a concept of universal design of research to promote routine inclusion of disabled people, enabling the potential participation of people who may otherwise be excluded.

In this paper we discuss the methodological instruments and processes that can maximise ‘voices’ of women with CP in research about their private lives. We offer insights into the issues that arise when conducting research about sensitive topics with women with CP, and by a researcher with the same impairment. We draw on two qualitative studies with women with CP specifically about their experiences of sexual and reproductive health and healthcare across the life course. Both examples show how the use of digital methods (for recruitment, consent and data collection); the researcher/researched shared identity; and feminist disability theoretical

frameworks can be enabling tools for researchers to facilitate marginalised perspectives and advance research in this field. We also show how involving people with CP as advisors provides an insider knowledge that can facilitate a more inclusive research design.

In this paper we favour the social model of disability perspective, which focuses on the structures and systems in society that position people with impairments as having unequal status and value compared to those without impairments (Oliver, 1990). From this stance, we believe that it is not an individual's impairment that restricts their ability to adopt the role of research participant, but more the macro and micro level systems and structures that are disabling and imposed on top of their impairments. Examples are the use of face-to-face interviewing as the only possible data collection tool; and a fixed time duration for the research interview. Such rules made to govern everyday lives and processes disadvantage the disabled body and voice, thus excluding people with speech impairments from informing the development of policies and practices which affect their lives (Paterson, 2012). Our commitment to inclusive research methodologies to enable disabled people to fully participate in research, and to have their say in their own way, adheres to Article 21 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) which asserts that measures should be taken to ensure disabled people can exercise their right to freedom of expression and opinion.

By sharing our reflections and experiences using of digital methodologies, we hope this article will provide some lessons for other qualitative researchers undertaking research with disabled participants, particularly around personal and sensitive topics. This can, in turn, start to address disparities in healthcare practice, potentially influenced by their missing voices in research. We begin with a brief background and context about CP and how the impairment interacts with the female life cycle.

## **BACKGROUND**

In the UK an estimated 2–3.5 per 1000 live births result in CP (Shaunak and Kelly, 2018). It is a lifelong impairment caused by damage to the infant brain before, during or after birth that affects motor control and mobility across the life course (Cremer and Hurvitz, 2017). It affects people differently depending on which part of the brain has been damaged. Accounting for gender, globally the prevalence of impairment (CP and other conditions) is higher for women than men—19.2% and 12% respectively (World Health Organization, 2011). Thus, it is fair to say that women with CP are a growing population who will experience ongoing as well as new health problems as they age (Gannotti and Frumberg, 2020). There is, however, scant evidence about the specific experiences for women and girls, but the early studies that do exist suggest they experience early hormonal changes in terms of menarche (Siddiqi et al., 1999; Worley et al., 2002; Zacharin et al., 2010) and menopause, osteoporosis and maintaining sexual function (Turk et al., 2001).

The two empirical studies reported below, and conducted by the authors, confirm that women with CP experience early hormonal changes across the female life cycle. Grounded in the first-hand accounts of women with CP, both studies evidence good practice and challenges experienced in relation to the provision of sexual and reproductive healthcare across the life course. The authors have published the full findings of both studies elsewhere (Shah et al., 2020; Shah et al., 2021), which emphasise the importance of enabling women with CP to participate in research, so they can be active agents in the production of guidance, both for practitioners and for other women with CP to direct their own health and healthcare.

## **THEORETICAL FRAMEWORKS**

It is important that research concerning women with CP is underpinned by appropriate theoretical frameworks which recognise that they, unlike disabled men and non-disabled women, can experience both disablism and sexism by systems and structures at micro, meso, and macro levels. Feminist disability theory addresses the limitations of disability theory and feminist materialism which has been criticised for privileging the experiences of disabled men and non-disabled women respectively, whilst failing to account for those specific to disabled women (Thomas, 1999; Garland-Thomson, 2002). Indeed, some non-disabled feminists may choose to separate themselves from disabled women, equating the image of the disabled or

deformed body to a negative position of oppression that they have fought hard to turn around (Samuels, 2002; Thomas, 2006).

Feminist disability theory seeks to highlight voices and experiences that have been silenced or misrepresented, such as those of women with CP, and situates the experience of disability within the context of rights and exclusions (Garland-Thomson, 2005; Thomas, 1999, 2006). It provides a lens to understand the intersection between the female body and its social, cultural and physical environments. In so doing it provides a clarity of the cultural meanings attached to the disabled female body, over time, and the structures and processes that have created and driven these meanings, as well as the consequential practices produced (Garland-Thomson, 2005). Viewing the personal as political, this lens favours the personal experiences of disabled women, but as a vehicle to expose experiences of disablism (and sexism) in the lives of disabled women as opposed to revealing their life experiences as women with CP. Although, as Garland-Thomson asserts, feminist disability theory seeks to avoid being impairment specific and rather, focuses on the collective experiences of disablism imposed on top of people with different impairments by their material environment, it rightfully recognises that communities of individuals with the same impairment can have shared experiences of disablism and embodied changes which are different from those with different impairments.

The organisation of social structures, processes and systems means that disabled women, including those with CP and other lifelong physical impairments, are particularly susceptible to inequalities and simultaneous oppression across different spheres of public and private life including healthcare, compared to non-disabled women and disabled men (Thomas, 2006).

In her empirical research with disabled women, Thomas (1999, 2001) indicates how the participants' narratives are constructed with reference to public discourses of womanhood and what this means, but the societal barriers that come with disability restricts their experiences of being a woman. For instance, all women are eligible to sexual and reproductive healthcare (SRH) across the life course, which is essential not just for the health of an individual, but also for the development of any society. However, disabling barriers at institutional and societal levels can impact disabled women's rights, access and choices to SRH, placing them at a greater risk of developing chronic diseases, compared to non-disabled contemporaries. For a transformation in thinking and practice, narratives about the lives of women with CP need to be informed by women with CP. This would encourage an understanding of the intersectional experience of disability, gender and other protected characteristics (e.g., age, ethnicity, sexuality), but also the women's impairment effects on sexual health needs and what is required to address them appropriately. Taking notice of the gendered character of disability and impairment (within both structures and cultures) would enable a shift in social understanding of disabled women in general, and thus a move towards greater inclusion, equity and citizenship for disabled women and girls (Thomas, 2006).

## **USING ENABLING AND FLEXIBLE RESEARCH METHODS**

Every funded research project has finite time and resources which indirectly influence selection of participants. The normative temporality of time has been critiqued as ableist, reinforcing the exclusion and estrangement of people with speech impairments from gaining and sustaining social and cultural capital to engage with systems and structures on an equal par to non-disabled contemporaries (Paterson, 2012). This includes their exclusion from being social agents in research about their own lives (Ison, 2009). Therefore, although qualitative research has the potential to enable oppressed groups to have their voices heard, how and how much 'voice' is given is largely dependent on the researcher and the techniques used to access the voices.

Prior to national and international disability policy and legislation, grounded on the 'Nothing About Us Without Us' principles of the UK Disability Movement, it was considered plausible for researchers to use proxy responses as evidence about the social worlds of disabled people if they could not engage with other methods of participation. Interviewing parents or carers of disabled people, instead of the disabled person themselves was seen as a plausible way to address concerns relating to issues of equity, inclusion and bias, while ensuring the research is conducted within the time and resource provided (Steel et al., 2005). However, proxies do not

live the life of the persons they are speaking for, therefore from an epistemological perspective this poses challenges as proxies and disabled people will have different perspectives from each other (Ison, 2009). Moreover, from a legal standpoint, the Equality Duty provided by the Equality Act 2010 (Gov.UK, 2010) in the UK states that, in order to conduct an equality analysis to advance equality and eliminate discrimination for people with different impairments, it is critical to involve them in the research process and collect evidence which is representative of their lived experiences (Farmer and Macleod, 2011). It is also clear from Article 21 of UNCRPD (United Nations, 2017) that efforts must be made to facilitate disabled people to express themselves, participate and communicate in ways that are accessible to them. Therefore, as the use of proxies have been based on assumptions that disabled people could not or should not speak for themselves, it has become quite a contentious form of data collection when working with participants with significant impairments (involving physical, communication and speech effects), who are likely to face substantial barriers to participation (Patterson, 2012).

## TWO STUDIES

In this paper, we draw on insights from two qualitative studies which successfully enabled a diversity of women with different embodied experiences of CP to tell their own stories in relation to their experiences of SRH. Both studies prioritised flexibility in terms of time and space; and use of technology and assistive resources to enable women to consent, participate, and communicate in their own way; and using internet-based methods so they could speak for themselves and about sensitive issues that are part of their private lives. The two studies were underpinned by feminist disability theory.

### STUDY ONE

The first study we draw on was funded by the Burdett Trust for Nursing (BTN). The purpose of the study was to examine and understand how women and teenage girls with CP, from across the UK, access and experience SRH across the female life cycle (from menarche to menopause). The study was conceived and conducted by the first author and designed in collaboration with nursing researchers (second and third authors) and an advisory group of researchers in disability studies, people with CP or representing organisations for people with CP. All brought their insider knowledge, of either living with CP or working in the area, to the research to ensure it was designed to enable the potential participation of all women with CP, in the UK over the age of 14 and with the mental capacity to consent. The total sample involved twenty-five women, aged between 15 to 65. The study was approved by the Health Research Authority (IRAS ID 268208) through the West Midland Coventry and Warwickshire Research Ethics Committee (20/WM/0003).

Digital strategies were employed to identify, recruit and interview the target sample. Such strategies facilitated consent among women with CP, their participation in the study and communication with the research team, without necessarily relying on others for physical or communication support. The use of digital technologies has brought a flexibility to the research process, overcoming time, resource and geography constraints (which would have hindered the participation of some of the women). It enabled women with certain impairment effects to participate in interviews and speak for themselves in a way that may not have been possible with in-person interviews with a set duration of time. Further the email and IM conversations put some distance between the participant and the researcher (S.S.) which was more comfortable for some women when disclosing personal information to a stranger. However, they still felt they were being 'listened to' as [insert author initials] would write things like 'I see' or 'very interesting', or ask participants to provide more detail about experiences, and check if they needed a break. Of course, textual internet-based interviews did not suit all women, and some preferred talking face-to-face with (S.S.), and to be prompted by visual and audio cues.

However, regardless of the interview method, [insert author initials] took great care how questions were phrased, making sure they were open questions, but also acknowledging they were about very personal and sensitive issues that participants may feel uncomfortable to discuss. For example, [insert author initials] would begin with statements like 'I want to know more about your experiences of sexual and reproductive health. These questions are quite

personal, but it will be useful to know your experiences around this, as your stories are very important to this research. You can stop anytime if you feel uncomfortable or need a break’.

The adoption of digital research instruments in Study One not only facilitated the inclusion of marginalised perspectives, but it allowed the whole study to continue throughout the 2020/2021 international Covid 19 pandemic, despite the restrictions on travel and limitations on in-person contact. This was especially crucial given that (S.S.) and participants have impairment effects that make them particularly at risk to the effects of the coronavirus.

## STUDY TWO

The second study was conducted on Facebook in 2018 [Insert reference after peer review]. It was designed to show the potential of using a closed global Facebook group to generate authentic narratives, from women with CP, about their embodied and relational experiences of ageing, sexual and reproductive health and healthcare. The closed Facebook group, Women Ageing with CP (WACP), was set up in January 2018, as an international support and discussion forum exclusively for women aged 21+ who identify as having CP. It was set up by the first author and her American colleague, both of whom were experiencing new health issues as they were growing older in relation to their sexual and reproductive health but could not access appropriate and accessible support. The study was approved by the University ethics committee, ERN 18-1899.

Facebook has been cited (Shpigelman and Gill, 2014) as providing an inclusive forum for disabled people to engage, participate and converse with other people in ways that may not be possible with offline networks. For people with CP, with embodied effects including speech impediments, a closed online forum provides a comfortable way for them to share sensitive information and support each other without experiencing difficulties relating to verbal communication and physical access.

The WACP Facebook group provided women with CP a forum to share their personal experiences of growing older and how that affected their body, their relationships and different roles, both personal and professional; and other issues pertaining to being a woman. Through the online forum women with CP could speak for themselves about their private lives, as well as offering new knowledge and support and advice to each other. It was also used as a research tool by the authors to explore how online forums can be used to capture digital ethnographies about experiences of SRH from a population whose voices have often been missing.

WACP had 180 members at the time of the study (at the time of writing this article, it has almost 500). Three discussion themes were posted onto the group to generate women’s experiences of ageing, SRH and healthcare. Women posted responses on WACP. However, 45 members consented to their responses being included in the study. The consent form was sent to potential participants via Instant Messenger, and their responses were returned to the researcher also via Instant Messenger. All consent messages were cut and pasted into a Word document and saved in a password protected folder.

Conducting ethnographic research, using Facebook as a fieldwork site, is beneficial as it enables the recruitment of large and diverse samples of participants perceived as ‘hard to reach’ via conventional methods. Such ‘hard-to-reach’ participants include people with embodied impairment effects that prevent their ability to communicate effectively using their speech. Several members of the WACP Facebook group identified as having speech impairments and chose ways of communicating which did not involve their speech. As mentioned above, such communities may be excluded from fully participating in research, due to a lack of flexibility in researcher knowledge, resources and time (Ison, 2009; Rios et al, 2016).

The digital methods adopted to conduct the WACP study had three main benefits: 1) they enabled women with different impairment effects to participate in the research in their own time and spaces and, if needed, using their own assistive devices. 2) the researcher (S.S.) could conduct the recruitment and data collection independently and using her own assistive hardware and software. Neither [insert author initials] or the participants had to negotiate disabling barriers that potentially come with travelling to research fieldwork sites, or pay the extra support costs it brings. 3) they enabled the generation of rich ethnographies of a diverse intersectional group of women with CP from across the UK and USA.

Reflecting on our experience of both studies, we have discerned two main groupings regarding the issues involved: 1) An enabling research environment; 2) Interpersonal relationships and identity.

### AN ENABLING RESEARCH ENVIRONMENT

The design of both studies, using flexible digital methods, enabled women with CP to participate in research about issues that affect their own lives without barriers that may come with non-digital methods. They could speak for themselves about some private and sensitive issues, and thus contribute to potential changes in knowledge and practice for individuals like them. One limitation found with the WACP study was that posts on Facebook group were not confidential, and are visible to other members of the group, However, all women were aware of this when they consented to participate.

All recruitment materials (including consent and participant information forms) were produced in digital formats so they could be emailed to participants or uploaded to social media sites. This was welcomed by the participants, who found digital communications easier than paper-based ones, due to the embodied effects of their CP. Participants also had the option of digital or in-person interviews (before the onset of COVID-19).

When developing this paper, we were fortunate enough to re-connect with some of the participants of Study One to generate additional data about the reasons for choosing digital interviews (via email or IM), as this was not part of the initial research question. Not all the women who were approached responded. The findings presented below reflect the views of those who did respond, and highlight three main benefits of digital interviews.

Having the time and space to reflect on and tell their own stories in their own words:

*The reason why I preferred email over face-to-face interviews is because I could answer the questions in my own time and at my own pace. It also allowed me time to answer the questions in more detail. This allowed my answers to be clear and coherent, and I had time to add or change or edit anything to the answers if I needed to (Ellie).*

Communicating personal and sensitive topics:

*The subject is quite private and personal, so I find it less embarrassing to use Facebook chat rather than face-to-face. Plus, I have a slight speech impairment, and tend to articulate myself better in writing. (Kay)*  
*I could never talk to someone about something so personal if I was talking face-to-face. That is where text chat and email help. (Nat)*

Making interviews easier for people with non-normative speech patterns to be understood:

*...because my speech is sometimes very difficult for strangers to understand and the sheer effort and time it takes to ensure that I have been properly understood is both exhausting and extremely frustrating (Poppy).*

One of the women, Anne, self-identified as having a severe form of quadriplegia which significantly affects her speech. In everyday life she communicates through a speech machine. She responded to recruitment advert by email and told (S.S.) that she was enthusiastic to participate in the research about sexual and reproductive health, and to present her own perspective independently, but this would mean doing the interview over email over a longer period of time. [insert author initials] disclosed to Anne that she had personal experience of CP and one of her own impairment effects was verbal communication, and she prefers written methods too. She reassured Anne that the most important thing was for Anne to be able to participate in the research in a comfortable and accessible way. Sharing this experience put Anne at ease and contributed to a comfortable understanding between the two women, which both enabled Anne to have a 'voice' in research that mattered to her and the researcher to collect rich data from someone perceived by some as being 'hard-to-reach'. Anne and the (S.S.) agreed that the most accessible method of interview would be via email, over a period of one



and a half months, which included a break of approximately two weeks for the festive holiday when she was not in communication with [insert author initials]. By mutual agreement Anne was sent one question every two or three days. She sent responses back when she was able to, within the same week. [insert author initials] would wait for Anne's answers before sending another question, feeding back on Anne's responses in a polite and encouraging manner, and sometimes asking follow-up questions to attain more details or examples (Ison, 2009). Anne explained the reason for her choice of interview method in an email to [insert author initials]:

*This is a very important topic, and thank you for making the methods accessible for me to participate. Email has allowed me to tell you my stories in my own time and from my home. I use assistive communication so easier to 'talk' using email.*

## **INTERPERSONAL RELATIONSHIPS AND IDENTITY**

Both (S.S.) and the participants had similar identities and experiences, resulting from the intersection of being women with CP and as such negotiating health and healthcare pathways. This contributed to the successful recruitment of participants, and the generation of rich data about a sensitive and personal subject. This shared culture, also offered opportunities for catharsis, problem solving and empowerment. For example, one participant used the pronouns 'we' and 'our' during a face-to-face interview, when describing the effects of a mammogram procedure on her CP body. Using both gestures and words, she drew parallels between her own impairment effects and those of [insert author initials]. This encouraged the participant to recollect and share some very personal experiences. Additionally, post-interview, she reported that she would not have been so open if the interviewer was not disabled.

We were, however, mindful of the challenges associated with the 'epistemological privilege' (Stanley and Wise, 2002) that was available to [insert author initials] by virtue of her intersectional identity. Although it is useful for establishing a trusting relationship with the participants so they are comfortable to let down their defences and be open and honest about sensitive and intimate issues as disabled women, it has the potential to introduce bias in reporting by some participants. Non-disabled scholars (Agula et al., 2015) have argued that a shared identity could lead to participants growing uncomfortable with disclosing certain types of information to the researchers, and therefore not providing honest responses, but instead, responses that the researchers would find pleasing. Further insider-researchers could also face challenges relating to participants 'talking back' and challenging the researchers' authority (Gajjala, 2002) However, we believe that this was not the case for the two studies we conducted. All of the participants established a good relationship with [insert author initials] (through email, IM and face-to-face), who, prior to the interviews provided a detailed explanation of the research aims and methods. Several of the participants were aware of [insert author initials] from her previous work in the disability field and also her disability activism. Further, they were keen to make a contribution to something that could benefit them and other disabled people in the future, and trusted the researcher's positionality as a disabled activist, disability researcher and disabled woman to ensure the participants are provided with an accessible platform to have a voice (Shah, 2006). As Gajjala (2002) argues, it is important for insider-researchers to adopt different strategies to build good quality relations with the participants and accept them as 'subjects with voices, views, and dilemmas—people to whom we are bonded through ties of reciprocity' (Narayan, 1997: 23).

[insert author initials] took care to be critically reflexive in terms of the risks of over-rapport, as pointed out by Hoolachan (2019). She made every effort to ensure that participants felt that their perspectives mattered and that their input had potential to inform future health practice for women with CP. Further, [insert author initials] was conscious that she was asking a great deal from the women, in the way of their time, cooperation and confidences on some personal and difficult matters in their lives, matters which they had every reason not to disclose to a stranger. Therefore, she did reveal some of her own experiences of impairment and disability when asked by the participants, either by words or confirming gestures. This information exchange made an important contribution to building a rapport and trust with the participants. Of course there is a danger that this sharing can lead to a loss of objectivity and participant exploitation, but the researcher's dual role (the insider role, and researcher role) coupled with their own perspectives can be used to avoid these risks (Unluer, 2012).

In sum, as regards interpersonal relationships and identity, bringing together an international community of women with similar identities to share their stories (as we did in study 2) ‘can turn personal chaos into order. They can help us to make sense of our lives and the world around us’ (Plummer, 2016). For research, it allows a ‘hard-to-reach’ population from two continents to speak for themselves, in relation to their private lives.

## DISCUSSION

It is crucial to find and use methodological instruments and research processes to enable women with CP to fully participate in research about personal and sensitive issues in their private lives. We agree with other researchers, that we need to be flexible in our attempts to make participants’ voices central, particularly when they do not communicate verbally (Ashby 2011; Forber-Pratt 2019). Reflecting on researcher experiences of designing and conducting qualitative research with women with CP, being flexible with interview methods to facilitate the inclusion of marginalised perspectives in health research may contribute to the reduction of health care inequalities. Indeed, ‘centering disability’, that is, turning to disabled person’s lived experiences, is all about making practices more equitable, including interview methods (Kerschbaum and Price 2017).

The researcher and participants ‘sharing the same world’ can also facilitate the participation of people with certain impairment effects, in terms of recruitment and rapport building to generate honest narratives (Author, [Insert reference after peer review]). This also has the cathartic value of being ‘listened to’ by someone ‘in the same shoes’ (Ison, 2009). We recognise and are aware of the debates around the potential of a power imbalance between researchers and participants and the ethical challenges pertaining to this; as well the role conflict related to being insider and outsider (Malacrida, 2007; Råheim, et al., 2016). We have observed the value of utilising researcher insider perspectives to ensure an inclusive research design.

Internet-based methods have the potential to advance the participation of people with different impairments and communication styles. It can reduce social isolation and increase social participation opportunities for those who have experienced exclusion and isolation in offline communities, as it cuts across time and space boundaries. For example, instant messaging (IM) technologies have provided opportunities for different people to connect and communicate with each other in a text-based environment, but in real time as is offered by face-to-face interactions (Flynn, 2004; Hinchcliffe and Gavin, 2008). Evidence reveals that engagement with IM and usage of social networking sites can be beneficial to the creation and maintenance of social capital, enhancement of psychological well-being, and reduction of isolation for different social groups. Such online communication and connection spaces offer a fruitful opportunity for qualitative research practice, offering a mechanism for exchange of questions and answers in almost real time (Lune and Berg, 2017).

Digital methods also enable disabled women to participate in research at their own preference of time and space, and using their own assistive communication hardware and software. Materials in digital formats can be made accessible with Augmented and Assistive Communication (AAC) technology (such as eye gaze, joystick/mouse keys, screen readers) for people who are non-verbal or have limited or non-normative speech patterns. Even people who do not necessarily identify as AAC users may use other assistive software and hardware technology (such as joystick, switches, mouse keys, keyguard, magnification) and thus prefer digital information and online forums, perceived as more accessible than paper-based alternatives. So, using digital methods for recruitment and data collection is crucial to include groups frequently perceived as ‘hard-to-reach’ (Ison, 2009; Rios et al., 2016).

Email or IM interviews also allow participant anonymity which can engender a self-confidence and facilitate reflection and honesty, especially when disclosing private and sensitive information, as there are no visual cues or perceived acts of distraction or discouragement such as nods, yawns or frowns (Cook, 2012). Further, for women with CP (with and without speech impairments), digital methods have been found as a means of providing easy access to communication, participation in activities and interaction with others without expending the physical or sensory capabilities that would be required in parallel offline situations (Shpigelman and Gill, 2014).

A US study exploring strategies to ensure disabled people are able to fully engage in decisions which affects their lives found that best practice participation involves time and resource

flexibility; planning ahead to allocate resources toward inclusive participation; and the use of technology to simultaneously support different communication styles (Patterson, 2012).

Internet-based methods also reduce the financial and time costs incurred from face-to-face interviews such as travel to and from the fieldwork site (for researchers or/and the researched), venue use, and transcription (James, 2016). In addition, for disabled researchers and participants, it reduces the extra costs required to cover disability access and the physical support that may be required to be involved in the fieldwork. This could include payment for personal assistance to provide support en route to, from and during the interview, or/and the cost of taxis (which are more accessible, but more expensive than bus or train). Furthermore, with internet-based interviews there is more opportunity to be flexible in terms of time and space to conduct and participate in research interviews. This can reduce the challenges of negotiating geographical boundaries as well as potential physical and social barriers that may come with participating in a face-to-face interview as a disabled respondent.

Although, in a way, telephone interviews overcome some of these practical constraints and associated costs, the depth and quality of the data generated can become compromised by an absence of visual cues due to the loss of non-verbal and contextual data. This, in turn, restricts relationship construction and rapport building between researchers and the researched. Although this is also the case with internet-based interviews, the difference is that internet-based methods, such as email or instant messenger (IM), provide a mechanism to probe with follow-up questions and have a real-time back-and-forth conversation similar to the exchange offered by face-to-face interviews. Furthermore, unlike telephone and face-to-face interviews, email and IM provide a means for researchers to communicate more inclusively and facilitate meaningful participation for women with CP.

As highlighted, digital methods have great benefits for including certain individuals and groups (disabled and non-disabled) in research. However, we are aware of critical scholarship that argues that digital methods can increase research exclusion of some disabled people (Cole et al., 2011), especially since everyone has differential levels of access to technology (Kennedy et al., 2015). According to an ONS survey (Great Britain, 2019) in 2018 there were 5.3 million people in the UK who would be described as 'internet non-users', referring to those who have never or only used the internet in the past three months). The report highlighted a digital disparity across areas in the UK, with London having the lowest number of internet non-users while Northern Ireland had the highest.

Since 2011 adults over 65 make up the largest proportion of adult non-users. However, across all age cohorts, disabled people make up the largest group of internet non-users in the UK. As in the offline world, disabled people face several barriers to accessing the online world (Dobrinsky and Hargittai, 2016). Barriers to education and accessibility are causes for digital exclusion and moreover, standard hardware and software is frequently poorly designed as regards meeting the needs of disabled people. Although assistive technology is increasingly available to enhance accessibility of technology for disabled people, this population continues to lag behind non-disabled people in terms of internet use. Therefore, it is important to ensure a range of digital and non-digital methods continue to be made available in research to maximise participation of the target sample.

Freedom from potential distractions or challenges could enable the generation of more accurate data, and richer narratives from disabled participants about their experiences of both private and public life (Hinchcliffe and Gavin, 2008). Ensuring women with CP can speak for themselves in research and fully participate in decision-making that affects their lives, has potential benefits for both researchers and participants. While the former can gain an in-depth understanding of the lives of the researched; the latter can gain empowerment, engage with different groups in society and become political players in a society where their voices were historically silenced (MacKeigan, 2020).

The advent of digital technologies has enabled stories to be told in a combination of different ways, that are not entirely, or at all, dependent on speech. This allows disabled women, especially those with embodied speech impairments, to use their own words to tell their stories about personal and sensitive issue (Aluwihare-Samaranayake, 2012). Further, disabled researchers have the tools to understand the social world of a historically marginalised population through accessing and amplifying their authentic voice.

Our reflections can be summed up as lessons learned in **Table 1**.

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## INTERPERSONAL RELATIONSHIPS AND IDENTITY    AN ENABLING RESEARCH ENVIRONMENT

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- The shared culture of disabled researchers and participants offers opportunities for catharsis, problem solving and empowerment.
  - The shared culture of disabled researchers and participants can contribute to the successful recruitment of participants, and generation of rich data about sensitive and personal subject.
  - Researchers can build a rapport with participants in email and IM interviews by writing something brief about their own experiences of healthcare and disablism, to indicate insider understanding.
  - The dual roles and perspectives of researchers (as insiders and researchers) can avoid the risks of over-rapport and loss of objectivity.
  - All recruitment materials (including consent and participant information forms) should be produced in digital formats so they can be emailed to participants or uploaded to social media sites.
  - Participants may find digital communications easier than paper-based.
  - Having access to information in digital formats provides time and space for participants to reflect on and tell their own stories in their own words.
  - Email and IM interviews can put some distance between participant and researchers which can be more comfortable for some women when disclosing personal information.
  - When using email and IM interviews, researchers can use written words, symbols and emojis to indicate they are listening to participants.
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**Table 1** Lessons learned.

## CONCLUSION

This paper contributes to a body of literature relating to using internet-based methods in qualitative research, while simultaneously addressing gaps in existing discourse in relation to doing research with disabled women about private and sensitive issues in their lives. Drawing on two qualitative studies with women with CP, we have explored how both email and IM research methods offer alternatives to face-to-face interviews and provide opportunities for some women, otherwise excluded from research, to speak for themselves in research about experiences of health and healthcare. We argue for the critical place of an enabling environment and interpersonal relationships and identity when designing research with disabled women, and especially those with speech impairments.

In conclusion we suggest that internet-based research methods can overcome the restrictions of face-to-face interviewing which prevent some disabled women from participating actively in research about their private lives, particularly topics that are personal or sensitive. This article describes and demonstrates how digital research methods are important to enable the recruitment of some disabled participants who are often excluded from research that use conventional research methods. It shows the value of internet-based interviews (such as email and IM), coupled with flexibility in terms of time, to generate rich and authentic narratives from women with CP. Adopting such research tools can contribute to the equal representation of disabled women's perspective in healthcare research.

## SUBMISSION DECLARATIONS

This paper is not under consideration for publication elsewhere. Its publication is approved by all authors and by the University of Birmingham, where the work was carried out, and, if accepted, it will not be published elsewhere in English or in any other language, without the written consent of the copyright-holder.

## ETHICS AND CONSENT

The studies discussed in this paper have been ethically approved by the University of Birmingham Ethics Committee. All participants provided written consent to be involved in the studies. Identities of all participants have been anonymised.

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## AUTHOR CONTRIBUTIONS

All authors contributed to the design, execution and analysis of both studies on which this paper is based. SS drafted the initial paper and contributed to subsequent revisions. SS was principal investigator of study 2. JT was principal investigator of study 1 and led on the critical input and revisions to the paper. CBJ was a co-applicant on study 1 and led on the construction of the analytical themes presented in this paper. She made critical revisions to drafts and the final version of the manuscript. All authors contributed equally to the intellectual content of the paper.

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