

Using Facebook to tell stories of premature ageing and sexual and reproductive healthcare across the life course for women with cerebral palsy in the UK and USA

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BMJ Open Using Facebook to tell stories of premature ageing and sexual and reproductive healthcare across the life course for women with cerebral palsy in the UK and USA

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ABSTRACT

Objective To enhance understanding of the bodily and lifestyle effects of ageing with cerebral palsy (CP) for women, with a particular focus on experiences with sexual and reproductive healthcare (SRH) services in the UK and North America.

Design A qualitative study underpinned by feminist disability theory and drawing on digital ethnographies to capture health and healthcare experiences for women with CP.

Setting A global community of 140 women with CP, who are members of the closed international Facebook group, *Women Ageing with Cerebral Palsy* (WACP).

Participants Forty-five members of WACP who were based in the UK and North America. The women were aged between 21 and 75.

Methods Messages posted on WACP between January 2018 and October 2018 were collated and underwent thematic analysis to identify themes relating to effects of ageing and experiences of SRH for women with CP at different points over the female life course.

Results The breadth of experiences in relation to the effects of ageing and access to reproductive and sexual healthcare for women with CP can be divided into three themes: (1) bodily effects of ageing; (2) lifestyle effects of ageing; (3) experiences of reproductive and sexual healthcare.

Conclusions Giving women with CP a platform to ‘speak for themselves’ in relation to effects of ageing and SRH provides health professionals with an informed knowledge base on which to draw. This might improve treatment for this growing adult patient community whose experiences have not received attention in health discourse or services. Including these experiences in public medical and social discourse can also bring a new knowledge to girls with CP about what ageing could mean for them so plans can be put in place for their future.

INTRODUCTION

Women with cerebral palsy (CP) are increasingly living into older adulthood. As they grow older, they experience specific bodily changes and related health issues, but are at risk of unmet needs due to structural barriers

Strengths and limitations of this study

- The study used creative methodologies that allowed the inclusion of social stories from otherwise marginalised participants.
- The use of digital ethnography allowed us to draw on traditional ethnographic approaches and combine them with technology.
- A closed Facebook group was used to further ensure the involvement of women with cerebral palsy.
- The study is limited in that it focused on a self-selected group of women with a specific impairment, although many of their issues are likely to apply to women with other impairments.
- The participants were from the USA and UK which may limit the transferability of findings.

to healthcare. The study on which this paper is based provided an accessible forum for women with CP (in UK and North America) to discuss (1) how ageing with CP effects their body and impacts their lifestyle, and (2) their encounters with sexual and reproductive health services (SRH).

BACKGROUND

Globally, 2 in 1000 live births result in CP.^{1 2} In 2019, England alone had a prevalence of 25 273.² Population data from CP registers in Europe for births between 1980 and 2003 showed a significant decline in CP, suggesting it has been stable in recent years.¹ Influencing factors include advancements in neonatal and childhood healthcare treatments and technologies.³ Recent unpublished data collated by Scope UK (www.scope.org.uk) suggest that the population living with CP in England and Wales is 141 750 273.⁴ In general, the prevalence of impairment (CP and other conditions) is higher for women than men—19.2%



and 12%, respectively,⁵ indicating that women with CP are a growing patient group.

Research has tended to focus on CP in childhood rather than its lifelong effects. A plethora of international studies demonstrate the unmet health needs of adults with CP,^{6 7} but there is little that focuses on how it affects women. Thus, the perspectives of women with CP are under-represented in contemporary understandings.

As women grow older, CP impairment manifests in different ways, leading to early onset of age-related health issues across biomedical, psychosocial and functional domains,^{6 8} including specific issues related to their reproductive health including early and severe menopausal symptoms.^{6 8–10}

Although motor function (mobility, strength, endurance) changes for all during the maturation process, in persons with CP, musculoskeletal problems may become more pervasive, often with an earlier onset than in non-disabled persons.¹¹ This process is sometimes referred to as accelerated ageing. A causal factor of this could be overuse syndrome, described as ‘forcing my body over the physical limits’.⁶ Pain may be due to how adults with CP perform routine movements, and is often related to soft-tissue injuries in muscles, tendons, ligaments or nerves.¹¹

Disabled women in general, and women with CP in particular, are likely to encounter physical and structural barriers to SRH facilities, medical equipment and procedures, such as breast scanners and cervical smears, and a lack of appropriate information about areas of reproductive health including menopause, pregnancy and contraception.^{12 13} Cancer Research UK¹⁴ reported that disabled women are a third less likely to participate in breast screening, and a quarter less likely to be screened for bowel diseases than non-disabled women. The picture is similar in the USA, as research indicates that disabled women, particularly those with physical impairments such as CP, underuse these preventative medical facilities.^{15 16}

Another factor often cited as a barrier to healthcare for women with CP is the pervasive misconception that disabled women are asexual beings and unable to pursue successful reproductive journeys.^{13 17} They have been discouraged and sometimes physically prevented from exercising their reproductive capacities and becoming parents.^{18–20} This has created a healthcare culture that may impact negatively on disabled women’s reproductive health, putting them at risk of developing preventable chronic secondary conditions. Another problem is the transition from child-centred to adult-centred healthcare, and lack of specialist multidisciplinary teams and expertise specific to women with CP.^{21 22} Knowledge, policy and practice systems in the UK tend not to take a life course approach to health, but instead view children, youth, young adults and older adults as distinct populations with separate service systems.²³ Rehabilitation services and other assistive interventions have been based on the ‘once and for all character’ of childhood impairments,²⁴ thus taking the view that once individuals with childhood impairments reach maximum functional capability there

is little need to worry about functional decline relating to secondary impairments.

Through the interdisciplinary lens of feminist disability studies, sociology and health, this article reports on the digital ethnographies of a global community of women with CP, who are members of the closed international Facebook group, *Women Ageing with Cerebral Palsy* (WACP). It focuses on the bodily and lifestyle effects of ageing with CP and women’s experiences of SRH.

The study addresses gaps in existing discourses on ageing, disability and women’s health, highlighting the health and healthcare experiences of disabled women in general, and women with CP in particular.

METHODS

Theoretical underpinning

We draw on feminist disability theory,²⁵ established to address the research limitations of feminist materialism and disability theory which exclude the experiences of disabled women and the specific issues they experience that are not experienced by disabled men or non-disabled women.^{26 27} It recognises the value of the macro and the micro, of both social structure and individual biography. Feminist disability theory views the personal as political, using experiences of disabled women as drivers of social change. Further, it is concerned with non-normative female bodies and their interaction with the social, cultural and political environment.^{28 29}

Context

Social media platforms are likely to be particularly beneficial for disabled people who may experience greater isolation and exclusion from traditional networks due to various barriers restricting access to social participation and engagement.³⁰ Facebook provides a channel of communication, collective action and awareness raising.^{31 32} It provides people who are otherwise marginalised, with opportunities to debate, discuss and communicate with people who share similar interests and concerns. They can become research participants,³³ become demarginalised³⁴ and become part of a community that supports and empowers people with similar identities.²¹ Moreover, as effects of CP include speech impediments and impaired mobility, online groups provide an accessible forum in comparison to traditional networking and support groups. WACP was set up in January 2018 as an international online information, support and discussion forum for women with CP, age 21+, and as a possible research resource. The purpose and origins of the group were made clear in the guidelines that new members were asked to read prior to contributing to or initiating discussions. Since inception, WACP has hosted discussions related to a plethora of embodied and relational impacts of being a woman with CP.

The idea of WACP stemmed from the first author (UK) and her colleague (USA)—two women with CP who were themselves experiencing new effects of age-related CP,

but a dearth of specialist support and resources. Bringing together an international community of women with similar identities to share their stories ‘can turn personal chaos into order. They can help us to make sense of our lives and the world around us; and in times of crisis, they can help repair damaged lives’.³⁵ To date, WACP has 140 members.

Methodology

The study adhered to the Consolidated Criteria for Reporting Qualitative Research.³⁶ Ethnography is instrumental to social research, as it is the art of telling the social stories of diverse populations. Therefore, when an ethnographer returns from the field, they always have social stories to tell.³⁴ However, with the increasing popularity of social media platforms in different areas of social, cultural and professional life, the way stories are communicated has changed. This study is described as a digital ethnography in that it is concerned with culture and social practices, but examined through the context of social media. This is recognised as a powerful research tool to capture the rich social stories of diverse subpopulations in contemporary society and those perceived as ‘hard to reach’.³⁷

Three research questions were posted on WACP, by the first author, from January 2018 to March 2019. These related to (1) bodily effects of ageing (physical and mental), (2) lifestyle effects of ageing and (3) experiences of SRH across life. Responses were posted by members of WACP. Forty-five members consented to include their posts in the study via a consent letter, sent to them individually via Facebook Messenger.

Patient and public involvement

The study engaged with women with CP throughout. It was designed by the first author who has CP and informed by the experiences of the forty-five members of WACP participants lived in the UK and USA and were aged between 21 and 75, with various classifications of CP which they were not required to disclose because effects of CP cannot be divided into neat classifications. Study results were shared with women via WACP.

Data analysis

We collated the participants’ posts and content, analysed them to identify themes relating to accelerated ageing and experiences of SRH for women at different points over their lives. Posts discussing ideas for improvements in healthcare were also inductively analysed.³⁸ Posts with specific words and phrases were extracted and organised into individual categories. These categories were grouped to form distinct themes.

To ensure rigour in our analytic process, the first author (SS) undertook the initial analysis of all data and then emerging themes were discussed and debated with the two coauthors until consensus was achieved. After several iterations, the themes were agreed as reported.

FINDINGS

Findings are presented under three themes: (1) bodily effects of ageing; (2) lifestyle effects of ageing and (3) experiences of reproductive and sexual healthcare. Pseudonyms have been used instead of real names to protect identities of participants.

Theme 1: bodily effects of ageing

There was much discussion about how women’s bodies changed between the ages of 30 and 50, resulting in pain, deterioration of balance, fatigue and health decline expected in old age for individuals seen as ‘able bodied’. The women seemed unaware of the concept of accelerated ageing and how their impairment would change as they got older:

Since I have gotten older my condition has gotten more pronounced. More pain, more stiff, just more of everything. And I have to do the things I usually do differently now...I want to do it for myself. But sometimes I just can’t. It is just frustrating. I just wish my body was like it was in my 20’s!! (Sasha)

I have always been prone to falling but it has increased over the years... It started for me in my 40s, usually when tired which is most of the time. My mobility had decreased along with my energy levels. It took me a while to accept these changes (Alison).

...Aches and pains started showing up when I hit 40. Started with lower back pain, they named ‘spondylolisthesis’, can’t walk more than a block nowadays, then OAB [over-active-bladder], need to go every 5 min, or not able to pee at all I got Cath’d [catheterised] twice, was hell. (Joanna).

A few women talked about experiencing what they termed as ‘brain fog’. This meant: *‘I go to move and I can’t, it feels like I’m stuck. As if I’m literally unable to move. It’s so frustrating’.*

Joan reflects on how the interplay of ageing and CP manifests in her body and what works to ease negative effects:

My observations on aging with hemi CP with a combination of spasticity and athetoid are: My athetoid symptoms have decreased my spasticity has increased. After using muscle relaxers I’ve realized spasticity stops information from getting through to the muscles. Spasticity in the back really impedes walking.

The younger members of the group realised that they are experiencing bodily changes as they grow older, and were curious about what this would mean for them, especially their functionality. For example, Hex was in her mid 20s and experiencing new pains and a loss of mobility:

I have mixed CP: spastic and ataxic hemiplegic...I’m mobile. However I’m finding as I’m getting older that my mobility is decreasing and the pain from my CP is increasing.

Rachel was in her early 20s, when she joined the online community as the youngest member of the group, for support after she was no longer eligible to access physiotherapy, *'I feel alone, I no longer have a therapist'*.

Theme 2: lifestyle effects of ageing

Women spoke about how the bodily effects of accelerated ageing impacted on their quality of life, triggering a change in terms of how much they worked or engaged in other physical and social activities:

One of my lifestyle changes is around work. For reasons to do with fatigue and the time I take to do things, I work part time and mainly from home. Although I used to go out to work don't think I could do so now. Fortunately...I have contact with people in the virtual world. That helps to reduce isolation and stay motivated (Rebecca).

Like Rebecca, other women in WACP had to change working patterns as a consequence of the new effects of CP which caused fatigue and pain:

I'm in my 50s...small business owner... I've recently had to cut back work partly because I'm now going at a snail's pace due to the effects of aging on my CP (Floss).

Alison—a wife, a writer and mother in her early 50s, reflects how the expectations to perform life roles and compete with non-disabled women in contemporary society, while simultaneously negotiating encounters with associated disabling barriers, influenced her decision to change her working pattern:

I crashed and burned out. No regrets though, I really enjoyed work, while I could do it. I think the hardest thing was trying to manage everyone's expectations, including my own...it was hard being a mum and working but the rewards, when they came, were worth it. Sadly it was unsustainable but I did it for 27 years which isn't bad.

Deterioration in mobility and functionality caused some women to experience difficulties in performing daily personal care and domestic duties. They recognised they needed to make appropriate changes to accommodate this:

I have someone to help me get dressed now. I'm still able to do it on my own (except for shoes and socks), but my attendant can do it faster and I look much nicer than when I did it myself... By the time I finally admitted I needed help, I'd been struggling to do it all, so it came as a relief to have help (Sam).

Thus, the ageing CP body can cause disruption to 'the expectations and plans that individuals hold for the future'.³⁹ Further, it can trigger a 'loss of self',⁴⁰ proposed to describe the negative change in identity, self-worth and social relationships instigated by trauma or illness. For instance Dolly, who was early 50s, reflects on how the

bodily changes experienced from ageing have influenced a change in her personal identity, generating a feeling of loss:

I am ambulatory but a recent worry rearing its head is: if I need to use a wheelchair because walking is becoming more and more unsafe for me, what will my family and friends think? This and other things trigger core values that were laid in childhood whether I want to admit it.... like fear of judgment and "letting people down"... Growing up, what I took in was that I will walk, will get good grades, and will have a career...So I'd liken it to the grieving process and its stages...I noticed I tend to grieve the loss before I'm able to accept/embrace.

Alison, from the UK, identifies with Dolly's experience. She recalls how, growing up in an ableist society, the aspiration of 'being able to walk' was instilled into her from childhood, but was being contradicted by the premature ageing process which was gradually eroding the mobility she worked for:

Walking was such a big issue at my special school and it is hard for me to let it go; even though I know my feelings are irrational and created by non-disabled people...I have always used a walking frame and will continue to do so for short distances as long as possible. There's a voice inside me that says if I stop moving, I'll stop living.

Amber (early 30s) has not lost her mobility. However, as her embodied presence is counter to societal expectations of womanhood, she has found that her way of being provokes 'sticky encounters'⁴¹ (occasions where normal social encounters become disturbed or unsettled by association with disability) in certain situations. She recalls how recent sticky encounters with her work colleagues dampened her psychosocial well-being:

I work for a well-known organisation and in the last two years I've had two experiences of disablism that have really knocked my confidence. The first was a man working for my dept (who was disabled himself) saying he wouldn't work with people with speech impairments. I raised this as an issue and the dept told me there was no malicious intent so no action would be taken. The second is a boss who makes a string of inappropriate comments, to everyone not just to me. But, unfortunately, with me it centres around the CP; she's disciplined me for being absent for disability related reasons...I used to be happy go lucky and friendly to everyone. But these incidents have massively affected my confidence and I feel diminished by them.

Theme 3: experiences of sexual and reproductive healthcare

On a macrolevel, there have been significant developments in SRH, in terms of rights, policy and practice. However, these have been largely based on the experiences

of non-disabled women.⁴² Several of the women in WACP are mothers and discussed temporal experiences of pregnancy and maternity care, prompted by an article shared on the forum, reporting access and quality of maternity care for disabled women.⁴³ For instance, Candy reflected on her experience of the maternity care in 2016:

...The midwives were not very clued up on anything and were unable to answer any questions I had about how to do things one handed... It was trial and error I guess. I bought a changing mat with a harness to strap the baby in to stop him from rolling...I bought a snuggle bundle to lift him from the changing mat to other rooms and a pair of little wings harness with straps when he was learning to walk...I was really saddened by the lack of info full stop.

Rana, mother of two, commented:

So sad that nothing seems to have changed since I had my first daughter in 1996. I was one of the founders of [a disabled parents' organisation] and was a full-time volunteer for 10 years. We offered a wealth of information and support on all aspects of parenting. Sadly, it is no more but the issues are still very much there.

Janet reflects on her experience, in the late 1970s:

There was no special or extra care when I had my daughter. It was 1979. The extent of special care was to hold my legs as I couldn't use the stirrup. I definitely think I should have had a caesarean as it would have helped. My pelvic floor, bladder and bowel were never the same. I only had the one child as it took a lot out of me to manage to do it.

The stories reveal how, despite changes in policy and practice over 50 years, the reproductive trajectories of women with CP continue to be interlaced with varying degrees of disability.

The gynaecological health of women with CP was a salient topic, with women expressing concern about limited access to preventative healthcare treatment and equipment:

Time to discuss everyone's favourite topic: the gynaecologist! As I've gotten older, my legs have gotten more spastic. My legs like to stay together. To prepare for my last visit, I took extra baclofen and some Ativan, so that they could hold my legs apart without me panicking. Despite this, the gyne couldn't get a view of my cervix and had to do a Pap smear by waving the scraper around and hoping she got some cervical cells...If they can't even get a look at my cervix, how am I going to figure out what's wrong (or even if anything is wrong)? (Linda)

I have had regular gynaecologist appointments since my mid 30s. It's annoying to me to have to explain to people that are helping me what I need, but most of-fices have accessible exam rooms these days (Natalie).

Some of the women admitted that they have stopped having smear tests as the methods used, coupled with their impairment effects, make it too uncomfortable:

In Scotland, it's offered from the age of 20. I don't have them, partly because I spasm too much and meds don't help. (Joy)

Older members shared experiences of having mammograms, where services were ill equipped to meet the needs of women with CP.

My first mammogram was a disaster, mainly due to the attitude of one of the professionals involved... The radiologist was just obnoxious in many ways but the final straw was when she shouted that my PA must remain in the waiting room. I tried to explain and she shouted again. I became tearful so left. When calm, I talked to a receptionist in a different part of the building who offered to go back with me to ask they talk with me respectfully. Mrs Obnoxious announced she had already written to her boss in case I complained!

DISCUSSION

The prevalence of CP in the UK and USA is 2 and 3 per 1000 live births, respectively.⁴⁴ In both continents, the stable prevalence rate of CP in live births coupled with the increased life expectancy of adults living with the impairment means that the number of women with CP in adulthood and older life is increasing. The participants of this study were members of a closed international Facebook group only open to women with CP. The 45 participants were based in the UK and North America.

To our knowledge, no other studies have directly explored how women with CP experience ageing and SRH. The findings shed light on unique experiences associated with women with CP. While a few previous studies (both UK and USA) have concluded that preventive screening interventions may be difficult for some women with CP,^{7 13 16 44} putting them at additional risk of fatal disease,¹⁵ our study is unique in illuminating the lifestyle and psychosocial impacts of ageing from a feminist disability studies lens. Thus, it considers disability as a cultural issue as opposed to an individual or medical one, and emphasises the value of 'what it feels like' accounts to understand the gendered nature of disability, impairment and impairment effects.^{28 29}

The digital ethnographies reported here inform an understanding of how disabled women's experiences intersect with systems and structures of healthcare and also with the ageing CP body. They reveal the hidden, often contested, histories of disability and sexual health that may collide with medical and ablist discourses which have traditionally pathologised and desexualised the lives of disabled women.⁴⁵ They allow for the focus to move beyond the 'life experiences of disabled people' and towards the 'experiences of disability in people's lives',⁴⁶

but that their experiences can provide unique evidence of the ways disability manifests itself.

Using the closed Facebook group as a research resource enabled us to capture the experiences of a 'hard to reach' population from two continents who traditionally have been excluded from speaking for themselves, in relation to their own health and healthcare. However, the study may have been affected by self-selection bias, as is often the case with offline research, where only certain kinds of people may respond to the research questions. Another limitation could be that participants' posts could be seen by each other, potentially influencing other participants' responses and potentially compromising anonymity. However, participants were made aware of this before they became members of the closed Facebook group and consented to be part of the study. Moreover, the influence on responses would be no more so than in some form of group discussion, such as a focus group.

As this study was concerned with the experience of ageing and SRH healthcare experiences of girls and women with CP, which are not applicable to men with CP or non-disabled women, feminist disability theory was deemed appropriate to underpin the study. Unlike disabled men and non-disabled women, disabled women can experience both disablism and sexism by systems and structures at microlevel, mesolevel, and macrolevel. As systematic norms are created by those in positions of power, the more marginal characteristics an individual has, the greater the gap between their own social position and those considered more socially acceptable.⁴⁵ The organisation of social structures, processes and systems means that disabled women, compared with non-disabled women, are particularly susceptible to inequalities across different spheres of public and private life, including healthcare. Sexual health is not covered in the current National Institute for Health and Care Excellence (NICE) guidelines on provision of services for adults with CP⁴⁷ nor previous NICE guidelines that focused on the transition from child to adult health services.^{48,49} This indicates an important policy gap in relation to the care of women with CP.

CONCLUSION

Giving women with CP a platform to 'speak for themselves', in relation to health and healthcare, provides health professionals with effective resources to improve treatment for this growing adult patient community whose experiences have not received attention in health discourse or services. Listening to their voices and including them in public, medical and social discourse can bring a new knowledge to young women with CP about what ageing could mean for them so plans can be put in place for their future.

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