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1 **Title : Dignity and respect during pregnancy and childbirth: a survey of the**

2 **experience of disabled women**

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Title : Dignity and respect during pregnancy and childbirth: a survey of the experience of disabled women

Abstract:

Background: Despite the increasing number of women with disability globally becoming pregnant, there is currently limited research about their experiences. A national survey of women's experience of dignity and respect during pregnancy and childbirth raised concerns about the possibility of women with disability having unequal care with overall less choice and control. To address this further we conducted a study to explore the experiences of dignity and respect in childbirth of women with disability.

Methods: The study involved a self-selecting, convenience sample of 37 women who had given birth in the United Kingdom and Ireland and had completed an internet-based survey. Women were identified through online networks and groups of and for disabled parents and for people with specific medical conditions. Data were collected using an online survey tool. Survey data were analysed using descriptive statistics. Thematic analysis was used for open questions.

Results: Despite generally positive responses, just over half of the group of women expressed dissatisfaction with care provision. Only 19% thought that reasonable adjustments or accommodations had been made for them (7/37). When reasonable adjustments were not in place, participants' independence and dignity were undermined. More than a quarter of women felt they were treated less favourably because of their disability (10/37, 27%). At all points in the pregnancy continuum more than a quarter of women felt their rights were either poorly or very poorly respected; however this was greatest in the postnatal period (11/35, 31%). In addition, more than

half of the women (20/36, 56%) felt that maternity care providers did not have appropriate awareness of or attitudes to disability.

Conclusions: Women’s experiences of dignity and respect in childbirth revealed that a significant proportion of women felt their rights were poorly respected and that they were treated less favourably because of their disability. This suggests that there is a need to look more closely at individualised care. It was also evident that more consideration is required to improve attitudes of maternity care providers to disability and services need to adapt to provide reasonable adjustments to accommodate disability, including improving continuity of carer.

Keywords: Disability: pregnancy; childbirth; human rights; internet survey; continuity of carer

Background

It is estimated that approximately 21% of the population in the United Kingdom (UK) has a disability, with the most common groups of disabilities reported being those associated with mobility, fatigue and mental health (1). Women are more likely than men to report disability and the prevalence rises with age (1). Among women of childbearing age the prevalence of disability is believed to be between 6-10% (2). However, identifying the number of women who would be considered 'disabled' is challenging, as in most health systems information about women with disability specifically is not gathered (3, 4).

Disability is regularly defined in contexts related to impairments, activity limitations, participation restrictions, and environmental factors (5). However, the World Health Organization (WHO) definition of disability has recently been revised from a disease focus to one that emphasises health. This change of focus is significant when considering pregnant women with disabilities. In a biopsychosocial model of disability, providers recognise that women with disabilities are knowledgeable about their disability, full partners in decision making and the experts on how their own bodies respond; having had their own lived and individual experience (6). Several studies highlight the following problems identified by women with disabilities: access; information; communication and choice (2, 7).

There are different 'models of disability' or theoretical positions that underpin divergent perspectives on disability such as whether disability is viewed as an individual or social phenomenon. Disability activists, for example, reject the WHO classification of disability and instead propose that while impairment is individual to the person, disability occurs due to barriers within the physical and social environment (8). It could be argued, therefore, that within a social or rights-based disability

86 model a person is ‘disabled’ by society; that is she is seen as a ‘disabled woman’ rather than a
87 woman who has a disability.
88
89 There has been considerable dialogue around access to health and social care for disabled
90 individuals (9), but reports rarely mention disability in relation to care at the time of birth. Studies
91 have examined interventions targeted at improving support for women with disability with children
92 (10) and access to care for women with disability affected by domestic abuse (11), but less is known
93 about the general experiences of maternity care and the issues encountered by women who are
94 disabled. A recent secondary analysis of a national survey conducted in England found that in many
95 areas there was no difference in the care that disabled and non-disabled women received (2).
96 However, the survey did identify the need for better communication in the context of individualised
97 care. There is some evidence that suggests that women with disability do not feel that staff have
98 adequate knowledge about their needs (12) and health carers have also identified a 'lack of
99 competence, knowledge and skill' around disability as well as not recognising that they may not be
100 providing individualised care to women (13).
101
102 Patient-centred care, that is compassionate and individualised care, has been the focus of a number
103 of studies and reports. In relation to maternity care, one study used data from a national survey to
104 identify evidence of concerns about care (2). Redshaw et al’s study was completed prior to the
105 report from the Mid-Staffordshire public inquiry, which highlighted serious failures in care at one
106 hospital and the lack of a “patient centred culture” across the National Health Service in the UK (14).
107 Their study also preceded the development of the UK strategy of developing compassionate care in
108 health services, which aimed to put patients first (15). These studies and reports have had a
109 significant impact on UK practice and are now intended to underpin nursing and midwifery care. The
110 recent National Maternity Services review in England (16) identified that women require care that is
111 individualised to their needs, autonomy in the choices they make and continuity provided by a

112 relationship with a known small group of midwives. Though not focused on women with disability,
113 this highlights that current organisation of services is not meeting all women's requirements or
114 expectations.
115
116 In 2013 Birthrights conducted the first large-scale maternity survey in the UK to focus exclusively on
117 women's experience of dignity and respect during pregnancy and childbirth. Although the *Dignity in*
118 *Childbirth Survey* did not set out specifically to examine the experiences of women with disability,
119 the survey findings indicated that the small number of women who identified themselves as disabled
120 appeared to have unequal care with less choice and control over their experience, including less
121 information and reduced choice in pain relief (17). The survey concluded that further research was
122 needed and with this in mind Birthrights collaborated with Bournemouth University to explore the
123 experience of women with disability throughout pregnancy, childbirth and the first few post-natal
124 weeks (the pregnancy continuum). The study had two consecutive phases: an initial quantitative
125 survey, to identify the experiences of women in the UK and Ireland with physical or sensory
126 impairment during the pregnancy continuum, and a follow-up qualitative study to establish in-depth
127 views and experiences of human rights and dignity in maternity care of a self-selecting group of
128 women. This paper describes the findings from the quantitative survey.
129
130 **Aim**
131 The aim of the study was to explore the experiences of dignity and respect in childbirth of women
132 with disability
133
134 **Methods**
135 The study involved a self-selecting, convenience sample of women who had given birth in the UK
136 and Ireland and who completed an internet-based survey. Women were invited to participate
137 through online networks and groups of and for disabled parents, and for people with particular

medical conditions (such as arthritis, multiple sclerosis, spinal cord injury and chronic fatigue syndrome). The self-selected sample was therefore drawn from the population of women who identified themselves as having a physical or mobility impairment, sensory impairment (such as impaired vision or hearing) or a long-term health condition that impacts on their daily life (such as chronic fatigue). As the specific needs of women with conditions related to emotional and psychological wellbeing would present different factors, and there are a range of specific perinatal mental health services already in place, this group was not included in the study. Similarly women with learning disabilities were excluded.

The research team recognised that it would be challenging to access a distinct population of women with disability who had experienced the pregnancy continuum. Since sampling from mainstream maternity services would lead to few participants available from a large volume of contact, women were recruited through organisations of and for disabled women / disabled parents and through social media networks. A list was compiled to include umbrella disability organisations, those that focus on one type of disability (e.g. Blind Mums Connect) and those for people with specific medical conditions (e.g. people with spinal cord injury). They were contacted by e-mail and through social media (including Twitter and Facebook) and asked to circulate the link to the online survey. Birthrights and other organisations focusing on maternity care also shared Tweets to inform potential participants of the study.

Data were collected using an open online survey tool delivered through Bristol Online Survey in 2016. The survey was based on the Birthrights' *Dignity in Childbirth Survey*, which was used with a large population of pregnant women including women with disabilities (17). The online format of the survey was designed to be accessible for participants who use assistive technology and supplementary information on how to access the survey was provided in a range of formats. There was a total of eight screens (pages) in the survey with an average of four items per page.

164 Respondents were able to review and change their answers through the use of a Back button. The
165 survey link was distributed via social media sites, and through connections via email to groups and
166 charities related to disability. The survey was also available to be answered orally if required, but no
167 one took up this option. The survey contained both open and closed questions relating to dignity,
168 respect, human rights and health equality issues. Questions covered the experience of women
169 during the antenatal, birth and early postnatal periods and related to physical, emotional and human
170 rights experiences. Many free-text boxes were also provided to enable opportunity to respond more
171 fully as required. Neither randomisation of items or adaptive questioning was used within the online
172 questionnaire.
173
174 Ethical approval was obtained from Bournemouth University's Research Ethics Committee.
175 Participant information was available in a range of accessible electronic formats (including large and
176 clear print, screen-reader and assistive technology accessible text; British Sign Language or Irish Sign
177 Language videos would have been provided if required). Consent to participate in the survey was
178 obtained on the landing page where information was provided and individuals were requested to
179 consent by clicking either 'agree to participate' or 'don't want to participate'. Participation was
180 voluntary, and those who did not consent were directed away from the survey to a page thanking
181 them for their time. Confidentiality was protected by ensuring that the survey did not contain
182 personal identification or information that would identify participants, such as names, email or IP
183 addresses. No incentives were offered for completing the survey.
184
185 All data presented in this paper came from the survey. Numerical data were analysed using
186 descriptive statistics. The study was specifically focused on women living in the UK and Ireland;
187 although some international responses to the online survey were received, these were removed
188 prior to data analysis. Thematic analysis was used (18) for open questions, which involved extracting
189 all of the text, open coding and drawing themes. This was completed by the third author and

190 reviewed by the first and second authors. Themes from each question were analysed first, resulting
191 in a small cluster of themes, which were used to provide a summary of the responses to that specific
192 question. Following analysis of all of the open-ended questions, the themes were compared to
193 produce overall themes from the open-ended questions. This enabled a form of constant
194 comparison analysis to be undertaken and differences and discrepancies between responses to
195 questions were explored. While this presentation of the final stage of analysis is not included in this
196 paper, it served to provide nuance and increase trustworthiness of the interpretation of responses
197 to the open-ended questions.
198
199 **Results**
200 A total of 46 surveys were completed, however 5 responses were excluded because they came from
201 women based in the United States of America (n=3) and Canada (n=2). A further four participants did
202 not consider themselves to be disabled or Deaf and so these responses were also excluded. This left
203 37 responses for analysis.
204
205 Participants ranged between 21 and 46 years of age with the majority being aged 30-39 years (Table
206 1). Most women had given birth, but for one woman this was her first pregnancy and she had not
207 yet given birth. Participants were asked how they characterised their primary impairment; most
208 women reported having a physical or mobility impairment. Participants were offered the
209 opportunity to describe their impairment using their own words. The two participants that identified
210 as deaf or hard of hearing simply stated, 'hearing impaired' or 'hard of hearing'. Of the seven
211 blind/visually impaired people, two identified as totally blind with the others identifying that they
212 are partially sighted. The majority of women who identified as having a physical impairment
213 described what would traditionally be classified as musculoskeletal problems, such as arthritis, joint
214 problems and conditions that cause joint hypermobility. Some of these accounts describe how
215 pregnancy exacerbated existing disability due to body changes in pregnancy. On-going health issues

216 **Table 1. Participant characteristics and care received**

		n	%
Age (n=36)	*mean 35.64 (SD 6.1.88)*		
	20-29	7	*19%*
	30-39	19	*51%*
	40-49	10	*27%*
Number of children (n=35)			
	0	1	*3%*
	1	13	*37%*
	2	14	*40%*
	3	5	*14%*
	4	2	*6%*
Primary impairment (n=37)			
	Deaf / hard of hearing	2	*5%*
	Blind / visual impairment	7	*19%*
	Physical or mobility impairment	19	*51%*
	On-going health issue that affects daily life	6	*16%*
	Mental health or emotional issue	3	*8%*
Antenatal care			
What kind of antenatal care did you receive? (n=37)			
	Community midwife only	6	*16%*
	Community midwife and GP	3	*8%*
	Community midwife, GP, and obstetrician	22	*60%*
	Other (specialist team or combination)	6	*16%*
Birth			
Place of birth (n=36)			
	Home	2	*5.5%*
	Stand-alone midwifery-led unit	3	*8%*
	Alongside midwifery-led unit	1	*3%*
	Obstetric unit	28	*78%*
	Theatre	2	*5.5%*
How long ago did you last give birth (in years)? (n=36)			
	0-2	21	*58%*
	3-5	6	*17%*
	6-10	7	*19%*
	>10	2	*5%*
Which country were you in when you gave birth? (n=36)			
	England	20	*55%*
	Scotland	2	*6%*
	United Kingdom	12	*33%*
	Ireland	2	*6%*
Postnatal care			
What kind of postnatal care did you receive? (n=37)			
	Care in hospital	22	*60%*
	Home visit – midwife	27	*73%*
	Home visit – maternity support worker	8	*22%*
	Home visit – Health worker	20	*54%*
	Other (day care, mental health team)	3	*8%*

217
218

219 were described in less detail, with one participant describing moderate ME/CFS.
220

221 *The maternity care received*

222 The majority of participants (21/36, 58%) had given birth within the last two years (Table 1). More
223 than two thirds of women (25/37) received shared antenatal care; this was most often shared
224 between the midwife, general practitioner and obstetrician (22/37, 60%). Most women reported
225 that they gave birth in an obstetric unit (28/36, 78%). All women (37) reported receiving some form
226 of postnatal support (participants could choose more than one option) and most indicated that they
227 had support in hospital (22/37) and in the community from a midwife (27/37), and a home visit from
228 a health visitor (20/37).

229

230 Participants were generally happy with the support that they received from maternity care providers
231 (Table 2). All women had received care from a midwife in their most recent pregnancy, and 71%
232 were satisfied or very satisfied with that support (25/35). Most women reported satisfaction with
233 general practitioner (20/35, 57%), obstetrician (19/32, 59%) and health visitor (19/34, 56%) support.
234 Fewer reported satisfaction with maternity support worker input (6/20, 33%), but only half of the
235 participants (n=20) answered the question. A number of women stated that they did not know what
236 a maternity support worker was.

237

238 Despite generally positive responses, just over half of the women (19/37) expressed dissatisfaction
239 with one or more care providers. The majority of participants (22/37, 59%) were happy with the
240 information about the services available (Table 2); however there was significant dissatisfaction with
241 other aspects of the service. Dissatisfaction was greatest for the statements "*The extent to which*
242 *your individuality and preferences were respected*" (21/37, 57%) and "*The overall understanding that*
243 *service providers showed of your specific situation*" (21/37, 57%).

244

245 **Table 2. Satisfaction with childbirth experience**

	Very Dissatisfied	*Dissatisfied*	*Neither*	*Satisfied*	*Very Satisfied*
Satisfaction with support received					
Midwife (n=35)	*9%*	*14%*	*6%*	*34%*	*37%*
General Practitioner (n= 35)	*6%*	*11%*	*26%*	*31%*	*26%*
Obstetrician (n=32)	*0*	*19%*	*22%*	*28%*	*31%*
Maternity Support Worker (n=20)	*5%*	*10%*	*55%*	*15%*	*15%*
Health Visitor (n=34)	*6%*	*18%*	*21%*	*32%*	*23%*
Satisfaction with childbirth experience					
Information about services available (n=36)	*16%*	*14%*	*11%*	*43%*	*16%*
Appropriateness of information for you (n=37)	*5%*	*40.5%*	*13.5%*	*24%*	*16%*
Extent services were tailored to your needs (n=37)	*13.5%*	*35%*	*19%*	*19%*	*13.5%*
Reasonable adjustments for you needs (n=37)	*13.5%*	*27%*	*27%*	*13.5%*	*18.9%*
Signposting to other services/local resources(n=36)	*22%*	*36%*	*17%*	*19%*	*6%*
Extent to which your individuality/preferences were respected (n=37)	*30%*	*27%*	*11%*	*24%*	*8%*
Overall understanding that service providers showed of your specific situation (n=37)	*30%*	*27%*	*13%*	*19%*	*11%*
Extent to which your privacy was protected (n=37)	*3%*	*19%*	*24%*	*35%*	*19%*

246

247 The information from the open-ended questions about the support received comprised of themes
248 about maternity care providers' awareness and attention to the impact of disability, the need for
249 continuity of carer, the perception of reduced choice or choices being overruled and care providers
250 needing more information. Many of the comments made by participants, particularly those with
251 physical disabilities, suggested that maternity care providers seemed to lack knowledge about
252 disability and how that can influence pregnancy, childbirth and parenting:

253

254 *No one understood my disability. No-one knew how to help or who to send me to for support*.
255 (Participant 14 with physical impairment and long-term health condition)

256

257 *Service providers had no understanding of specific needs and are only equipped for the*
258 *mainstream.* (Participant 9 with visual impairment)

259

260 *My community midwife was amazing as was my GP. The consultant was unfamiliar with my*
261 *disability and its implications. The midwife on day of delivery was beyond useless deciding*
262 *she knew better than specialist of my disability. Anaesthetist was oblivious of my disability*
263 *and failed to read the notes from my specialist. The labour ward were unaware I was*
264 *disabled prior to arrival for induction, it took 36 hours for them to get me a toilet frame and*
265 *told me it was ok because there was 1 grab rail. The registrar decided what was best for me*
266 *and baby without even considering my disability and its implications. The post labour ward*
267 *did not provide sufficient space for wheelchair or safe use of crutches. They had a perch stool*
268 *rather than shower stool which I slipped off the moment it got wet and soapy. Postnatal*
269 *ward could not meet my physical need so said I should go home. Postnatal were infuriating,*
270 *they wouldn't take needles out of my hands until I had walked to the toilet, I could not walk*
271 *without crutches and could not walk on crutches with needles in my hands. Anaesthetist did*
272 *not listen to what I had to say or to my husband or mother who were there to advocate for*
273 *me when I was unable.* (Participant 19 with physical impairment)

274

275 Two participants specifically highlighted the need for maternity care providers to have knowledge of
276 breastfeeding; both of the participants were blind or partially sighted so it could be that provision of
277 information about breastfeeding for this group is particularly challenging.

278

279 Participants, particularly those who experienced pelvic girdle pain or pain due to other disability,
280 commented on how little attention was paid to their experiences of pain and its impact on
281 pregnancy and childbirth, or to how they manage their disability.

282

283 *In the hospital I had other midwives. One of them was very dismissive of my PGP. I also*
284 *found that the obstetrician's team didn't have a clue about PGP. I asked them at the*

285 *beginning as I had a previous back injury and they said it wouldn't cause a problem. They*
286 *still didn't acknowledge it even when I was on crutches!* (Participant 3 with physical
287 impairment)
288
289 Some participants differentiated between different maternity care providers, finding one provider
290 more helpful than others.
291
292 *Midwife and obstetrician couldn't have been better. OT was completely useless.* (Participant
293 1 with a physical impairment)
294
295 *I loved my community midwife but she was the only one who wanted to know how I was*
296 *feeling about things or if I needed explanations. Everyone else made assumptions, talked*
297 *about guidelines or looked at monitors.* (Participant 3 with physical impairment)
298
299 Women suggested that continuity of carer and follow-through with the same provider was better for
300 them than meeting different maternity care providers throughout their pregnancy continuum.
301 Challenges arose where different maternity care providers were involved.
302
303 *The issues were continuity of care. For "my" midwife who knew my history she was great.*
304 *When she went off work and I saw others, they appeared to neither know nor care.*
305 (Participant 21 with a physical impairment)
306
307 *Midwife was fantastic. Due to my disability she decided to make herself fully available to me,*
308 *I saw only her, didn't have to explain my impairment repeatedly to different people. GP was*
309 *generally useless, had to be reminded by me what each appointment with him was actually*

310 *for, kept forgetting to do various tests. HV [Health Visitor] was fine, very 'nosy'!* (Participant

311 33 with visual impairment)

312

313 Two of the responses particularly relate to choice. One participant, who has a physical disability and

314 mental health condition described that ‘I had to fight for the birth I wanted’, whereas another

315 participant, who has a physical disability described her choice to have a caesarean section as being

316 ‘overruled’.

317

318 *My Disability is unseen and was not recognised by midwives when in labour. I was put under*

319 *tremendous pressure to give birth naturally when I had already planned a c section. My baby*

320 *was breech, I had a dislocated hip and was scared my pelvis would literally snap. This was*

321 *ignored when I went in to spontaneous labour 3 weeks early. C section was safest option for*

322 *both of us but midwives know best and were pushing so hard for a natural delivery.*

323 (Participant 23 with a physical impairment)

324

325 Another participant described the need to demonstrate her ability to adopt certain positions for her

326 choice of birthplace to be possible, which she describes as ‘insulting’.

327

328 *The midwives were fine but I told the obstetrician I didn't want to give birth on the delivery*

329 *suite and they asked me to physically demonstrate I could get into certain positions that they*

330 *considered necessary for giving birth. I found that quite insulting. It also undermined my*

331 *confidence in my body...*

332 *My midwife antenatally and postnatally was great in community, but the midwives in*

333 *hospital made me feel like they did not have time for my questions, they told me what*

334 *hospital guidelines were but I didn't feel like they took into account what I wanted. They*

335 *spent more time with monitors than actually supporting me. The health visitor dumped loads*

336 *of leaflets that were supposed to answer my questions but they didn't. If I wanted support or*
337 *my baby weighed I had to go to clinics but they didn't usually have a health visitor, just a*
338 *nursery nurse who didn't answer my questions.* (Participant 3 with a physical impairment)
339
340 The quote above also highlights the need for continuity of carer and the need for staff to have
341 information to answer women's questions, an experience shared by other participants. One blind
342 participant described employing an independent midwife to provide care for her second pregnancy
343 due to negative experiences with her first birth.
344
345 *Dignity and respect*
346 Participants were split over whether they were treated differently as a result of their disability (Table
347 3). A third of the women reported that having a disability put them in a high risk category. The
348 comments also give some insight into how being treated differently was perceived. Some women
349 saw different treatment as positive, where they wanted and/or received different treatment to take
350 account of their disability. Other participants said they did not want or expect different treatment as
351 this could lead to them being treated less favourably.
352 *I feel that my disability was largely ignored. I cope well but continuity of care could have*
353 *been so much better last time. I had to keep going over the same things to different*
354 *midwives last time. This time I have just one midwife and my consultant. They know me*
355 *really well and it's so much better.* (Participant 1 with physical impairment)
356
357 *Only one person [treated me differently]: lady giving me epidural though I didn't understand*
358 *her, and I was answering different questions as a result. In fact I do lip read, but during the*
359 *procedure I couldn't lip read. She was frustrated and shouted at me. The midwife and my*
360 *husband had to explain to her that I was hard of hearing. She calmed down... A little bit.*
361 (Participant 6 who is hard of hearing)

362 **Table 3. Dignity and respect**

	n	%
Do you think that your disability, impairment or health issue led to people treating you differently (n=37)		
Yes	17	*46%*
No	16	*43%*
Don't Know	4	*11%*
Do you feel that your disability, impairment or health issue automatically placed you at high risk (n=37)		
Yes	11	*30%*
No	21	*57%*
Don't Know / Other	5	*13%*
Do you think that reasonable adjustments or accommodations were made for you (n=36)		
Yes	7	*19%*
No	24	*67%*
Don't Know / Other	5	*14%*
Were you told that you were more likely to meet the same health care provider at each of your appointments because of your disability, impairment or health issue (n=37)		
Yes	4	*11%*
No	30	*81%*
Don't Know / Other	3	*8%*
Do you feel that communication was good throughout your experience (n=37)		
Yes	11	*30%*
No	19	*51%*
Don't Know / Other	7	*19%*
Do you feel that you experienced less favourable treatment because of your disability (n=37)		
Yes	10	*27%*
No	19	*51%*
Don't Know	8	*22%*
Do you feel that health care providers had appropriate attitudes to disability (n=36)		
Yes	9	*25%*
No	20	*56%*
Don't Know	7	*19%*

363

364

365 *I didn't feel like I was treated any different most of the time which is good.* (Participant 27
366 with visual impairment)
367
368 *I say yes [I was treated differently] in a positive way as everything was done to make my*
369 *pregnancy and delivery go as smoothly as possible.* (Participant 8 with physical impairment)
370
371 *Yes while they do [treat me differently] they often don't know what to offer in support or*
372 *even operate from charitable model which can be ostracising at times.* (Participant 9 with
373 visual impairment)
374
375 *They should have treated me differently - to allow for my situation but didn't appear to.*
376 (Participant 21 with physical impairment)
377
378 *At times it is right to be treated different. My disability is unseen and even when I signpost*
379 *educate and explain, my needs are ignored.* (Participant 15 with physical impairment)
380
381 Only 19% of women thought that reasonable adjustments or accommodations had been made for
382 them (7/36). Participants' disability did not increase their likelihood of being told that they would
383 see the same care provider and just over half the women felt that communication was not good
384 (19/37, 51%). Some of the communication issues related to access to information, such as the way a
385 health professional communicated with a person with a sensory impairment. Adjustments to
386 communication would potentially have resulted in better communication with these participants.
387
388 *People did not make the effort to look into my face when speaking which is what I need to*
389 *fully see what they are saying.* (Participant 2 who is hard of hearing)
390

391 *NHS [National Health Service; UK] letters such as scan aps all inaccessible.* (Participant 5 with
392 visual impairment)
393
394 Other types of adjustments described by participants included better continuity of carer, so that
395 participants did not need to repeat information about their disability at each visit, additional
396 screenings if required, choice of birth options or a carer being able to stay in the hospital setting.
397 Some participants described needing extra help to care for their baby.
398
399 *My community midwife was really on top of everything and even slotted in extra visits when I*
400 *went past my due date to give me extra sweeps. She was fab. No one else really asked what I*
401 *wanted or presented options that weren't in guidelines.* (Participant 3 with physical
402 impairment)
403
404 *… midwife argued my case for a homebirth due to disability, familiarity etc, some weren't*
405 *[providing reasonable adjustments] i.e. not being allowed to move in hospital.* (Participant 34
406 with visual impairment)
407
408 *Allowed into birthing pool even though midwife believed it would slow labour down, but I*
409 *knew if I could get off my knees it would help. So they felt they were humouring me but they*
410 *listened to me.* (Participant 25 with physical impairment)
411
412 *I had my own room on postnatal so my husband could stay but we'd had to travel a long way*
413 *from home to get the appropriate care so this was a minor consolation.* (Participant 36 with
414 physical impairment)
415

416 *after giving birth I found it very difficult to stand and walk due to my disability I would not be*
417 *able to do it on my own, the care I got in hospital was amazing they let my partner stay with*
418 *me over night and we were put in a room with a double bed and en-suite so I would have*
419 *everything I needed near me without any difficulty I could not have been any happier with*
420 *the care I received* (Participant 30 with physical impairment)

421

422 When reasonable adjustments were not in place, participants' independence and dignity were
423 undermined. For some of the participants with physical and mobility impairments, the reasonable
424 adjustments could have been provision of accessible rooms with assistive equipment to facilitate
425 mobility.

426

427 *None [no reasonable adjustments were provided]. I had to remain in bed because my*
428 *wheelchair couldn't fit in the room. Totally removed my independence.* (Participant 30 with
429 physical impairment)

430

431 *Postnatal should have given me a bed with wheelchair access. I should have had immediate*
432 *access to toilet frame and bath or shower stool.* (Participant 19 with physical impairment)

433

434 A quarter of women reported that they felt they were treated less favourably because of their
435 disability (10/37, 27%). In addition, more than half (20/36, 56%) felt that maternity care providers
436 did not have appropriate attitudes to disability (Table 3). These findings from the quantitative
437 analysis are strongly echoed in the qualitative comments, with communication and attitude to or
438 knowledge of disability being the most common and strongest themes. Some women described how
439 the challenges that they faced due to disability were not always recognised or managed
440 appropriately, and as a result the lack of support due to disability resulted in less favourable
441 treatment.

> *If I were not disabled none of these things would have been an issue. I feel not meeting those needs means I was treated with less favour due to my disability.* (Participant 19 with physical impairment)

> *I was told I couldn't have a water birth in case I couldn't get out of the water in a hurry despite demonstrating at 36 weeks I could do it unaided. This made me really cross as what would they do if someone collapsed in the pool anyway.* (Participant 36 with physical impairment)

Participants were asked how well they thought that their rights and their dignity were respected during pregnancy, labour and birth and the postnatal period. More than a quarter of women felt that their rights were either poorly or very poorly respected (Figure 1: How well were your rights respected). Several participants described their choices over care being limited, that they were not listened to and that their suggested forms of support were not available. When analysing the text, it is noteworthy that the term 'allowed' is frequently used, suggesting a power differential where the service providers are ultimately making decisions, allowing or disallowing women's choices.

> *not allowed birthing ball, not allowed to walk around etc* (Participant 34 with visual impairment)

> *I wasn't allowed to go to low risk centre despite my disability not affecting my capacity to give birth. Problems in pregnancy weren't addressed i saw a specialist but too late then needed my care transferring urgently but this took over a week introducing another significant delay and has left me with long term problems (daughter is fine). Because my problems were related to my disability I felt they weren't addressed with the same sense of urgency as with pregnancy related problems.* (Participant 36 with physical impairment)

468

469 *They would not allow my carer to stay overnight* (Participant 32 with physical impairment)

470

471 Slightly fewer women felt that their dignity was either poorly or very poorly respected in the
472 antenatal period (11%) or during labour and birth (19%); however a third felt that their dignity was
473 either poorly or very poorly respected in the postnatal period (33%) (Figure 2: How well was your
474 dignity respected?). Dignity seemed to be interpreted as being able to make choices by some
475 women. Other women described undignified care as when their individuality (and disability) was not
476 respected and they felt to be considered to be an 'annoyance' by service providers. The key themes
477 arising from the perception of dignified care echo comments from the earlier parts of the survey:
478 women want to be listened to, taken seriously and to have their wishes respected.

479

480 *I felt that staff were annoyed by my requests, and that they behaved as if my physical*
481 *limitations were an inconvenience.* (Participant 32 with physical impairment)

482

483 *I was treated as though I was being dramatic. The communication was poor. All of my*
484 *options if there were any were not explained.* (Participant 17 with physical impairment)

485

486 *I find being in a wheelchair means I am regularly not listened to. My husband or mum are*
487 *asked questions instead of me. When the professional doesn't like what I have to say they*
488 *looked to my mum or husband to put me in my place (at least that is how it felt).* (Participant
489 19 with physical impairment)

490

491 *I was told I was a health and safety risk, people didn't speak directly to me, felt smothered.*
492 (Participant 34 with visual impairment)

493

494 *Improving the experience*

495 Participants were asked to provide advice and suggestions for maternity care providers to improve
496 the experience of women with disability during pregnancy, childbirth and early parenting. Women
497 overwhelmingly highlighted the importance of communication, particularly listening, and respecting
498 a woman's wishes, her difference and that she knows her body and disability best. Continuity of care
499 was raised by many of the women. In addition, participants highlighted the importance of learning
500 about disability and having a better understanding of a condition, particularly if it is likely to be
501 exacerbated in pregnancy, and to read women's notes. The below quotes illustrate this:

502

503 *Listen to what women tell you about what they want and ask them if they can do things,*
504 *don't request them to. Don't tell them what the policies are without explaining how you can*
505 *adapt them or why they are recommended in that way.* (Participant 3 with physical
506 impairment)

507

508 *Listen to the individual. I know my needs and limitations better than anyone else* (participant
509 34 with visual impairment)

510

511 *Ask on first visit what supports are required an put a plan in place to meet needs that is on*
512 *file and reviewed and updated regularly which will be available to all health care*
513 *professionals at the front of file. This will ensure that people with a disability are not*
514 *constantly explaining their needs. Staff also need to be trained in equality and a rights based*
515 *model to disability. (*participant 9 with visual impairment)

516

517 *Remember every mum is different whether disabled or not.* (Participant 35 with visual
518 impairment)

519

520 *Each woman is different as is each baby. If a woman says she's in pain she invariably is. Just*
521 *because the general advice following a section is to be as mobile as possible that doesn't*
522 *mean it is possible for everyone and just because some women feel very little pain post*
523 *section doesn't mean that those who do suffer are weak or less deserving of your support.*
524 *Please tailor your care accordingly and listen to what you are being told* (participant 16 with
525 physical impairment)
526
527 *Research medical conditions before you try to treat. If you are told something about the*
528 *individuals needs/condition, make a note of it and ensure all are aware. Do not say you know*
529 *what someone feels or needs unless you have been in the exact same position as them.*
530 *(*Participant 19 with physical impairment)
531
532 *If a patient has a syndrome please have a quick google or look at the charity website*
533 *associated with the condition. In 2 minutes you'll be able to see the main issues associated*
534 *with the condition, which aren't always what you would expect. Patients know you are*
535 *unlikely to be an expert in their condition, but they do expect you to know what it is.*
536 (Participant 24 with physical impairment)
537
538 *They need to have more detailed understanding of the variety of disabilities or even have*
539 *some equality champions who can be called upon to liaise with mum (*participant 30 with
540 physical impairment)
541
542 *Put yourself in my shoes and figure out how to help rather than follow the standard path.*
543 *Make an effort to understand how my disability affects me - I'm not asking for extra*
544 *assistance to be awkward but to try and create a circumstance I can cope with.* (Participant
545 37 with long-term medical condition)

546

547 *Think 'can do' rather than can't!* (Participant 8 with physical impairment)

548

549 Some participants also noted that the staffing levels meant that there was not enough time to meet
550 their needs and that for women with disability, additional support and appointments may be
551 needed.

552

553 *I think if the mother is experiencing any kind of difficulty they should automatically be*
554 *offered extra midwife appointments and more emotional support.* (Participant 13 with
555 physical impairment)

556

557 *To allow women to labour in their own time and accept that refusing drugs is not about*
558 *being stoic but more about accepting sensitivities to chemicals.* (Participant 25 with physical
559 impairment)

560

561 **Discussion**

562 This study used an on-line survey to seek the experiences of pregnancy, childbirth and early
563 parenting of women with disability. While there was no comparison with non-disabled women in the
564 current study, some of the women did describe less positive experiences, which replicates findings
565 of other studies (2, 7, 19), including that undertaken by Birthrights (17). However, it is important to
566 acknowledge that this was a self-selecting sample and as a consequence it is open to selection bias.
567 That is, it could be argued that women who responded to the invitation to participate might be more
568 likely to have previously experienced poor maternity services and therefore were more motivated to
569 provide feedback. Selection bias is a known problem with online surveys, particularly where a link is
570 circulated to interested groups (20). The small sample size, and the fact that it contained a high
571 proportion of women with certain types of physical disability, means that it is unlikely to be

572 representative of the population of women with disability as a whole. In the future, more specific
573 sampling of a smaller population – for example, women with specific impairment types – may yield
574 more representative results.
575
576 In spite of these limitations, the women's accounts clearly point to aspects of care that could be
577 improved. Indeed, we believe that this is the first study that has specifically looked at the
578 experiences of dignity and respect in relation to childbirth of women with disability. Lowe has noted
579 that 'dignity in health care is defined as encompassing respect and autonomy' (21) p137). Our
580 findings indicate that this was sometimes missing in the interactions between women and their
581 maternity care providers. Women explicitly indicated feeling that they were not being listened to
582 and that they had fewer choices and this affected their sense of dignity. In a review of complaints in
583 relation to UK maternity care, Morad et al found that poor communication, and specifically a failure
584 to listen or consider the woman's viewpoint, was the primary cause for complaint (22).
585
586 Morad et al (22) highlight that dignity can be maintained when women are treated as individuals and
587 when they can build a relationship of trust with their maternity care providers. For the women with
588 disability in our study this point was key. Women reported that a lack of continuity of carer caused
589 them significant problems as their condition was not understood and adjustments were not made.
590 Women reported needing to repeat themselves again and again and their wishes, as discussed and
591 agreed with one maternity care provider were not followed through by another. The most often
592 repeated theme from the open-ended questions was that women felt that they were not being
593 listened to and that this had the potential to reduce their choices and made them feel like they had
594 less control. These findings echo previous research about the experience of women with disability
595 (12). Others have suggested that women with disability may experience greater continuity of carer
596 or more ante-natal care (2), but there was limited evidence of this in our study.
597

598 More concerning was the fact that more than a quarter of women felt that their rights were poorly
599 or very poorly respected; a quarter felt they were treated less favourably because of their disability
600 and more than half (56%) felt that maternity care providers did not have appropriate attitudes to
601 disability. Discriminatory behaviour and lack of respect was also highlighted in the national survey
602 completed for the Care Quality commission (19). A few participants explicitly described situations in
603 which they felt their dignity was undermined, for example being asked to demonstrate being able to
604 get into a specific position and being asked to mobilise when they felt unable to do so due to
605 physical disability. Participants criticised the lack of knowledge that maternity care providers had
606 about disability and its impact on pregnancy, childbirth and parenting, highlighting that this was, for
607 some, offensive and made them feel less confident in themselves. The call for all women to receive
608 respectful maternity care is not new, but it has received added impetus with the publication of *the*
609 *Respectful Maternity Care Charter* (White Ribbon Alliance, 2011) and Birthrights' *Dignity in Childbirth*
610 *Survey* (17). Our findings highlight the urgent need for maternity care providers to develop better
611 understanding and approaches when supporting women with disability. Additional education for
612 maternity care providers should include information about different approaches to disability and
613 highlight the need to listen to the woman to understand her unique disability experience.
614
615 However, there is evidence that simply implementing the recommendations of a recent maternity
616 services review (16) would address many of the challenges in England. *Better Births* highlights the
617 importance of personalised care, which is woman-centred, with opportunity for choice and control,
618 and continuity of carer. Adapting services to provide continuity of carer for all women would make it
619 more likely that women with disability have the appropriate accommodations and support in place.
620
621 Continuity of carer is particularly important as only 19% of the women in our study described having
622 the reasonable adjustments that they are legally entitled to receive. Women described inadequate
623 physical environments, space and equipment to cater for physical disability in ante-natal, labour and

post-natal facilities, thus reducing their access to services or the dignity with which these could be used. While environments may be universally challenging in terms of protecting the dignity of women, the experiences of women in the current study suggest that, particularly for a woman with a physical disability, inadequate environments can pose additional challenges.

Conclusion

This is the first study that has specifically looked at the experiences of dignity and respect in childbirth of women with disability. More than a quarter of the women in the study felt that their rights were poorly respected and that they were treated less favourably because of their disability. It was also evident that more consideration needs to be made to improve attitudes of maternity care providers to disability, and services need to adapt to provide reasonable adjustments to accommodate disability, including improving continuity of carer.

Abbreviations

WHO	World Health Organization
UK	United Kingdom

642 **Declarations**

643 **Ethics approval and consent to participate**

644 Ethical approval for this study was received from Bournemouth University's Research Ethics

645 Committee Ref: 8910

646 Written informed consent was obtained from the participants prior to completion of the survey.

647 **Consent for publication**

648 Not applicable

649 **Availability of data and material**

650 The dataset of this study is available from the corresponding author following a reasonable request.

651 **Competing interests**

652 The authors of the study do not have any competing interests.

653 **Funding**

654 The project was partially funded by Birthrights charity and Bournemouth University

655 **Authors' contributions**

656 JH secured funding for the work. JH, VH, BC & JI contributed to all aspects of the study design and

657 construction of the survey. JH has overall responsibility for the study and with BC obtained ethical

658 approvals. JH, JI and BC devised the recruitment strategy and identified target groups. JH and VH

659 developed the quantitative data analysis plan. JH and BC developed the qualitative data analysis

660 plan. All authors contributed to the discussion and interpretation of the findings. All authors

661 contributed to the writing of the manuscript and approved the final version.

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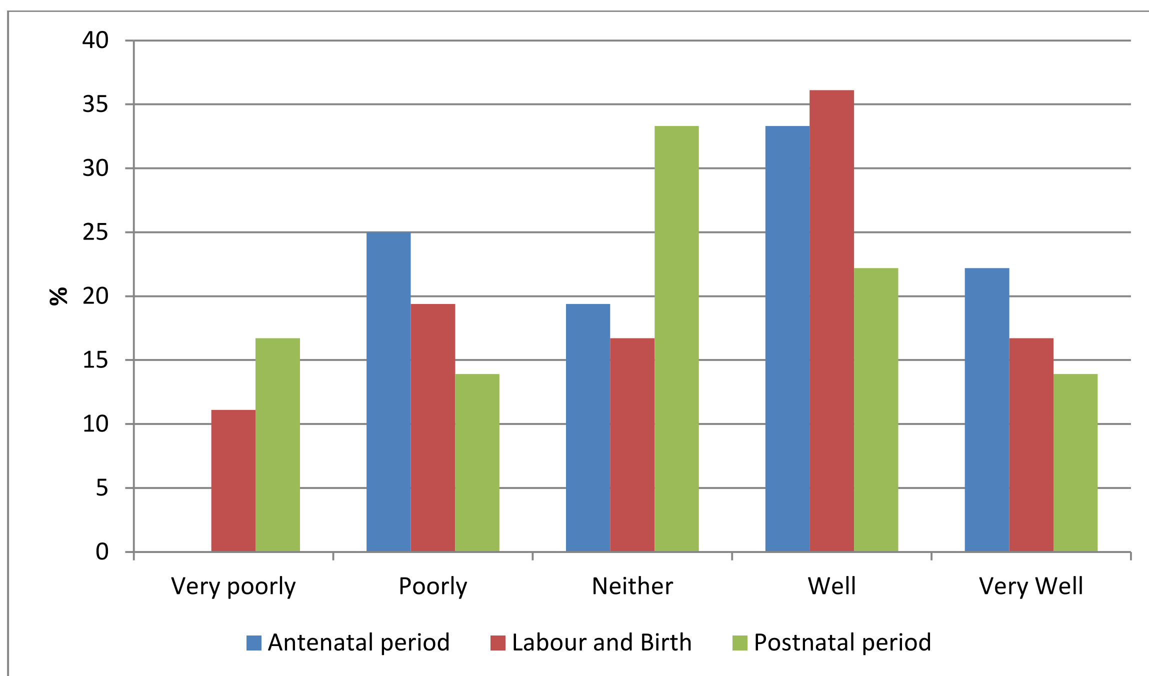

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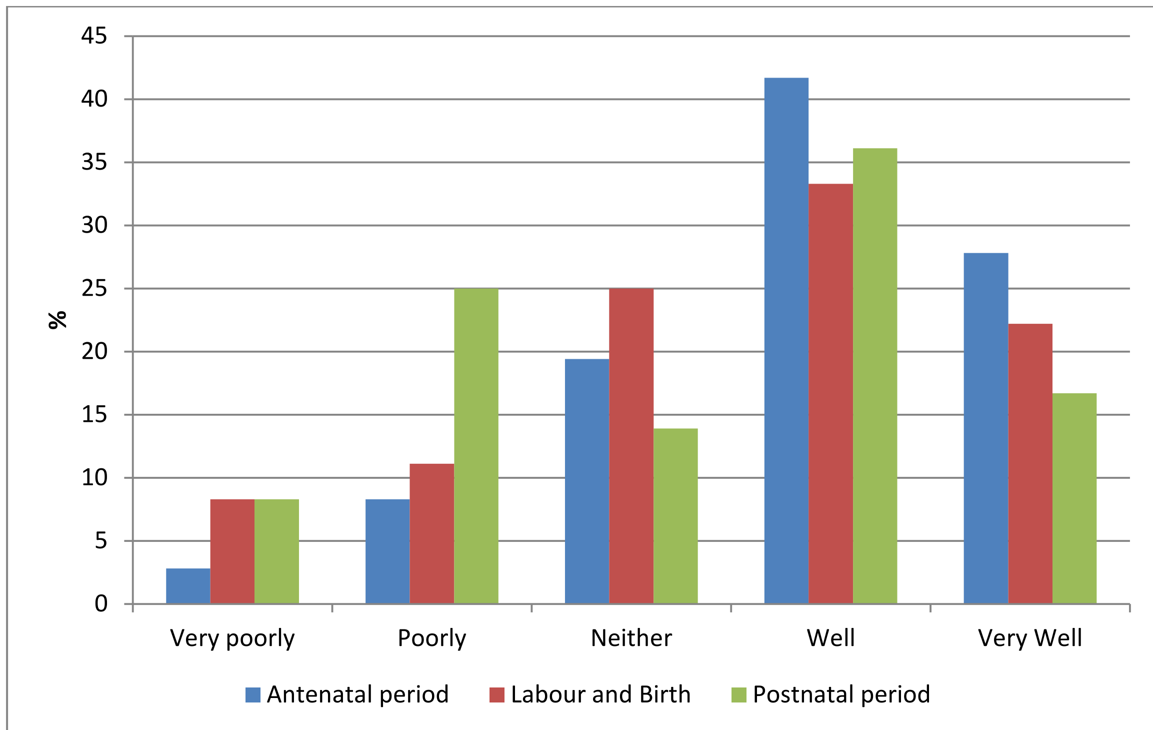

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