ETERNAL: h**e**al**t**hcar**e** for gi**r**ls and wome**n** with cerebr**a**l palsy (CP) across the **l**ife course

Dr Sonali Shah, Dr Caroline Bradbury-Jones, Prof Julie Taylor
School of Nursing, Institute of Clinical Sciences
University of Birmingham

s.shah.3@bham.ac.uk

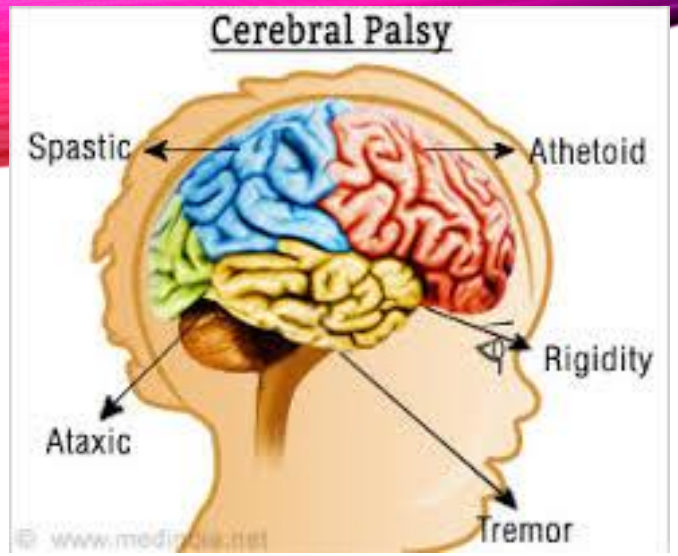
Burdett Trust for Nursing

AIMS OF ETERNAL PROJECT

- To understand how girls and women with CP experience UK healthcare, including sexual and reproductive healthcare, across the life course:
  - **From** manarche *(adolescence, age 14-17)* **through** fertility, family planning and pregnancy *(young and middle adulthood, age 18-54)* **to** menopause and post menopause *(older adulthood, age 55 and above)*
- To understand the physical, social and psychosocial effects of growing older with CP
- To understand what are the barriers and facilitators to access good quality UK nursing care/practice for girls/women with CP across the life course.
- Provide evidence base for future interventions to advance access to healthcare for girls and women with CP across their life course in particular, and for disabled women in general.

WHY IS THIS IMPORTANT?

- "disabled women have the right to access "the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health". – (Article 25a UNCRPD, 2006).
- Advancements in public health has led to increased life expectancy = generations of older people with CP (Hemming et al, 2006)
- the prevalence of impairment (CP and other conditions) is higher for women than men - 19.2% and 12% (World Report on Disability, 2011)
- Girls & Women with CP experience ageing and age-related health problems earlier than non-disabled women (Turk et al, 1997) - musculo-skeletal and neurological , puberty and menopause
- Disabled woman face physical, structural & informational barriers to healthcare across the female life cycle – from manarche to menopause (Piotrowski, & Snell, 2007)
- Primary health prevention crucial to overall health of population. Women & girls with CP are less likely to participate in regular preventative screening, or be targeted by health promotion and prevention activities (Cancer Research UK, 2017; WHO, 2016)
- There is no research within the UK of how CP manifests for women across the life course or on how nurses play a role in their lifelong care.
- A life course approach to healthcare for women with CP would be beneficial for health practitioners and service users to plan and ensure long-term health needs are addressed and the key risks are reduced at different stages of the life course.



CEREBRAL PALSY (CP) – CHALLENGING TRADITIONAL DIAGNOSIS

- A childhood motor impairment causing permanent disorders of movement and functionality due to non-progressive motor dysfunctions in the foetal or infant brain (Mudge et al, 2016)
- In UK, 2 in 1000 births result in CP (NICE, 2010)
- 90% of individuals with CP live beyond their 18th birthday (Strauss et al, 2008) depending on severity
- Increase in life expectancy but impaired communication → poor diagnosis (Balandin & Morgan, 2001)
- Organs don't always develop fully → work harder to compete with non-disabled bodies
- **CP is a life-long impairment → needs life-long health services and a *life course approach***

AGEING WITH CHILDHOOD IMPAIRMENT

"I hate cats! I want a dog scan."

- Accelerated ageing – deterioration of neurological and musculoskeletal systems earlier than non-disabled bodies –

"We wear out quicker, there is no doubt about it" (research participant from Patterson & Watson, 2013)

"I think that cerebral palsy in general, from a health perspective, is just viewed as a static condition and you either have it or you don't… you're not unwell with it… unless you have profound disability and there might be a risk of infections but… but even, my neurology colleagues were not really aware of this. Consultant neurologist." (Dr Z, GP; Patterson & Watson ,2013)

TIME OF YOUR LIVES

We would like to hear your stories about:

- healthcare services used at different times of life
- Nurses at different points in your life
- Your body growing older – what does that mean
- Good health, poor health
- Good times, bad times
- Barriers, opportunities
- Helpful people, unhelpful people
- Successes, problems
- Important decisions
- Big life changes
- Choices, dreams

CONCERNS & CONCEPTS

- Elder (1994, p 5) identified four key concerns –
- ‘the interplay of human lives and historical times
- the timing of lives
- linked or interdependent lives
- human agency in choice making’.

- Life course
- Time
- Trajectories
- Turning Points
- Interdependence
- Resources
- Agency

- Cerebral palsy
- Female life cycle – menarche to post menopause
- Healthcare & Sexual/Reproductive Healthcare
- Ageing
- Barriers
- Women – adult and older
- Teenage girls

TEENAGE GIRLS (14-17) – PUBERTY & SEXUAL HEALTH

- Puberty generally starts earlier for girls with CP
- Impairment effects + oestrogen-progestin → risk of thrombosis & weight gain → problematic functionality (Murphy et al, 2006)
- Milestones for physical social and sexual development extra challenging for teenagers with CP – disabling barriers
- Sexual exploration may be inhibited by surveillance, infantilisation, truncated learning and exclusionary practices
- Limited or absent sex and relationship education for disabled teenagers
- Vulnerable to "bad sex" ranging from areas such as prostitution and pornography, to sexual violence, unplanned pregnancies, and sexually transmitted diseases (Shakespeare, 2000; Shah et al, 2016)
- Have limited independence due to care needs
- Barriers to gynaecological examinations
- Developing positive/negative disability identity – 'passing'

ADULT WOMEN (18-54) – AGEING, FERTILITY AND REPRODUCTION

- Problematic transition from child-centred to adult-centred healthcare due to focus on single life stages → increase in unmet need
- Early onset of age-related impairments across biomedical, psychosocial and functional domains among 35-50 year olds → musculoskeletal changes and lifestyle changes
- Changing bodies, and deterioration in mobility and functionality → reduced independence → reduced QoL, self-esteem and happiness (Goodwin and Crompton, 2004)

> I have noticed that since I have gotten older my condition has gotten more pronounced. More pain, more stiff… And I have to do the things I usually do differently now... I try not to complain about the pain or even ask for help. Being the Leo that I am, I am very prideful. Lol. 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, age 50)*

UNCRPD Article 23 – Right to Respect and Family Life

Disabled women prevented/ actively discouraged from motherhood:

- Inaccessible physical spaces & hostile attitudes
- Portrayal of disabled woman incongruous to mother – *asexual, vulnerable, dependent* **VS** *independent, authoritative, capable*
- Social disapproval by 'societal supervisors' (Longhurst, 2001) who perceive disabled bodies as deviant
- Sterilisation ultimate invasion to control reproductive capability
- Not approved for non-disabled women but recommended for disabled women

…he [consultant] said "I meant to say, do you want me to sterilise you while we're at it? " I said "no, I maybe get sterilised in a few years time if that's what I want to do. "Oh no, we can do it while we are in delivering the baby. "I said "no, I don't want that. "... I was thinking I don't want to go to sleep, what if they sterilise me and don't tell me, because I was convinced they were going to do it' (McFarlane, 2004:159)

OLDER WOMEN (55+) – MENOPAUSE & POST MENOPAUSE

- Early onset of menopause
- Increased pain, risk of osteoporosis/bone fractures due to reduction in estrogen, coupled with inactivity, likelihood of falls
- Greater risk for developing a number of other bone, muscle, and joint-related diseases as they age, such as scoliosis (abnormal curvature of the spine) and spinal stenosis (neurologic problems associated with narrowing of the spinal canal)
- Lifetime of barriers & adversity → high unmet health needs
- Mortality from breast cancer 3 times higher than non-CP (Grono, 2016)
- Low mammography participation: (Nandam et al, 2017)
  - Lack of education around need for/availability of preventative treatment
  - Environmental/attitudinal barriers – lifts/ramps,
  - GP's focus on underlying conditions rather than preventive health care
  - difficulties interacting with HCPs/technologists due to speech impairments
  - the mechanics of the mammogram procedure

METHODS

- **Phase 1: Scoping review** - synthesis of global literature
- **Phase 2**: **Life course interviews with girls & women with CP across UK**

14-17 (teenage years),

18-54 (young and middle adulthood)

55 and above (older adulthood):

- **Phase 3: Interviews with nurses and midwives (n=20-30):**
- Nurses'/midwives' knowledge of CP and how it affects women at different points in their life
- Nurses'/midwives' experience of treating women with CP and interventions used to treat them.

WHO WE WANT TO TALK TO

Females (from birth)

- Ages 14-17 (teenagers), 18-54 (young/middle adult), 55+ (older)
- Identify as having CP
- Intellectual capacity to participate and consent
- With and without children
- Able to participate in English
- Based in the UK – England, Scotland, Wales, N. Ireland

Nurses & midwives

- who work (or have in last five years) in areas of SRH (at different stages of female life cycle)
- who work (or have in last five years) with disabled people or people with lifelong impairments
- Work across the UK
- May work in NHS, private or third sector settings

SMALL GROUP EXCERCISE

- 3 Groups: 1) ***TEENAGERS*** ***2: ADULT WOMEN*** ***3. OLDER WOMEN***

- WHAT ARE THE MAJOR ISSUES IMPACTING HEALTH AND WELLBEING OF YOUR GROUP? – 1-3
- WHAT IS NEEDED TO MAKE SURE YOUR GROUP HAS REGULAR GOOD ACCESS TO SEXUAL & REPRODUCTIVE HEALTHCARE – RANK 1-3
- WHAT IS NEEDED FOR PEOPLE WITH CP TO MAINTAIN GOOD HEALTH AND WELLBEING ACROSS THE LIFE COURSE? – RANK 1-3

FEEDBACK