

The experiences of orthopaedic and trauma hospital care from the perspectives of adults with an intellectual/learning disability: An Interpretative Phenomenological Analytical (IPA) study

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Aim

To present an overview of the study undertaken with adults with an intellectual disability about their orthopaedic and trauma hospital experiences



Background to the study

People with intellectual disabilities have a greater prevalence of musculoskeletal conditions and poorer bone health than the general population

Many reports, policies and legislation related to poor general hospital care for people with intellectual disabilities

The study was undertaken as part of a Professional Doctorate in Health and Wellbeing Award



Health and people with learning disabilities



Closing the Gap (Disability Rights Commission)

Death by Indifference (Mencap)

Healthcare for All (Sir Jonathan Michael)

Six Lives (Parliamentary and Health Service Ombudsman + Local Government Ombudsman)



Background

- Several reports and inquiries have said that people with learning disabilities are not getting good health and social care
- Some people are dying too soon

These reports include:

Mencap – *Death by Indifference* (2007)

The Confidential Inquiry into deaths of people with learning disabilities (2013)



This information can be made available in formats such as easy read or large print, and may be available in alternative languages, upon request

Annual Report
December 2017



Integrative review (IR) of the literature

- Rationale for IR- broad review
- 2007-2018
- Literature used to present the background and context of the study
- Primary research studies (n=9) included in the final review
- No study focused on orthopaedic or trauma hospital care of people with an intellectual disability



Research question

- How do adults with an intellectual disability describe their orthopaedic or trauma hospital experiences?



Introduction to study

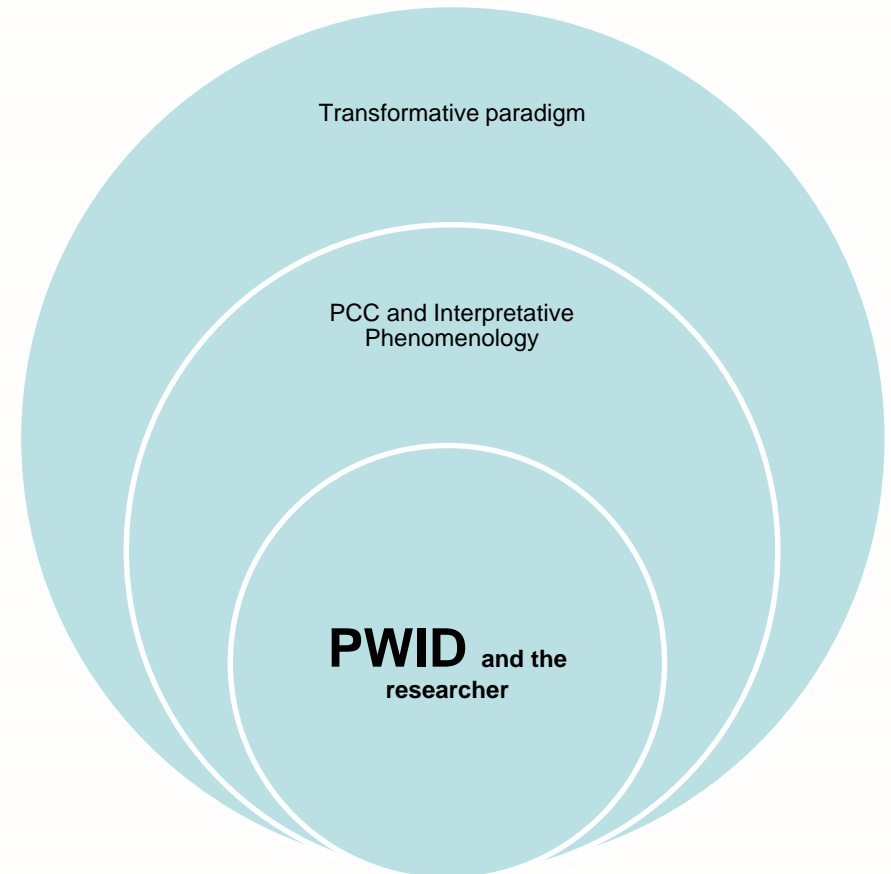
- Exploratory study
- 5 participants
- 4 with an intellectual disability
- 1 carer: Son had profound and multiple intellectual disability (PMID)





The design of the study

- Purposive sample
- Theoretical framework:
Person-Centred Care
(PCC)
- Interpretative
Phenomenological
Analysis (IPA)
- Transformative paradigm





Some of the ethical issues and challenges

- Access to people with an intellectual disability
- Perceived to be more vulnerable participants
- Informed consent
- Ethical approval received



Details of the participants

NAME	Gender	AGE	Elective orthopaedic or trauma hospital care
Kay	Female	25	Elective orthopaedic
Ted	Male	45	Elective orthopaedic and Trauma hospital care
Kelly	Female	32	Elective orthopaedic
Len	Male	44	Trauma
Sue (Carer)	Female	unknown	
Alex	Male	24	Trauma



Kay, Ted, Kelly, Sue and Len

Kay: hip problems, attended self advocacy group. Co-presented at a conference

Ted: lower limb deformities and traumatic fractures. Difficulty understanding speech, email used and face-to-face interview

Kelly: hip and knee problems. Met again a year later

Sue and Alex: fractures of lower limb, fingers and toes. Co-presented at RCN Orthopaedic and Trauma nursing conference

Len: fractured ankle. Attends self-advocacy group



Data collection: semi-structured interviews

- Interviews conducted, audio recorded and transcribed by the same researcher
- Face-to-face, telephone, email
- Analysis and interpretation using approach advocated by Smith, Flowers and Larkin (2009)



Quotations from Kay

...I found it hard to understand... erm... long words...(Kay, line 373)

... when I don't understand long words... sometimes they have to tell my mom and then my mom tells me what it means...

(Kay, line 220-226)

...sometimes you have to wait ages for...tablets... when you say you're in pain...they say they're gonna get tablets... they don't come back for ages...and then I end up crying...because I'm in a lot of pain... (Kay, line 228-233)

... what they used to do is say...in the morning was have a wash, get ready...but I was scared to ask um to help me...so I just waited for my Mom to come... it was about how busy they are... (Kay, line 278-281)



Quotations from Ted

...some said things what made sense but sometimes they said things which were not true or (did) not make sense...I was not always aware what was happening (Ted Email 13.6.16 at 21:27)

...in a room on my own...I had blood in my mouth... but no-one came in...it went on for 14 hours... yeah every person had a nurse after their operation... right but I was left for 14 hours ... 14 hours I didn't see anyone...(Ted line 133-141)

...He was the only one who even thought, I will try... I might not be walking now if he didn't try... (Ted, line 123-125)



Quotations from Kelly

...I had 30 clips in my hip...I was shouting, screaming and crying...I want my Mom and Dad...the nurse did it...

(Kelly, line 266-269)

...I'm 32...and I'm not a child, I'm an adult (Kelly, line 291-293)

...I used to facetime my Dad...and my Mom...and my Sister... (Kelly, line 212-216)



Quotations from Len

...horrible...what was it like...absolutely horrible (Len, line 34)

...it was cold...and not too much privacy neither...noisy (Len, line 90)

...it was really, really, noisy....you know what hospitals are like...” (Len, line 200)

...erm...listen to what we say...more about our rights... that we're disabled... and understand (Len, line 180-186)



Quotations from Sue (carer for Son with PMID)

...having nurses that took responsibility, that have some common sense, that listened, actually took notice of what I said, that I'm not just this mother, that I actually have some information that could be helpful and that they could work WITH me and not me feeling I had to work against them all the time... (Sue, line 479-482)

... well they talked to the carer rather than to him...so...I always say to them; will you talk to him please?! (Sue, line 258-260)

He'd have died if he'd have stayed in hospital... He'd have died (Sue, line 414-416)

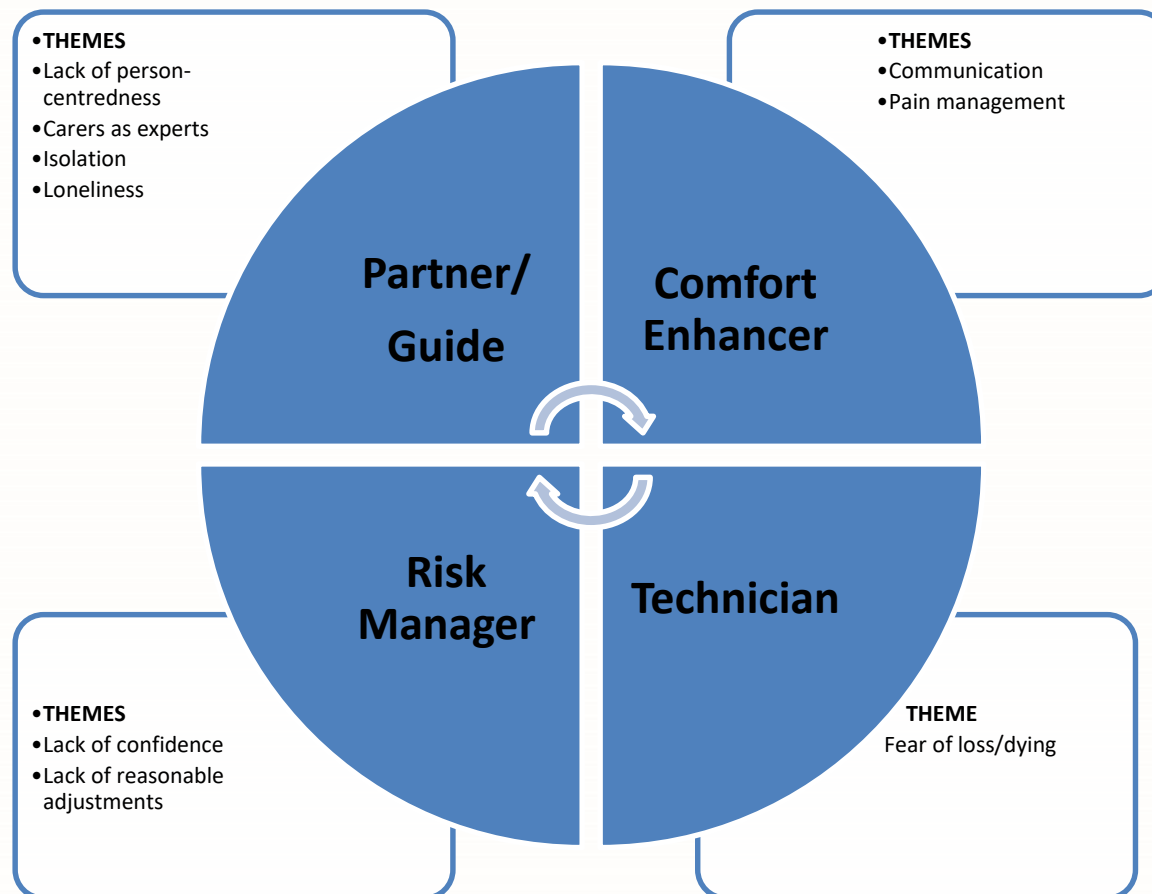


Findings across the participants

- Communication problems
- Lack of person-centred care
- Issues related to pain management
- Lack of confidence in hospital care
- The valuable support and expertise of carers
- Incompetence of hospital staff to make adjustments
- Isolation and loneliness



The themes derived from a cross case comparison situated within the domains of orthopaedic and trauma practice (RCN SOTN 2019)





Conclusion

- The findings are confirmatory of other studies
- The majority of participant experiences were exceedingly poor
- The fundamental needs of PWID were not met
- Further empirical exploration of the reasons for these failings is required
- Addressing these issues might enhance the hospital experiences for PWID, their health outcomes and ultimately avoid premature deaths



Tentative implications and recommendations

- Education and training
- Orthopaedic and trauma hospital practice
- Policy
- Further research



Limitations and strengths of the study

- Novice researcher
- Small participant group to enable gathering of rich qualitative data and congruent with IPA
- Unique contribution to orthopaedic nursing knowledge
- Often a voiceless and overlooked group – this study begins to correct that oversight



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