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Effective communication: core to promoting respectful maternity care for disabled women

Abstract:

Objective : Previous research highlights that disabled women have less choice, control and respect of their dignity during pregnancy, childbirth and parenting. The experience of dignity and respect during pregnancy and childbirth for those with physical and sensory disability in the UK and Ireland is explored.

Design, setting and participants: Narrative, semi-structured telephone and Skype interviews were conducted with ten disabled women in the UK and Ireland. Interviews were audio-recorded and transcribed verbatim. Intra- and inter-thematic analysis was undertaken, beginning with a process of open coding. As themes developed, a process of constant comparison was used.

Findings: The key finding is that effective communication with women was perceived to best respect the women's dignity in childbirth. This meant enabling women to feel heard, enabling women to make informed decisions about their care and providing individualised care. The single most important factor that enabled this communication was continuity of carer.

Key Conclusions: The factor that most promoted maternity care that was perceived to be respectful was effective communication. This is not so different in other parts of the world, or for non-disabled women, however care providers should be particularly careful to enable good communication with disabled women.

Keywords: dignity, disabled woman, communication, continuity of carer, individualised care, pregnancy continuum, maternity care.

Introduction

Childbirth is a time of significant social and cultural importance for both the woman and her family; yet for some women the experience is marred by a lack of respect and dignity. It has been more than a decade since Bowser and Hill's (2010) landmark study highlighted women's experiences during childbirth and the White Ribbon Alliance (2011) brought together a multi-stakeholder group to develop the *Respectful Maternity Care Charter*. The launch of the World Health Organization's (2018) recommendation on respectful maternity care was seen by many as a watershed for health care, but with a decade of campaigning for dignity and respect how far have we really come (White Ribbon Alliance [WRA], 2011)?

The definitions and meanings of dignified and respectful care are complex (Vogel et al., 2015); a recent review of qualitative evidence highlights twelve 'domains' relevant to respectful maternity care, but also identifies that there is significant difference in the political and healthcare expectations across countries and cultures, along with an education focus on biomedical topics rather than humanised care (Shakibazadeh et al., 2018). Beck (2018) has identified six types of disrespect and abuse during childbirth: *Failure to Meet Professional Standards of Care, Poor Rapport Between Women and Providers, Verbal Abuse, Physical Abuse, Health System Conditions/Constraints,* and *Stigma/Discrimination*.

The promotion of dignity and respectful care during pregnancy and childbirth are accepted to be of global importance (World Health Organisation [WHO], 2014). The International Confederation of Midwives (ICM) (2019) international competencies recognise the importance of the role of the midwife in advocating and respecting the needs of the woman. The White Ribbon Alliance 'Campaign for respectful care' to improve the care of women in childbirth is internationally supported (WRA, 2011; Bohren et al., 2015; Freedman & Kruk, 2014). Within the campaign the role of interpersonal relationships as providing respectful care is significant (WRA, 2011). [see Table 1]

Insert Table 1 in here

Despite dignity being viewed as a basic right for all in the Declaration of Human rights (United Nations Universal Declaration of Human Rights, 1948), there is still much to do (Freedman & Kruk, 2014). More than one third of women in some countries experience mistreatment, which is often physical and verbal, with younger women and those women with limited education being more likely to experience abuse (Bohren et al., 2015). Although there is a growing body of work focusing on the high rates of disrespect and abuse in low and middle income countries (Bohren et al., 2015; Miltenburg, van Pelt, Meguid, & Sundby, 20182) where this can deter women from attending facilities for birth (Milne, van Teijlingen, Hundley, Simkhada, & Ireland, 2015; Nawab, Erum, Amir, Khalique, Amsari, and Chauhan, 2019); advocates are quick to point out that high income countries also need to look carefully at the maternity care they provide (Birthrights, 2013). There are few UK based studies that have looked at respect and abuse in childbirth, but Beck, looking across a number of high income countries, confirmed similar mistreatment in childbirth (Beck, 2014).

The 2017 UK national review of maternity services reported that only 85% of women felt that they were always treated with respect (NHS England, 2017) and there is evidence from personal experiences highlight the damaging effect of disrespect (Kay & Calonder, 2019). In the UK the concepts of dignified care are embedded in the values of the National Health Service (Department of Health [DoH], 2018). Midwives are expected to provide care that meets these values, which also lie in the Code of Practice (NMC, 2018), as well as in current maternity transformation plans (DoH Ireland, 2016) and country equivalents (Healthcare Inspectorate Wales, 2019; The Scottish Government, 2017). Similar policy also exists in Ireland, with the 2016 National Maternity Strategy suggesting that maternity care in the future will offer a better experience and more choice for women and their families (National Maternity Strategy, 2016). In the UK and Ireland, there is also Equality legislation, which states that all services should be provided to disabled people without discrimination and further that ‘reasonable adjustments’ (in UK legislation), ‘reasonable accommodations’ (in Irish legislation) or changes to normal practice may be required and should be provided to ensure equal treatment (Equality Act, 2010; Equal Status Act, 2000; Disability Act, 2005).

This study was initiated by the UK human rights in childbirth charity Birthrights, who, during their 2013 Dignity in Childbirth study showed that women who identified as disabled reported less positive experiences than women who did not report disability (Birthrights, 2013). This study is not alone in highlighting challenges for disabled women. Studies of the experiences of disabled women have found that women recieve inadequate information specifically about the interaction between pregnancy/childbirth and disability (Blackford, Richardson, Grieve; 2000, Heideveld-Gerritsen, van Vulpen, Hollander, Oude Maatman, et al 2021); assumptions are made about women being ‘high risk’ and reducing choices available to them (Lipson & Rogers, 2000) and that midwifery service providers lack awareness of disability (McKay-Moffat & Cunningham, 2006). Several studies also suggest less choice for disabled women, particularly in childbirth (Redshaw, Malouf, Gao, & Gray, 2013).

Disability, itself, is a contested issue (Johnstone, 2001). Typically health services are described as having a ‘professional view’ of disability (Reindal, 1999), where the disability is conceptualised as arising as a result of impairment. A person with an impairment is therefore limited in their participation in activities and the goal of typical health services is to remediate or rehabilitate that impairment. Disability scholars and activists, on the other hand, present a contrasting commentary where disability is conceptualised as due to an environment which does not take account of difference (Reindal, 1999; Oliver, 1990; Goble, 2014).

This research specifically sought the lived experience of women in the UK and Ireland about their experiences of pregnancy, childbirth and early parenting, with a view to examining feelings of dignity and respect.

Methods

A qualitative, narrative approach was used where women were interviewed over the telephone or Skype, to elicit the ‘story’ or narrative of their experiences. A semi-structured format was used that involved asking women to recount their experience throughout the pregnancy continuum and specific questions were asked about how they felt about care. They were also asked about what advice they would give care providers, based on their experience.

Ethical approval for the study was obtained from the University’s Research Ethics Committee (Ref 11752). Consideration of equity of participation was considered and information about the study was available in a range of accessible and electronic formats (including large and clear print, screen-reader and assistive technology accessible text and British Sign Language videos would have been provided if required).

Participants who completed an online survey that preceded this research and is described elsewhere (Hall, Hundley, Collins & Ireland, 2018) were invited to leave contact details at the end of the survey if they wanted to participate in the qualitative research. All participants who left their details were contacted by e-mail using a specific account set up for this research. Women from the UK and Ireland were invited to participate. Recruitment aimed to be purposive, to include women with different disability experiences, one or more children and ideally with different experience of care. The women had received recent maternity service care. Exclusion criteria included those unable to participate in an interview using English or British Sign Language and those who had not taken part in the quantitative study. Though specific attempts were made, it was not possible to recruit D/deaf participants. From a total of 21 potential participants, 10 agreed to be interviewed. No participants withdrew once interviewed.

A relationship was established with interviewees prior to the interviews through e-mail, and in some cases, telephone conversations where [author 4 initials] introduced herself and detailed participant information was provided. Participants were informed that the interviewer was a female midwife. Interviews were undertaken using Skype or telephone to allow a larger geographical spread of participants. Interviews were conducted by [author initials], an experienced midwife. The design of the semi-structured interview was compiled by all authors and [author initials] provided training on disability issues, in which potential assumptions and bias were discussed. The interview questions were derived from experiences with narrative research, where participants were asked to narrate their lived experience and also from findings of the 2013 Birthrights study that specifically sought to ask about dignity in childbirth.

Most participants were in their own homes for the interviews, where there was no-one other than the participant present. One interview took place in a private room in the participant's workplace and another interview took place as the participant was walking to work. These arrangements were made to facilitate participants. The interviewer was located in a private room in the University. Only one participant was interviewed over two separate occasions, all other interviews took place in one sitting. Participants were offered the opportunity to be interviewed repeatedy or for shorter times if that would have suited their needs.

Each interview was audio recorded and transcribed verbatim. The interviews lasted between forty minutes and one hour. The decision was made by the research team not to return transcripts to participants due to the team's inability to support participants should they become upset when reading these alone. Also, as some of the participants have low/no vision or experience fatigue, it was felt that provision of transcripts would be an undue request for participants. All participants were offered a summary of findings, once these were compiled and were informed of the decision not to provide transcripts as a means of member-checking.

Transcripts were independently analysed by hand using a system of open coding by [author initials], both experienced qualitative researchers. These initial codes and themes were compared and more detailed intra- and inter-thematic analysis was undertaken by [author initials]. Once the coding tree was created, this was discussed with the research team. While the interview schedule does provide some direction about themes, and particularly sought the experiences in relation to dignified care, many themes (such as communication, feeling listened to, needing to be enabled to make choices, continuity of carer etc) were generated inductively from transcripts rather than being sought in advance.

The researchers reflected on their role in the research, particularly the interaction between different experiences of service provider, researcher and disabled parent, throughout the research process. The topic of dignity was the focus as this was of concern to Birthrights, the charity that part-funded the research and it was a direct follow-on to their previous work and the quantitative aspect of this study.

Findings

Participants

Ten women participated in the semi-structured telephone or Skype interviews. All had a physical or sensory disability and had one or more children. Pseudonyms are used and personal details are removed to protect their identities.

- Ella was visually impaired; her narrative included experience during two pregnancies. Her second child died soon after birth due to a complex medical condition.
- Freya was visually impaired, had a medical condition characterised by fatigue and experienced severe pelvic girdle pain (PGP) during her pregnancy. Her son was two years old.
- Geraldine was blind and described her experience with her third pregnancy. She booked into services late in the pregnancy to avoid the need to decline features of care which she did not want.
- Holly had a mobility impairment and experienced anxiety. She described her experience with her first child.
- Immy has had a form of arthritis since early childhood. She was very aware about how it can affect pregnancy and childbirth. She described the birth of her first child, who was two and a half at the time of interview.

- Jane had joint hypermobility syndrome but did not like to consider herself as ‘disabled’. Jane described her experience with her first child.
- Kate had multiple sclerosis (MS) and chose to have an elective caesarean section. She described her first pregnancy.
- Louise had a physical disability. She primarily spoke about her most recent, third, pregnancy, although did contrast this with previous experiences.
- Mandy had a physical disability and experienced severe PGP during pregnancy. She described her experiences with her first child, who was born by emergency caesarean section.
- Naomi and her husband were both disabled. Naomi used a wheelchair outdoors. She described the experience of her second pregnancy; her first child was stillborn.

Overarching Themes

The overarching theme from the women’s narratives is that effective communication is essential to promoting dignity. Women described their dignity and rights being best respected when they felt that they were listened to, were enabled to make informed decisions about their care (and when those decisions were respected) and when they were treated as an individual. Throughout all of the narratives, continuity of midwifery carer was described as the best way to promote effective communication.

While other themes were identified, such as the importance of physically accessible facilities, specific needs (due to disability) during pregnancy, childbirth and parenting and the longer-term impacts of experience, these are beyond the scope of this paper and have been described elsewhere (Hall et al. 2018a; Hall et al. 2018b).

The theme of the importance of communication was evident in every single narrative and can be broken down into sub-themes, some of which overlap, as depicted in figure 1.

[Insert figure 1 in here]

Feeling heard

In their narratives, each of the participants described the importance of being listened to and feeling that they were heard. As each participant has long-term experience of disability, some since birth and others for several years, they each felt that they had an expertise in their own bodies and condition and that this needed to be heard. The women wanted the option to discuss their circumstances, their hopes for their pregnancy, birth and parenting and to discuss options for their care. They gave examples of when they felt that they could communicate well with care providers and also challenges and repercussions of when communication was not effective.

Several participants described feeling that their care providers did not give adequate time or attention to listening to them or hearing their disability-related experience. Some participants acknowledged that care providers may be reluctant to discuss disability, but Geraldine, Immy, Jane and Ella explained that it is more important that care providers attempt to listen and that the impact of their impairment is discussed openly; not discussing disability can cause problems.

> I would [have preferred to discuss being blind and coping strategies] if it had set people's minds at rest. Rather than having to make phone calls saying, well why am I having a risk assessment, what is going on? It would have been much nicer to just to be able to sit down and talk about things I think. (Geraldine)

Jane did not feel that she was being listened to or understood but she did feel that she had some control. She described the feeling that midwives were 'humouring' her rather than understanding her. When, in the course of the interview, she was asked how she felt about being 'humoured' she described not really minding, because at the end, she could access the care that she wanted.

> you could tell they were humouring me because obviously they all knew how long my first labour was and then they actually broke the waters for me and then I got into the pool and even that they were saying 'we're doing this just to make you feel a bit better' (Jane)

Some of the participants described expecting that they would be listened to. For example, Immy describes assuming that she would be treated respectfully as an expert on her own body.

> [My] expectation was that I would be listened to. I have had my disability all my life and know how my body works. (Immy)

Her experience, however was not as she expected. Rather, she was asked to physically demonstrate her ability to move into specific positions, particularly lying on her back with her legs parted, to satisfy care providers rather than being for her benefit. She did not intend to give birth in this position and had explained this to care providers. She did not feel that care providers listened to her rationale for the choice of a birth centre as her birthplace. The experience of needing to demonstrate positions to be able to have choice in place of birth undermined her dignity; and she explicitly describes this as disrespectful care.

> that particular doctor, wouldn't take my word for it… I remember saying 'I'm a grown woman' [laughs] I know how my body works. I just felt I wasn't being very well respected at that particular moment in time… I think I left the room thinking 'is that the way you speak to everyone?' Because it wasn't kind. I didn't find her kind, I didn't think she listened to me and I do think those things are important. Not just to women, to everyone. You want to be listened to; you want your healthcare professionals to listen … the only reason that I wanted to go to the midwife-led unit was because I felt that it would be a good environment for me and I'd be comfortable (Immy)

Holly described a similar experience: she felt that no matter what she asked for, and no matter how rational her request was, that it would be ignored. Her feeling was that she did not have control or choice in the decisions, and, like Immy, she felt that her dignity and knowledge of her own body was undermined, resulting in her perception that care was undignified.

> you kind of think they're, they're the midwives they should know but certainly I did not feel respected, I did not feel erm that you know my that my wishes were being respected, that my dignity was being respected, that my erm physical limitations were being respected (Holly)

Some of the women described feeling let down when their wish to discuss things of importance to them were dismissed or ignored. Holly gives an example below:

> Even things like the birth plan… it's not so much about me saying I want to be wearing my pink pyjamas and having [music] playing in the background, it's really about the different pain killers and not only their effect at the time… it's I guess it's going through things one to one in more detail than the antenatal classes have time for (Holly)

Naomi expressed frustration at the lack of recognition of her knowledge and preparation for parenting.

> the first thing they can do is actually listen to the parents, not listen with their agenda. Listen to what they have planned and what they are going to do because the parents know and have worked it out. They have looked at the fact that they can't do X, Y and Z. As a disabled person, everything in your life is planned out… you have to plan things out in a much bigger way… Not once did they listen to a word we said (Naomi)

Naomi's example highlights how women in the study described their needs due to disability. Immy, Holly, Freya, Kate and Geraldine all made decisions about the birth of their child based on their disability experience. Their choices were not simply preferences but are described in their narratives as considered decisions based, at least in part, on the impact of disability. The frustration described relates to this decision-making and their experience of disability not being listened to or respected. Freya, Geraldine, Naomi and others highlight that communication needs to be meaningful and supportive, whereas some questions were being asked out of interest of the care provider rather than to support the woman. Freya described this as an 'inquisition' and 'really quite stressful'.

Immy described an example of good communication, where she did feel listened to, respected and supported. The key element of this seems to be that the care provider took time to be with her and respected her – the language, as quoted below of 'she didn't fob me off' highlights her (and the other women's) need to be taken seriously and respected.

> She didn't fob me off, she came round straight away and she really listened to me. … She gave me that time, because she was listening to me…. actually feeling that someone is listening to you…. that makes a massive difference. (Immy)

Drawing from the narratives, being heard means that the women's expertise in their own bodies and disability needs to be respected and actively listened to by health care providers. Women said they needed an acknowledgement that their concerns and choices were recognised and that their own judgements on the best type of care for them are taken seriously. This idea of women's choices and concerns being listened to overlaps with the next subtheme that emerged: women needed the opportunity to discuss options to make informed choices about the care they would receive.

Being able to make informed choices

Alongside women being listened to, each of the narratives included examples of when women wanted support to make informed choices. This not only involved space and time to explain their situation, but, in some cases, also required the care provider to have some knowledge of disability. A lack of knowledge of disability and its impact on pregnancy, childbirth and early parenting is almost universally described in the narratives of the participants.

Kate described how she wanted to have the opportunity to discuss the specific impact that MS could have on pregnancy and childbirth. She described experiencing poor communication – not only with her but also between professionals. She wanted support to decide whether or not to have an elective caesarean section, due to fatigue being a major element of her condition. While she felt listened to, the care providers had limited understanding of MS and therefore could not support her to make informed choices. Her recommendation was that there should be someone available who understands both disability and pregnancy so that they can provide advice, rather than the decision, 'being left up to you' (Kate).

Staff's lack of knowledge or understanding of disability had negative implications for participants. Several participants described negative attitudes or assumptions about how they would be able to manage pregnancy, childbirth and parenting. As Geraldine described, this can be any member of the multi-disciplinary team and is often due to not even being asked about disability. In some cases, participants described misunderstandings about disability that led to them being excluded from aspects of care.

When health care providers did ask about how women will manage parenting, particularly when this is done in an open and supportive manner, it was helpful. For Louise, this was done early in the pregnancy and additional equipment for home was provided.

Enabling women's choices to be respected

The women described the importance of feeling heard, being able to discuss their options and then wanted their choices to be respected. This was not always the case. A perceived lack of respect for the women's choices and the poor communication was described by six of the women and directly linked to perceptions of reduced dignity, lack of respect and/or controlling care.

> I have realised now how much we are, em that we're not *allowed*, that's the word that keeps cropping up. That we're not *allowed* to have the birth that we want to have… if you add disability you are funnelled off into this controlled sort of manner, (Ella)

> I needed to choose the position that best suited me, but I wasn't listened to (Holly)

While Ella described a perception of being allowed or not allowed aspects of care or choices, Others, such as Kate described the importance of a woman being assertive in asking for the care they feel would suit them best.

> I think like if someone is not a bit strong willed or something they might easily end up doing something that they are not 100% comfortable with (Kate)

> Yeah it's getting to a point of unless you are going to fight… I think it's a lot of: you need to know what you want before you get pregnant and then you need to have it all lined up. It's constant pushing for choice when we shouldn't have to. (Ella)

Some of the women such as Holly, felt that despite being assertive and stating what she wanted, she was not listened to. Others, such as Jane, felt that staff thought she was ‘stubborn’ for asking for what she wanted, even though this, in her view, was due to disability. Further, others, such as Freya and Gemma, describe being assertive and ‘sticking to your guns’ and that meant that they did have a birth that worked for them and also that resulted in a sense of pride.

> they very much treated me as someone who was very stubborn really… I think that is the kind of attitude, it was that they felt that I had this kind of complete birth plan in my head of how I wanted a natural birth. Well I wanted a natural birth because I know what I cannot tolerate, I have never been able to tolerate any sort of umm [medication] really (Jane)

> I’m glad I had confidence in my decisions and that I wasn’t afraid to tell people that that was what I wanted. (Freya)

This was in contrast to the experience Louise described. She described a conversation with her midwife and then being provided with the opportunity to find out what facilities would physically work for her.

> my midwife is brilliant, I wasn’t sure whether I could get in or out [of the birthing pool]so she actually arranged for me nearer the time umm to go out and try the water birth at the water birth pool with a member of staff at the maternity hospital to see that I was comfortable there and if I could comfortably get in and out. They were brilliant, I went for it and it was fine (Louise)

Being treated as an individual

While the language of individualised care was not used by the women, they did describe situations in which different care or treatment could have better met their needs. In some cases, this was directly related to disability, for example, access to printed information for blind and partially sighted women. Being treated as an individual, to the participants, meant accepting that the women do have different needs, often due to disability.

For some participants, extra support or a change in ‘normal’ process was needed.

> after I gave birth they actually let my partner stay with me because umm I needed his care after birth because obviously it was very difficult for me to walk and they made sure I had an en-suite room with the baby and my partner to stay in one room and which is absolutely fantastic and if I didn’t tell them I wouldn’t have got that (Louise)

Being treated like an individual was perceived differently by participants. Some, such as Holly, argued that treating each woman differently should be the norm, and that different treatment could be positive, as women’s different needs are being catered for.

Others, like Ella highlight that being disabled inevitably leads to different treatment and that this is not necessarily positive.

> I would say you’re seen different but then for whatever reason they make assumptions and they assume that you are higher risk or that you are, that was a silly thing you did – and got pregnant. How could you put your, how could you put any child through that? (Ella)

Her experience was that the presence of disability led to assumptions about risk and Geraldine highlighted assumptions being made about challenges the women would have with parenting.

Continuity of carer

The factor that the women highlighted as most important in enabling good communication was continuity of carer. When there was one care provider who could support the woman throughout pregnancy and childbirth, as was the case for Freya, this meant that the women did not need to repeat themselves and repeatedly describe disability.

> As soon as I met her [midwife] on the first meeting and I explained about my eye condition. She was wonderful and she said, ‘it’s not normal in this area to have one midwife throughout but I want to be your midwife so you don’t have to explain it every single time.’ That was fantastic because it meant that I was assigned to her. She understood the condition and what it might mean… she did actually make sure that locations were OK for me to get to so em she kind of tried to understand: could I get on buses?; how far could I walk?; she came to my house quite a few times. (Freya)

A lack of continuity of carer was a particular issue for Ella and Kate , which led to Kate feeling that her care was dehumanising and undignified.

> it was hard seeing a different obstetrician every single time. I think I saw 4 different obstetricians and some were more experienced than others, I mean a lot of them didn’t really have much experience of MS at all. (Kate)

> it's like there's no one there to hold your hand for want of an expression. There's nobody there in your corner, it's up to you. If you are a strong enough person you can fight it but if you're not, you're just going to roll over and let whatever happen and that's only during pregnancy. I mean it gets worse when you get to the hospital to have the actual baby. I mean, you know it's a very confusing, lonely sort of a time unless you have a perfect, picture perfect sort of a pregnancy when you can stay with kind of not having to go near the consultant. (Ella)

Some of the participants provided poignant descriptions of the impact that an undignified birth had on them, long after the birth. This can affect self-confidence, confidence in parenting skills and a lack of confidence in healthcare systems as a whole.

> I question everything now... It has affected me in lots of different ways. What it has affected is my view of the system [crying] more than anything because that's what it is. It's a system and it's a conveyor belt, and you're just the next body, You're not a pregnant woman you're just a body, Because if I was a person to them, if I was a pregnant woman they would have read my file. (Ella)

Discussion

The key finding from the narratives of disabled women was that communication, above all else, enabled or inhibited women to feel that their treatment was dignified and their rights were respected. Communication as a key factor in personalising care is consistently mentioned in reviews of maternity services (National Maternity Review, 2016), but it has particular resonance with this group of women. The women explained effective communication as feeling heard, being able to make informed choices and those choices being enacted. Effective communication enabled women to be treated like individuals and was best enabled by continuity of carer. While the women in this study do have specific circumstances, and a particular perspective, effective communication, personalised care and continuity of carer have been core to strategies to improve the experience for all women (WRA, 2011; WHO, 2018; National Maternity Review, 2016). So, despite disability, a key finding of our work is that getting the 'basics' right for all women would also support disabled women.

The importance of communication, and particularly interpersonal relationships in respectful maternity care is at the heart of the White Ribbon Alliance 'Campaign for respectful care' (WRA, 2011). Therefore, while suggesting the importance of communication in maternity care is not new, what this particular study adds is disabled women's narratives on what actually makes communication effective and how, for them, effective communication is essential in promoting their dignity and rights.

While there were some positive aspects to communication, many of the women described communication as being difficult, potentially due to a mismatch between their expectation that they would be listened to and their expertise and experience with their own disability being respected on the one hand and the reality of the communication that they experienced on the other. The narratives of the participants of this study show a frequent lack of caring or compassionate communication, where women didn't feel listened to or respected and where they felt helpless in the decision-making. The same themes have arisen from women in the

UK National Maternity review, Better Births (Cumberlege, 2016). Beck's definition of disrespect specifically highlights 'poor rapport between women and providers' as a potential element (Beck, 2018), so the women's experiences align with experience for the wider community. However, there were also examples of where communication was described as positive, including when there was some continuity of carer and when professionals took the time to actively listen and respond to the women, as individuals.

Listening to disability experience

The sense that women feel listened to is core to much midwifery practice (WHO, 2018; Cumberlege, 2016; Cheyne, McCourt, & Semple, 2013). However, the women's experience as articulated in their narratives, was that they particularly wanted their experience of disability to be heard and respected. However, all but one of the women in this study suggested that the staff did not have enough knowledge or experience of disability. This finding replicates other studies, such as that by Blackford, Richardson and Grieve (2000) which found that women perceived that there was inadequate information about how pregnancy and childbirth can be affected by disability, and how disability can be affected by pregnancy or childbirth, thus our findings replicate those of others (e.g. Redshaw, Malouf, Gao, & Gray, 2013).

While some of the women in the current study suggested roles such as disability liaison midwives, who have more information on disability, others simply wanted to be treated as experts in their own bodies. Specialist roles may be most helpful for women with relatively common conditions, such as for Kate who has multiple sclerosis. Other women, particularly those with less common or more complex conditions were explicitly not asking for staff to know about the condition; their request was for their own expertise of disability to be valued.

The women in the current study have experience of disability and impairment and therefore have experience negotiating barriers. They wanted this experience to be recognised. The NHS long term plan addresses this through the model of personalised care plans to enable those with complex and long term needs have more control over their health (NHS, 2019). The challenge, however could be that health providers tend to assume a medical model of disability (Reindal, 1999) and therefore attribute the challenges to the underlying impairment rather than a more social model approach where disability is considered to be constructed within socio-cultural and physical environmental contexts (Oliver, 1990). The women in the current study discuss challenges like their underlying disability being questioned rather than their specific needs about pregnancy.

A solution to this may be to enable care providers to have further information on different disability orientations (Darling & Heckert, 2010), which can be understood as an individual’s understanding of their disability and the norms they accept (McCormack & Collins, 2012). Note, the suggestion is to understand the way women may perceive their disability, not care providers being experts in disability themselves. This may help care providers appreciate that, as with any diverse client group, disabled women will have different conceptualisations of what disability means and will consequently benefit most from approaches that suit their own perspective. Similarly, midwifery education should recognise that individualised care for disabled women may involve understanding a woman’s perception of her disability (Smelzer, 2007).

Enabling informed choices

Another important aspect of being heard, as discovered in the current study, is that women wanted informed conversations, with care providers that understand disability. Currently, the literature suggests that disability experts are rare in maternity practice, so the women do not have anywhere to go to discuss their ideas. The finding that midwifery service providers typically lack awareness of disability has been discussed by others, such as McKay-Moffet (McKay-Moffat & Cunningham, 2006); lack of awareness was clearly a concern for the women of this study, but a greater concern seemed to be that their own experience and the rationale for their choices were not being fully respected. Suggestions of a liaison midwife were made, however the challenge with this approach could be the marginalisation of disabled women into 'special' care rather than adapting standard care to meet the needs of all women, as suggested by Ella and others in this study. Several studies already suggest disabled women have less choice, particularly in childbirth (e.g. Redshaw et al., 2013), relying on specialist services rather than better communication in standard services could further restrict choice.

Individualised care

Choice for women in maternity care has long been argued as essential (Cumberlege, 2016; Department of Health [DoH], 1993), however this study highlights that, for disabled women, this is only meaningful if the choices can be enacted and are made in the context of informed discussions, where disability experience is recognised and valued. The importance of enacting choice links to individualised care, where women have different needs and choices and therefore neeed and want to be treated as individuals. Further, 'reasonable adjustments' or changes to normal practice may be required and should be provided to ensure equitable treatment (Equality Act, 2010), as requested and indeed experienced by some of the women in this study.

Continuity of carer

The women indicated that their needs were met more effectively when they received continuity of maternity carer. The current maternity transformation programme across the countries of the UK place continuity of carer as a priority for all women (National Maternity Review, 2016; Healthcare Inspectorate Wales, 2019; The Scottish Government, 2017). For disabled women, this may mean that they do not need to repeat themselves and discuss aspects of disability repeatedly, which has also been echoed in other studies (Redshaw et al., 2013) .

Impact of less dignified care

While dignity may be conceptualised differently in dissimilar birthing conditions and countries, the importance of good communication and respect have been commonly discussed (Birthrights, 2013; McKay-Moffat & Cunningham, 2006). In the global context, disrespect and abuse often deter women from attending facilities for birth (Milne et al., 2015). While the women in the study did not describe disrespect leading them to avoid services (possibly with the exception of Geraldine, who decided to access services late to avoid needing to decline care that she did not want) in this high-income context women were describing disrespect. However, establishing services centred on respectful care will recognise the accessibility needs for all persons and create facilities and services where women feel welcome and valued (Newburn & Singh, 2003). For disabled women lack of respectful care has had a long term impact that is remembered as a negative experience.

Limitations

The participants in this study self-selected from the preceeding quantitative aspect of the research. and therefore there is potential for selection bias. They may have agreed to participate in the survey and/or in stage 2 as they had a particular experience or interest in the topic. While this study does not attempt to be generalisable, we do recognise that there may a wide range of alternate perspectives that have not been uncovered in the current work. The use of Skype and telephone interviews may have also impacted on the quality of the discussions, it may have been more challenging to elicit the full, rich experiences of women by telephone whereas it may have been easier face-to-face. The interviews however did reveal aspects of maternity services that could be improved for disabled women. Future research could involve more specific targeting of women with specific impairment experiences.

Conclusions

The narratives of ten women with physical disability highlight the importance of good communication to enable them to feel that they have respectful care during pregnancy, childbirth and early parenting. Good communication is conceptualised as enabling women to feel ‘heard’, make informed decisions about their care and respecting their choices.

While good communication is essential for all women, and the UK maternity strategy has highlighted the importance of individualised care (National Maternity Review, 2016; Healthcare Inspectorate Wales, 2019; The Scottish Government, 2017), this is particularly important for women with disability. Strategies to enhance these women’s experience could be facilitated through practical steps such as providing a liaison midwife and continuity of carer. Fundamentally, however, we conclude that getting the basics right for all women, including good communication, listening to the woman and her unique circumstances and following through with consistency of carers would support disabled women in the same way that it would support the dignity and rights of all women accessing maternity services.

References

Beck, C.T. (2018). A Secondary Analysis of Mistreatment of Women During Childbirth in health Care Facilities. *JOGNN, 47(1)*, 94-104. doi: https://doi.org/10.1016/j.jogn.2016.08.015

Birthrights. (2013). *Dignity in Childbirth: The Dignity Survey 2013: women's and midwives' experiences of UK maternity care*. Retrieved from: http://www.birthrights.org.uk/wordpress/wp-content/uploads/2013/10/Birthrights-Dignity-Survey.pdf

Blackford, K., Richardson, H. and Grieve, S. (2000). Prenatal Education for mothers with disabilities. *J Adv Nursing, 32,* 898-904.

Bohren, M.A., Vogel, J. Hunter, E, Lutsiv, O., Suprita, K., Souza, J. P., … Gülmezoglu, A.M. (2015). The mistreatment of women during childbirth in health facilities globally: a mixed methods systematic review. *PLoS Med, 12(6),* 1750-1763. doi: https://doi.org/10.1016/S0140-6736(19)31992-0

Bowser D., Hill K. (2010). Exploring Evidence for Disrespect and Abuse in Facility-Based Childbirth. Report of a Landscape Analysis. *USAID-TRAction Project,* Harvard School of Public Health and University Research Co., LLC; 2010 September 20.

Cheyne, H., McCourt, C., & Semple, K. (2013). Mother knows best: Developing a consumer led, evidence informed, research agenda for maternity care. *Midwifery, 29 (6),* 705-712.

Cumberlege, J. (2016). *Better Births. Improving outcomes of maternity services in England. A Five Year Forward View for maternity care.* Retrieved from: england.nhs.uk/wp-content/uploads/2016/02/national-maternity-review-report.pdf

Darling, R.B., & Heckert, D.A. (2010). Orientations toward disability: differences over the lifecourse. *International Journal of Disability, Development and Education, 57(2),* 131-43.

Department of Health Expert Maternity Group. (1993). Changing Childbirth: Report of the Expert Maternity Group, Part 1, H.M. Stationery Office.

Department of Health. (2015) *The Handbook to the NHS constitutionfor England.* Retrieved from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/474450/NHS_Constitution_Handbook_v2.pdf

Department of Health (Ireland), (2016) *National Maternity Strategy – Creating A Better Future Together 2016-2026* https://assets.gov.ie/18835/ac61fd2b66164349a1547110d4b0003f.pdf

Equality Act. (2010). Retrieved from: http://www.legislation.gov.uk/ukpga/2010/15/contents

Freedman, L. P., & Kruk, M. E. (2014). Disrespect and abuse of women in childbirth: challenging the global quality and accountability agendas. *Lancet, 384(9948),* e42–e44. doi: https://doi.org/10.1016/S0140-6736(14)60859-X

Goble, D. (2014). Dependence, Independence and Normality. In J. Swain, S. French,C. Barnes, & C. Thomas (Eds), *Disabling Barriers – Enabling Environments* (3rd ed). London: Sage.

Government of Ireland, (2000). *Equal Status Act* Dublin: Stationery Office

Government of Ireland, (2005). *Disability Act* Dublin: Stationery Office

Hall, J., Collins, B., Ireland, J., & Hundley, V. (2018b). *The Human Rights & Dignity Experience of Disabled Women during Pregnancy, Childbirth and Early Parenting.* Centre for Midwifery Maternal and Perinatal Health, Bournemouth University: Bournemouth.

Hall, J., Hundley, V., Collins, B., & Ireland J. (2018a). Dignity and respect during pregnancy and childbirth: a survey of the experience of disabled women. *BMC Pregnancy and Childbirth, 18 (328),* 1-13. doi: https://doi.org/10.1186/s12884-018-1950-7

Healthcare Inspectorate Wales. (2019) National review of maternity services. Retrieved from: https://hiw.org.uk/national-review-maternity-services

Heideveld-Gerritsen M, van Vulpen M, Hollander M, Oude Maatman S, Ockhuijsen H, van den Hoogen A. Maternity care experiences of women with physical disabilities: A systematic review. Midwifery. 2021; 96:102938.

International Confederation of Midwives [ICM]. (2019). *Essential competencies for midwifery practice 2019 update*. Retrieved from: https://www.internationalmidwives.org/assets/files/general-files/2019/10/icm-competencies-en-print-october-2019_final_18-oct-5db05248843e8.pdf#:~:text=The%20International%20Confederation%20of%20Midwives%20%28ICM%29%20Essential%20Competencies,midwife%20as%20defined%20by%20ICM1when%20entering%20midwifery%20practice.

Johnstone, D. (2001). *An introduction to disability studies* (2nd ed). London: David Fulton Publishers.

Kay, L. & Calonder, C. 2019. 'dis ɔhord' : one woman's experience of confronting and understanding the lived experience of birth. *MIDIRS Midwifery Digest*, *29(1)*, 90-94. ISSN (print) 0961-5555. https://eprints.kingston.ac.uk/42613/1/Kay-L-42613-AAM.pdf

Lipson. J.G., & Rogers, J.G. (2000). Pregnancy, birth and disability: women's health care experiences. *Health Care Women Int, 21,* 11-26.

McCormack C & Collins B (2012) The affirmative model of disability: a means to include disability orientation in occupational therapy? *British Journal of Occupational Therapy 75(3), 156-158. doi:10.4276/030802212X13311219571909*

McKay-Moffat, S., & Cunningham, C. (2006). Services for mothers with disabilities – mothers' and midwives' views. *British Journal of Midwifery, 14(8),* 272- 477.

Milne, L., van Teijlingen, E., Hundley, V., Simkhada, P., & Ireland J. (2015). Staff perspectives of barriers to women accessing birthing services in Nepal: A qualitative study. *BMC Pregnancy and Childbirth, 15(142)*. doi: https://doi.org/10.1186/s12884-015-0564-6

Miltenburg, A.S., van Pelt, S., Meguid, T., & Sundby, J. Disrespect and abuse in maternity care: individual consequences of structural violence. *Reproductive Health Matters* 2018; 26(53), 88-106. doi: https://doi.org/10.1080/09688080.2018.1502023

National Maternity Review. (2016). *Outcomes of maternity services in England A Five Year Forward View for maternity care.* Retrieved from: https://www.england.nhs.uk/wp-content/uploads/2016/02/national-maternity-review-report.pdf

Nawab, T., Erum, U., Amir, A., Khalique, N., Amsari, M.A., & Chauhan, A. (2019). Disrepect and abuse during facility-based childbirth and its spociodemographic determinants – A barrier to healthcare utilization in rural population. *Journal of Family Medicine and Primary Care, 8(1)*, 239-245. Doi: 10.4103/jfmpc.jfmpc_247_18

Newburn, M., & Singh, D. (2003). Creating a better birth environment: Women's views about the design and facilities in maternity units: a national survey. *The National Childbirth Trust.* Retrieved from: https://www.nct.org.uk/sites/default/files/related_documents/BBE_report_311003.pdf

NHS England.(2017). *National Review of Maternity Services: Assessment of Quality in Maternity Services*. Retrieved from: https://www.england.nhs.uk/wp-content/uploads/2015/07/Assessment-of-Quality-in-Maternity-Services.pdf

NHS. (2019). The NHS Long Term Plan. Retrieved from: https://www.longtermplan.nhs.uk/publication/nhs-long-term-plan/

NMC. (2018). NMC The Code: Professional standards of practice and behaviour for nurses, midwives and nursing associates. Retrieved from: https://www.nmc.org.uk/standards/code/

Oliver, M. (1990). *The politics of disablement*. London: Macmillan Education.

Redshaw, M., Malouf, R., Gao, H., & Gray, R. (2013). Women with disability: the experience of maternity care during pregnancy, labour and birth and the postnatal period.*BMC Pregnancy and Childbirth, 13(174)*, 1-14. doi: https://doi.org/10.1186/1471-2393-13-174

Reindal, S. M. (1999). Independence, Dependence, Interdependence: some reflections on the subject and personal autonomy. *Disability & Society, 14*, 353-367.

Shakibazadeh, E, Namadian, M., Bohren, M.A., Vogel, J. P., Rashidian, A., Nogueira Pileggi, V., ... Gülmezoglu, A.M. (2018). Respectful care during childbirth in health facilities globally: a qualitative evidence synthesis. *BJOG*, *125(8)*, 932-942. doi:10.1111/1471-0528.15015

Smelzer, S.C. (2007). Pregnancy in Women With Physical Disabilities. *JOGNN, 36 (1),* 88-96.

The Scottish Government. (2017). The Best Start: A Five-Year Forward Plan for Maternity and Neonatal Care in Scotland. Retrieved from: https://www.gov.scot/publications/best-start-five-year-forward-plan-maternity-neonatal-care-scotland/pages/0/

United Nations Universal Declaration of Human rights. (1948). Retrieved from https://www.un.org/en/universal-declaration-human-rights/index.html

Vogel, J.P., Bohren, M., Tunçalp Ö., Oladapo, O.T., Adanu, R.M., Baldé, M.D., Maung, T.M., … , WHO Research Group on the Treatment of Women During Childbirth. (2015). How women are treated during facility-based childbirth: development and validation of measurement tools in four countries - phase 1 formative research study protocol. *Reprod Health*, *12 (60)*, 1-11. doi: 10.1186/s12978-015-0047-2.

White Ribbon Alliance [WRA]. (2011). *Respectful maternity care: The universal rights of childbearing women.* Retrieved from: http://whiteribbonalliance.org/wp-content/uploads/2013/10/Final_RMC_Charter.pdf

World Health Organization [WHO]. (2018). *WHO recommendation on respectful maternity care during labour and childbirth*. WHO: Geneva. Retrieved from: https://extranet.who.int/rhl/topics/preconception-pregnancy-childbirth-and-postpartum-care/care-during-childbirth/who-recommendation-respectful-maternity-care-during-labour-and-childbirth

World Health Organization [WHO]. 2014. *WHO statement on the prevention and elimination of disrespect and abuse during facility-based childbirth.* Available at: http://apps.who.int/iris/bitstream/10665/134588/1/WHO_RHR_14.23_eng.pdf?ua=1&ua=1

Table 1 Tackling Disrespect and Abuse: Seven Rights of Childbearing Women

Category of Disrespect and Abuse	**Corresponding Right**
1. Physical abuse	Freedom from harm and ill treatment
2. Non-consented care	Right to information, informed consent and refusal,and respect for choices and preferences, including the right to companionship of choice wherever possible
3. Non-confidential care	Confidentiality, privacy
4. Non-dignified care (including verbal abuse)	Dignity, respect
5. Discrimination based on specific attributes	Equality, freedom from discrimination, equitable care
6. Abandonment or denial of care	Right to timely healthcare and to the highestattainable level of health
7. Detention in facilities	Liberty, autonomy, self-determination, and freedomfrom coercion