

THE VOICES OF ADULTS WITH A LEARNING DISABILITY AND A CARER ON
THEIR ORTHOPAEDIC AND TRAUMA HOSPITAL CARE IN THE UK

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Abstract

Introduction: People with learning disabilities have a greater prevalence of musculoskeletal conditions and injuries than the general population and these have significant impacts on wellbeing. Despite this, orthopaedic and trauma hospital care has not been investigated with this group who seldom have their voices heard or their experiences valued and interpreted. This study contributes to the existing evidence base by exploring the experiences of people with a learning disability who have received orthopaedic and trauma hospital care.

Aim: To understand the orthopaedic and trauma hospital experiences from the perspective of adults with a learning disability.

Methods: A qualitative approach, focusing on peoples' lived experiences, was utilised. A purposive sample of five participants was recruited and one-to-one, semi-structured interviews were undertaken. Analysis of the interviews employed an interpretative phenomenological analytical framework.

Findings: Findings from each participant in the study was discussed in relation to their orthopaedic and trauma hospital care. A cross-case comparison was then undertaken and the themes below represent common experiences across participants:

- Communication challenges
- 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
- Isolation and loneliness

Discussion & conclusions: This study contributes to the evidence base by being the first to specifically focus on and provide experiential findings pertaining to the orthopaedic or trauma hospital experiences of adults with learning disabilities. There were significant shortcomings in the orthopaedic and trauma hospital experiences of adults with learning disabilities who perceived they were unsupported and received poor care in orthopaedic and trauma hospital settings.

Recommendations and implications for practice: Person-centred care for adults with learning disabilities in orthopaedic and trauma hospital settings is needed along with specific education and training which includes close liaison with the experts by experience - people with learning disabilities and their carers as well as the specialists in learning disabilities.

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Abbreviations

ARMA:	The Arthritis and Musculoskeletal Alliance
BPAT:	The Bolton Pain Assessment Tool
BILD:	The British Institute of Learning Disabilities
BMD	Bone Mineral Density
BNI:	British Nursing Index
CQC:	Care Quality Commission
CIPOLD:	Confidential Inquiry into the Premature Deaths of People with Learning Disabilities
CINAHL:	Cumulative Index to Nursing and Allied Health Literature
DA:	Discourse Analysis
DEXA:	Dual-energy X-ray absorptiometry
DfES:	Department for Education and Skills
DH:	Department of Health
DNACPR:	Do Not Attempt Cardio-Pulmonary Resuscitation
DRC:	Disability Rights Commission
DSM:	The Diagnostic and Statistical Manual of Mental Disorders
EWS:	Early Warning Score
GAIN:	Guidelines on caring for people with learning disabilities in general hospital settings
GBD:	Global Burden of Disease
GP:	General practice/practitioner
GT:	Grounded Theory
HEF:	Health Equality Framework
HEI:	Higher Education Institute
HES:	Hospital Episode Statistics
HQIP:	Healthcare Quality Improvement Partnership
HRA:	Health Research Authority
ICD:	International Classification of Diseases
ID:	Intellectual disability
IPA:	Interpretative Phenomenological Analysis
IR:	Integrative Review
IQ:	Intelligence Quotient

LD:	Learning disability
LeDeR:	Learning Disabilities Mortality Review Programme
MCA:	Mental Capacity Act
MEDLINE:	Medical Literature Analysis and Retrieval System Online
MHRA:	The Medicines and Healthcare Products Regulatory Agency
MMAT:	Mixed Methods Appraisal Tool
MSK:	Musculoskeletal
MSK-HQ:	Musculoskeletal Health Questionnaire
NA:	Narrative Analysis
NEWS:	National Early Warning Score
NHFD:	National Hip Fracture Database
NHS:	National Health Service
NHSE:	National Health Service England
NHS LTP:	National Health Service Long Term Plan
NJR:	National Joint Registry
NICE:	National Institute for Health and Clinical Excellence
NIHR:	National Institute for Health Research
NMC:	Nursing and Midwifery Council
NOS:	National Osteoporosis Society
NPSA:	National Patient Safety Agency
OA:	Osteoarthritis
PCC:	Person-Centred Care
PHE:	Public Health England
PMLD:	Profound and Multiple Learning Disability
PROMs:	Patient Reported Outcome Measures
PWLD:	People with Learning Disabilities
PsychINFO:	Psychological Information Database
QOF:	Quality Outcome Framework
RCN:	Royal College of Nursing
RCP:	Royal College of Physicians
RN:	Registered Nurse
SIGN:	Scottish Intercollegiate Guideline Network
SOTN:	Society of Orthopaedic and Trauma Nurses

SUFE:	Slipped upper femoral epiphysis
SUCCESS:	Service User and Carers Contributing to Educating Students for Services
T & O:	Trauma and Orthopaedic
THR:	Total hip replacement
UK:	United Kingdom
UN:	United Nations
UNCRPD:	United Nations Convention on the Rights of People with Disabilities
USA:	United States of America
VNPS:	Verbal numerical pain scale
WHO:	World Health Organisation

Glossary of Terms

Arthroplasty: The surgical reconstruction or replacement of a joint in the body.

Diagnostic overshadowing: Refers to when symptoms arising from physical or mental health problems are misattributed to an individual's learning disability, leading to delayed diagnosis and treatment.

Disenfranchised: Deprived of rights. A feeling of not belonging and powerlessness.

Equality: The state of being equal, for example, in status, rights or opportunities.

Equity: The quality of being fair.

Fibula: The outer and usually smaller of the two bones between the knee and the ankle.

Fracture: A break in a bone of the body.

Marginalised: An unimportant or powerless position within society.

Musculoskeletal: Relates to the muscles, joints, bones, ligaments, tendons and nerves of the body.

National Hip Fracture Database: A nationwide audit within the NHS concerning the management and outcomes of patients with hip fractures.

National Joint Registry: A register set up in 2002 by the Department of Health to collect information on joint replacement operations and to monitor the performance of implants, hospitals and surgeons.

Orthopaedic: A specialty which focuses on injuries and conditions of the musculoskeletal system and includes bones, joints, ligaments, tendons, muscles and nerves.

Osteoarthritis: A condition that causes joints to become painful and stiff. It is the most common type of arthritis in the UK.

Osteoporosis: A bone condition which weakens bones making them more fragile and more likely to break.

Hip Fracture: A serious and common injury- a break in the proximal femoral bone (top of the thigh bone).

Tibia: Also known as the shin bone. It is the larger of the two bones in the leg below the knee.

Trauma: Musculoskeletal trauma includes all kinds of injuries affecting the bones, joints, muscles, tendons and ligaments in any part of the body that are caused by trauma.

Vulnerable: Exposed to the possibility of being harmed. PWLD may be vulnerable due to dependence on others, for example, due to complex physical needs, sensory needs and communication challenges.

Dedication

This thesis is dedicated to 'Kay', 'Ted', 'Kelly', 'Len' and 'Sue', the participants in this study. Thank you for being involved in the research study and sharing your experiences about orthopaedic and trauma hospital care.

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Whatever their gifts, or their limitations, people are all bound together in a common humanity. Everyone is of unique and sacred value and everyone has the same dignity and the same rights.

Jean Vanier

(1928-2019, p.1)

Chapter One Introduction

1.1 Introduction to the Thesis

This thesis presents a research study undertaken with adults with a learning disability to explore their orthopaedic and trauma hospital experiences. People that have been recognised as having a learning disability have more health care needs than people without a learning disability and are very likely to come into contact with hospital services (Royal College of Nursing, (RCN), 2017) and this includes significant conditions related to their musculoskeletal system (Kinnear *et al.*, 2018). It has been known for some time that people with learning disabilities (PWLD) experience more unmet health needs than the general population (Iacono and Davis, 2003). However, it is encouraging that PWLD now have a greater life expectancy than in previous years (Coppus, 2013) but, despite this improved longevity, there was a national confidential inquiry into premature deaths among PWLD in England and this highlighted the premature deaths of PWLD who have died, on average sixteen years earlier, than the general population (Heslop *et al.*, 2013). This was attributed to potentially modifiable poor care and service provision as 42 per cent of the deaths that the panel investigated and agreed upon were assessed as premature deaths, with repeated problems of delayed diagnosis, poor identification of needs and inappropriate care (Heslop *et al.*, 2013).

The Health Charter produced by the Learning Disabilities Public Health Observatory (2015) provided details of health inequalities which affect this specific group of people and NHS England (NHSE) (2015a; 2015b) continues to work to transform health care for PWLD. However, a recent inquest highlighted by the media, continues to illustrate that PWLD still receive extremely poor general hospital care

resulting in death in England. A recent example is Richard Handley, a young man with a learning disability, who died as a consequence of constipation. The inquest into the early and preventable death of Mr. Handley, a 33-year-old man who had Down syndrome and suffered lifelong constipation, found “gross [and] very significant failures” at almost every stage of his care. Multiple omissions of care led to Mr. Handley’s death from constipation, a “condition that one is not expected to die of” (The Guardian, 8th February 2018). Such shocking examples demonstrate the need for further hospital focused research pertaining to PWLD within the United Kingdom (UK).

This chapter provides the background and contextual information for the thesis. It presents the definitions of learning disability, the prevalence of learning disabilities in England, the prevalence and impact of musculoskeletal conditions and injuries, the policy drivers for change and the context of hospital care for PWLD. The position of the researcher is discussed along with the conceptual underpinnings of ‘Person-Centred Care’ (PCC) that has guided the study. Finally, the structure of the thesis is outlined.

1.2 Defining learning disability

The terminology used to describe ‘learning disability’ has changed over the years from, for example, ‘mental retardation’, ‘mental sub-normality’, ‘mental deficiency’ and ‘mental handicap’ to ‘learning disability’ which is currently used in England. Whereas in other parts of the UK and internationally other synonyms are used such as ‘intellectual disability’ (ID), ‘cognitive impairment’ and ‘developmental disability’.

The RCN, (2017, p. 1) define a learning disability as:

a lifelong condition, resulting in a reduced intellectual ability and thus difficulty with everyday tasks.

The Department of Health (DH) (2001, p. 14) refers to a similar definition:

a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence) along with a reduced ability to cope independently (impaired social functioning). The onset of disability is considered to have started before adulthood, with a lasting effect on development.

Historically, learning disability has been divided into a number of categories that were intended to reflect its nature and extent. These range from 'mild', 'moderate' and 'severe' to 'profound' and generally these have been based on measured intelligence. This represents one understanding of learning disability from a medical model perspective. However, Nunkoosing (2012) asserted that the term 'learning disability' is socially constructed, historically and culturally bound, and is used to label a particular group of people within society. Whilst the RCN (2013) described learning disability as a common, lifelong condition which is neither an illness nor a disease, The International Classification of Diseases, (2010) (ICD-10) describes learning disability as follows:

...a condition of arrested or incomplete development of the mind, which is especially characterised by impairment of skills manifested during the developmental period, which contribute to the overall level of intelligence, i.e. cognitive, language, motor and social abilities.

Another internationally recognised definition is from the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2013) (DSM-V) which defines 'Intellectual Disability' by referring to limited functioning in three areas:

- Social skills (e.g. communicating with others)
- Conceptual skills (e.g. reading and writing ability)
- Practical ability (e.g. clothing/bathing one's self)

There is an implication that the diagnosis of 'learning disability' is a matter of determining whether an individual has impaired social functioning and an Intelligence Quotient (IQ) of less than 70. However, Whitaker (2008) highlights significant problems with the reliability of assessing a person's intelligence quotient (IQ) for use in the diagnosis of learning disability. He argued that IQ tests are unreliable for this diagnosis because a person's level of adaptive behaviour and IQ cannot be measured with sufficient accuracy. For example, if a person scores over 70 on an IQ test it may suggest they do not have a learning disability which can then have significant consequences for their future health care provision. A learning disability is not a discrete entity so an IQ test may not always identify it. Moreover, Whitaker (2008, p. 8) suggests the following:

A person can be identified as having an intellectual disability if they are judged to be in need of community care or educational services due to failure to cope with the intellectual demands of their environment and are suffering significant distress or are unable to take care of themselves or their dependents or unable to protect themselves or their dependents against significant harm or exploitation.

A PWLD is likely to experience difficulty in understanding new or complex information or learning new skills (RCN, 2017). The person may also have difficulties

with social and/or communication skills, with carrying out activities of daily living independently and may have associated physical and sensory disabilities (ICD 10).

Some PWLD prefer the term 'learning difficulties' to be used (Gates, 2009, p. 5), but for the purposes of this thesis, 'learning disability' has been adopted as its usage is common and widely shared in meaning in the UK and there are groups of PWLD who prefer this term. These broad definitions of learning disability attempt to identify PWLD collectively; it is acknowledged that the terminology used to describe learning disability has changed over time to reflect the language that is more acceptable by society.

In relation to healthcare provision, in *Healthcare for All: Report of the independent inquiry into access to healthcare for people with learning disabilities* (2008, p. 5), Sir Jonathan Michael wrote:

I have since recognised that addressing the difficulties faced by people with learning disabilities in accessing general healthcare services does not require specialist knowledge about learning disabilities; the issues they face are relevant to all members of society. What matters is that people with learning disabilities are included as equal citizens, with equal rights of access to equally effective treatment. I have also learnt that 'equal' does not always mean 'the same' and the 'reasonable adjustments' that are needed to make services equally accessible to people with learning disabilities, are not particularly difficult to make.

To summarise what it means to have a learning disability, NHSE (2017) believe that a learning disability affects the way a person understands information and that they will have a lifelong difficulty learning new skills and understanding information and they may socialise differently. Moreover, people may be disabled by society or indeed, orthopaedic or trauma hospital care, if their needs are not accommodated.

These definitions of learning disability provide an overview of the areas where PWLD may need more support with understanding new information and this must be considered in relation to how care is provided for PWLD in orthopaedic and trauma hospital settings.

The researcher's view is that definitions of 'learning disability' can be helpful for health care staff if they enhance understanding and ultimately the specific care and support needs that a PWLD has. However, it is important that PWLD are not constrained or solely defined by this label as this can lead to discrimination of a marginalised and vulnerable group of people. All people, including PWLD, are unique and will have different strengths and limitations and therefore it is of paramount importance to build a relationship in order to get to know the person to find out about their strengths and weaknesses. Having a learning disability is simply another way of being and adds to the rich diversity of the human family.

1.3 Prevalence of learning disabilities in England

Public Health England (PHE) (2016) stated that there is no definitive record of the number of PWLD in England as no government department collects comprehensive information on the presence of learning disabilities in the population. Learning disabilities are not recorded in the decennial Census of the UK population. It is, however, possible to estimate the number of PWLD in England by combining information collected by government departments on the presence of learning disabilities among people using particular services. However, not all PWLD will be known to services therefore the actual numbers may be higher. From the overall

population predictions for England and from the results of epidemiological research it is estimated that in 2015 there were 1,087,100 PWLD, including 930,400 adults.

The Quality and Outcomes Framework (QOF) is the annual reward and incentive programme detailing General Practitioner (GP) practice achievement results. It is a voluntary process for all GP practices in England and was introduced as part of the GP contract in 2004. As part of the QOF, there is a measure on the prevalence of patients recorded as having a learning disability in England. Data for 2014/15 shows that 0.4% of patients are registered with their GP as having a learning disability, this equates to approximately 217,266 people in England. It is estimated that 2.16% of the adult population have a learning disability in England. These estimates suggest that only 23% of adults with learning disabilities in England are identified as such on GP registers, the most comprehensive identification source within health or social services in England. The remaining 77% have been referred to as the 'hidden majority' of PWLD who typically remain invisible in data collection endeavours (PHE, 2016).

That said, the numbers of people on GP learning disability registers, and prevalence per 1,000 people in England from 2006/07 to 2014/15 showed increasing numbers of PWLD each year on GP registers. The reasons for the continuing increases in numbers are not clear although it is thought that it may reflect greater recognition by GPs of PWLD along with an increase in the current population with learning disabilities possibly from greater numbers surviving very premature birth or a decrease in mortality (PHE, 2016). However, more than three times the number of PWLD die than would be expected when taking into account age and sex (PHE, 2016).

1.4 Prevalence and impact of musculoskeletal (MSK) / orthopaedic and trauma conditions

The terminology 'musculoskeletal' and 'orthopaedic and trauma' is used interchangeably in the thesis. The Global Burden of Disease (GBD) study (2016) provided evidence of the impact of musculoskeletal conditions and highlighted the significant disability burden associated with these conditions. In this study, musculoskeletal conditions were the second highest contributor to disability, and lower back pain remained the single leading cause of disability. The World Health Organisation (WHO) (2018) illustrated that musculoskeletal conditions affect people across the life-span and in all regions of the world with more than 200 musculoskeletal conditions. The most common and disabling musculoskeletal conditions were osteoarthritis, back and neck pain, fractures associated with bone fragility, injuries and systemic inflammatory conditions such as rheumatoid arthritis (WHO, 2018).

NHSE (2018a) has focused on musculoskeletal (MSK) conditions and Table 1 highlights the reasons for prioritising musculoskeletal health care in the UK. Conditions of the MSK system affect the joints, bones and muscles, and also include rarer autoimmune diseases and back pain. More years are lived with musculoskeletal disability than any other long-term condition.

Table 1 Key information and the impact of MSK conditions in England
(adapted from NHS England, 2018a)

- Affects 1 in 4 of the adult population which is around 9.6 million adults in the UK
- Account for 30% of GP consultations in England
- Have an enormous impact on the quality of life of millions of people in the UK; 10.8 million days are lost as a consequence of musculoskeletal conditions
- Associated with a large number of co-morbidities, including diabetes, depression and obesity
- Account for over 25% of all surgical interventions in the NHS, and this is set to rise significantly over the next ten years
- Account for £4.76 billion of NHS spending each year

Musculoskeletal conditions may develop in utero and be present at birth or develop during childhood, adolescence or adulthood through to old age (Clarke and Santy-Tomlinson, 2014; PHE, 2019). For example, in utero as well as at birth, congenital abnormalities such as developmental dysplasia of the hip can be detected; developmental abnormalities may present during childhood such as Perthes disease of the hip or a slipped upper femoral epiphysis (SUFE) and during the adult years other MSK conditions can be acquired such as osteoporosis or osteoarthritis along with injuries such as fractures. These MSK conditions can affect all people and can lead to significant problems if they are not detected early and managed effectively (PHE, 2019).

1.5 Musculoskeletal health and people with learning disabilities (PWLD)

Michael (2008) asserted that PWLD were at increased risk of poor bone health but despite this, assessment of bone health is often not undertaken. Moreover, there is an underutilisation of the preventative services related to MSK conditions and injuries amongst PWLD (Srikanth *et al.*, 2011). Peak bone mineral density (BMD) is attained in early adulthood but PWLD may not reach an optimal BMD and therefore they are at an increased risk of developing osteoporosis (Srikanth *et al.*, 2011). Osteoporosis is a common bone disease characterised by reduced BMD which is associated with an increased risk of fractures. Fractures are an important cause of morbidity, and people who suffer hip and vertebral fractures have a decreased life expectancy (Scottish Intercollegiate Guideline Network, (SIGN) 2015).

Lifestyle factors are contributors to poor bone health in PWLD, such as poor dietary habits, constipation, poor mobility, low levels of exercise, low levels of vitamin D and obesity in PWLD (McCarron *et al.*, 2011). In a study conducted in Ireland by Burke *et al.* (2016) three out of 10 PWLD that were diagnosed with osteoporosis were not prescribed first line preventative treatment which protects against future injuries such as fractures. Furthermore, there were over three quarters of PWLD who had a history of a fracture that were not prescribed vitamin D, calcium or a combination. This is extremely concerning as having a history of a fracture is a risk for a future fracture (National Institute for Health and Care Excellence (NICE), 2012/2017).

A meta-analysis of 11 cohort studies included in the NICE guideline (2012/2017) on osteoporosis, assessing the risk of fragility fracture, reported that a history of previous fracture was associated with an increased risk of any fracture, osteoporotic

fractures and hip fractures. The potential outcome of poor bone health is fracture which can result in unnecessary pain, physical disability and impact negatively on activities of daily living, quality of life and quality of life years lived (Burke *et al.*, 2016). In a more recent study, Burke *et al.* (2019) demonstrated that the prevalence of poor bone health in PWLD is substantial implying an increased risk of fracture due to reduced skeletal integrity.

Despite advances in diagnosis and prevention of osteoporosis in the general population, Burke *et al.* (2016) highlighted that PWLD also present with risks similar to the general population. However, as well as having additional risks, such as epilepsy, use of anti-epileptic drugs, early menopause, poor dietary intake and low levels of physical activity, they were not undergoing risk assessment for fractures or having the gold standard, DEXA scan, to diagnose osteoporosis or receiving preventative measures. A study undertaken in Norway by Skorpen, Nicolaisen and Langballe (2016) concurred with the study undertaken by Burke *et al.* (2016), that osteoporosis is under-diagnosed in PWLD. A fracture risk assessment should be undertaken with PWLD as the SIGN, (2015) guidelines recommends that people with epilepsy over the age of 50 who are taking anti-epileptic drugs and especially those with additional risk factors should be considered for fracture risk assessment. Although the guideline does not mention PWLD specifically, epilepsy affects around one third of PWLD (RCN, 2006).

The exact mechanism by which anti-epileptic drugs affect bone strength is not fully understood. It is thought that some anti-epileptic drugs alter the way vitamin D is metabolised by the body (National Osteoporosis Society, (NOS), 2015). The body

needs vitamin D for the absorption of calcium which is a vital nutrient for healthy bones. Most people obtain the majority of their vitamin D from exposure to sunlight. A drug safety update from the Medicines and Healthcare Products Regulatory Agency (MHRA) (2009) found that long-term treatment with carbamazepine, phenytoin, primidone and sodium valproate, can reduce BMD which may lead to osteopenia, osteoporosis and increased fractures in certain 'at risk' groups. Particularly at risk are PWLD who may be immobilised for long periods, not receiving enough dietary calcium and for whom there may be insufficient exposure to sunlight to maintain adequate vitamin D levels (NOS, 2015).

There are a wide range of treatments available that can reduce the risk of fractures occurring in people with osteoporosis and these have the potential to improve clinical outcomes along with reducing the personal impact and societal costs of medical care associated with fractures (SIGN, 2015). Vitamin D supplementation should be considered for people 'at risk' who receive long-term treatment with primidone, phenytoin, carbamazepine, phenobarbital or sodium valproate (MHRA, 2009).

Furthermore, Finlayson (2011) and Finlayson *et al.* (2010; 2014) reported that PWLD sustain more injuries, falls and accidents than the general population. Eye disease is associated with falls risk and is highly prevalent among older PWLD (McCarron *et al.*, 2013). Fractures may occur from a low impact injury if a person has osteoporosis and this places PWLD at an increased risk of injury following a fall (Cox *et al.*, 2010).

A large, population-based cross-sectional study was undertaken in Scotland recently and concluded that the most prevalent physical health conditions affecting PWLD included: osteoporosis, bone deformity and musculoskeletal pain (Kinnear *et al.*, 2018). A staggering 48% of PWLD in this large study with 1023 participants had MSK conditions. Interestingly, prior to the study by Kinnear *et al.* (2018), it was unknown how prevalent musculoskeletal conditions were in PWLD. Although this study was undertaken in one region of Scotland it highlights the prevalence of MSK conditions as well as the complexity related to multi-morbidity for PWLD.

1.5.1 The main symptoms of musculoskeletal conditions or injuries: Pain and limitation of physical movement

Musculoskeletal conditions are typically characterised by pain which may be persistent as well as limitations in mobility, dexterity and functional ability (WHO, 2018; PHE, 2019). However, dealing with pain can be a challenging task for some PWLD who may face barriers to having pain addressed if they cannot provide valid self-reports or are unable to explain their symptoms (Skorpen, Nicolaisen and Langballe, 2016). Burke *et al.* (2016) agree that as communication may be difficult for PWLD, osteoporotic fractures may go undiagnosed. Notwithstanding the difficulties that a person can have in communicating their pain, the carers may not know or understand that the person is in pain and therefore pain assessment and subsequent management is often difficult.

1.5.2 Musculoskeletal services

Musculoskeletal / orthopaedic and trauma services focus on the prevention and treatment of musculoskeletal disorders and associated traumatic conditions (RCN,

Society of Orthopaedic and Trauma Nurses (SOTN) 2019). This involves assessment, planning and implementation of possible conservative or surgical interventions for people who experience conditions or injuries of the MSK system. In the UK, MSK conditions are mainly managed in primary care, with referral to clinics and secondary hospital care for more complex management or specialist treatment and surgery, such as joint replacement surgery (Hill *et al.*, 2016).

Musculoskeletal Networks of Care, a new partnership between NHSE and the Arthritis and Musculoskeletal Alliance (ARMA), aim to foster relationships between care sectors, and share innovative and best practice. They plan to bring together all the musculoskeletal key stakeholders including professional organisations, the third sector, people with musculoskeletal conditions and carers. NHSE is currently developing and sharing a number of musculoskeletal resources, including expert webinars, blogs, and presentations for commissioners, providers, clinicians and patient groups. However, it is unclear if any of these resources are specifically aimed to help and support PWLD.

Hill *et al.* (2016) have developed and validated a single musculoskeletal outcome measure for use throughout the MSK pathway for patients with different musculoskeletal conditions. The Patient Reported Outcome Measure (PROM) tool is called The Arthritis Research UK Musculoskeletal Health Questionnaire (MSK-HQ). Patients generally have reported MSK-HQ items to be 'highly relevant' and 'easy to understand' and Hill *et al.* (2016, p. 5) conclude that this new MSK outcome measure has been developed through a coproduction process with patients to capture prioritised outcomes for use throughout the MSK pathway and with different

musculoskeletal conditions. However, it is not evident if PWLD were involved in the coproduction or how they will access or successfully complete this tool. An easier to read tool or clear information was unavailable and there was a lack of evidence that PWLD had been consulted with or involved despite PWLD having a high prevalence of MSK conditions. Jester, Santy-Tomlinson and Drozd (2018) asserted that PWLD are regular recipients of orthopaedic and trauma interventions and should receive PROMS questionnaires to evaluate the impact of an intervention. There was no published data about how PWLD complete a PROMs questionnaire either before or after orthopaedic or trauma interventions. If PWLD do not complete a PROMs questionnaire then their unique experiences are not captured or evaluated which has implications for this marginalised and disenfranchised group of people, commissioners of services as well as health care providers as it results in a significant amount of data that has not been captured. Moreover, if someone else, such as a health care professional or support worker, a family or a paid carer has completed the PROMs questionnaire on behalf of the PWLD, there is a risk that the person's experiences may not have been captured reliably.

1.5.3 Joint replacement surgery

In England alone, over a one-year period there were 114,500 hospital admissions due to osteoarthritis which is one of the most prevalent musculoskeletal conditions (NICE, 2014). It is defined as persistent joint pain that becomes worse with use, predominantly in people age 45 years or older and accompanied by morning stiffness lasting no more than half an hour (NICE, 2014). The statistics are interesting as the majority of people with osteoarthritis are managed in primary care.

The National Joint Registry (NJR) is the largest arthroplasty register in the world and contains data with the numbers and demographics of people who receive a hip, knee, ankle, shoulder or elbow replacement in England, Wales, Northern Ireland and the Isle of Man. During 2016/17 there were a total of 242,629 people who had received a joint replacement which represents an increase of over 20,000 on the previous year and brings the total number of records in the registry to approximately 2.35 million. The consistently high number of cases submitted per year suggests continuing high levels of patient confidence and clinical performance in what is a remarkably successful surgical intervention (NJR, 2017).

King, March and Anandracoomarasamy (2013) assert that obesity contributes to the incidence and progression of osteoarthritis (OA) which is a leading driver of joint replacement demand. They also highlight that obesity imposes increased risk of complications from surgery. Moreover, it has been recognised for many years that PWLD are at increased risk of obesity compared to the general population, with poorly balanced diets and very low levels of physical activity (PHE, 2016b). However, it is not clear how many PWLD receive a joint replacement as this data is not currently collected. The primary reason for undergoing joint replacement surgery is due to osteoarthritis which is impacting on a person's quality of life due to pain and or disability (NJR, 2017). PWLD also develop osteoarthritis but their numbers and clinical outcomes from receiving joint replacement surgery are unknown (NJR, 2017).

1.5.4 Hip fractures

Hip fracture is the most common serious injury in older people and in 2016, over 65,000 people aged 60 or older presented to 177 hospitals in England, Wales and Northern Ireland (National Hip Fracture Database, (NHFD) 2017). The NHFD is a national clinical audit undertaken by the Royal College of Physicians on behalf of the NHS. Data is collected on many aspects of the hospital care that is given to patients who have sustained a hip fracture in England, Wales and Northern Ireland aged 60 and over. This data is fed back to hospital staff in a number of ways, including annual reports, to allow hospitals to track their performance and to facilitate quality improvements. The database does not record if people have a learning disability, however. Alongside this, PWLD may suffer from a hip fracture before the age of 60 due to the prevalence of osteoporosis and falls in this population and this data is not captured on the database currently. Büchele *et al.* (2017) found that there was a high fracture rate in PWLD and the comparable risks of femoral fracture occurred about 10–15 years earlier in females and even 20–40 years earlier in males with learning disabilities than in the general population.

The NHFD (2018) illustrated that a hip fracture is the most common serious injury in older people and it is the commonest cause of death following an accident. Alongside this, patients may remain in hospital for a number of weeks with only a minority completely regaining their previous abilities. This increased dependency along with difficulty walking results in a quarter requiring long-term care (NHFD, 2018). As a result, hip fracture is associated with a total cost to health and social services of over £1 billion per year (Leal *et al.*, 2016).

1.6 Policy drivers for change

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), (2006) which has been endorsed by the UK, states the rights of disabled people to *'enjoyment of the highest standards of health without discrimination on the basis of disability'* (article 25). Valuing People (Department of Health, (DH), 2001) purported that health action plans would be designed to meet the specific needs of every PWLD and should include valuable patient-specific information that can aid assessment and care in different healthcare sectors. Alongside this, the principles of rights, independence, choice and inclusion of PWLD were emphasised. Later, 'Valuing People Now' (DH) (2007a) reaffirmed that general hospitals should review their capacity to provide quality services to PWLD. However, capacity is only one aspect of care and treatment for PWLD.

Following the harrowing report, 'Death by Indifference' (Mencap, 2007) in which it was alleged that PWLD died as a result of poor hospital care, there have been numerous reports, policy guidance and legal requirements issued to provide direction for hospital services that support PWLD, for example: Michael (2008); Emerson *et al.* (2012a; 2012b). Every person in the UK has the right to good health care services and the NHS Constitution (2015) lists the rights that all people are entitled to receive in the National Health Service (NHS).

1.7 The context of the hospital experiences of people with a learning disability

In 1989, 'Caring for People' a White Paper, set out priorities for the shift to community care and there followed a resettlement of PWLD over time into the

community with differing models of support. However, there is evidence that mainstream health services have difficulty in providing an equitable service for PWLD compared with the general population (Mencap, 2007; Emerson and Baines, 2011; Heslop *et al.*, 2013; Iacono *et al.*, 2014). As far back as 2004, The National Patient Safety Agency (NPSA) identified the vulnerability of PWLD in general hospitals and found that they were at an increased risk of harm whilst in this environment. Particular areas of concern and potential risk factors were: communication difficulties; lack of learning disability training for health staff; additional health concerns such as epilepsy not being recognised by the hospitals; the assumption by general hospital staff that learning disability staff and carers can provide full nursing care; and issues around consent (NPSA, 2004).

The Department of Health's 2016–17 mandate to the National Health Service (NHS) in England included the goal to:

close the health gap between people with mental health problems, learning disabilities and autism and the population as a whole by 2020 (DH, 2015, p. 17).

In the UK, the responsibility and accountability for meeting the health care needs of PWLD has moved from large institutions where people lived separately from the general population and were treated within this environment to mainstream primary and secondary health care providers (Brown *et al.*, 2010). The move from long-stay institutions to community-based care was prompted by reports of abuse and neglect in these institutions. There were a series of scandals about treatment of patients and the general conditions in these institutions with controlling, restrictive

environments run by under-resourced, over-stretched and sometimes abusive regimes (Brend, 2008).

The level of care provided to PWLD in general hospitals has been an area of concern due to evidence of abuse, neglect and discrimination (Disability Rights Commission, 2006). The exposure of widespread abuse at Winterbourne View hospital in 2011, a private and specialist inpatient hospital for PWLD with behaviour that challenges, led to a review of care provided in this hospital, and across England more widely, for PWLD and behaviour that challenges (NICE, 2018).

The publication of 'Death by Indifference' by Mencap (2007) and 'A Life Like no Other' by The Healthcare Commission (2007) raised serious concerns about the quality of healthcare provided to PWLD. Mencap (2007) highlighted the cases of PWLD who have died as a result of poor hospital care. One case in particular relates to orthopaedic and trauma hospital care; Mark Cannon, a man with a learning disability aged thirty who sustained a fracture to his femur. His mother complained about various aspects of his care and the Health Ombudsman stated that:

... "Mark died on 29 August 2003 of bronchopneumonia. He was 30 years old. He had a severe learning disability and had very little speech, though he had his own way of communicating his needs which his family understood. Two months before his death, Mark had been admitted to hospital with a broken femur. After an operation in which he lost a lot of blood, Mark was discharged and re-admitted twice in two months, finally dying in intensive care eight and a half weeks after the operation" (Mencap, 2007, p. 8).

The ombudsman concluded that Mark's death was avoidable as it arose as a consequence of service failure and maladministration. The ombudsman identified

the lack of pain management by medical professionals, which was described as '*the most striking and significant area of service failure.*' Alongside this, all other complaints were upheld including failures in epilepsy management, assessment and monitoring, arranging and providing support services, making reasonable adjustments, maladministration in the complaints process by the hospital and the Healthcare Commission.

It appears that PWLD have been marginalised and disenfranchised as a group of vulnerable people in general hospital settings for a variety of reasons. The hospital can be a high-pressure environment for staff with challenging targets to achieve such as seeing and treating people quickly as well as reducing length of stay of patients in hospitals. Blair (2017) affirmed that there were challenges for PWLD receiving hospital care as hospitals can be very frightening environments for a PWLD, they are often unfamiliar places and the PWLD may have had previous negative experiences. Alongside this, Blair (2017) contended that health care professionals may have limited knowledge about PWLD as they may not have been prepared, trained or educated to adequately care for PWLD. This can result in health care professionals lacking in understanding of the fundamental needs and abilities of PWLD. Essentially, 'equal' health care provision of PWLD is different to 'equitable' health care which is also needed. PWLD may require equity in the form of the provision of reasonable adjustments in order to achieve effective clinical outcomes.

The researcher's view is that health professionals must see the 'person' with a learning disability and not just the 'disability'. Diagnostic overshadowing is dangerous and occurs when a health professional makes the assumption that the behaviour of a PWLD is related to their disability without exploring other factors such as illness

(Blair, 2017). Furthermore, a PWLD may be unable to communicate their symptoms to health care professionals and therefore are at risk of symptoms being missed which can lead to clinical deterioration and premature death.

1.8 Rationale for the focus on hospital care

Orthopaedic and trauma hospital care is the focus of the study as there is a gap in the knowledge base about these specific hospital experiences of PWLD. Furthermore, the numbers of PWLD requiring orthopaedic or trauma hospital care may increase in the future as this population is expected to increase over the next 20 years due to advances in neonatal care which needs to be factored into all planning arrangements (Carmichael *et al.*, 2009). Alongside this, as previously stated, there are high rates of obesity and osteoporosis in PWLD which can lead to MKS conditions and injuries and further illustrates the importance of this study.

A more recent publication by NHSE, (2018b), 'The Learning Disabilities Mortality Review' (LeDeR Programme), reported the deaths of PWLD and demonstrated that many died in hospital care and on average up to twenty years younger than people without a learning disability. Exploration of the lived experiences of PWLD to inform the evidence base regarding orthopaedic and trauma hospital care is timely.

1.9 Relevance of the present study

The aim of the study was to contribute to the evidence base by gaining knowledge and understanding of the orthopaedic and trauma hospital experiences of PWLD.

The people who identify themselves as having a learning disability and who have experienced the phenomenon of orthopaedic and trauma hospital care can enrich the current limited empirical knowledge base. Moreover, the involvement of PWLD gives a voice to those who have previously either not been recruited into research studies or are seldom heard (Read and Maslin-Prothero, 2011; Jack, 2016). This study provided an opportunity for them and their carers to “tell it as it was” so that an understanding of the richness of a personal event and the factors surrounding it could be gained (Jack, 2010, p. 5).

The study was important:

- firstly, for PWLD who have experienced orthopaedic or trauma hospital care to have their voices heard and their experiences valued and interpreted;
- secondly, for health care educators and health care staff working in orthopaedic or trauma hospital settings who regularly care for PWLD to improve their understanding of the particular needs of PWLD and
- thirdly, for the commissioners of orthopaedic or trauma hospital services along with regulators and policy-makers in health care to consider and provide effective support for PWLD.

The study adds to the evidence base by adopting an interpretative phenomenological analytical (IPA) approach to explore the lived experiences of PWLD who have received orthopaedic or trauma hospital care as this had not been explored in the published literature previously.

1.10 Conceptual framework of Person-Centred Care (PCC)

A conceptual framework of PCC underpinned and guided this study as it was congruent with the researcher's philosophy about health care. The commitment to PCC is evident in the research question, the approaches adopted and the methodological decisions taken in the study. Alongside this, PCC has been the theoretical framework that has guided the collecting, analysing, describing and interpreting of the data throughout the study (Ravitch and Riggan, 2017).

Person-centredness is a term that has become internationally recognised within health and social care. McCormack and McCance (2010, p. 13) describe person-centredness as:

An approach to practice established through the formation and fostering of therapeutic relationships between all care providers, people and others significant to them in their lives. It is underpinned by values of respect for persons, individual right to self-determination, mutual respect and understanding. It is enabled by cultures of empowerment that foster continuous approaches to practice development

The benefits of person-centred care have been recognised by the WHO (2015) and the recent proficiencies for future registered nurses in the UK (Nursing and Midwifery Council (NMC), 2018b, p. 38) include a definition of 'evidence-based person-centred care'

making sure that any care and treatment is given to people, by looking at what research has shown to be most effective. The judgment and experience of the nurse and the views of the person should also be taken into account when choosing which treatment is most likely to be successful for an individual.'

However, it seems that the person's views could be perceived as secondary to the judgement and experience of the nurse rather than of central importance to care. McCormack *et al.* (2017) concurred that the skill involved in balancing a duty of care to the patient while at the same time maintaining a focus on working with the 'best' evidence in care decisions is a significant challenge in person-centred healthcare. However, maintaining the person's identity as central to care decisions and helping to maintain that in the sense of who they are in the context of their lives is a key pillar of person-centred practice.

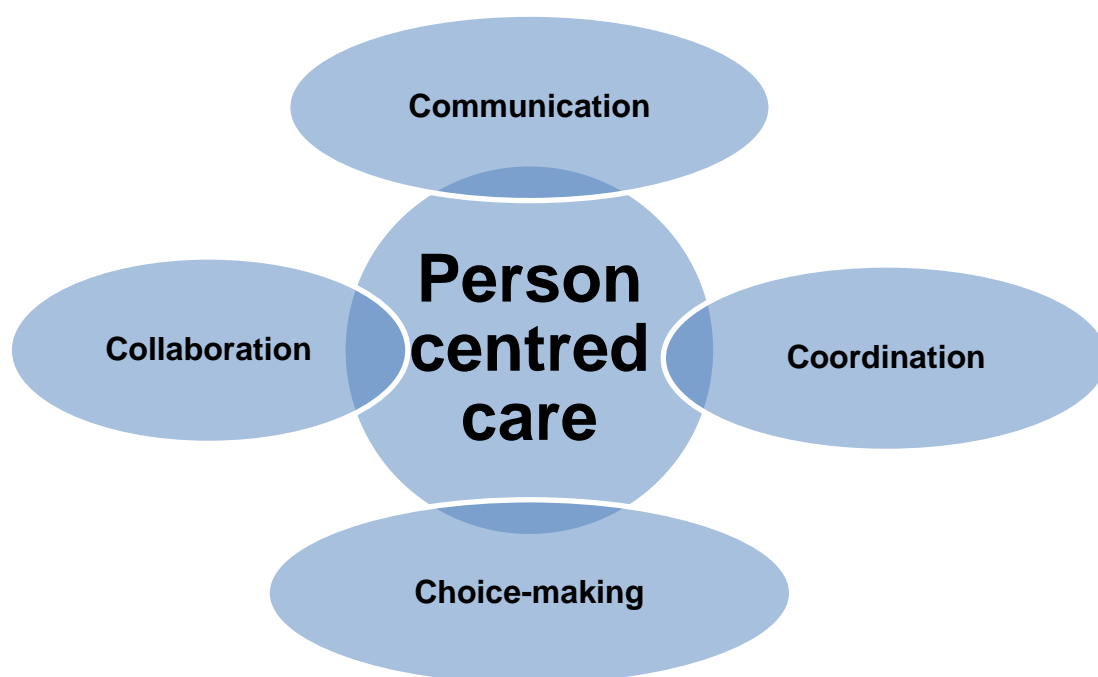
A central requirement in the provision of quality hospital care to PWLD is underpinned by a philosophy that requires staff to recognise the human worth of PWLD and to adopt care practices that respect diversity (Guidelines on caring for people with learning disabilities in general hospital settings, (GAIN) 2010). This is a central value of nursing and is explicit in the professional code for registered nurses (NMC, 2018a). Back in 2001, McCormack highlighted that there was a need for a cultural shift in philosophical values in healthcare if authentic person-centred healthcare is to be realised for all persons. The following quotation from one of the participants in McCormack's research highlighted the need for this shift:

...people need to be able to take on a different view of things and able to see a different kind of potential when the whole system is kind of set up in a particular way and how do you change it? Because you've got teachers and educators and you've got role models and supervisors and people in clinical settings who have all been socialised in this system and what I think it needs is actually a complete culture shift, a shift in philosophical values, to see people as people who have responsibility for their own health and come into a system that should not totally remove that, that kind of ownership...

Since then there have been significant developments globally in advancing person-centred health care. The terminology 'Person-Centred Care' is cited frequently in healthcare policy and practice (for example, NMC, 2018a; NICE, 2018). The Care Quality Commission (CQC), an independent regulator of health and social care in England, stated that the intention of the specific regulation in the Health and Social Care Act, (2008) on 'PCC' is to ensure that people using a service have care or treatment that is personalised specifically for them. This regulation describes the action that providers must take to ensure that each person receives appropriate PCC and treatment that is based on an assessment of their needs and preferences (CQC, 2015). Table 2 in Appendix 1 illustrates the fundamental requirements of PCC (CQC, 2015). Hospital care should never fall below these essential and fundamental standards.

Marsden and Giles (2017) developed a framework with the aim of enhancing the care of PWLD in a hospital in England, UK. This '4C framework' aimed to assist ward staff to identify and manage the challenges of delivering person-centred, safe and effective healthcare to PWLD. Marsden and Giles (2017) undertook a fourth-generation evaluation (Lincoln and Guba, 1989) with a collaborative thematic analysis, reflection and a secondary analysis to develop a framework for making reasonable adjustments in a hospital setting. The '4C framework' very clearly focuses on PWLD in a general hospital setting in relation to providing reasonable adjustments in four key areas, communication, choice-making, collaboration and coordination (Figure 1).

Figure 1 The Person-Centred Practice Framework adapted from Marsden and Giles (2017) 4C framework



1.11 The ontological and epistemological positioning of the researcher

The perspective of the researcher can have an influence on the study. Her socio-cultural background was as a British mother of a teenager with a learning disability, a Registered Nurse (Adult) with over thirty years of orthopaedic and trauma hospital

experience and a course leader/senior lecturer in an Institute of Health within Higher Education. Alongside this, she has the privilege and joy of being a volunteer in her parish community and has supported PWLD and their families to feel welcome and valued. These roles and experiences have shaped and underpinned her interest in the experiences of PWLD.

The researcher was a novice undertaking this study as part of a Professional Doctorate award in Health and Wellbeing. As a nurse in the field of orthopaedic and trauma hospital care this could affect how much information participants are willing to share with the researcher. Raheim *et al.* (2016) highlighted that research participants who have expert knowledge, in this case about their orthopaedic or trauma hospital experiences, might feel slightly threatened by a researcher whose intent was to explore her own specialist area of practice. Alongside this, the researcher was an 'outsider' to adults with learning disabilities as she is not perceived as being part of the group being studied. Moreover, she had not experienced orthopaedic or trauma hospital care as a patient, was not identified as a PWLD and did not work in the professional field of learning disability. Some of the objections that have been raised against the use of an outsider in research include the increased likelihood of rejection or non-acceptance by the participants (Kerstetter, 2012). The researcher's position within the study required regular self-reflection and discussions with the supervisors regarding how her identity can impact on the research study.

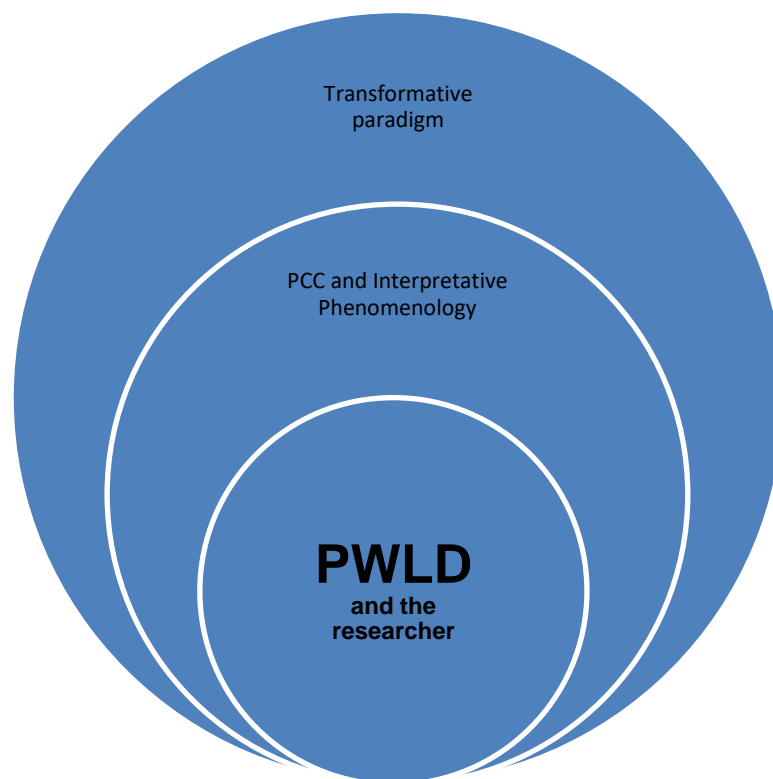
The researcher's position accords firmly with Jean Vanier, a philosopher and humanitarian, who set up communities world-wide called 'L'Arche' where PWLD and

people without learning disabilities live and work together. These are places of belonging; the unique value of each person is embraced and Vanier illuminated how PWLD enrich and transform the lives of people without a learning disability (Vanier 1989). However, there are others such as the Australian moral philosopher, Peter Singer (2011) who contends that it is ethical to give parents the option, in consultation with doctors, to euthanise infants with disabilities. In his book, 'Practical Ethics' (1979), Singer argues that the value of a life should be based on traits such as rationality, autonomy and self-consciousness. The researcher strongly opposes this view and believes that Singer sees disability through a disablist, medical lens which serves to dehumanise people who do not conform to a prescribed view of what it is to be human.

The PCC framework which guided the study was congruent with the theoretical underpinnings of interpretative phenomenological analysis (IPA) and subjectively resonated with the researcher. The transformative paradigm (Mertens, 2009) was fitting for a study with vulnerable, marginalised and disenfranchised PWLD who have been recipients of inequitable health care in hospital settings. The voices of PWLD were missing in health care research despite their much poorer general health and frequent use of hospital services. Moreover, PWLD have been excluded from research due to their perceived vulnerability or inability to consent or communicate in traditional ways. Furthermore, in the past some PWLD were subjected to research studies without their consent. The transformative paradigm enabled a focus on human rights and social justice which aligned with the researcher's perspective.

Figure 2 illustrates the researcher's ontological and epistemological position. The PWLD were at the core of the study which reflected her beliefs and values that they were first and foremost central to the study.

Figure 2 The researcher's positioning



1.12 Structure of thesis

The following chapters are presented in the thesis. Chapter two presents a review and critique of the literature related to the hospital experiences of PWLD. An integrative literature review concludes with a summary of the findings and the aims,

objectives and the research question for this study. Chapter three describes the research approach and the methodology utilised within the study. A qualitative approach using IPA has been discussed with the supporting rationale. Chapter four presents the findings from the study, including each participant's individual experiences along with a comparison of the themes across the participants. Chapter five provides the discussion, the unique contribution to knowledge and further evaluates and synthesises the findings with the current literature and policies available. Chapter six presents the conclusion, reflections on the study, its strengths and limitations along with the recommendations for current and future clinical practice, policy and research.

1.13 Summary

An introduction and background to the study has been presented. Definitions of learning disability have been provided although these tend to be broad and potentially problematic if there is a reliance on measuring a person's IQ and social deficits. It is estimated that approximately 2% of the adult population in England have a learning disability and the numbers are increasing each year. Musculoskeletal conditions and injuries are prevalent in PWLD and, in England, the initial assessment and management is in primary health care with referral to secondary hospital care for more complex cases requiring potential surgical interventions. Although there are validated MSK tools available to assess people with these conditions before and after interventions, for example, the Musculoskeletal Health Questionnaire (MSK-HQ), it was not evident if PWLD receive or complete these tools as it was validated for the general population. Currently an easier read version was unavailable and therefore, the clinical effectiveness and

outcomes of MSK interventions will not be known for this significant and often hidden group of PWLD. Furthermore, the orthopaedic and trauma hospital experiences of PWLD have not been previously explored and are therefore unknown. The conceptual underpinnings of person-centred care have been introduced and have guided the design and the interpretation of the study.

Chapter two Literature Review

2.1 Introduction

This chapter provides a review of the literature on the hospital experiences of PWLD. A comprehensive and systematic approach was undertaken to provide an integrative review of the literature and the process undertaken is detailed below.

2.2 Rationale for conducting an integrative literature review

An integrative review (IR) is the broadest type of research review method and therefore allowed for the inclusion of data from the theoretical as well as empirical literature. This enabled a wide and diverse range of literature to be incorporated and allowed for the combination of diverse methodologies (Whittemore and Knafl, 2005). This review aimed to provide a comprehensive understanding of the orthopaedic and trauma hospital experiences of adults with a learning disability. The relevant literature did not lend itself to a systematic review as there was a diverse methodological approach and no randomised controlled trials in this field. According to Whittemore and Knafl (2005) an IR has the potential to play a greater role in evidence-based practice for nursing.

2.3 Methods

The integrative review was guided by the method described by Whittemore and Knafl (2005) and included the following five stages:

- a. Problem identification
- b. Literature search
- c. Evaluation of data
- d. Data analysis and
- e. Interpretation and presentation of results.

2.3.1 Problem identification

The first chapter discussed the background and the rationale for the study. A chronological timeline with key reports, policies, legislation and theoretical literature provides an overview of the challenges that PWLD have faced and unfortunately, they continue to endure related to health care (see Table 3 in Appendix 2). The evidence demonstrated that experience of mainstream health services has been consistently extremely poor for PWLD (Mencap, 2004, Mencap, 2007; Michael, 2008; Heslop *et al.*, 2013). The CQC (2012) previously raised concerns that general hospital services for PWLD were underperforming. Moreover, the population of PWLD has increased with more adults living into older age and many experiencing complex multiple morbidity including a high prevalence of musculoskeletal conditions and injuries (Maulik *et al.*, 2011; Kinnear *et al.*, 2018).

Stain (2019) alleged that health care professionals discriminate against PWLD perceiving that their quality of life was poor due to suffering. However, Tuffrey-Wijne *et al.* (2019) argued that not only was this judgement about quality of life of PWLD inaccurate, it was also of serious concern because it influences decisions about life and health care which can be detrimental for PWLD.

The common themes across the non-empirical literature were that PWLD were known to have poorer general health than the general population and health care was not regularly adjusted to meet the needs of PWLD who were a very vulnerable group of people (DH 2001; UNCRPD 2006; DH 2007; DH 2008; DH 2009; NHSI, 2018). As a consequence of poorer health care, PWLD experienced poor clinical outcomes including avoidable and premature death. In the first 'World Report on Disability' (WHO, 2011 p. 3), Professor Stephen Hawking reminded us all that:

We have a moral duty to remove the barriers to participation, and to invest sufficient funding and expertise to unlock the vast potential of people with disabilities. Governments throughout the world can no longer overlook the hundreds of millions of people with disabilities who are denied access to health, rehabilitation, support, education and employment, and never get the chance to shine

The importance of supporting PWLD as individuals with the need to give due regard to their human, civil and legal rights was consistently highlighted in the literature. Barr and Gates (2019) concluded that the key principles that must be applied in health care were: PWLD should be valued; PWLD should be helped and supported; PWLD should be actively included and involved in decision-making; PWLD should have services that take account of individuality and they should have full access to health services. These are the human rights of all people and it is a sad indictment and reflection on our society that these principles were not routinely embedded in health care practice for PWLD. However, the researcher suggests that health care staff want to give the best care for all people and may not recognise or understand

the impact of having a learning disability. It may not be obvious on initial presentation, for example, if a person has a mild learning disability and it may not be identified on hospital systems.

PWLD have been failed in health care services over many years despite the introduction of a series of inquiries, reports, legislation and policies. This raises serious concerns about the level of risk for PWLD in hospital who are recipients of unsafe, impersonal and ineffective health care. Moreover, if health care provision was improved for PWLD, it could also enhance health care for other vulnerable groups, such as people with dementia.

In 2018, The National Institute for Health Research (NIHR) published a report, 'Moving Forwards' which detailed a themed review of the funded research studies that were undertaken specifically with physiotherapists to benefit people with MSK conditions and injuries. The report supported the move towards more individualised patient care with a focus on supported self-management, shared decision-making and prevention through life style changes, particularly around activity. However, none of the studies in the report included PWLD although it stated that NIHR-funded and other research will continue to drive the development of the most effective prevention, intervention and self-management in MSK conditions, allowing better access and improved support for the current patients and prevention of significant MSK disease in the future. It is of concern that PWLD who have a high prevalence of MKS conditions and injuries have not been included or considered in this funded research.

The aims of this IR were, firstly, to provide an overview and appraisal of the research studies which represented the hospital experiences of adults with a learning disability and, secondly, to highlight the gaps in the evidence-based literature in this area. The review question was:

What are the orthopaedic or trauma hospital experiences of adults with a learning disability?

2.3.2 Literature search

The following electronic databases were searched:

ACADEMIC SEARCH COMPLETE

NURSING AND ALLIED HEALTH

BRITISH NURSING INDEX (BNI) and RCN Library archive

CUMULATIVE INDEX TO NURSING AND ALLIED HEALTH LITERATURE
(CINAHL)

MEDICAL LITERATURE ANALYSIS AND RETRIEVAL SYSTEM ONLINE
(MEDLINE)

PSYCHOLOGICAL INFORMATION DATABASE (PsychINFO)

THE COCHRANE COLLABORATION DATABASE

GOOGLE SCHOLAR

By searching these databases, it was anticipated that relevant material could be accessed, retrieved and critically reviewed. After this, the reference lists from the papers that were included in the final review were scrutinised by hand for relevant papers and key authors were also searched for relevant papers.

2.3.2.1 Study selection criteria

The literature search included a review of information from books, journal articles, policy documents and national guidelines. However, the final sample of literature was limited to primary research literature about hospital experiences of PWLD as this was consistent with the overall purpose of this review.

The inclusion criteria were empirical studies including qualitative, quantitative or mixed-methods which related to the hospital experiences of adults with a learning disability. The inclusion criteria are detailed in Table 4 and the exclusion criteria can be seen in Table 5.

Table 2 The inclusion criteria

Age: Adult patients 18 years old and over
Study type: Qualitative, quantitative or mixed methods
Population: Adults with a learning disability including studies which include both PWLD and their carers
Condition: Orthopaedic/trauma/musculoskeletal
Outcome measure: Exploration or evaluation of the general hospital experience
Published January 2007 - July 2018
Peer reviewed paper
English language
General NHS Hospital care

The literature search was undertaken in 2014, 2015 and again in July 2018. The time period included was January 2007- July 2018 which spans eleven years. The

rationale for this time period was that a highly influential and public landmark report entitled, 'Death by Indifference' (Mencap, 2007) was published and received sustained media attention in the public domain due to the shocking and preventable deaths of six young adults with learning disabilities in hospital care. This was a watershed report where the lack of equity and quality of care for PWLD was raised in the public domain. No further searches were undertaken after July 2018 as this was the writing up period for the researcher. The searches were limited to title and abstracts that were available in the English language, adults and evidence that a peer review process had been undertaken.

Table 3 The exclusion criteria

AGE: Children under 18 years old
Study type: Not primary research
Population: Not identified as adults with a learning disability. Studies that had only carers or health professionals' views of hospital care for PWLD.
Condition: Psychiatric, psychological or condition specific (e.g. end of life) as the reason for hospital care, other disabilities such as physical or sensory disabilities.
Outcome measure: No exploration or evaluation of the general hospital experience
Published: Before January 2007 or after July 2018
Not peer reviewed
Not available in English language
Psychiatric or specialist learning disability hospital care

The search terms that were used are listed in Table 6. The asterisk indicates that all terms beginning with this root were searched. The Boolean operators 'or' and 'and' were utilised to obtain the available studies.

Table 4 The search terms that were used in each of the electronic databases

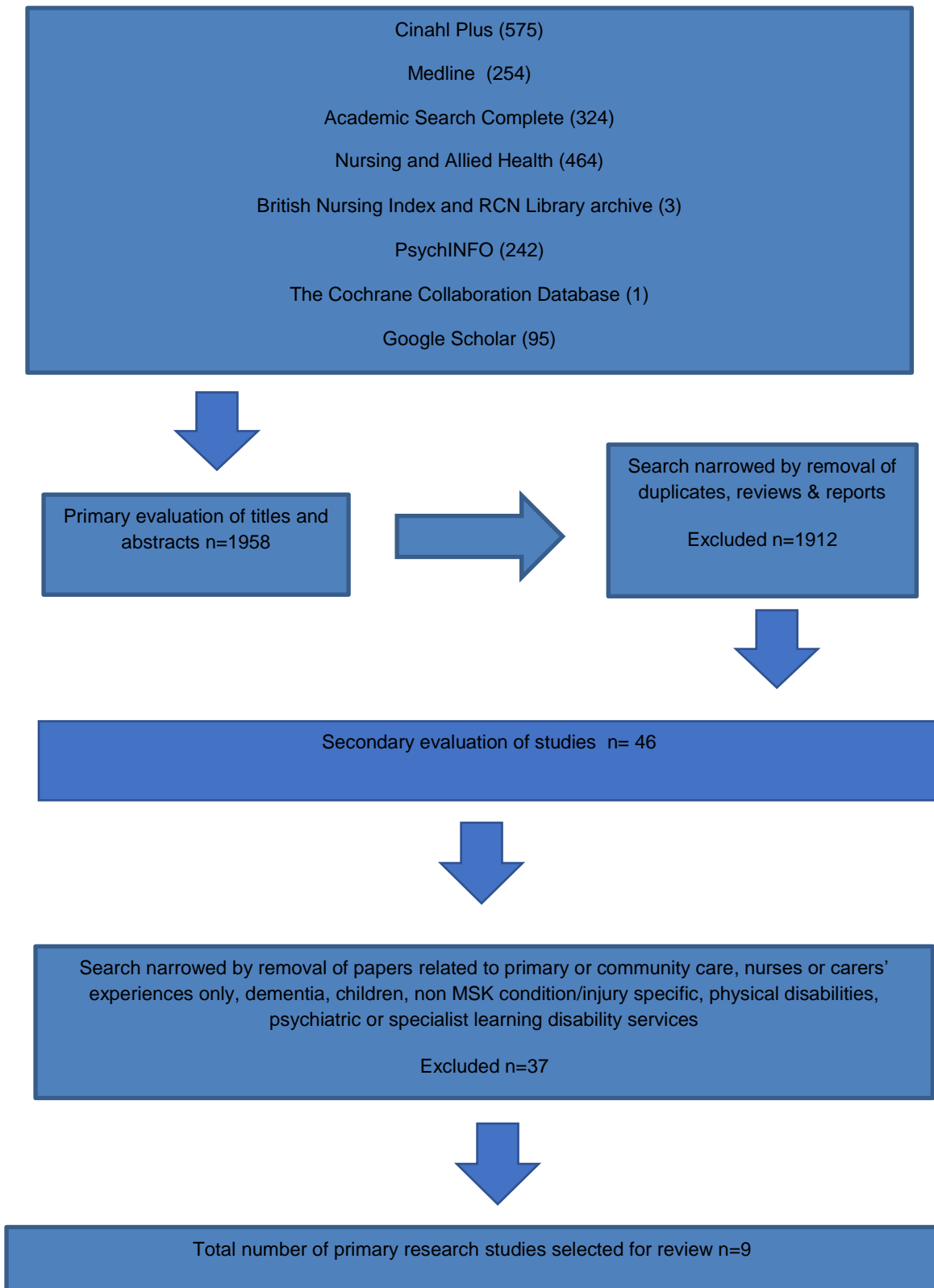
1	Learning disab* or
2	Intellectual* disab* or
3	Learning difficult* or
4	Developmental* disab* or
5	Cognitive* impair* or
6	Intellectual* impair* or
7	Mental* handicap* or
8	Mental* deficien* or
9	Mental* disab* or
10	Mental* retard* AND
11	Hospital care or
12	Secondary care or
13	Acute care or
14	Health care or
15	Orthopaedic or
16	Orthopedic or
17	Trauma or
18	Muscul*skeletal

2.3.3 Evaluation of data

The first stage of the literature review involved the screening of all the titles and abstracts against the inclusion criteria. Duplicates were then removed. The reviews

and reports were retained and this theoretical literature has been discussed in Chapter One as it provided contextualisation to the study. The next stage involved a closer reading of the titles and the abstracts and a further number were excluded as they did not meet the inclusion criteria (n=1912). Some studies were related to primary or community care, nurses' or carers' experiences, dementia, children, condition specific such as cerebral palsy and Down syndrome, end of life care, other disabilities and not learning disabilities, psychiatric or specialist learning disability services rather than the general hospital experiences of adults with a learning disability and therefore were rejected. A secondary evaluation of the retained papers (n=46) was undertaken to assess the eligibility for inclusion in the final review. Figure 3 is a flowchart showing the process undertaken and the amount of literature that each database displayed when the key search terms were used. A total of nine primary research studies were identified for inclusion in the final review. Each study was read thoroughly prior to extracting data.

Figure 3 A flowchart showing the searches undertaken in the electronic databases



2.3.4 Data analysis

There were nine primary research studies that related to the general hospital experiences of adults with a learning disability and therefore fulfilled the criteria for inclusion in the review. The majority of studies (n=8) reflected a qualitative approach using semi-structured interviews or focus groups as the data collection methods. One study was reported in two papers and employed a mixed methods approach (n=1). Table 7 in Appendix 3 provides a summary of the studies included in the review in chronological order.

2.3.5 Interpretation and presentation of the data: An overview of the studies in the final review

Overall, there were very few studies undertaken with PWLD in relation to general hospital care over the period 2007-2018. This could be due to the difficulty that exists in accessing and recruiting PWLD into research studies. Moreover, this area of research may not be deemed important as it has not, to the author's knowledge, received substantial research funding. Overall, there was agreement about the experiences of PWLD in general hospital care in the body of literature as a whole.

2.3.6 The qualitative studies

There were eight studies that employed a qualitative approach with the majority, five, using semi-structured interviews and three used focus groups as the data collection method. The majority of the studies, five, were conducted in the United Kingdom (UK), two studies were conducted in the United States of America (USA) and one study was undertaken in Australia. The studies were published from 2008-2018.

2.3.7 The mixed methods study

Tuffrey-Wijne *et al.* (2014a; 2014b) undertook one of the largest studies to date focusing on the safety of PWLD in acute general hospitals in the UK. This was a mixed methods study and several papers have been published from this one large study.

Two of these papers were included in the review and both papers were published in 2014. The data collection methods included interviews with hospital staff, carers and adults with learning disabilities, questionnaires to hospital staff and carers, observation of people with learning disabilities in hospital and monitoring of incident reports. The study was conducted at six NHS acute hospital trusts in England (Tuffrey-Wijne *et al.*, 2014a; Tuffrey-Wijne *et al.*, 2014b). The sites were purposively selected to cover a range of different hospital sizes, demographic areas and models for accessing learning disability expertise.

2.4 Quality appraisal: Methodological quality of existing research

Due to the different methodological approaches adopted in the retrieved studies, they have been split according to their methodology which is a common approach to ensure the clarity of synthesis (Gray, Grove and Sutherland, 2017). The larger number of qualitative studies indicated the appropriateness of this research approach for exploring the hospital experiences of PWLD.

2.5 Methodological critique

2.5.1 The qualitative studies

Only one of the eight studies clearly referred to a theoretical framework to situate the study (Webber, Bowers and Bigby, 2010). The majority of studies (n=6) had a clear research question or objectives for the study. Only two studies provided evidence of reflexivity.

2.5.2 The mixed methods study

Tuffrey-Wijne *et al.* (2014a) reported on the findings in relation to the barriers to providing reasonably adjusted health services to PWLD in NHS acute hospitals. The study employed interviews and questionnaire surveys from July 2011–March 2013. Data collected included staff questionnaires (n=990), staff interviews (n=68), interviews with PWLD (n=33), questionnaires (n=88) and interviews with carers of PWLD (n=37) and expert panel discussions (n=42). The number of PWLD participating in the study was relatively small in relation to staff participants although the sample size was large in comparison with existing studies and the researchers believed that saturation of data had been achieved.

Sampling of patients and carers was facilitated by the learning disability liaison nurse (LDLN) or Learning Disability Lead at each study site, leading to sampling bias. This could have been reduced if the selection of patients and carers had been undertaken in a more randomised way, for example, if every third patient with a learning disability on the list was selected. The research team had no access to a sample of patients who had not been identified or flagged as having learning disabilities.

Tuffrey-Wijne *et al.* (2014b) also aimed to explore the challenges in monitoring and preventing patient safety incidents involving PWLD, to describe patient safety issues faced by PWLD in NHS acute hospitals and to investigate underlying contributory factors to these safety issues. Data collection methods included interviews, questionnaires, observation and monitoring of incidence reports. There were a total of 1251 participants; n=990 clinical staff completed questionnaires; n=88 carers completed questionnaires; n=68 interviews with hospital staff (senior managers, nurses and doctors); n=37 interviews with carers; n=8 observation of in patients with learning disabilities and n=272 monitoring of incident reports.

2.5.3 Summary of methodological critique

All of the studies had varying levels of methodological weaknesses alongside limitations. However, they were all included in the final review as they added to the limited evidence base relating to the hospital experiences of PWLD since 'Death by Indifference' (2007). Furthermore, an important consideration was that good research may not be 'well' reported in the retrieved papers (Pluye *et al.*, 2011; Newton *et al.*, 2012) which could be due to journal word count limitations.

2.6 Synthesis of the study findings

Synthesis of the studies involved clarifying the meaning obtained from the sources as a whole (Gray, Grove and Sutherland, 2017). When the methodological critique was completed, each study was read again several times before initial codes were generated and then themes were extracted, reviewed and then named relating to the

hospital experiences of PWLD. The themes were derived by undertaking a constant comparative analysis (Lincoln and Guba, 1985). Table 8 shows the steps that were followed to extract data, develop initial codes which then formed subthemes and overall themes from the research papers (adapted from Aveyard, Payne and Preston, 2016).

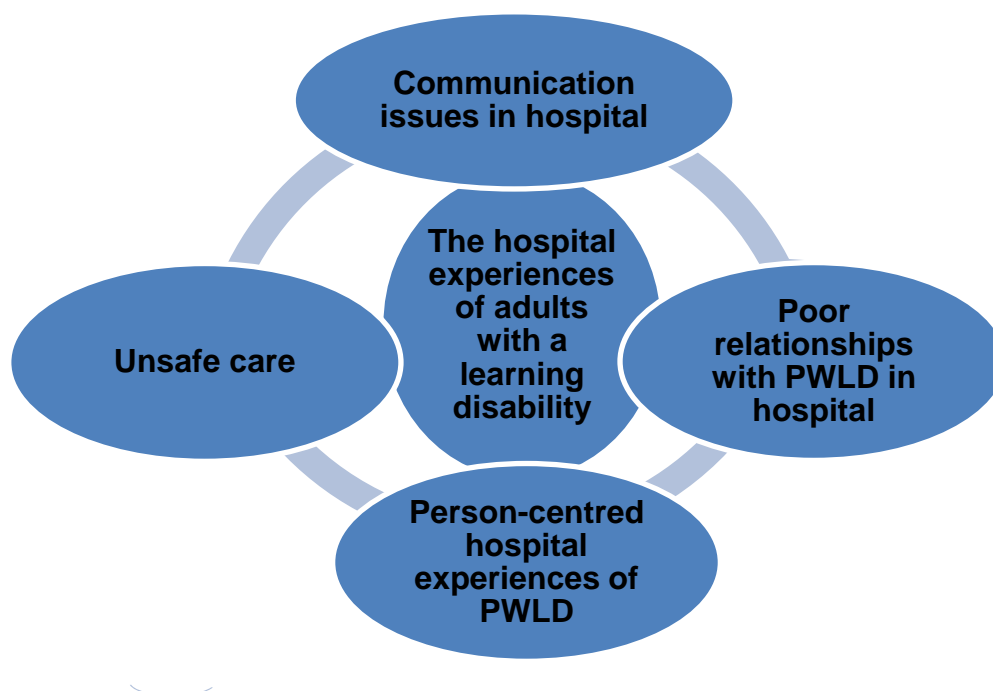
Table 8 The steps taken in the constant comparative analysis method

Step 1	The data was coded from the main findings in each paper
Step 2	Themes were developed from the codes
Step 3	The themes were named
Step 4	The themes were compared
Step 5	The impact of poorer quality studies was considered in relation to the themes
Step 6	The consistency of all the data was considered
Step 7	The results were interpreted and explained

A list of the themes and subthemes arising from the initial codes with the supporting references is presented in Table 9 in Appendix 4.

The overall themes were: communication issues in hospital; unsafe care; poor relationships with PWLD in hospital and person-centred hospital experiences of PWLD which were derived from the subthemes and initial codes. The four themes were inter-linked and illustrate the reported general hospital experiences of PWLD. The research supervisors independently verified these themes. Figure 4 shows the over-arching themes from the studies.

Figure 4 The themes derived from the studies



Theme 1: Communication issues in hospital

All nine studies highlighted that there were communication issues for PWLD in hospital. Two subthemes, 'increased fear and anxiety due to poor communication' and 'a lack of person-centred communication' emerged from the initial codes and formed the main theme, 'communication issues in hospital'.

Subtheme: Increased fear and anxiety due to poor communication

The study conducted by Gibbs, Brown and Muir (2008) was one of the strongest methodologically in this IR and investigated the experiences of PWLD in general hospitals. Focus groups were used to collect information from PWLD (n=11) who

had been in hospital within the previous year and their carers (n=14). All participants (n=25) very commonly described feeling anxious and fearful. The consequences of anxiety and fear can be detrimental for all patients but for those with a learning disability it can result in behavioural disturbance and have a negative influence on subsequent care (Tuffrey-Wijne *et al.*, 2016). Both the patients and the carers were anxious about investigations, injections, procedures, operations and situations involving other patients. Dinsmore (2011), Webber, Bowers and Bigby (2010) and Gibbs, Brown and Muir (2008) concur in that there was a failure of hospital staff to communicate effectively with other staff regarding PWLD in their investigation findings. Alongside this, PWLD were fearful about having their assistive devices taken away from them in hospital as these aided their communication, and in essence acted as their expressive 'voice' (Smeltzer, Avery and Haynor, 2012).

Subtheme: A lack of person-centred communication

Problems with communication were discussed by 12/14 PWLD in the study by Ali *et al.* (2013). Hospital staff did not modify or adapt communication to the needs of PWLD and examples were relayed such as, asking too many questions, speaking too quickly, giving too much information and not giving the PWLD time to respond. Furthermore, hospital passports, which contain key information about a PWLD were not used (Dinsmore, 2011). Similarly, Webber, Bowers and Bigby (2010) found that key information from carers, which could support staff in caring for PWLD, was not used by staff in hospital and instead, information methods that were inaccessible for PWLD were employed (Howieson, 2015; Read *et al.*, 2018; Ali *et al.*, 2013). Alongside this, some hospital staff spoke to the carers instead of the PWLD (Gibbs, Brown and Muir, 2008).

Theme 2: Unsafe care

All nine studies discussed aspects of hospital care that resulted in unsafe care for PWLD. The subthemes, 'lack of reasonable adjustments' and 'fundamental care omissions and mistakes' were formed from the initial codes and the overall theme, 'unsafe care' was developed.

Subtheme: Lack of reasonable adjustments

Hospital strategies that supported implementation of reasonable adjustments did not reliably translate into consistent provision of such adjustments (Tuffrey-Wijne *et al.*, 2014a). Good practice often depended on the knowledge, understanding and flexibility of individual staff and teams, leading to the delivery of reasonable adjustments being haphazard throughout the organisation. Tuffrey-Wijne *et al.* (2014a) found that the major barriers to implementing reasonable adjustments included: lack of effective systems for identifying and flagging PWLD; lack of staff understanding of the reasonable adjustments that may be needed; lack of clear lines of responsibility and accountability for implementing reasonable adjustments; and lack of allocation of additional funding and resources. Similarly, Ali *et al.* (2013) and Howieson (2015) found that reasonable adjustments such as using pictures, large print and easier read information were not implemented in hospitals.

Subtheme: Fundamental care omissions and mistakes

Ali *et al.* (2013) conducted semi-structured interviews to examine the extent to which PWLD and their carers' experiences of health care had improved over the last decade. Some of the findings were particularly concerning as they included the

prescription of incorrect medication, investigations and treatments being delayed or lacking altogether. Moreover, there were reports of neglect of basic needs on hospital wards including a lack of support to use the toilet.

Webber, Bowers and Bigby (2010) highlighted that the greatest concerns expressed from family members and carers were around eating and elimination needs as PWLD in hospital were often unable to access food which was left unopened and uneaten. Furthermore, there was inadequate pain assessment along with carers noting that PWLD who were continent had incontinence pads applied in hospital (Webber, Bowers and Bigby, 2010). Tuffrey-Wijne *et al.* (2014b) found that patient safety issues were mostly related to delays and omissions of care, in particular inadequate provision of fundamental nursing care, misdiagnosis, delayed investigations and treatment, non-treatment decisions along with 'Do Not Attempt Cardiopulmonary Resuscitation' (DNACPR) orders. However, acts of omission (failure to give care) were more difficult to recognise, capture and monitor than acts of commission (giving the wrong care). Furthermore, staff did not always identify safety issues for PWLD or report those and monitoring of safety incidents for PWLD was difficult (Tuffrey-Wijne *et al.*, 2014b).

Similarly, Ali *et al.* (2013) highlighted the substandard care of PWLD in hospital, such as inadequate follow-up, incorrect medication, unnecessary investigations or investigations and treatments being delayed, inadequate discharge arrangements along with a lack of support with toileting needs. Alongside this, Webber, Bowers

and Bigby (2010) reported the early inappropriate discharge of PWLD from hospital and care home staff unable to continue the level of care needed.

Theme 3: Poor relationships with PWLD in hospital

Seven of the nine studies highlighted concerns relating to the relationships with PWLD in hospital. There were two subthemes that emerged from the initial codes, 'lack of caring and understanding for the individual PWLD' and 'perceived discrimination towards PWLD' which resulted in the overall theme, 'poor relationships with PWLD in hospital'.

Subtheme: Lack of caring and understanding for the individual PWLD

Accounts of negative hospital staff behaviour along with a lack of support for and involvement of PWLD and their carers were evident in the majority of the studies (Ali *et al.*, 2013; Gibbs, Brown and Muir, 2008; Gibbons, Owen and Heller, 2016; Howieson, 2015 and Read *et al.*, 2018). Webber, Bowers and Bigby (2010) highlighted that staff incorrectly assumed that PWLD were unable to understand and therefore did not provide information that might have helped PWLD during their hospital stay. Hospital staff were reported to have poor knowledge about PWLD which led to PWLD being left on their own in hospital (Webber, Bowers and Bigby (2010).

Subtheme: Perceived discrimination towards PWLD

Participants with mild-moderate learning disabilities who were part of a focus group in the study conducted by Howieson (2015) felt disrespected and not valued during their acute hospital experiences. This appeared to be related to a lack of reasonable adjustments to the communication methods used by hospital staff. Dinsmore (2011)

also found that the hospital experiences of PWLD and carers remain poor and it was not possible to assert that the recommendations of the reports produced after Death by Indifference, 'Valuing People Now' and 'Healthcare for All' were being acted upon by health care staff. There were PWLD who continued to contest with the same difficulties during hospital experiences as have been identified previously by numerous national investigations.

Smeltzer, Avery and Haynor (2012) found there was poor communication on the part of nursing staff, compromised care and negative attitudes among staff towards PWLD. A more recent study by Read *et al.* (2018) demonstrated that disabled people felt their unique needs in hospital were not addressed or accommodated which has professional, legal and ethical implications.

Theme 4: Person-centred hospital experiences of PWLD

Three out of nine studies reported person-centred hospital experiences of PWLD (Ali *et al.*, 2013; Howieson, 2015; Gibbons, Owen and Heller, 2016). This theme had the least number of studies supporting it and although the study conducted by Howieson (2016) was the weakest methodologically, the study by Ali *et al.* (2013) was one of the highest scoring studies methodologically. One subtheme emerged from the initial codes: 'evidence of reasonable adjustments made in practice' which then formed the overall theme of, 'person-centred hospital experiences of PWLD'.

Subtheme: Evidence of reasonable adjustments made in practice

In the study by Ali *et al.* (2013) there were examples of good practice and improvements to hospital services as 12/14 PWLD and 13/15 carers reported examples of good practice which included good communication skills, friendly and

helpful staff and the incorporation of reasonable adjustments, such as longer appointment times which catered for the individual needs of PWLD. In the study conducted by Howieson (2015) two out of seven participants had good hospital experiences as they felt that nurses and doctors explained what was happening and they could understand this. Although the study by Gibbons, Owen and Heller (2016) was undertaken in the USA and was specifically related to Medicaid Managed Care so the health care system differed from the UK, the participants were people with an intellectual or developmental disability who shared what good health care meant to them via an exploratory, semi-structured telephone interview. This included having a good relationship with medical providers, being treated as an individual and receiving personalised care when doctors listened, demonstrated concern and exhibited patience. Table 10 shows a summary of the overall themes that were derived from the research papers that were included in the IR.

Table 50 A summary of the themes derived from the research studies included in the IR.

Themes Author(s) & Date	Communication issues in hospital	Unsafe care	Poor relationships with PWLD in hospital	Person-centred hospital experiences of PWLD
Gibbs, Brown and Muir (2008)	✓	✓	✓	✗
Webber, Bowers and Bigby (2010)	✓	✓	✓	✗
Dinsmore (2011)	✓	✓	✓	✗
Smeltzer, Avery and Haynor (2012)	✓	✓	✓	✗
Ali <i>et al.</i> (2013)	✓	✓	✓	✓
Tuffrey-Wijne <i>et al.</i> (2014a) *	✓	✓	✗	✗
Tuffrey-Wijne <i>et al.</i> (2014b) *	✓	✓	✗	✗
Howieson (2015)	✓	✓	✓	✓
Gibbons, Owen and Heller (2016)	✓	✗	✓	✓

Read <i>et al.</i> (2018)	✓	✓	✓	*
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*These 2 papers were from a single research study

2.7 Discussion

The majority of the studies in this review adopted a qualitative approach to explore the perspectives of PWLD who had previous experience of hospital care. All of the studies demonstrated that the experiences of PWLD in hospital were poor overall with the potential for serious health consequences. There was a link between the themes identified, for example, poor communication can negatively affect people's experiences of hospital care. In some studies, carers and family members were participants alongside the PWLD and contributed to the data collection which may have influenced the voice of the PWLD. It was unclear in all of the studies if the PWLD received alternative or additional support with the use of communication aids to help them to share their experiences. The majority of the qualitative studies included the carers' perspectives too and it is accepted and understood that for some PWLD, the carers are needed to facilitate the discussion during the interview or focus group.

The standards of hospital care were of concern due to the potential for serious morbidity and mortality and this concurs with Heslop *et al.*'s (2013) Confidential Inquiry into Premature Deaths of People with a Learning Disability (CIPOLD). In this report it was recognised that PWLD have greater health care needs due to multiple co-morbidities. There were concerns about poor communication, unsafe care and poor relationships with PWLD in hospital. Furthermore, fundamental care was

omitted, delayed and mistakes were made, all of which could lead to the subsequent development of complications that are preventable in hospital.

Although inconsistent, there were participants in three studies who highlighted areas where their experiences of being in hospital were positive. It was encouraging that this theme emerged in three of the later studies in the review which may indicate that some positive changes in hospital practices have been implemented since the report, 'Death by indifference (Mencap, 2007), or simply that these studies incorporated questioning regarding the more positive aspects of care people had experienced.

2.7.1 Strengths of the review

The strengths of this review were the use of a systematic and replicable search for empirical studies over a period of eleven years, from 2007- 2018. A rigorous approach was undertaken to interpret the collective findings from the studies to enable synthesis and evaluation of the pool of studies about PWLD who have experienced hospital care.

2.7.2 Limitations of the review

There were a number of limitations to this review. Firstly, the orthopaedic or trauma hospital experiences of PWLD were not the primary focal aim of any of the included studies. There was a gap in the research literature as orthopaedic and trauma hospital care is a distinct specialty within general hospitals where patients may

present with mobility issues leading to greater dependence on hospital staff for support with activities of living than in other specialties delivering hospital care.

Secondly, there was a narrow pool of research studies in the final review and they all had methodological weaknesses. The participants in the studies conducted by Smeltzer, Avery and Haynor (2012) and Read *et al.* (2018) were people with various disabilities which included PWLD. Despite this, all the studies were retained because they provided evidence of the experiences that PWLD and their carers have shared about their care in general hospitals.

Thirdly, while studies were identified from a range of countries, the review was restricted to publication in the English language as there was no funding for translation services therefore there might be studies available in another language that were not accessed. Finally, as there were no studies in the review that included the 'hidden majority' of PWLD who remain unknown to learning disability services (Emerson, 2011), this presents a gap in the research literature as all participants within the studies were known to learning disability services at the time they entered hospital.

2.8 Summary and research implications

This chapter provided a review and an appraisal of the research literature related to the general hospital experiences of PWLD. There was a narrow pool of research studies exploring the hospital experiences of PWLD which could be due to the historical lack of involvement of PWLD in research. Although the research consistently conveyed negative general hospital experiences which spans eleven

years and followed on from the scandalous report, 'Death by Indifference', two UK studies (Ali *et al.*, 2013; Howieson, 2015) discussed positive hospital experiences by some participants and it was encouraging that hospital experiences might have improved in some areas for PWLD. The participants in all the studies were already known to learning disability services and this facilitated the recruitment of participants to the studies. However, there were PWLD not known to learning disability services that have been missed in the current research literature and their experiences of hospital care remain unknown. Furthermore, there were no published empirical studies available that related specifically to orthopaedic or trauma hospital experiences of PWLD therefore the aims and objectives of the current study set out to address this omission.

2.9 Rationale for the present study

The experiences of patients have increasingly been used to assess, plan and implement changes in service provision and policy development (Lees, 2011) and forms one of the cornerstones of evidence-based practice for health care practitioners (Sackett *et al.*, 1996). The majority of PWLD in the studies had poor experiences of hospital care despite numerous policies, guidelines and legislation in place to counteract this. However, there were no published empirical studies available that related to orthopaedic or trauma hospital experiences specifically, despite PWLD having a greater prevalence of conditions and injuries affecting the MSK system (Kinnear *et al.*, 2018).

The IR has confirmed the need for robust and rigorous research studies examining the question, 'what are the orthopaedic or trauma hospital experiences of adults with

a learning disability?’ The present study, therefore, offered a new perspective to enhance the current research evidence base by exploring the orthopaedic or trauma hospital experiences of adults with a learning disability using interpretative phenomenological analysis (IPA).

2.10 Study aims and objectives

The study aimed to contribute to the understanding of the experiences of PWLD who have received orthopaedic and trauma hospital care in the UK.

The objectives of the research study were:

- 1 To gather, collate and add to the research evidence base about orthopaedic and trauma hospital care for PWLD.

- 2 To collect data about orthopaedic and trauma hospital care for PWLD via a semi-structured interview with relevant stakeholders:

- (i) PWLD who have experienced orthopaedic or trauma hospital care;
- (ii) Paid and family carers of PMLD who have received orthopaedic or trauma hospital care and can act as proxy participants for people with the most severe and profound learning disability which may prevent their participation in an interview.

The research question was:

How do adults with a learning disability describe their orthopaedic or trauma hospital experiences?

Chapter Three Methods and Procedures

3.1 Introduction

This chapter presents the design of the research study and introduces Interpretative Phenomenological Analysis (IPA). A description of the overall design of the study and how it was arrived at, along with a discussion about the sample size, decisions about the method of data collection, inclusion criteria, ethical approval and recruitment is detailed. The data collection process is described along with the interview schedule, consent form, venue decisions, the participants, length of interviews and the interviewing process itself. Finally, there is an explanation of how the analysis of the data was conducted.

3.2 Positioning the research within a philosophical framework

This study sought to understand the meanings that the participants assigned to their experiences of orthopaedic or trauma hospital care in the UK. This was an exploratory study and therefore it was believed that the most appropriate research approach for analysing the participants' experiences was a qualitative methodology using a phenomenological perspective. Braun and Clarke (2013) asserted that qualitative research puts emphasis on meanings rather than cause and effect and argued that this approach captures the complexity, disorderliness and ambiguity of the real world. As PWLD have not been included in research traditionally along with evidence of inequalities in health, a transformative paradigm was applicable (Mertens, 2009).

Amongst the most prominent approaches available to the qualitative researcher are: Grounded Theory (GT), Narrative Analysis (NA), Discourse Analysis (DA) and the phenomenological approaches.

This section briefly considers where IPA sits in relation to some of the other qualitative methods considered for use in the study. First, GT is often seen as an alternative to IPA (Smith, Flowers and Larkin, 2009) and second, NA because its theoretical foundations overlap with those of phenomenology. In comparison to IPA, GT uses larger samples and is directed at a more macro level of analysis. GT is concerned with developing codes and categories from qualitative data that are used to construct theories about the topic of interest. Unlike IPA, GT adopts theoretical sampling techniques whereby the emerging categories and theory are tested and refined through the ongoing identification and recruitment of participants. Sampling continues until saturation, the point at which no new data emerges from further sampling (Glaser and Strauss, 1967). IPA differs from GT because of its focus on making sense of individuals' lives, and in its careful, step-by-step approach toward making more general claims (Smith, Flowers and Larkin, 2009).

NA explores the life story of an individual and combines this with an explicit interest in the social backdrop of the recounted life (Hyde'n, 1997). The story is the object of investigation and the researcher explores how narrators impose order on the narrative and how they place themselves within it (Riessman, 1993). The narrative account is not deconstructed into themes as the researcher accepts the structure imposed on the story by the narrator and analyses the structure of the account and how the narrator made sense of it (Riessman, 1993).

One distinction between IPA and DA is that DA examines the role of language in describing the person's experience whereas IPA explores how people ascribe meaning to their experiences in their interactions with the environment (Smith, Jarman and Osborn, 1999).

Phenomenology is both a philosophy and a family of research methods concerned with exploring and understanding human experience (Langdrige, 2007). The aim of using phenomenological methods was to uncover the meaning of an individual's experience of a specified phenomenon through focusing on a concrete, experiential account, grounded in everyday life (Langdrige, 2007).

The possibility of a power imbalance between the researcher and participants was considered, particularly given her professional background. The researcher tried to ensure that her approach was non-judgemental although she did disclose that she was a nurse, a researcher and a teacher of nurses. It is important to present the researcher's perspective for transparency as this can impact on the methodology.

This study was exploratory, seeking to understand the orthopaedic or trauma hospital experiences of PWLD and it did not seek to test an already pre-defined hypothesis. Human beings are sense-making creatures and thus it was important to consider their reflections or attempts to make sense of their own experiences (Smith, Flowers and Larkin, 2009). The RCN (2017a, p. 11) purport that PWLD are a diverse group, therefore it was important to recognise each person as an individual, with a unique personality, history as well as range of abilities which was congruent with PCC.

3.3 Design and methodology of the research

A qualitative approach was used to explore the experiences of PWLD and having a positive regard for the perspective of PWLD was of paramount importance (Bigby, Frawley and Ramcharan, 2014, p. 4). This approach was guided by PCC and IPA as the study was designed to answer the following open and exploratory research question:

How do adults with a learning disability describe their orthopaedic or trauma hospital experiences?

This IPA research study was concerned with investigating how PWLD make sense of their orthopaedic or trauma hospital experiences. The theoretical perspectives of IPA include phenomenology, hermeneutics and idiography (Smith, Flowers and Larkin, 2009). The aims of the study were, 'giving a voice' to participants who have not traditionally taken part in research along with 'making sense' and offering an interpretation of the data that was grounded in each of the participant's accounts (Larkin and Thompson, 2012, p. 101). This approach provided the most appropriate context for facilitating and 'including the perspectives of vulnerable people' (Gibbs and Read, 2010, p. 233).

Taylor *et al.* (2014) describe interpretative research as concerned with context and subjectivity and consider the relationship between the participants and the researcher. Creation of meaning by human beings and their interpretation of reality are central. This type of research seeks to understand the complexities of the world

and the experience and meaning found within interactions between individuals, groups and systems in a wide range of situations. This paradigm has traditionally had a particular affinity with the nursing profession as it focuses on the holistic perspective of certain circumstances, settings or people (McLiesh and Rasmussen, 2017). Other methodologies such as ethnography and case study also employ an inductive approach and could result in rich accounts of the participant's experiences of orthopaedic or trauma hospital care (Newell and Burnard, 2010). However, IPA appeared to be the most appropriate methodology for an inclusive participatory research study and after reading around the different qualitative approaches, subjectively resonated most strongly with the researcher. Furthermore, it was congruent with the underpinning theoretical framework, 'PCC' which features throughout the thesis and was discussed in Chapter One.

3.4 Inclusive and participatory research

Historically, PWLD have been excluded from participating in research as it was believed this protected them as a vulnerable population (Crook *et al.*, 2015). Other barriers to participation of PWLD in research have been cited as: ability, ethical considerations, practicalities and restriction by 'gatekeepers' (Crook *et al.*, 2015). Though distinct, both inclusive and participatory approaches overlap in their focus on PWLD taking a meaningful role in the research process. These approaches have been successfully used to identify research topics which are important to PWLD. Inclusive research is described as research with, by and for vulnerable people and not research done to them (Nind and Vinha, 2014). The extent to which research is inclusive or participatory is dependent upon the degree to which PWLD are in control as co-researchers with the researcher. This can include involvement at one or more

of the following stages, developing the research question, recruitment of participants, undertaking data collection and analysis, presenting the findings and disseminating these.

Inclusive and participatory research entails PWLD taking a meaningful role within the research process. This study was based on issues that were highlighted in the introductory chapter as well as the findings from the literature review which consistently demonstrated that PWLD had very poor experiences of health care services. The study draws on the experiences of PWLD and therefore can be positioned in the participatory tradition on the inclusive continuum (Walmsley, Strnadova and Johnson, 2017). In this study, though not directly involved in the conception of the study, all of the participants were involved in providing data in the interviews and two participants co-presented their hospital experiences at local and international conferences.

3.5 Introducing IPA

The chosen methodology was IPA because of its commitment to explore, describe, interpret and situate the participant's sense of their experiences (Smith, Flowers and Larkin, 2009). IPA is a qualitative, hermeneutic phenomenological approach (Finlay, 2011) that was first proposed by Jonathan Smith in 1996 in a paper that argued for an experiential approach in psychology. IPA is relatively new to nursing although there has been a rise in popularity in many academic disciplines due to its useful methodology in studying the existential and illness experience (Finlay, 2011).

IPA has received criticism for being overly descriptive and not sufficiently interpretative and Hefferon and Gil-Rodriguez (2011) and Giorgi (2010) suggested that IPA was riddled with ambiguities and lacking in standardisation. Nonetheless, Smith (2011) rejected these criticisms by drawing attention to the increasingly large quantity of publications that outline IPA's theoretical, methodological and philosophical underpinnings (for example, Biggerstaff and Thompson, 2008; Snelgrove and Liossi, 2009). Moreover, IPA offered an adaptable and accessible approach to phenomenological research which intended to give a complete and in-depth account that privileged the individual. Alongside this, it enabled the researcher to reach, hear and understand the experiences of participants.

3.5.1 IPA and Phenomenology

Phenomenology was introduced by Edmund Husserl and developed further by Martin Heidegger and seeks to study lived human experiences. Finlay (2011) identified two broad phenomenological research categories: descriptive and hermeneutic, which follow the broad philosophical traditions of Husserl and Heidegger respectively. The general focus of the descriptive phenomenological approach is to examine the essence or structure of experiences in the way they occur to the conscious and therefore the descriptions of the experiences are anchored rigorously in the data without the influence of any external theory. The researcher adopted a phenomenological attitude and bracketed past knowledge or presuppositions whilst collecting the data. In some forms of phenomenology, for example, those grounded more strongly in Husserlian rather than Heideggerian philosophy, the researcher attempts to bracket predefined theories and assumptions

at this design phase so that data collection can be truly exploratory and participant led. The extent to which this is possible is discussed below but crucially the IPA researcher should aim to follow the participant in novel and unanticipated directions as the story of their experience unfolds (Smith and Osborn, 2008).

The ideas of the hermeneutic or interpretative approach are a sharp departure from the above as this is based on the principle that reduction is impossible and thus rejects the idea of suspending personal opinions in favour of interpretation of experiences (Smith, Flowers and Larkin, 2009; Finlay, 2011).

3.5.2 IPA and Hermeneutics

A major theoretical underpinning of IPA is hermeneutics, which is the art and science of interpretation or finding meaning. Meaning in this context is deemed to be fluid and is continuously open to new insight, revision, interpretation and reinterpretation. Smith, Flowers and Larkin (2009) purport that IPA employs four influential philosophers; Heidegger, Schleiermacher, Ricoeur and Gadamer. Significantly, Heidegger and Gadamer believe that all understanding assumes an essential element of presumption and interpretation and thus, making sense of the participants' narratives requires the IPA researcher to engage in close interpretation although the researcher may not necessarily be conscious of her preconceptions beforehand. IPA researchers do not attempt to produce an objective or definitive account of a phenomenon and only claim to access a version of the experience as the participant makes sense of it through their narrative account (Smith and Osborn, 2008).

The researcher's own resources and experiences, what Smith (2004) refers to as the 'biographical presence' of the researcher, are needed to make sense of what is said. However, this can create a dynamic tension throughout the research process as the researcher uses her own contexts as sources of insight whilst being, or trying to be, explicit about the influence of her perspectives on the analysis and interpretation of the narrative (Finlay, 2008).

The researcher using IPA engages in a 'double hermeneutic', in that the researcher is making sense of the participant's sense making. The researcher assumes a central role in the analysis and interpretation of the participant's experiences (Smith, Flowers and Larkin, 2009). Therefore, the researcher intuitively seeks to probe the surface meanings by reading between the lines for deeper interpretations (Finlay, 2011). The dynamism of interpretation and reflection resounds with the hermeneutic circle model that deals with the dynamic relationship between the 'part' and the 'whole' at numerous levels for a holistic analytical interpretation. In relation to IPA, the 'part' corresponds to the encounter with the participant in a research project, and the 'whole' to the drawing of knowledge and the experience of the researcher (Smith, Flowers and Larkin, 2009, p. 28).

The identity and experiences of the researcher as an orthopaedic nurse and mother of a teenager with a learning disability could potentially bias the interpretation of the participants' experiences. However, by incorporating reflexivity and approaching the interpretation with an open mind in order to explore the experiences of the participants', the researcher endeavoured to bracket her own preconceptions to find

meaningful ways to interpret their experiences without imposing her values (Smith, Flowers and Larkin, 2009).

3.5.3 IPA and Idiography

IPA is fundamentally idiographic in that it is committed to the detailed analysis of the phenomenon under investigation (Eatough and Smith, 2006). As an approach IPA can be used to take great care of each case, offering detailed and nuanced analysis, valuing each case for its own merits before moving to a more nomothetic general cross-case analysis focusing on convergence and divergence between cases (Smith, Flowers and Larkin, 2009).

3.5.4 Differences between IPA, thematic and content analysis

IPA adopts an idiographic approach with the focus more on the experience of each individual participant and as such sample numbers are usually smaller than used for other types of qualitative analysis (Reid *et al.*, 2005). This was preferable to a broader, shallower and simply descriptive analysis of many individuals, as commonly seen in thematic analysis. Whereas the emphasis in IPA is to analyse each interview as completely as possible on a case by case basis, thematic analysis involves the searching across a data set, which could be a number of interviews or focus groups, to find repeated patterns of meaning (Braun and Clarke, 2006).

IPA focuses on convergence and divergence within a participant group's experience of a phenomenon. Comparisons are undertaken at the individual level and across cases. IPA seeks patterns in the data and it is embedded in a phenomenological

epistemology which gives experience primacy and is about understanding people's everyday experience of reality, in great detail, so as to gain an understanding of the phenomenon in question. IPA engages with a double hermeneutic cycle which relates to the participant making sense of their experience first and then the researcher making sense of the participant's experience (Smith, Flowers and Larkin, 2009).

In contrast, Braun and Clarke (2006) advocate reading all of the data before one begins any coding in thematic analysis. With regard to types of coding, IPA refers to both 'descriptive' and 'conceptual' comments and these are very similar to 'semantic' and 'latent' codes in thematic analysis. Codes are more specific than themes as they capture a single idea associated with a segment of data. Codes are the building-blocks that combine to create themes during the process of thematic analysis and IPA. However, in terms of procedures for theme development, there are two levels of theme development in IPA. The subordinate themes are developed from the emergent themes and these are consolidated into a superordinate (main) theme. There is one level of theme development in thematic analysis.

Some of the phases of thematic analysis and content analysis are similar to the phases of IPA. The process starts when the analyst begins to notice, and look for, patterns of meaning and issues of potential interest in the data. IPA as a method of analysis is driven by both the research question and the broader theoretical assumptions. Thematic analysis and content analysis also offer a flexible approach and can be used across a range of epistemologies and research questions. That said, thematic and content analysis have also been conceptualised in numerous

ways by different writers and although thematic analysis can be of a phenomenological orientation, this is only one approach to thematic analysis whereas for IPA, this is fundamental.

Content analysis is a method that can be used to identify patterns across qualitative data and Erlingsson and Brysiewicz (2017) explain that the objective is to systematically transform a large amount of text into a highly organised and concise summary of key results. Analysis of the raw data from verbatim transcribed interviews to form categories or themes is a process of further abstraction of data at each step of the analysis; from the manifest and literal content to latent meanings. In content analysis, the main themes can be quantified to illustrate their prevalence and thus significance. Given the small sample size in this study, quantification of themes was not desirable.

3.6 Rationale for IPA

The rationale for using IPA was that it was a flexible and creative methodology to employ with the sample of PWLD. The idiographic approach lent itself to develop a rich account for each participant and was consistent with PCC. The primary concern of IPA was to elicit rich, detailed, and first-person accounts of experiences and phenomena under investigation (Pietkiewicz and Smith, 2012).

3.7 Data collection: Semi-structured interviews

Semi-structured interviews are commonly used in IPA studies and the interview schedule (Appendix 5) was used flexibly to ensure that the participants had an

important stake in how their lived orthopaedic or trauma hospital experiences was covered (Smith, Flowers and Larkin, 2009). Identifying what matters and then exploring what this means to the participant was important in a study employing IPA (Larkin and Thompson, 2012). Semi-structured, in-depth, one-on-one interviews were used although other alternative methods of data collection were considered (Smith, Flowers and Larkin, 2009). Although focus groups have been used in other studies involving PWLD, it was the individual participant's experiences that were being sought and therefore focus groups were not used (Mansell *et al.*, 2004).

Observation as a method of data collection was considered as it adds breadth and can provide answers that cannot be answered by interview alone (Morse and Field, 1996). The reasons what this method was not used includes: issues related to gaining informed consent from PWLD during an anxious period of hospitalisation, potential difficulty recruiting participants as PWLD are not routinely identified in hospitals, there was no funding for this study and observation is known to add to the costs of the study as well as being time-consuming.

There were other methods available such as 'Photovoice' and video analysis although the researcher was not familiar with these until after the data collection had been undertaken. Photovoice is an innovative and creative method that has been used to engage PWLD in research exploring loss and bereavement (Tajuria, Read and Priest, 2017). Video analysis could assist in the analysis of the participant's verbal, non-verbal (e.g., pitch, intonation) as well as non-vocals, such as posture, eye contact, and facial expression (Mitchell *et al.*, 2018).

A semi-structured interview format was chosen as studies have shown that PWLD can benefit from some level of structure when being interviewed (Gilbert, 2004). Herron, Priest and Read (2015) advocated planning prior meetings with participants in order to establish and build a rapport and level of trust and also to enable the researcher to judge the communication level of participants. The researcher was the interviewer for each participant and time was allocated with each participant to establish a rapport and build trust before gaining valid consent prior to taking part in the study interview.

Data were collected using a semi-structured interview guide and interviews were undertaken between May 2016 and October 2016. Four interviews took place in person and one was via telephone.

The effect of the location of interviews on data collection has been subjected to discussion as the meanings attached to the location of an interview can influence the research process (Braun and Clarke, 2013). That said, each participant's safety and wellbeing had to remain of paramount importance and the location of the interview was agreed with the participant and the advocacy managers or carer as well as the researcher's supervisors.

One interview was undertaken via the telephone due to the geographical location of the participant who lived in Wales and this was at the specific request of the participant. Novick (2008) suggested that telephone interviews may miss vital body language cues and thus be detrimental to qualitative research. However, Smith (1989) argued that there was no loss of quality with a telephone interview which can

be more convenient for the participant and allows a greater freedom for unedited disclosure along with a reduced social desirability bias due to the lack of face-to-face contact. Furthermore, a telephone interview had the potential to allow more reassurance regarding anonymity and confidentiality. Rahman (2015) conducted a literature review that determined that the in-person and telephone interviews are equally effective in gathering valid data. Telephone interviews have an advantage with cost and ease of use; however, the in-person interview can provide additional benefits to the research that outweigh the additional costs.

The semi-structured interviews allowed the researcher and the participant to engage in a dialogue in real time. They also gave enough space and flexibility for original and unexpected issues to arise, which the researcher could investigate in more detail with further questions. The interview questions were open and broad with some prompts available if needed.

3.8 Interview Schedule

Smith, Flowers and Larkin (2009) recommended the creation of an interview schedule to facilitate the interaction with the participants and to prepare for less engaging participants. A draft interview schedule was produced that incorporated open and exploratory questions that aimed to encourage the participants to talk. The questions were designed to start with easy to understand questions before they proceeded to more sensitive topics (Smith, Flowers and Larkin, 2009).

The emotive and possibly distressing nature of the subject matter covered in the interviews was considered in the context of the need to be inclusive and give PWLD

the opportunity to express their perspective. It was concluded that willingness to participate and share their experience transcended any presumed negative effects. In addition, the researcher reminded participants that if they became distressed, the interview could be stopped and support offered. The researcher was a Registered Nurse who could provide support if this situation arose; it did not. Furthermore, the interviews took place in the vicinity of advocacy group meetings for the majority of the participants where there were people that were known to them that could also offer further support and reassurance.

The Hospital Communication book which was produced by Mencap (2016) was available during the interview as a visual aid to facilitate communication between the participant and the interviewer (Gibbs and Read, 2010). Flexibility was required prior to and during the interviews in accordance with the IPA approach. This was important as the researcher needed to be guided by the PWLD and be prepared to deviate from the original plan (Herron, Priest and Read, 2015). This valued the participant's voice as being more important.

The self is always embedded in the research process (Holloway and Biley, 2011) and therefore it was recognised that assumptions, preconceptions and biases may have influenced the design of the interview schedule. Thus, as required in IPA research, reflexivity was employed throughout the interview process to demonstrate transparency by setting aside any preconceptions (Smith, Flowers and Larkin, 2009). A research diary was maintained throughout the study (Appendix 6). Holloway and Wheeler (2010) suggest that keeping a research diary does not ignore the fact that the qualitative researcher is the main instrument for collecting data but it provided a

place for a conscious form of self-monitoring that articulated how interactions among researcher, data and process can affect the final research report.

3.8.1 A practice interview

A practice interview was conducted with one member of the supervisory team with expertise in the field of learning disabilities in February 2016 and the draft interview schedule was revised following this. The rationale for the practice interview was to practise asking the questions and check the structure and the flow of the interview. The revision involved the removal of various questions that were believed to be ambiguous, directive or repetitive. These changes simplified the final interview schedule to the most suitable questions, prompts and probes addressing the prominent issues of the research question.

The research question was, 'How do adults with a learning disability describe their orthopaedic or trauma hospital experiences?' It was believed that this method would yield the data to answer the research question. Trustworthiness of the study is discussed in more detail on pages 115-120.

3.8.2 Sampling

There are no firm rules regarding sample size in IPA (Smith, Flowers and Larkin, 2009) although some authors believe that the idiographic nature of IPA necessitates a small sample size to provide sufficient comparisons and interpretation without getting overwhelmed by the data (Smith and Osborn, 2003; Hefferon and Gil-

Rodriguez, 2011). The original plan was to recruit six participants and five participants were purposively recruited in total. The research supervisors were in agreement that five participants were sufficient for an IPA study as the emphasis was on depth rather than quantity.

3.8.3 Inclusion and exclusion criteria for participants

Potential participants were required to self-identify as having a learning disability and to have experience of orthopaedic or trauma hospital care. There was no time frame regarding when the orthopaedic or trauma hospital experience took place. Participants that accessed the self-advocacy groups or other learning disability services were, by their acceptance as members of these groups, already identified as having a learning disability. Participants were required to have the mental capacity to give informed consent to participate in the research and adequately understand easier read written and verbal information in the English language as there was no budget to provide translation of written information or interpretation services. Mental capacity was assessed by the researcher who observed the participant's ability to understand and retain the information in the adapted participant information sheet and the adapted consent form as well as checking their understanding of what their participation would involve by asking participants to repeat back what participation involved, clarifying any misunderstandings and then rechecking. This process informed decision making regarding being involved in the study. The function of a consent form is to record the participant's decision, and to indicate that the process was conducted appropriately and with suitable discussion.

Participants were included if they were aged 18 or over and had adequate communication abilities to participate. This was initially discerned by the gatekeepers in the advocacy groups who selected and also by the researcher when she met the participant. Participants were excluded if participation was deemed to be detrimental, for example, if the person was extremely distressed about the hospital experience, however this did not occur. In line with the theoretical underpinnings of IPA, participants were selected purposively because this allowed the researcher to find a defined group for whom the research question had relevance and personal significance.

3.9 Recruitment Process

There were significant barriers to accessing the participants to take part in the study which resulted in an extended period of time recruiting and it took over a year to gain access to a purposive sample of participants. Sydor (2013) discussed the terms, 'hard to reach' and 'hidden' which both apply to the participants in this study. 'Hard to reach' describes a population that is difficult for researchers to access and 'hidden' refers to a population with no defined limits such that the exact size cannot be known (Sydor, 2013, p. 35). The researcher did not work in the specialist field of learning disability and therefore was an 'outsider' which may have made access more difficult.

Participants were recruited in various ways including: through the managers of local self-advocacy groups for PWLD in the West Midlands region of England; through national organisations that work with PWLD and their health care professional members. It was acknowledged that not all PWLD attend self-advocacy groups or

will be in receipt of learning disability services therefore the sample recruited may be unrepresentative due to the hidden majority of PWLD. That said, the aims of the study were to illuminate the experiences of the participants in the study rather than be representative of all PWLD (Newell and Burnard, 2010). The advocacy group managers were gatekeepers as well as facilitators and were important in terms of safeguarding PWLD because they discussed the study with potential participants to establish if they were interested so potential participants could make an informed choice about their involvement in the study.

The managers of the self-advocacy groups were contacted by letter, telephone and email to inform them about the study. The letter and email described the aims and purpose of the research, what the participation would involve and easier read information was included so that the language was accessible for potential participants (Appendix 7). A poster for display in their group settings was also sent with the letter and attached to the email (Appendix 8). This did not generate any responses despite follow-up emails and a telephone call from the researcher.

However, during a learning disability national conference, the researcher was introduced by a colleague who was well-known in the field of learning disability, to one of the advocacy group managers who was attending the conference. Following an informal discussion, the manager agreed that she would ask her group if anyone would like to be involved in the study. Nicholson, Colyer and Cooper (2013) highlighted that the gatekeepers were most likely to promote participation when benefits to the participant or to the gatekeeper were easily identified. Crook *et al.*, (2015) also believed that by clearly outlining the rationale for the research and giving

time to address gatekeepers' concerns may encourage greater support and enthusiasm. This face-to-face meeting was instrumental in gaining access to potential participants. After this meeting, an email from this manager confirmed that there was one person, Kay, who was very keen to share her orthopaedic hospital experiences with the researcher. The 'easier read participant information' was sent to the manager again so she could discuss the study with the potential participant. After this, a date was set to meet the participant at a day centre where the advocacy group meet twice a week and the manager agreed to be there also. A private room just off the main hall where the group were meeting to do various activities was allocated and Kay and the researcher sat down and had a conversation about the group initially before the interview commenced.

As there was continuing difficulty in accessing a purposive sample, national learning disability organisations were contacted by telephone and email informing them of the study along with confirmation that the study had received full ethical approval and requesting if they could advertise the study on their website or through their self-advocacy groups. Two of the organisations that were contacted advertised the research study through their websites and a members' journal. The British Institute of Learning Disabilities (BILD) and Health Stones, an online national collaboration both communicated the details of the study to their members (Appendix 9).

At the HEI where the researcher works, a group of people who have been patients or carers in the health care system are employed to support research, teaching and learning on all courses in the Institute of Health. This group are known as the 'SUCCESS' team (Service User and Carers Contributing to Educating Students for

Services) and their manager agreed to share the poster and the participant information with other members of this group which included PWLD.

3.10 The study procedure

The principles stated in the UK Policy Framework for Health and Social Care Research (Health Research Authority, (HRA) (2018) were adhered to throughout the study in line with good practice for researchers. To facilitate the active engagement and participation of PWLD, Watchman (2014) highlighted the importance of a flexible and individualistic approach although her research was aimed at people with both dementia and learning disabilities. The recruitment process was flexible and individualised and a brief description of each participant is detailed below.

3.10.1 Kay

Kay was recruited through a local self-advocacy group after meeting the manager and the group at a national learning disability conference in Nottingham. Kay had been in four different hospitals in England for orthopaedic hip surgery. The researcher met the participant in the self-advocacy group and she agreed to be interviewed in a room just away from the main hall where the group were involved in various activities that afternoon. The manager had arranged access to a quiet, private room. After the interview, the researcher was invited to stay and participate in the group's activity which was beneficial in helping to build rapport with this group.

Some months later, at a conference organised by the Wolverhampton Intellectual Disability Network (WIDeN) held at the University of Wolverhampton, Kay co-presented the findings of this study at a plenary session entitled, 'What WE think about hospital care.' Kay was able to share her orthopaedic hospital experiences with the delegates. Kay requested that the presentation was videoed as she wanted her Mother to see it too and a member of Kay's self-advocacy group undertook this task.

3.10.2 Ted

Ted was recruited through the university 'SUCCESS' (Service User and Carers Contributing to Educating Students for Services) group. One member of the SUCCESS team who has a learning disability was an administrator for an online national closed support group called, 'Always learn about disability and never judge disability' and she was aware of someone who might be interested in taking part in the study and a snowball effect took place. Ted was very interested and agreed for the researcher to send details of the study to him via email. There was dialogue via email and Ted asked if the researcher could telephone also. Ted lived in Kettering and it was agreed to discuss the study on the telephone. However, this presented a difficulty for the researcher because it was extremely difficult to understand all of Ted's verbal speech as he struggled to form some words when he was speaking. This combined with the researcher's unfamiliarity with his expressive communication made comprehension difficult for the researcher. Ted did use the email system well whilst on the telephone and indicated that his speech gets easier to understand over a longer duration. The telephone call lasted for 90 minutes and some information about Ted's life and hospital experiences were gathered from this. As a child, Ted attended a special residential school for PWLD. Ted agreed that he would complete

the questions that the researcher would ask in the interview and email them back which he duly did. Some of Ted's written answers via email were brief and he agreed to elaborate on some questions (Appendix 10). Although he lived in Kettering, Ted was an avid football supporter and emailed the researcher to inform her that he was attending a football match in Wolverhampton in the summer of 2016 and he requested a meeting the following day. This took place and an 85-minute, face-to-face audio-recorded semi-structured interview was conducted at the University of Wolverhampton. Ted had received extensive orthopaedic surgery to his lower limbs over a considerable period of time. The use of an inclusive communication approach where all means of communication were valued was an important principle for decision-making purported by BILD (2009) and informed Ted's inclusion in the study. Total or Inclusive Communication uses all possible ways of communicating according to each situation and person. It depends on people without communication disabilities making adjustments to their communication to include the other person rather than expecting change from them (BILD, 2009). Ted was able to write on a pad of paper during the interview to clarify words that the researcher was unable to understand.

3.10.3 Kelly

In the summer of 2016, the father of a 32-year-old lady with Down syndrome contacted the researcher via email as he had been informed about the study from a health professional who was working with his daughter. The father was keen to find out more and then he agreed to discuss the study with his daughter who agreed to take part along with the support of her carer who could facilitate verbal communication between the researcher and Kelly. Kelly lived in a house with three

friends and they were supported by family and carers. Kelly's father informed the researcher prior to the interview, via email, that Kelly had a slipped upper femoral epiphysis (SUFE) aged 14 which was treated surgically, a total hip replacement six months prior to the interview and was awaiting knee surgery. The researcher met with Kelly again one year after the interview as her father invited the researcher to the launch of a book that Kelly had co-authored. The official launch of the book took place in London and the researcher was able to see and speak with Kelly again as well as meet her parents.

3.10.4 Len

Len was recruited to the study through a self-advocacy group for PWLD following an advertisement in a parish magazine appealing for volunteers and support to enable the group to continue to function. After the researcher contacted the project leader of the advocacy group, their governing body conducted an independent review of the research proposal and ethical approval processes and requested an interview with the researcher. Subsequently the researcher was granted permission to meet the manager of the advocacy group for an informal interview about the study and how it would be conducted. The manager agreed to discuss the study at the next group session and then inform the researcher if there was anyone interested in taking part in the study. There were adults in the group who had orthopaedic and trauma hospital experiences and were keen to know more about the study so the researcher was invited to join them during their usual planned activities and also to explain further and answer questions about the study. The researcher met the group on three separate evenings for two hours 7-9pm over a six-week period. The researcher helped with the organised activities such as cooking, colouring, singing and

discussions with the group. The self-advocacy group were interested in the presence of the researcher and had the opportunity to ask questions about the study over a period of time. After this, one gentleman agreed to participate in the study. Len had a fracture to his ankle after a road traffic collision whilst he was a pedestrian. The interview took place in the corner of the large hall where the group meet so that the researcher and the participant were within sight of the manager.

3.10.5 Sue

Sue contacted the researcher via email after reading an advertisement for participants for the study. Sue was the mother of twin boys aged 24 years old and lived in Wales. Alex, Sue's son, had profound and multiple learning disabilities (PMLD) and was non-verbal; Sue was his family carer. Her other twin son, George was a university graduate and did not have a learning disability. It was important to include Sue in the study as she was a family carer with experience of her son's orthopaedic and trauma hospital care and her son, due to the PMLD was unable to participate in a traditional research interview. It was important that a person with PMLD should be included in the study via a proxy participant. Alex had a fractured tibia and fibula for which he was hospitalised. A telephone interview took place and this was audio-recorded. Sue requested to co-present some of the research findings from the study during a plenary conference session in September 2016. Alex and George also came onto the stage to be present during the session. The experiences that were shared contained shocking but powerful messages which were conveyed to approximately 130 orthopaedic and trauma nurses, educators and medical colleagues who were delegates at the conference with an aim to enable learning

from this mother's and her son's experience. Sue commented that if the presentation changed just one health professional's views about PWLD then it was worth her efforts. See Appendix 11 for Table 11 for the details of the participants.

3.11 Ethical Procedure

Ethical approval was granted by the University of Wolverhampton Research Ethics Committee in 2014 (Appendix 12). Given the potential vulnerability of PWLD, a number of ethical issues were considered and these are detailed below. Although these principles apply to any research participant, the focus is on the additional requirements for PWLD.

3.11.1 Informed consent

Valid informed consent for research was required and ensured the following: information has been effectively communicated and understood, decisions about participation are recognised as voluntary, benefits are appropriately weighed up against risks and the participant's capacity to give their informed consent is recognised (HRA, 2018). Consent was gained from each PWLD who could understand what their involvement in the study would mean (section 3.8.3). Assessment of the participant's mental capacity was needed to evaluate if they could provide valid and informed consent (Hamilton *et al.*, 2017). Furthermore, the researcher had an ethical and a legal responsibility when obtaining consent to judge the capacity of participants and the quality of the consent itself. Jepson (2015) highlighted that judgements about capacity can fluctuate when recruiting potential participants with learning disabilities who may exhibit good social communication

strategies but may have underlying difficulties with memory or may need further time to communicate their thoughts.

The Mental Capacity Act (2005) was adhered to and the participants were deemed as having capacity to provide informed consent to participate in the study. The Mental Capacity Act (2005) directs that all reasonable steps are taken to support capacity and states that *'A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success'* (Mental Capacity Act, 2005, p. 1). There are five principles underpinning the Mental Capacity Act (2005) and there was a legal obligation to ensure that the researcher was working within the framework of these principles when gaining informed consent from a person with a learning disability. The first principle states that one must assume a person has capacity unless proved otherwise. The second principle states, 'Do not treat people as incapable of making a decision unless all practicable steps have been tried to help them'. The participants were given time to consider being involved in the study and easier read information was developed to support this. Principle 3: A person should not be treated as incapable of making a decision because their decision may seem unwise. The participants' decisions were respected and all five agreed to take part in the study. The last two principles apply to people who do not have full mental capacity. Principle 4: Always do things or take decisions for people without capacity in their best interests. This principle was not required as all five were assessed as having full mental capacity to make their own decisions. The last principle 5 states, before doing something to someone or making a decision on their behalf, consider whether the outcome could be achieved in a less restrictive way (BILD, 2009).

The Mental Capacity Act (2005) Code of Practice (The Stationary Office, 2007) informs that the assessment of capacity is a two-stage test. Stage 1: The diagnostic approach which asks the following: 1. Does the person have an impairment or disturbance of the functioning of the mind or brain? This can include people with a learning disability. As four of the participants identified themselves or were identified by others as having a learning disability the next stage of the process was applied, Stage 2: The decision-making process. The participants were assessed using the following criteria which confirmed if a person had the capacity to make a decision themselves if the answer to these statements was yes:

- they understand the information about the decision that needs to be made
- they can retain the information for long enough to make a decision
- they can weigh up the pros and cons of the options available to them and understand the long-term implications of the decision
- they can communicate their decision to you (BILD, 2009).

Developing a rapport with each participant was a crucial factor in successfully recruiting a sample and gaining informed consent. The consent process began with a discussion with the participant to ensure that the participant understood the rationale for the study and what was expected of them along with how the data would be captured, stored and used (Llewellyn and Northway, 2008). Communication is a particularly important component of the consent process for PWLD and opportunities were given for participants to discuss the study with others, such as the local advocacy group managers or their carers before taking part (McCarthy, 1998).

Information was provided in an accessible and comprehensible manner to ensure that the person had sufficient information on which to base their decision to be involved (Nind, 2008). Furthermore, all participants received an accessible, easier read information sheet describing the full implications of being involved in the research (Appendix 13). Appendix 14 has the participant information sheet for carers. The participant information sheet and the consent form were developed collaboratively into easier read formats with the researcher's supervisors and the learning disability nursing team who possessed this expertise. Alongside this, the DH (2010) guidance for developing and adapting information into easier read was used.

Verbal and written informed consent were obtained prior to the interview and verbal consent was checked again at the end of the interview. Crook *et al.* (2015) believe that there can be concerns about acquiescence among PWLD and they stress the importance of frequent re-assessment of consent. The HRA (2018) acknowledges that a signature on a consent form does not in itself make consent valid. A person's agreement with each statement contained in the consent form was indicated by ticking boxes and providing the answers 'yes' or 'no' after each statement. The form itself is then signed by the parties involved in the consent conversation. Alongside this, the advocacy group managers and carers who had been involved in selecting the participants were informed to contact the researcher if the participant changed their mind and wished to withdraw from the study. Smith, Flowers and Larkin (2009) suggest up to one month after the interview is reasonable to accept withdrawal because otherwise the analytical work can be made redundant.

3.11.2 Confidentiality and anonymity

Information about confidentiality was discussed verbally with the participants and this was detailed in the easier read participant information sheet. To ensure confidentiality, at the point of transcription, all identifying data from the digitally recorded interviews were removed and each participant was allocated a pseudonym (NMC, 2018a) which was then used during interview transcription and the rest of the research process. All data were stored on password protected drives and computers only accessible to the researcher.

Two of the participants, Kay and Sue, requested to co-present their experiences at conferences which created tension related to maintaining their confidentiality and anonymity because their identity would then be known. At the outset of the study, it was not anticipated that the participants would want to present their experiences of orthopaedic and trauma hospital care in a public domain and therefore it was not considered in the design of the study. However, one of the advocacy group managers contacted the researcher to inform her that Kay, one of the participants, wanted to share her experiences at a local conference that the researcher was due to present at as Kay was attending it with her advocacy group. Discussions were held with the research supervisors, one of whom was the co-chair of the Institute of Health Sub-Ethics Committee, and it was agreed that the participants had a right to present their experiences and support was provided by the researcher and her supervisory team to enable this. Sue, the carer participant in the study, was aware that some of the findings were being presented at an international nurses' conference and she requested to attend and share her experiences. Sue and her twin sons (Alex has a PMLD and George does not have a learning disability)

attended the conference and Sue presented her experiences during a plenary session.

This tension involved balancing the right to confidentiality and anonymity with autonomy and empowerment of participants to co-present their experiences. Tuffrey-Wijne, Bernal and Hollins (2008) concur that providing recognition for participants and respecting the ownership of participant's work were essential. The two participants had full mental capacity to make decisions. All the participants were aware that the researcher would be sharing the findings more widely.

Manning (2009) highlighted that in contrast to ethical requirements for anonymity, some PWLD may want their names to be known. However, if there was a possibility that identification of the participants in the study may expose them to certain risks or harm, this must be considered. Nuwagaba and Rule (2015) recognised that tensions occur in research ethics if PWLD are viewed through a medical model of disability which would want to protect the 'rights' of PWLD to anonymity due to the belief that PWLD may be unable to make rational decisions. Conversely, if PWLD are viewed through a social and human rights model of disability, the reality can mean that PWLD increasingly may want to speak for themselves (Nuwagaba and Rule, 2015) which was the case after the data collection process in this study. Therefore, whilst it may be appropriate for some groups of people, such as people with severe learning disabilities, to receive special ethical considerations, it is important that these considerations do not undermine the autonomy and self-efficacy of other groups of PWLD (Nuwagaba and Rule, 2015). Although the dominant research discourse classifies PWLD as vulnerable (Silverman, 2011), Kay and Sue (carer)

sought to share their experiences in a public domain and it was established that they understood this would mean that their identity would be known. It was deemed to be low risk that their identities were known and they were empowered to co-present at two different conferences; their wishes and voices were respected.

3.11.3 Due care and avoidance of coercion to participate in the study

To reduce potential coercion or acquiescence to participate in the study, the PWLD met the researcher after they had already expressed their interest in participating in the study. Prospective participants were given the opportunity to choose convenient dates and the place they wished to be interviewed via the advocacy managers or carers. Participants were informed verbally about the research study again before and after the interview, as well as through the easier read participant information sheets and consent forms that were sent in advance of the interview and presented again verbally with each step on the consent form being explained prior to the interview. Participants were informed that their involvement in the study was voluntary; that they could stop the interview or withdraw from the study and this would not impact on future hospital care. The process of continuous consent was adopted whereby informed consent was gained before the interview with the participant aware that they could stop the interview at any point and also withdraw from the study following the interview.

3.12 Conducting the Interviews

Interviews were conducted from May 2016 - October 2016. It has been suggested that a good interviewer-participant relationship inevitably affects participant's self-

disclosure and the depth of the experiences they are willing to share (Braun and Clarke, 2013). Efforts were made to build a good rapport with each participant prior to and throughout the interview process with careful consideration given to allow time for this before the commencement of all the interviews. Each participant was asked to sign a consent form (Appendix 15 and 16) to confirm that they understood what the study was about and that they were agreeable to take part in the research. It was explained that they could stop the interview at any time without any explanation. The participant's body language was observed, along with how they answered questions, in order to get an indication of whether they were becoming uncomfortable with the line of questioning. The rationale was to help to reduce or contain any distress to the participants and to explore only the lived experiences they were comfortable to discuss. Herron, Priest and Read (2015) demonstrated that researchers need to be guided by the PWLD in the interview and be prepared to deviate from their original plan. A discursive rather than a formal interview approach was used to help put participants at ease (Dias *et al.*, 2012). The researcher attended a training day with the British Institute of Learning Disabilities on 'Communicating with PWLD' prior to undertaking the interviews to gain skills and prepare for interviewing PWLD (Appendix 17).

The interviews commenced with informing each participant about the aim of the study and asking them to talk about their hospital experiences. The interview gradually progressed with the researcher requesting that the participant talk about their orthopaedic or trauma hospital experiences. The pictorial Hospital Communication Book was available as a visual resource to support the participant's communication as well as to promote understanding, memory and recall. Although

qualitative nursing research often depends on people's memories to describe past experiences (Barusch, 2011), memory, as a concept, is rarely discussed or described in qualitative nursing publications (Blakey *et al.*, 2019). Baddeley *et al.* (2015) suggested that memory is complex and subjective with no agreed theory that explains what memory is and how it works. Blakey *et al.* (2019) asserted that participants' memories, when explored in qualitative interviews, are socially constructed and co-constructed and the dialogue between the researcher and the participant affects the memories that are reported. Jedlowski (2001) argued that it was possible for the past to be presented differently in a different context. Although Cohen *et al.* (2010) contended that what people remember is significant to them, Baddeley *et al.* (2015) highlighted that recall is imperfect and a memory is modified each time it is recalled (Young Rojahn, 2013).

Morales *et al.* (2017) acknowledged a dearth of research regarding the memory abilities of PWLD and asserted that their testimonies are often not believed due to negative stereotypes of PWLD. In relation to autobiographical memory in young PWLD, Morales *et al.* (2017) conducted a study which analysed the stability of the memory of a medical examination within a hospital setting over time in young people aged 12-21 with mild or moderate learning disabilities. An interview was conducted an hour and a week after the medical examination which assessed memory of people, memory of actions, memory of objects, identifying roles along with touch and feelings. They found that the verbal IQ was an important factor to consider when predicting performance in a memory task and the greater the ability, the better the performance when recalling people, objects and actions. It was observed that time modified the autobiographical memory of complex events although the memory of

the people involved in the medical examination, the apparatus used and the parts of the body explored were maintained after a week had elapsed. The lower the IQ ability, the more negatively time affects memory although the only type of information that was free from the influence of time and level of intellectual ability was emotional information as emotions remained stable over time. This study demonstrated that assumptions should not be made that the memory of PWLD is poor. Moreover, a comparison of autobiographical memory of a medical examination with people without a learning disability would be useful.

Furthermore, Laney and Loftus (2013) warn that it is important to avoid asking leading questions during an interview because this can potentially create false memories. That said, Blakey *et al.*, (2019) affirmed that it was acceptable in qualitative research to value experiences and feelings over any alleged accuracy of memory and this was the stance that was adopted in this study.

Broad, open questions with prompts were used to elicit more information about the hospital experiences (Smith, Flowers and Larkin, 2009). The interviews lasted between 24 minutes - 85 minutes with a mean time of 43 minutes. See Appendix 18 for Table 12 with further details of the interviews. The duration of individual interviews was influenced by the participant's responsiveness to the questions, the prompts and probes. The participant interviews were approached with sensitivity, a non-judgmental attitude, flexibility and patience in order to capture the richness and complexity of each participant's meaning making and in accordance with the principles of IPA (Eatough and Smith, 2006; Smith, Flowers and Larkin, 2009; Finlay,

2011). A personal thank you card was given to each participant at the end of the interview.

3.13 Transcription of Interviews

As recommended by Smith, Flowers and Larkin (2009), the researcher did her own transcribing to allow for full immersion in the data. Each transcript was transcribed verbatim and the following transcript notations were used in the quoted extracts, '...' indicated a significant pause, [] indicated that material was omitted and [for example, unable to understand the participant's speech] included explanatory material added by researcher and capital letters were used when the participant emphasised the words loudly. A reflective diary was maintained to record the researcher's initial thoughts after each interview and throughout the study (Appendix 19).

3.14 Data Analysis

Data were analysed according to the principles of IPA (Smith, Flowers and Larkin, 2009). The interviews were audio-recorded and after each recording the researcher noted her reflections on the interviews. The individual recordings were listened to several times and then the interview was transcribed verbatim by the researcher. In 2009 Smith, Flowers and Larkin produced the (to date) definitive book on IPA in

which they stated: "... we would advise the novice embarking on an IPA study for the first time to begin by working closely with the suggested set of steps, and then adapt them when and where they feel comfortable to do so [...] once one has mastered those steps and seen the finished product, one is more able to recognise that IPA is an approach and sensibility" (p.81).

The initial stage of analysis involved a close line-by-line reading of the transcript a number of times and the audio recording was listened to again several times. This helped the researcher to be immersed in the data, recall the atmosphere of the interview and the setting in which it was conducted. At this stage, the researcher made exploratory notes about her observations and reflections about the interview experience or any other thoughts and comments of potential significance. Each reading and listening to the recording provided some new insights. Following this, identification of emergent patterns was documented and these later formed the themes. Due to the idiographic nature of IPA, each transcription was analysed in its entirety before moving on to the next participant's transcript. It was acknowledged that the end result was an account of how the analyst thinks the participant was thinking, which is known as the 'double hermeneutic' and therefore the claims made in IPA are tentative. That said, although the analysis was subjective, the outcomes can be creative and insightful (Smith, Flowers and Larkin, 2009).

Data analysis was guided by an attitude of openness and a willingness to dwell in the data, consistent with the approach taken toward data collection. The focus remains the participant's attempt to make sense of their experience and the analysis

progresses from the particular to the shared and from the descriptive to the interpretative (Smith, Flowers and Larkin, 2009). A table was created for each of the interview transcriptions and data from each individual interview were pasted and exploratory notes were made in another column. Appendix 20 provides the transcription of an interview with one participant. The aim of the analysis was to actively focus on the participant's data and to gain an overall understanding of the structure of the interview, while reflecting on the interview experience with annotations recorded to bracket any pre-conceived ideas.

The second stage included initial identification of exploratory themes (Smith, Flowers and Larkin, 2009). This stage involved descriptive comments on the participant's thoughts or experiences, with attention to usage of language to describe their experiences. This process involved using experiential and professional knowledge and asking a range of questions to find provisional meanings (Appendix 21).

The third stage involved returning to the transcript with a fresh perspective to check whether new themes would emerge. The extraction of emerging themes was developed into initial themes and supported by the participant's quotations (Appendix 22). A sample cluster of themes can be found in Appendix 23.

The fourth stage involved mapping the connections between the main superordinate themes and the subordinate themes and summarising them (Appendix 24).

The fifth stage was about moving to the next transcript and repeating the entire process above. This required bracketing of preconceived ideas acquired from the previous transcript and treating each case as unique.

The sixth stage included looking for patterns of themes across the participants. A series of master themes were developed from the analysis of the subordinate and superordinate themes of the participants and these were integrated into a table to illustrate the comparison of master themes across the participants (page 168).

3.14.1 Trustworthiness of the study

Quality in qualitative research is contingent upon demonstrations of trustworthiness (Williams and Morrow, 2009). This concept is used to convey the researcher's accountability to the broader research community and the participants. Williams and Morrow (2009) describe three dimensions of trustworthiness to which qualitative researchers are bound: integrity of data, clear communication of findings, and balance between subjectivity and reflexivity. Back in the 1980s, Lincoln and Guba transformed the nature of qualitative inquiry by developing criteria to assess rigour, which they termed 'trustworthiness', during qualitative inquiry, to evaluate the credibility, transferability, dependability, and the trustworthiness of the completed product (Lincoln and Guba, 1985, 1989). The strategies for demonstrating reliability and validity identified by Lincoln and Guba (1985) have become standards for attaining rigour in qualitative inquiry. The overall goal of trustworthiness, consisting of credibility, transferability, dependability, and confirmability were identified to be respectively equivalent to quantitative criteria of internal validity, external validity, reliability, and objectivity (Lincoln and Guba, 1989).

There are many ways to judge the validity of qualitative research and whilst there is no specific method that can be applied to IPA, Smith, Flowers and Larkin (2009)

favour the 'four principles' approach of Yardley (2000; 2008; 2017). In this assessment of quality, reviewers are asked to look at the research from the perspective of four broad areas: sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance. As well as discussing the criteria for assessing the validity of this study as described by Lincoln and Guba (1985), it was believed that Yardley's criteria (2017) could be combined with this. These criteria were examined together in the next section.

3.14.2 Credibility and sensitivity to context

Credibility included prolonged engagement with the participants and the transcribed data. The research method has been described in detail including the recruitment, interviewing of the participants, data collection and analysis as well as an independent audit could be used to check the rigour.

Morse (2015) endorsed that prolonged engagement and persistent observation were both necessary for producing thick, rich data. The assumption underlying these criteria was that spending more time on data collection in a particular setting provides time for trust to be established with participants. With increased trust, richer data may be gathered. More will be revealed, and therefore, data will be more valid. Review and debriefing with the supervisors were intended to minimise bias and aid conceptual development of the study.

A detailed contextualisation and background to the study was presented in Chapter One along with the analysis of the relevant existing literature relating to the study in Chapter Two. There was evidence of sensitivity to context by the establishment of a

good rapport with the gatekeepers and potential participants during the recruitment process. Furthermore, the ethical issues related to recruiting and interviewing a sample of PWLD has been explored and sound ethical principles have been adhered to throughout the study. The researcher has an orthopaedic and trauma nursing background and was also the mother of a child with a learning disability with awareness of a dearth of research in this area.

Member checking refers to giving the transcribed interview, or the completed analysis, back to the participant to obtain additional information or to correct data (Morse, 2015). It is not clear why one should provide the participant with such an opportunity to change his or her mind and this is not required in other types of research (Birt *et al.*, 2016).

In this IPA study, member checks were not undertaken although two participants co-presented their orthopaedic and trauma hospital experiences at conferences after the interviews which enabled the researcher to hear about their experiences a second time.

3.14.3 Transferability, transparency and coherence

The key concepts of IPA have been detailed in this chapter including the rationale for using IPA as the research methodology along with its epistemological assumptions. The transparency of the data analysis is available in an audit trail in the appendices. The research supervisors read the participants' transcripts and coded three of the transcripts independently. There was coherence between the exploratory research

question and the principles of IPA which is committed to examining how people make sense of their major life experiences (Smith, Flowers and Larkin, 2009). Moreover, in accordance with the principles of PCC and IPA, the analysis and presentation of the findings demonstrated commitment to this approach to make sense of the participants' experiences. Reflexivity has been undertaken throughout the study with an exposition of the researcher's positioning, ontology and epistemology and how these could impact on the research process.

3.14.4 Dependability, commitment and rigour

Dependability is the ability to obtain the same results if the study were to be repeated and this was attained through credibility and use of an audit trail. There was an explicit description of the research process including the recruitment of the participants, a description of the construction of the interview schedule and the interview process. Alongside this, there was a commitment to adhering to the principles of PCC and IPA and a systematic idiographic analysis of the data was undertaken. Rigour refers to the thoroughness and robustness of the study and therefore it was important to demonstrate rigour through the integrity and competence of the study (Tobin and Begley, 2004). The study could be replicated from the audit trail that was available to check the quality of the study (Smith, Flowers and Larkin, 2009). A sample of the documentary evidence for each stage of the study can be found in the appendices. Alongside this, the research supervisors independently assessed each stage of the research process. Although Morse (2015) argued that replication of a project is unnecessary and undesirable in qualitative inquiry it was important that the steps undertaken could be followed. The final step,

addressing all of the above criteria, was the use of a reflexive journal during the study.

3.14.5 Confirmability, impact and importance

Confirmability was achieved through the use of triangulation strategies and the audit trail. Other validation strategies were also used including the independent coding of the original transcripts by two supervisors. This approach was congruent with the epistemological stance. This study explored the lived experiences of PWLD who were willing to share their perspectives of their orthopaedic or trauma hospital experiences. There was no published research available that has explored this aspect of hospital care therefore highlighting a gap in the literature. There is a high prevalence of musculoskeletal conditions or injuries in PWLD and their orthopaedic or trauma hospital experiences were unknown. There has been a dearth of research available involving PWLD and therefore it was important to undertake this inclusive study.

3.15 Reflexivity

Reflexivity is a requirement during each phase of the IPA process. Willig (2013) describes two types of reflexivity: personal reflexivity and epistemological reflexivity. Personal reflexivity involved reflecting upon the ways in which the researcher's values, experiences, interests, beliefs, political commitments, wider aims in life and social identities have shaped the research. This required reflection on the reason for choosing this topic and on how the researcher might change as a person and as a researcher through this research process (see p. 204-209).

Epistemological reflexivity required engagement with questions such as: How has the research question defined and limited what can be 'found'? How has the design of the study and the method of analysis 'constructed' the data and the findings? How could the research question have been investigated differently? To what extent would this have given rise to a different understanding of the phenomenon under investigation? (Willig, 2013, p. 10). Epistemological reflexivity encouraged reflection on the assumptions that the researcher had made in the course of the research along with the implications of such assumptions for the research and for the findings. Engagement in personal and epistemological reflexivity throughout the research study was captured through the use of a research diary as well as through critically reflective discussions with the research supervisors.

3.16 Summary

This chapter has presented a detailed description and rationale for the design of the research study and the methods used. The recruitment process, ethical procedures and considerations, data collection and the process of data analysis were discussed. The quality criteria suggested by Lincoln and Guba (1985) and Yardley (2008; 2017) have been combined to evaluate the rigour and trustworthiness of the study. The next chapter presents the findings of the study.

Chapter Four Findings

4.1 Introduction

Each participant's 'experience' has been written up individually with their superordinate and subordinate themes including their words to illustrate the themes that were derived from the data. Each participant's voice is indicated by the direct quotations; the interpretations are those of the researcher. A cross case comparison of the themes from each participant was then undertaken.

There were five participants: Kay, Ted, Kelly, Len and Sue who took part in the study by sharing their experiences of their orthopaedic and trauma hospital care. All names have been changed to maintain the participants' confidentiality in accordance with the requirements of the NMC (2018a). The participants' ages ranged from 25 - 45 years old, however one participant, Sue did not disclose her age. All were white and three were female and two were male. Kay and Kelly shared their elective orthopaedic hospital experiences, Sue and Len shared their hospital experiences related to orthopaedic trauma and Ted shared both elective and orthopaedic trauma hospital experiences. The 1:1 face-to-face interview lasted from 24 minutes to 85 minutes. There was one telephone interview which lasted 45 minutes. The amount of time that had lapsed since the orthopaedic or trauma hospital experience ranged from seven days to ten years. Kay and Kelly were receiving hospital care for musculoskeletal conditions at the time the interviews were conducted.

Each participant is presented with a brief overview at the beginning to help to provide some contextualisation to the research findings. The superordinate themes and subordinate themes are presented with an analysis and an interpretation of the themes along with quotations from each participant to illuminate the theme. The final section in this chapter presents a cross case comparison of the themes for all the participants.

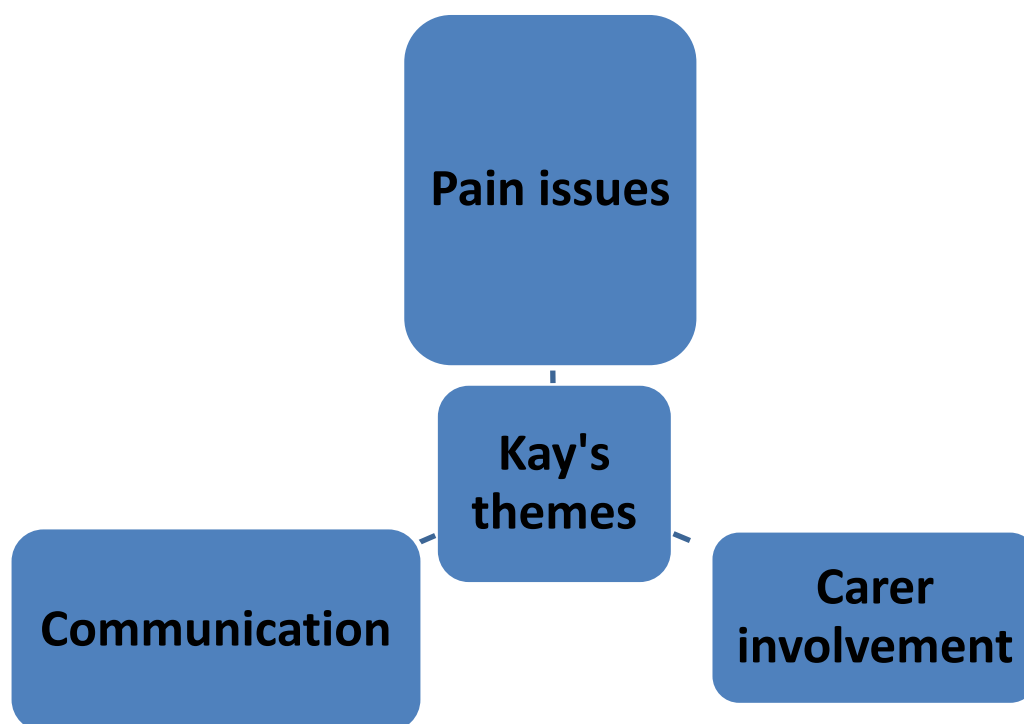
4.2 Kay: An overview

Kay was 25 years old and had problems with her hip since she was ten years old. She had experience of being in four different hospitals for substantial amounts of time with her hip problems since the age of 10. Kay continued to attend the hospital for her on-going musculoskeletal problems. Kay lived with her mother; she did not work and attended an advocacy group for PWLD each week.

4.2.1 Kay's Themes

The superordinate themes for Kay were: 'Pain issues', 'Carer involvement' and 'Communication'. See Appendix 25 for Table 13 for a summary of Kay's themes and Figure 5 illustrates Kay's themes.

Figure 5 An illustration of Kay's themes



4.2.2 Pain issues

Pain was a word that was repeated many times by Kay throughout the interview. 'Anxiety about the hip pain', 'pain assessment and management in hospital' and 'living with the pain' were the subordinate themes.

4.2.2.1 Anxiety about the hip pain

Kay talked about her pain as a child. She had pain in her hip as a child and was taken to the General Practitioner (GP) by her mother but the pain was dismissed as growing pains.

... and they said it was growing pains... (Kay, line 26)

Kay was dismissed at this stage by her doctor as having pains that were not of a serious nature. As Kay limped and continued in pain her mother returned to the GP and Kay was later referred to specialists in orthopaedics at the hospital:

... but I was still limping on it so my Mom took me back... and they said they would do an X-Ray and then they phoned us up and said you've got to go to [] to have an operation cos the hip was out of place... they just said it was something to do with puberty or something...

(Kay, line 23-28)

An X-Ray was requested because Kay's mother returned to the GP seeking further investigation. Once the X-ray was taken and reviewed it was evident that there was a problem with Kay's hip which accounted for her pain and limp. Furthermore, Kay was requested to go straight to the specialist orthopaedic hospital where surgery was then planned.

Kay had multiple operations on her hip once the problem was diagnosed as a developmental condition that required surgery. However, Kay's hip pain did not abate after the initial operation:

... so I went back and they did em...you know, tests on me. I was in hospital for a week having tests done on me and they couldn't find anything wrong...though they sent me to the children's hospital in []... and they found out straight away that ...that the socket's still out of place...

(Kay, line 111-114)

In the general hospital various tests were undertaken to try to establish the cause of Kay's continuing hip pain and eventually Kay was referred to a children's hospital where the on-going hip pain was diagnosed. The hip joint remained out of alignment

after the operation which caused the pain. The expertise to diagnose Kay and treat this further at the general hospital appeared to be lacking:

...and I've had , I've had...er...God knows how many plates put in...er...I've had a plate and then a claw...onto the side of the socket...I've had it all took out and had it shaved and I've had you know...them pain needles...them what they put into your leg...

(Kay, line 120-122)

Kay reported having many operations on the same hip joint as her pain did not subside.

4.2.2.2 Pain assessment and management in hospital

Kay remembered being in pain in hospital and waiting for long periods to have the pain relief medication:

...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)

Kay relayed that she was in pain to hospital staff but did not receive prompt intervention in the form of analgesia. Kay seemed distressed that she had to wait a long time for the analgesia because she was experiencing a lot of pain. Kay was aware that she should have received the analgesia earlier than she did and she remembered crying because she was in so much pain while awaiting analgesia. Kay's pain assessment and management were below an acceptable standard as no-one should be left in pain in the 21st Century, and it was concerning that this happened in hospital. Kay was not treated as promptly as she should have been.

4.2.2.3 Living with the pain

Kay remained in pain with her current musculoskeletal problems. Although this started in her hip, the pain had affected some of her other joints too:

... I'm still in a lot of pain... and erm... and it's affected other parts of my body now

(Kay, line 430-432)

Kay endured pain which worsened every couple of months and this was not relieved:

... so every other couple of months...I end up having flare ups...where I can't get out of bed...I'm in a hell of a lot of pain ...pain...I can't move... and em... all they say is because my leg is so weak... so I have to have...I have to have a couple of days in bed... have stronger tablets... so its... it gets me down...and it gets me down when I have these flare ups

(Kay, line 306-317)

Kay had to live with this situation of experiencing so much pain because she had been informed that her muscles in her leg were weak. Kay stayed in bed for a couple of days until the pain settled but this made her feel low in mood.

4.2.3 Carer involvement

Kay's mother was very important to her and especially during her hospital admissions because she helped and supported Kay with fundamental care. The subordinate themes were 'Help with fundamental care' and 'Trust as a pre-requisite for a therapeutic relationship'.

4.2.3.1 Help with fundamental care

Kay waited for her Mother to come in to the hospital to help her with washing and dressing along with other fundamental aspects of care. Kay was nervous about asking hospital staff to help her with her care needs:

... 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)

The hospital staff were too busy to help Kay with fundamental care and therefore she waited for her mother to come into the hospital to help her to get washed and dressed. Alongside this, the staff conveyed that they were too busy to help Kay.

Kay's Mother did not stay overnight with Kay in hospital except at the children's hospital. Kay's mother was not allowed to stay overnight in the other hospitals:

...my mom was allowed to stop... when I was at the children's hospital...

(Kay, line 206-208)

4.2.3.2 Trust as a pre-requisite for a therapeutic relationship

Kay trusted her mother who had helped her over many years and she was not given the time required to get to know the hospital staff or vice versa. The hospital staff did not take enough time to get to know and understand Kay as a person:

...and my Mom...em...I know her and she's, she doesn't hurt me when I'm getting ready, when she gets me dressed...

(Kay, line 287-288)

Kay's mother was gentle, knew how to support Kay and did not hurt her while helping with washing and dressing. Kay preferred her Mother to help her to get dressed because she was familiar with her and she knew the routine that Kay was used to in the mornings when getting washed and dressed.

On another occasion, Kay felt nauseous after taking her iron tablets for anaemia and it was her mother that helped to resolve this rather than the nurses who were administering the medication to Kay:

... and the thing is what they was doing wrong was...because em...because em... when I had my first operation...em...em...I had the pins put in...em...em...cos I lost a lot of blood...they put me on...this thing where I had blood pumping into my body... and I was on er... iron medicine... and er... they was giving it me before I had my food and kept making me be sick... so my Mom said, K try and have something to eat first... and then have the stuff after you've had something to eat...but I did it and it worked...

(Kay, line 237-247)

Nurses administering medication should understand which tablets need to be taken with or after food. Iron tablets are administered regularly for patients on orthopaedic hospital wards and it was concerning that Kay was not given this important information or Kay may have not understood if the information was given. This served to further the distrust Kay felt about the staff in hospital as it was Kay's mother that informed her to take her iron tablet after food to reduce the side-effect of nausea.

Kay did not like the food in the hospital and her mother brought food into hospital for her. Kay did not communicate her dislike of the food to hospital staff as she did not have a trusting, therapeutic relationship with them:

... see I'm a fussy eater... I used to get Mom to bring me sandwiches in and stuff like that... (Kay, line 244-6)

On another occasion, Kay asked the hospital staff to telephone her mother to request her to come in to the hospital and Kay felt that this request was ignored for some time. Kay was powerless in hospital and needed her mother there for support as well as for aspects of her care:

...I had to ask them to call my Mom to get her to come to the hospital and they took ages to do that as well

(Kay, line 408-9)

Kay did not feel like she was taken seriously by the hospital staff because when she asked for analgesia as well as the request to contact her Mother it took a long time for the staff to respond to Kay's requests.

4.2.4 Communication

The subordinate themes were, 'effective communication' and 'mother as translator for Kay'.

4.2.4.1 Effective communication

Kay approved of two of the hospitals that she had been in because they helped her to understand what was happening to her in hospital:

... em...I liked it at the children's hospital...and em...and I liked it at the orthopaedic hospital in []...yeah... em...there was more...em... they

was more helpful...and they...they explained things...easier to me...they explained things...

(Kay, line 187-194)

Kay understood more at these two hospitals because she felt they helped her by explaining to her what was happening in ways that she could understand. She was much more satisfied with the care she received in these two hospitals as opposed to the two general hospitals.

4.2.4.2 Mother as translator for Kay

In the two general hospitals, there was a struggle for Kay to understand some of the spoken words used by hospital staff and therefore Kay did not always understand what was happening to her there, leading to a sense of powerlessness and dissatisfaction:

...I found it hard to understand... erm... long words...

(Kay, line 373)

Kay relied on her mother to interact with the hospital staff to find out what was happening and then Kay's mother would explain this in an understandable way to Kay. As Kay's mother did not stay all the time with Kay there were periods where Kay did not seem to know what was happening to her in hospital:

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

(Kay, line 220-226)

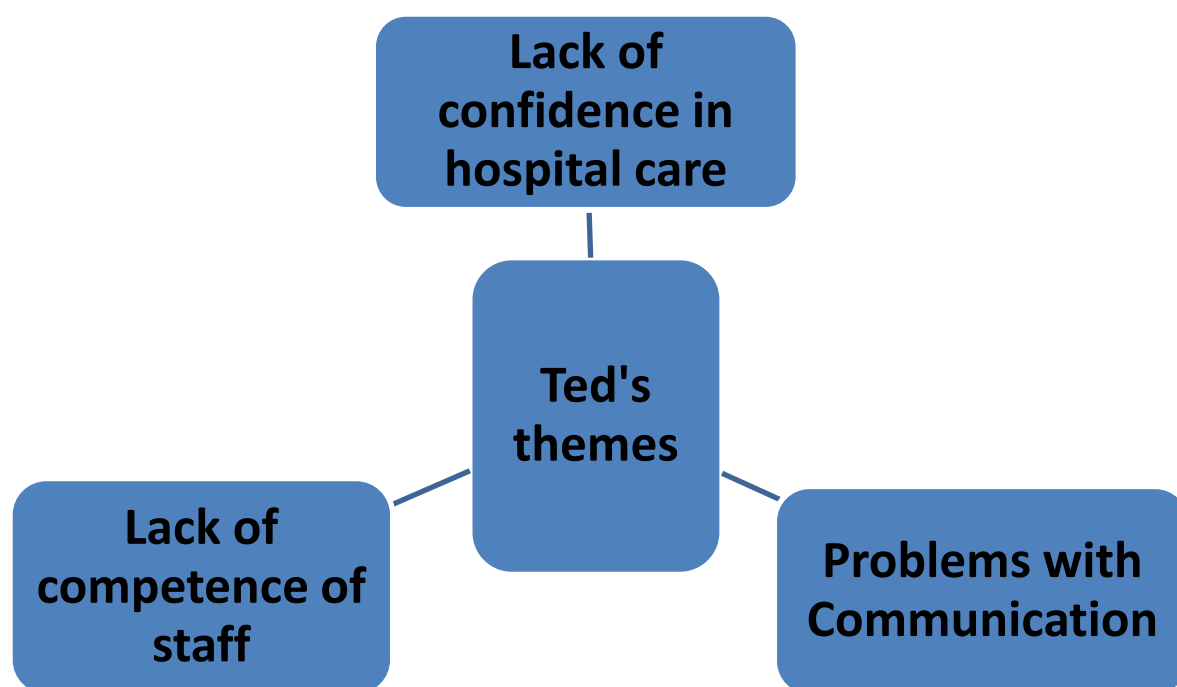
4.3 Ted: An overview

Ted was 45 years old and suffered with meningitis as a baby which affected the development of his lower limbs and he had dysarthria making it difficult to communicate verbally and be understood clearly. Ted lived alone in supported accommodation and had worked in a factory in the past. He also had epilepsy which made it difficult to maintain employment. Ted had had over 40 orthopaedic operations on his lower limbs to enable him to walk without any aids. He attended a special school and had been in many different hospitals since being a child. Ted used to live with his father until he died a few years ago; his mother left the family home when he was a child and he had no contact with her since.

4.3.1 Ted's Themes

The superordinate themes for Ted were: 'lack of confidence in hospital care', 'problems with communication' and 'lack of competence of staff'. Table 14 is a summary of Ted's themes, see Appendix 26. An illustration of these themes can be seen in Figure 6.

Figure 6 An illustration of Ted's themes



4.3.2 Lack of confidence in hospital care

The subordinate themes were: 'lack of continuity', 'errors in hospital administration system' and 'the belief of only one doctor'.

4.3.2.1 Lack of continuity

Ted was dissatisfied because he saw a different doctor each time he attended hospital and this resulted in a lack of continuity. Ted endured questions from the medical team that he felt were unnecessary. Although there were written reports available, the doctor still asked questions that Ted believed the doctor should have known the answers to rather than asking these:

every appointment I have is with a new doctor...what's the point in that...they ask me what's wrong, why don't they look at the report or

ask the nurses, they must know what I come in with...in the end I walked out... (Ted, line 298-300)

Ted continued that the report was filed away and was not available with his notes for the doctor to review:

...I thought why does the doctor ask me each time what happened and I found out that the report is put away... it's all on the report but they can't find it...

(Ted, line 200-203)

Ted was frustrated that there was a written report, it was not readily available and it could not be located which impacted negatively on his care. Ted felt he was not valued as a person because the staff did not seem to care enough to ensure that all the information about him was available at the appointment because without this it appeared a waste of time to go to the hospital for Ted.

4.3.2.2 Errors in hospital administration system

Ted was exasperated that even his name and address were incorrect on the hospital computer system:

...they can't even put the right name on the computer properly... my surname, my second name...they put an S on it. They put the wrong number on my address also...they can't even put the right number...

(Ted, line 205-209)

There was a lack of attention to Ted's demographic details that were important if Ted was to receive written communication from the hospital. Ted had already asked for these details to be corrected and this had resulted in a lack of trust in the hospital systems because it was not actioned.

4.3.2.3 Belief of only one doctor

Ted had over 40 operations on his legs and he was extremely grateful to one doctor who was the only doctor prepared to try to help Ted to enable him to walk:

...they said impossible... it wasn't only that ... yeah the bones, my hips... like that- (showing again with his hands that his lower legs were twisted)

(Ted, line 67-72)

40 operations on my lower legs and feet to make able to walk which were done by Dr [name omitted] which did the operation on motor biker racer [name omitted] ...

Email 13.6.16 at 21:22

Ted was disappointed that only one doctor was willing to operate to correct his lower limbs to enable him to walk. Ted was aware that it was very complicated surgery and if it was not for the belief of one surgeon, he still would be unable to walk:

...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)

4.3.3 Problems with Communication

Ted experienced difficulties with communication whilst in hospital. The subordinate themes were, 'ineffective and unclear communication' along with what Ted believed to be 'conflicting information'.

4.3.3.1 Ineffective and unclear communication

Ted was surprised when doctors asked him questions related to his seizures due to his epilepsy as Ted was not aware when he would have a seizure. The impression gained was that Ted could not possibly know the answer to this. Ted thought the doctors lacked knowledge and understanding of him or how his epilepsy affected him:

some doctors asked me when will I have a seizure, but how would I know that?

Email from Ted, 13.6.16 at 21:22

Ted did not trust the communication in hospital because he believed that some things that were communicated to him were untrue or did not make sense:

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

(Email from Ted, 13.6.16 at 21:27)

The communication between the staff and Ted was not consistently clear or understood by Ted as he did not always know what was happening to him in hospital.

4.3.3.2 Conflicting information

Ted received conflicting information about the need to have an X-ray of his nose and this caused some confusion which led to Ted feeling suspicious of the reason why he was sent to an X-Ray department and subsequently sent back to the ward without having the X-Ray:

They said things which were not true

he said they don't do x-rays on noses

(Email from Ted, 13.6.16 at 21:22)

This seemed to impact the level of trust that Ted had in the health care team. The reason Ted did not have the X-Ray of his nose was not communicated clearly enough to him as he did not understand the reason for being sent back to the ward. Radiographers use their professional judgement based on the information given to them to determine if an X-Ray is necessary. There was a breakdown in clearly communicating this information to Ted.

4.3.4 Lack of competence of staff

Within this theme Ted believed that the hospital staff lacked competence when caring for PWLD. The subordinate themes were, 'a need for additional and specific education and training for hospital staff and a special facility', 'isolated and abandoned' and 'pain assessment and management'.

4.3.4.1 A need for additional and specific education and training for hospital staff and a special facility

Ted believed that nurses and doctors required additional and specific education and training to look after PWLD:

*... nurses and doctors are not trained to look after disabled people...
most people in hospital don't have a disabled problem ...*

(Ted, line 261-264)

Ted also suggested that other staff in the hospital needed further education and training, such as the telephone operator, who might be the first person that a PWLD has contact with on a telephone call to a hospital:

...operators are not expecting anyone with any disabled problem to contact them...

(Ted, line 266-267)

Ted suggested that there should be special areas in hospitals for PWLD so that staff that are competent in this area then care for PWLD. Ted suggested that PWLD would be more satisfied as well as safe in these specific areas:

hospitals ought to have special wards + clinics for the disabled people to be more happier + safer to be in so all the nurses are not only trained nurses but as well trained to know to cope with all sort of disabled problems like speech, hearing, learning problem, memory problems and more

(Email from Ted, 15.6.16 at 18:20)

4.3.4.2 Isolated and abandoned

Ted was in a room on his own after an operation and he felt isolated as no-one seemed to check on him for 14 hours:

...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)

Ted was aware that everyone should have a nurse allocated to look after them after an operation but this was not the case for him which was unfair. Ted felt isolated in hospital and alongside this, there was no evidence of a caring, therapeutic relationship between Ted and the hospital staff indicating a lack of person-centred care.

On another occasion, Ted remembered being left alone after he hit his head on a wall. Ted felt as if no-one cared for him on this occasion:

...I had hit my head on the wall... but they left me there...

(Ted, line 173-175)

Furthermore, Ted felt abandoned in hospital as he was always on his own since being a child. Ted's mother did not stay with him:

...No-one has ever, ever stayed with me...

... even from being small... not even my Mom...

(Ted, line 38-44)

Moreover, Ted was unhappy in hospital when he was younger but because he has to be strong, this enabled him to cope:

'It was not nice at all when I was younger but I am a strong person so I got used to it...'

(Email from Ted, 13.6.16 at 21:21)

4.3.4.3 Pain assessment and management

Ted experienced uncontrolled pain at times in hospital and although the nurses asked about the pain, he did not feel that this happened regularly. There was an impression that Ted might not have communicated his level of pain to the nurses along with a lack of regular assessment of his pain and appropriate management by the hospital staff. A caring, person-centred, therapeutic relationship with Ted was missing:

...sometimes I had very awful pain

...The nurses didn't ask about the pain that often...

(Email from Ted, 13.6.16 at 21:22)

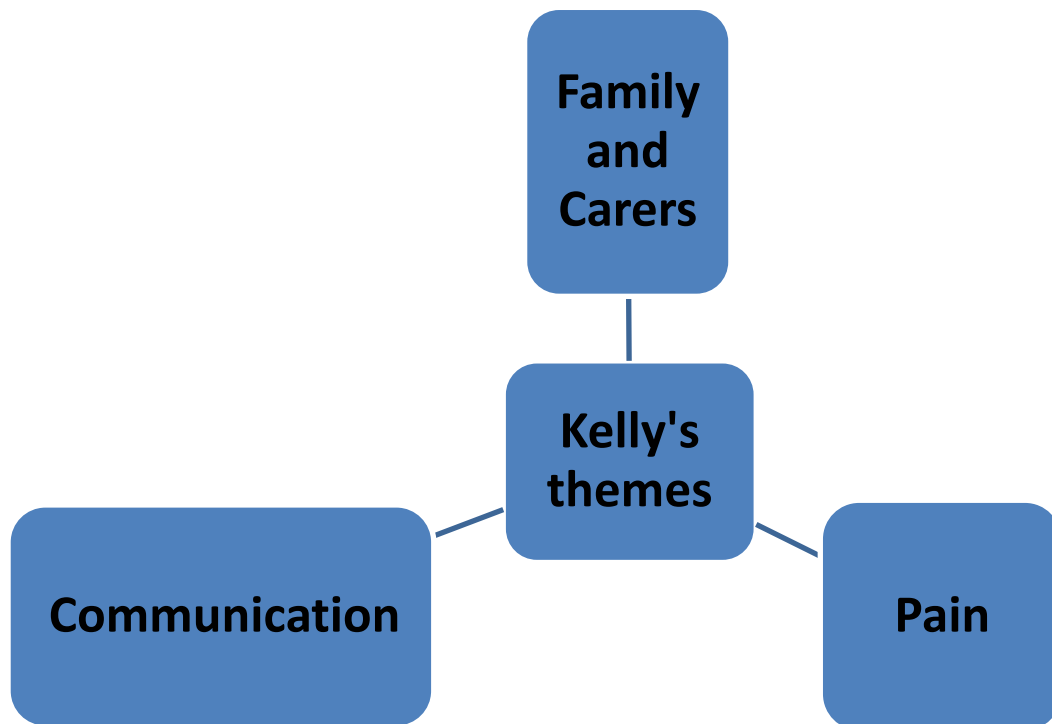
4.4 Kelly: An overview

Kelly was a 32-year-old lady who had a total hip replacement six months previously and was currently awaiting knee surgery. Kelly had been in two different specialist orthopaedic hospitals due to problems with her hip which started at the age of 14 when she required orthopaedic surgery. Kelly lived in supported accommodation with two other friends and enjoyed drama and attending book clubs. She worked in a charity shop and also had a voluntary role at a school. Kelly had Down syndrome and Nat is one of her paid carers who facilitated the communication between Kelly and the researcher.

4.4.1 Kelly's Themes

The superordinate themes for Kelly were, 'Family and Carers', 'Pain' and 'Communication'. See Table 15 in Appendix 27 which provides a summary of Kelly's themes. Figure 7 illustrates these themes.

Figure 7 An illustration of Kelly's themes



4.4.2 Family and carers

The subordinate themes were, 'importance of family and carer support' and 'carer advocacy'.

4.4.2.1 Importance of family and carer support

Kelly trusted her Dad to help her when the problem started with her hip:

...I said, Dad, my hips not moving...and after that he took me to the hospital...

(Kelly, line 239)

Kelly was in a specialist orthopaedic hospital for her 14th birthday which she recalled with joy. Kelly was happy to share that her family brought in a cake and birthday cards which brought back happy memories:

... yes I was 14... I had my birthday in hospital...my Mom and Dad came in... and brought a cake...and a card... my auntie came too

(Kelly, line 241-247)

Kelly's parents and family were of central importance to her and they were welcomed and accommodated in the children's ward of the hospital.

4.4.2.2 Carer advocacy

Kelly received blood tests during the recent pre-operative assessment prior to her knee surgery but she was not shown the ward or introduced to staff that might be caring for her on admission to hospital. Nat, her carer, was aware of the supportive role of a learning disability liaison nurse that Kelly received when she had her hip replacement six months previously:

...Yeah, we had a LD nurse then...I know she was very good and she organised everything but we haven't had it this time...

(Nat, line 79-81)

Nat accompanied Kelly to the recent pre-operative assessment clinic which was to prepare Kelly for knee surgery and she was surprised at the nurse's response in relation to a request to see the learning disability liaison nurse:

...we asked the nurse that we first saw, didn't we? But she didn't really know what we were talking about...

(Nat, line 85-86)

Although the role of the acute liaison learning disability nurse is relatively new, Kelly received this support in the same hospital six months previously. The nurse in the pre-operative clinic was unaware of the role and did not look further into finding out about it. Nat was knowledgeable about Kelly's support needs and did not passively accept that there was not a learning disability nurse to support Kelly for this next admission to hospital for imminent surgery. She planned to follow this up after the hospital appointment:

... and I asked a physio as well who said she would look into it and get back to me...but...she hasn't...yet...I need to chase it up again but...the social worker was going to look into it as well...

(Nat line 86-88)

Nat accepted that she would need to follow this up rather than wait for the hospital to contact her about it.

4.4.3 Pain

Within this superordinate theme, levels and types of pain experienced by Kelly are discussed. The subordinate themes were, 'no hip pain after major surgery', 'knee pain', 'abdominal pain on discharge home' and 'distress caused by the removal of the surgical clips'.

4.4.3.1 No hip pain after the major surgery

It was significant that very early in the interview, Kelly shared that she no longer had hip pain and there was an impression that she had a great amount of pain before the

hip operation. Kelly was pleased with the outcome of this major hip replacement surgery because it eliminated the pain:

no pain...no hip pain

(Kelly, line 6)

Nothing wrong with my hip... the pain has gone

(Kelly, line 31)

4.4.3.2 Knee pain

Kelly had pain in her knee and was awaiting surgery on this at the same hospital where she underwent the hip replacement surgery:

...my hip went...then my knee pain...

(Kelly, line 45)

...the doctor knows there's something sharp in my knee

(Kelly, line 54-55)

Kelly was not anxious about returning for further surgery and the previous hospital experience was positive. Kelly was in pain with her knee during the interview as her facial expression indicated she was uncomfortable at times and she winced and rubbed her knee too.

4.4.3.3 Abdominal pain on discharge home

Kelly had abdominal pain which resulted in nausea and vomiting following her discharge home from hospital after the hip replacement:

When I had my hip operation...I was really poorly...sick...for a few days after...I was back at home and I feel sick

(Kelly, line 185-187)

Nat explained it was very bad pain and that it was worse than Kelly's hip pain before the surgery:

It really hurt, the painkillers, they really constipated her really bad and I think the pain from that was worse than the hip...

(Nat, line 230-231)

Kelly was very constipated which could have been due to the side effects from the analgesia that she had been given for pain relief in hospital. The situation could have been avoided if Kelly had been thoroughly assessed prior to discharge home. It is fundamental to check if patients have had their bowels opened as it is well known that the analgesia that is used often causes constipation. This was overlooked in Kelly's case.

4.4.3.4 Distress caused by the removal of the surgical clips

Kelly shared her distressing experience of when she had removal of the clips from her hip wound:

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)

This was a distressing time as well as a painful procedure for Kelly as she was shouting, screaming and crying for her parents while the nurse removed the clips from the surgical hip wound. This was an unpleasant experience for Kelly who had

no control over what was happening to her as the nurse continued to remove the clips despite Kelly's protestations and her request for the presence of her parents. Kelly was powerless to stop the procedure which suggests that the care was not person-centred.

4.4.4 Communication

Communication was a theme that incorporated communication with Kelly which was facilitated by carers and the use of technology to stay connected with family, carers and friends. The subordinate themes were, 'communication with Kelly facilitated by carers' and 'use of technology to stay connected with family, friends and carers'.

4.4.4.1 Communication with Kelly facilitated by carers

Kelly was able to ask for help when she needed it which suggested that a good rapport had been built between Kelly and the nurses:

...I used to say to the nurse, nurse can you take me to the toilet please...they took me there...washed my hair, shower, toilet...I got changed in the daytime...my Mom and Dad came in again ...

(Kelly, line 257-260)

Kelly was confident to ask the nurses to help her with fundamental aspects of care which they did. However, it appeared that the communication between the doctor and Kelly was less than satisfactory at times as some medical staff spoke to the carer rather than directly to Kelly. This undermined Kelly as a person with a right to be respected and communicated with directly:

...I would say the nurses were good but the consultant, he spoke to me and not K...which I really hate when Doctors do that...just stuff like how old is she...K knows how old she is...K knows how old she is

(Nat, line 285-287)

Kelly was upset as she remembered that one doctor had mentioned about the possibility of her going on to a children's ward rather than an adult ward when she was preparing for the hip replacement surgery:

...I'm 32...and I'm not a child, I'm an adult

(Kelly, line 291-293)

Nat confirmed that this conversation took place when Kelly's father had taken her to the hospital prior to the hip replacement surgery.

Nat: ah was that when you went with Dad?

Kelly: yeah

Nat: the time before they were talking about children's wards and children's services, something to do with children's services

Kelly: yeah

Nat: which quite upset Kelly...because she's not a child...and he was talking about her to her Dad as if she was

(Nat and Kelly, line 294-300)

The doctor was talking about the children's ward to Kelly's father prior to her hip replacement with a suggestion that Kelly may go there rather than to an adult ward. Alongside this, Kelly was communicated about rather than with and the content was inappropriate because Kelly was an adult and not a child.

Moreover, at the most recent consultation regarding Kelly's knee pain, Nat felt that the doctor spoke to her rather than to Kelly. Furthermore, Nat acknowledged that she did not understand the language that the doctor was using and therefore it was unlikely that Kelly would understand either:

...I mean it's rude really...and he spoke in another language...I didn't know...if I didn't understand it, K isn't going to understand it ...

(Nat, line 289-290)

The communication from the doctor was disrespectful towards Kelly and it was concerning that the operation was explained to Nat in an inaccessible way that she did not understand and therefore she would be unable to explain it clearly to Kelly.

4.4.4.2 Use of technology to stay connected with family, friends and carers

Kelly used an iPhone while she was in hospital to communicate directly with her parents, her carers and friends. Kelly used this technology, 'FaceTime' very well to meet her needs to be connected with the people she missed while she was in hospital. Furthermore, Kelly was in control when she used FaceTime as she initiated the contact with her family, carers and friends and this brought her contentment in hospital:

'I used to facetime my, Dad...and my Mom...and my Sister...'

(Kelly, line 212-216)

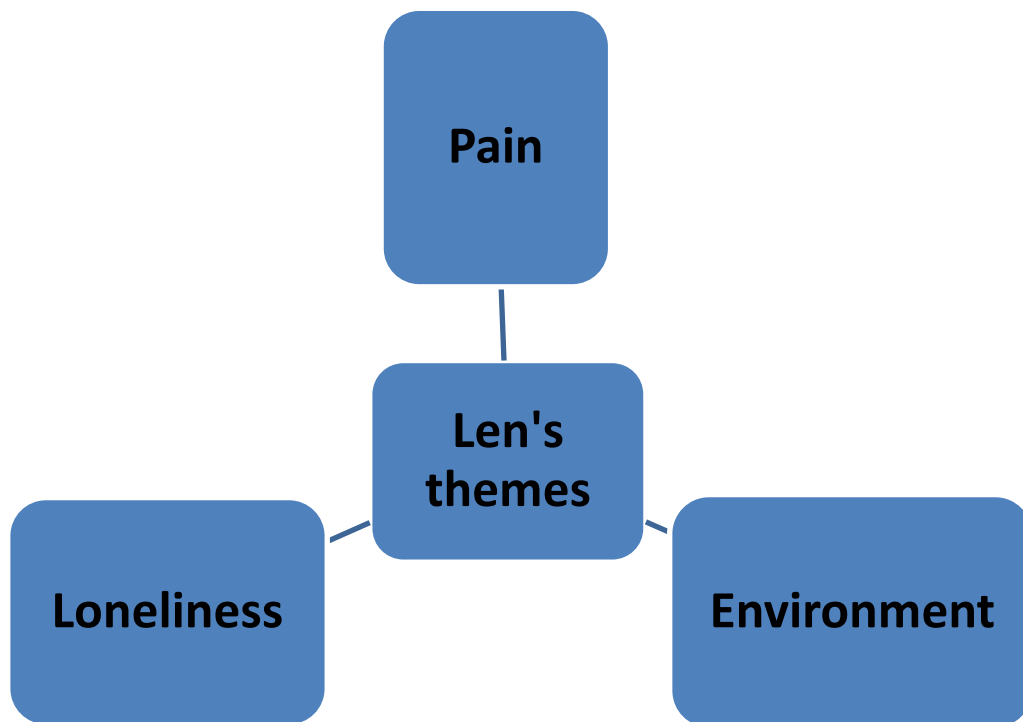
4.5 Len: An overview

Len was 44 years old and lived alone in an upstairs flat. He attended a club for PWLD twice a month from 7-9pm. Len had been in a road traffic collision as a pedestrian a few years ago when he was hit by a car as he was returning home from a disco at night. The car did not stop and Len was left in agony with broken bones in his ankle. He was in hospital for a couple of days and had investigations and treatment for the fractures in his left ankle. Len did not work.

4.5.1 Len's Themes

The superordinate themes for Len were, 'Pain', 'Environment' and 'Loneliness'. See Table 16 in Appendix 28 which provides a summary of Len's themes. Figure 8 illustrates these themes.

Figure 8 An illustration of Len's themes



4.5.2 Pain

Pain was the superordinate theme with 'acute pain and management following the injury' and the 'on-going aches and pains in the ankle' as the subordinate themes.

4.5.2.1 Acute pain and management following the injury

Len had been to a disco and was walking home alone when he was hit by a car:

...well...I got ran over, I got ran over...by a car...obviously...and er...when I did it it was very painful...I got ran over by a car... I couldn't even move...

(Len, line 27-28)

After it happened, Len had to cope alone and he went back to his flat as he did not have his phone with him to call an ambulance:

...well...I couldn't go through the pain and the agony of it...

(Len, line 36)

Len was in a great amount of pain:

...yeah...um...very, very, very painful, yeah ...

(Len, line 52)

Len received medication for the pain when he arrived at the hospital:

...they gave me painkillers and everything they did...

(Len, line 178)

Len believed that he had appropriate care once he arrived at the hospital. His pain appeared to be assessed and managed within the hospital environment. The investigations and management of Len's fractured ankle involved an X-Ray and he understood that there were two broken bones in his ankle:

...um...it had to be x-rayed obviously...to see which bones I'd broken...obviously... it was 2 broken bones in my ankle and foot...unfortunately...it was very, very painful...

(Len, line 47-50)

Following the X-rays Len had a boot applied to immobilise his fracture in his ankle to allow it to heal over time:

...I had to have one of those special boots put on... oh...for a while...till it healed up the bone...

(Len, line 56-64)

4.5.2.2 On-going aches and pains in the ankle

Len received follow up clinic appointments with the hospital that required him to attend for review of his fractured ankle:

...yeah, yeah I had to go back for check-up see...you know see how you was doing and...so yeah...

(Len, line 112-113)

Len continued to complain of pain in his ankle. It was observed that he did not walk very far and tended to sit most of the time at the advocacy group rather than get involved in any physical activity.

...well, well erm...erm...I still get aches and pains from it occasionally still...so yeah...

(Len, line 145-146)

Len accepted that he had aches and pain in the ankle even though this was years later and the fracture should have healed.

4.5.3 Environment

The subordinate themes were, 'an unwelcoming place' and 'listen to understand the rights of people with disabilities'.

4.5.3.1 An unwelcoming place

Len initially seemed to dislike the hospital environment as he recalled that it was cold, noisy and not private:

...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)

Len was used to living on his own and having privacy but in hospital he had to share facilities on a busy hospital trauma ward. Len was accepting that hospitals were busy places but it was not a good experience on the ward due to it being cold, noisy and lacking privacy.

4.5.3.2 Listen to understand the rights of people with disabilities

Len thought some of the nurses were kind which might have contributed to him not wanting to go home alone:

...I had some nice kind nurses looking after me...

(Len, line 74-75)

However, Len suggested that hospital staff needed to listen to people like him who were disabled:

...erm...listen to what we say...more about our rights... that we're disabled... and understand

(Len, line 180-186)

Len felt that there was a need to be listened to much more in hospital, particularly as he was a person with a disability. Len knew he had rights as a disabled person but he did not believe that hospital staff were aware of these rights or really listened to people with disabilities.

4.5.4 Loneliness

There was a sense of loneliness throughout Len's account and the subordinate themes were, 'living alone' and 'isolation'.

4.5.4.1 Living alone

Len lived alone and was unhappy about this as he used to live with his mother until she remarried and he did not see her as much anymore. Alongside this, Len did not feel ready to go home:

...but then going home on your own, it's horrible...it's lonely...

(Len, line 131)

4.5.4.2 Isolation

Len felt isolated once he returned home from hospital as he felt unable to leave his flat. Furthermore, Len was discharged home from hospital without adequate support being arranged to support him socially as he felt he was unable to go out:

...it was horrible...I couldn't go out to places neither when I did it...I had to be stuck in the flat all the time, didn't I... all the time basically

(Len, line 64-66)

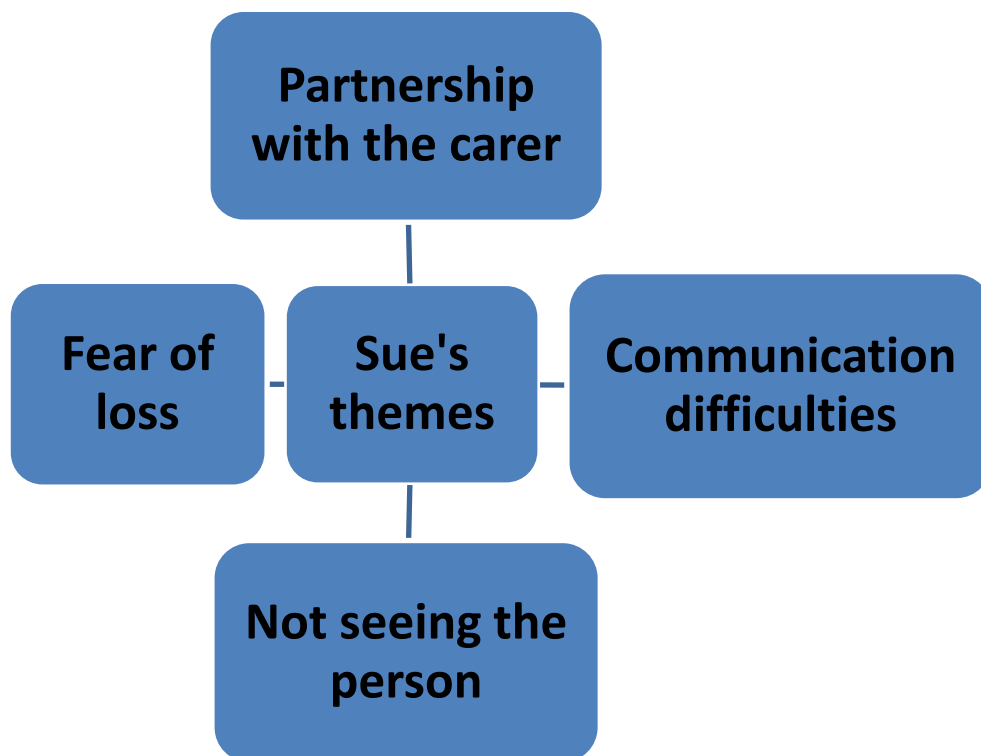
4.6 Sue: An overview

Sue is the mother and carer for Alex who has multiple and profound learning disabilities due to cerebral palsy which developed as a consequence of a 'Never Event' that occurred soon after his birth. A 'Never Event' is one that should never happen. Sue shared that Alex was jaundiced at birth and was receiving treatment for this until his blood results returned which suggested the treatment could stop. The wrong blood results were interpreted and Alex developed Kernicterus which is a rare but serious complication of untreated jaundice in babies. Brain and spinal cord damage can be caused by this condition. Alex was 24 years old, lived at home with his family and was cared for and supported by his family and carers. Alex had a twin brother, George, who did not have a learning disability. Alex did not walk or talk and had a wheelchair that he sat in during the day and he communicated by smiling for 'yes' and frowning for 'no'. Sue has experienced different general hospitals with both her sons for traumatic fractures of the tibia and fibula.

4.6.1 Sue's Themes

The superordinate themes for Sue were: 'Partnership with the Carer', 'Communication difficulties', 'Not seeing the person' and 'Fear of loss'. See Table 17 which provides a summary of Sue's themes in Appendix 29. Figure 9 is an illustration of these themes.

Figure 9 An illustration of Sue's themes



4.6.2 Partnership with the carer

Sue, as the mother and carer for Alex, stayed in hospital with him as he was fully dependent on her and others for all his health and care needs in hospital. The subordinate themes were, 'the carer as expert by experience', 'care for the carer' and 'work with the carer'.

4.6.2.1 The carer as expert by experience

Sue felt exasperated as well as experiencing a lack of confidence in the team caring for Alex in hospital. Although Sue was assertive regarding Alex's needs, this seemed to be ignored or was not communicated effectively within the nursing team:

...again utterly hopeless they just don't understand, you know, you say to them, you need to watch his arms cos he'll get them caught...they put the cot sides up and he gets his arms caught in them and then you have another injury to deal with...

(Sue, line 200-202)

Sue was frustrated that staff did not understand how to position Alex in bed and she gave an example of Alex being sat up by the hospital staff but because he did not have core body strength, he did not maintain this position and slipped down in the bed:

...propping the bed up is a useless idea so they had the back pumped up and he's slumped down, slumped in a crumpled heap at the bottom of the bed with a broken leg... and so the first thing I did was to say let's just flatten the bed shall we...then laid him down and stretched him out...

(Sue, line 75-78)

Sue demonstrated how to position Alex in bed to the hospital team as they did not know that this was the best position for Alex. There was a lack of knowledge about Alex's needs amongst the staff who were caring for him.

4.6.2.2 Care for the carer

Sue undertook most of the nursing care for Alex in hospital and rarely left him alone. However, she was aware how exhausted she became and highlighted that carers must be enabled to sleep in hospital too:

...and I think the carers take on so much...you need to sleep too as you can end up exhausted at the end of it all, so we need to take care of the carers too...

(Sue, line 443-444)

Sue was not adequately supported in the hospital setting by the staff.

4.6.2.3 Work with the carer

Sue and the nurses did not work together. As Sue knew and understood Alex better than any of the hospital team, she believed she should be considered as an asset that could help the nursing team to understand and care better for Alex. Sue did not believe the nurses actively listened to her or respected her as an expert in caring for Alex:

...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)

There was conflict between Sue and the nurses regarding Alex's care in hospital.

4.6.3 Communication difficulties

Communication difficulties were presented on two different levels including 'communication with Alex' by the hospital staff and 'communication with Sue' by the hospital staff.

4.6.3.1 Communication with Alex

Sue believed that Alex understood verbal communication although he was unable to communicate verbally. Furthermore, Sue had explained to staff about how to communicate with Alex:

...they had a go...um....and I explained to them all that... how he smiles for yes and frowns for no and that he understands everything that you are saying and stuff...yeah they did have a little bit of a go but pretty ineffective really ...

(Sue, line 425-428)

Although staff attempted to communicate with Alex, Sue felt it was ineffective overall. Moreover, Sue felt that Alex was ignored in hospital because he did not speak and that he was not valued as a unique human being:

...you know because they just seem to think that he's not [human], that he's stupid or something...he doesn't answer or say anything but he might one day...

(Sue, line 262-263)

Sue discussed an example of when hospital staff spoke to the carer rather than to Alex:

... 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)

There was dismay that hospital staff had spoken to a carer rather than to Alex. Sue believed that this undermined Alex as a human being who needed to be communicated with like everyone else:

... that they could treat the disabled person as a human being... rather than just a nothing...

(Sue, line 484-486)

This statement that hospital staff should treat a disabled person as a human being suggested that Sue felt this was not currently happening. The staff did not have the confidence or competence to communicate effectively with Alex and resorted to communicating with Sue instead.

4.6.3.2 Communication with Sue

During one of the conversations with the medical staff, Sue was angry by what was expressed as it seemed to convey that it did not matter if the treatment for Alex was unsuccessful. Alongside this, it was communicated in front of Alex who Sue believed understood what was being said:

...in front of Alex this is now, who perfectly understands everything that's going on although he can't talk... He said well I don't suppose he's ever going to walk, is he? It doesn't matter if I make a mess of it...absolute Bastard...then...well...um...I said I'm a vet as well and I work with animals and they can't respond... but I certainly would never make a mess of it because they can't tell me ...and he kind of gave me a strange look...

(Sue, line 97-108)

The medical staff had judged Alex as not ever going to walk and therefore if the operation that they were planning went wrong it would not affect Alex's already immobile status. Sue, as a veterinary surgeon who worked with animals, compared her desire to do her best even though animals cannot respond, with that of the orthopaedic surgical team who did not seem to care about her son, a human being, who did not walk or talk.

4.6.4 Not seeing the person

Sue exhibited a lack of trust in the care provided for Alex as there were fundamental failures. Alongside this, Sue believed the hospital staff did not see Alex as a human being. The subordinate themes were, 'lack of fundamental care', 'lack of advocacy by staff for Alex' and 'lack of concern'.

4.6.4.1 Lack of fundamental care

There was a lack of essential equipment to support Alex in hospital and this occurred regularly:

...and that was terrible again because there were no hoists to get A to the toilet and this was at [name of hospital]. I've been there 3 times with him...

(Sue, line 308-310)

Furthermore, Sue did not believe the younger nurses had the basic knowledge, skills or competence to care for Alex:

...they don't understand about giving enemas or anything, no common sense at all. Unless it's a drug, they don't know what the hell else to do...anyway I gave him an enema...so that cleared that load of stuff...

(Sue, line 348-350)

Sue was distressed with the lack of care and attention to Alex while she slept as she had arranged for a nurse to stay with Alex during her absence:

...he's peed and the pad was full and it was soaking wet, so he was, he was completely soaking...head to toes...and he was comatose. He was absolutely comatose, he didn't even recognise me... and so I... I... got hold of the nurses and really gave them a rollicking, I asked someone to come over and help me change everything, give him a sponge bath and got him cleaned up...

(Sue, line 383-387)

Sue was also very disappointed that Alex was left in this unacceptable and neglectful state when she had arranged with a nurse to stay with Alex while she slept:

The nurse SAID that she would stay with him all night until I came back but she was nowhere to be seen...

(Sue, line 419-420)

These incidents served to undermine the trust that Sue had placed in the nurse to stay with and care for Alex. There was a misunderstanding between the nurse and

Sue which highlighted that the nurse did not understand the needs of Alex or the request from Sue to provide one- to-one, person-centred care during the night too.

4.6.4.2 Lack of advocacy by staff for Alex

Sue was angry that Alex was left without a splint on his fractured tibia and fibula for some time when splinting and support for a fracture is part of the initial treatment:

... and all this time they hadn't put support on it...

(Sue, line 66)

Sue had seen Alex's X-ray and understood that it was a spiral fracture of the tibia and fibula which she believed could be treated conservatively in a plaster cast as Alex had very thin and weak lower limbs:

...and I had had a look at the X-ray by then ...it was a spiral fracture and thought great that's perfectly stable if you put a plaster cast on it... and they were talking, the consultant was talking about surgery...and he said well we could plate it and I just thought... A's legs were just so thin that surgery would make such a terrible mess and he would end up with an amputation if they plated it...the screws would break through the skin, he'd be bashing it on the wheelchair...it would break through the skin, he'd be back in...absolute disaster...so I said, you know, how about... um using a plaster cast ...it's a spiral fracture so...if you're clever about it you should be able to get it exactly in the right place and then it should be fine...

(Sue, line 85-95)

The decision to operate on Alex was made by the orthopaedic surgical team on the basis of an X-ray and Alex's unique needs were not considered at this point. Moreover, Sue had not been involved in these discussions and she continued to challenge the consultant orthopaedic surgeon regarding the plan. It was a tense situation as the doctor had not fully considered the impact of surgery or the

application of a full-length cast on Alex in terms of his schooling and other activities that he was involved with:

...he said we have to of course stabilise the joint above and below so we'll put a cast on and it'll probably be up to his thigh and include his foot...and I said...OK... so how do you think he is going to manage in a wheelchair then if you put his leg in a straight cast. And he said, oh well, he'll just have to stay in bed and... I said there's another alternative...you could put a cast on to stabilise above and below and do this with his leg bent, couldn't you...and he said, oh well, we haven't done that before...and I said, I'm sure you haven't but actually it could work really well because A will be able to continue going to school and he'll be able to sit in his chair and... and he won't be incapacitated and he won't get sores and he won't die of boredom... and it will heal...don't you think that's a good idea? Man, you have to be so strong with these consultants! So, so stupid! Just shocking...so...they did do that um and I wanted to get him out of there and bring him home...

(Sue, line 113-127)

This lack of person-centred care undermined the relationship between Sue and the health care team.

4.6.4.3 Lack of concern

Sue expressed extreme dissatisfaction with the type of care Alex received in hospital. A comparison was made with the care that her other son, Alex's twin brother, George (who does not have a learning disability) received when he fractured his tibia and fibula:

...gross isn't it? Compared then with my other son, I can take any number of his incidences...broken legs and stuff... um... so I can take one where it was a fairly comparable injury in fact due to his bike and he came off his bike and was in a heap...and he was screaming and

he was like screaming and so I said stop screaming and tell me what's wrong...and he could tell me ...he could tell me what was wrong so I said um...you can hop on one leg, can't you? Then I can pick you up and you can hop over to the car and we can get you to the hospital...but it hurt too much and I couldn't move him at all...so the ambulance came and they strapped him up before they moved him and... and put him on a stretcher and took him straight to hospital... but he was treated straightaway...no question about, oh he's never going to walk on it...there was no question of anything like that at all...

(Sue, line 215-235)

This episode of care and treatment for her other son who sustained a similar fracture to Alex was fundamentally different to the care and treatment that Alex received. The emergency staff treated Alex's brother immediately and appropriately with a splint. Sue believed that Alex's care was inferior to the care and treatment that her other son received because George could speak and did not have a learning disability. Sue expressed the inequality of care provision for Alex who was viewed as less human in the orthopaedic and trauma hospital setting.

4.6.5 Fear of loss/dying

Sue was left feeling that there was an overwhelming lack of concern in hospital for Alex and ultimately, she was fearful that he would die if he stayed in hospital. The subordinate theme was 'fear of death in hospital'.

4.6.5.1 Fear of death in hospital

Sue had decided that she must take Alex home from hospital as she believed he would die if he stayed in hospital:

...I thought, my God, he's dying and so when the consultant came round and he was asking me if he had improved I said, yeah, yeah, lying through my teeth. He said, is he normally like this, totally unresponsive? Yes, yes, yes that's normally how he is, yes that's absolutely right, yes he's much better than he was um and er..I'll just take him home now and er...nurse him at home...

(Sue, line 401-405)

Sue admitted to lying about Alex's unresponsive condition in order to get him back home so that she could care for him properly. Sue was exhausted and exasperated during the period of Alex's care in hospital and was convinced that Alex would have died if he stayed in hospital. There was to a lack of appropriately and reasonably adjusted care. Alex was nursed back to health by his mother at home following discharge. Clearly Sue believed Alex did not receive appropriate care in the hospital:

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

4.7 Cross case comparisons

The five participants' idiographic accounts and subsequent themes were analysed and interpreted in the preceding section of this chapter. This section presents the comparisons of themes that were common across the five participants. All the participants' themes were compared and the following master themes resulted from this, see Table 18.

Table 18 A cross case comparison showing the frequency of cases within each master theme

		Participants				
Master themes across the cases	N	Kay	Ted	Kelly	Len	Sue
Communication challenges	5	✓	✓	✓	✓	✓
Lack of person-centred care	5	✓	✓	✓	✓	✓
Issues related to pain	4	✓	✓	✓	✓	*
Lack of confidence in hospital care	4	✓	✓	✓	*	✓
The vital support and valuing of carers	3	✓	*	✓	*	✓
Incompetence of hospital staff	2	*	✓	*	*	✓
Loneliness	2	*	✓	*	✓	*
Fear of loss/dying	1	*	*	*	*	✓

--	--	--	--	--	--	--

4.7.1 Communication challenges

This theme was represented in all five of the participants' accounts. They all had difficulties with communication while they were in hospital particularly with communication between hospital staff and the PWLD. Nat gave an example of communication by a doctor who spoke with the carer rather than Kelly who could have answered the questions:

...I would say the nurses were good but the consultant, he spoke to me and not K...which I really hate when Doctors do that...just stuff like how old is she...K knows how old she is...K knows how old she is

(Nat, line 285-287)

Len did not feel he was adequately listened to in hospital:

...erm...listen to what we say...more about our rights... that we're disabled... and understand

(Len, line 180-186)

Ted received unclear communication in hospital:

but sometimes they said things which were not true or (did) not make sense

I was not always aware what was happening

(Email from Ted, 13.6.16 at 21:27)

The hospital staff tried to communicate with Alex but these efforts were minimal overall:

...they had a go...um....and I explained to them all that... how he smiles for yes and frowns for no ...yeah they did have a little bit of a go but pretty ineffective really ...(Sue, line 425-428)

Although the hospital staff spoke with Kay, she did not always understand the language that they used:

...I found it hard to understand... erm... long words...

(Kay, line 373)

All five participants experienced challenges around communication whilst in orthopaedic or trauma hospital settings.

4.7.2 Lack of person-centred care

All five participants experienced a lack of person-centred care.

Len felt that he was being discharged home before he was well enough and that he had no choice in this decision. When he was asked if there was anything that made him feel unhappy in hospital it was centred around his discharge home from hospital:

Interviewer: or made you feel unhappy?

Len: going home lonely then

Interviewer: did you feel well enough when you were going home?

Len: no

(Len, line 136-141)

Kay required staff to help her to move in bed after her hip operations and she recalled an occasion where she had difficulty in conveying her wishes for the staff to stop what they were doing as more patience and a person-centred approach was needed:

... because um...they was trying to get me on my side and...em...and I couldn't do it...and I was trying to tell them...to stop but they wouldn't... they wouldn't stop...

(Kay, line 158-159)

Ted felt that the hospital staff did not know him as a person due to a lack of consistency in the medical staff he was seen by as well as a lack of preparation to find out more about him from the medical notes or from the other staff:

... every appointment I have is with a new doctor...what's the point in that...they ask me what's wrong, why don't they look at the report or ask the nurses, they must know what I come in with...in the end I walked out...

(Ted, line 298-300)

Sue was highly dissatisfied with Alex's care in hospital because the care given was inferior for a person with a disability:

... that they could treat the disabled person as a human being... rather than just a nothing...

(Sue, line 484-486)

Kelly was not always communicated with directly by hospital staff and there was a sense that this was because Kelly had Down syndrome which is synonymous with having a learning disability. Some hospital staff spoke to the carer rather than to Kelly which the carer perceived as being both disrespectful and an infringement on Kelly's personhood as a 32-year-old woman:

...and he was talking about her to her Dad ...

(Nat, line 299-300)

4.7.3 Issues related to pain

All the participants except Sue, the carer, discussed issues related to experiencing pain while they were in hospital. Kelly was distressed while the clips were being removed from her hip wound which is known to be an uncomfortable procedure:

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)

Kay experienced uncontrolled pain in hospital and the nurses did not take her reported pain level seriously. Kay waited a long time to receive the analgesia:

...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 217-219)

Len experienced severe pain in hospital:

...yeah...um...very, very, very painful, yeah ...

(Len, line 52)

Ted also had uncontrolled pain when he was in hospital which he appeared to cope with rather than inform the nurses. Regular assessments of his pain level were not undertaken:

...sometimes I had very awful pain

...The nurses didn't ask about the pain that often...

(Email from Ted, 13.6.16 at 21:22)

4.7.4 Lack of confidence in hospital care

Four of the five participants, (Kay, Sue, Ted and Kelly/Nat) experienced a lack of confidence as a consequence of their experience of poor care in hospital. Prompted by his negative experiences of general hospital care, Ted went as far as to suggest there should be a special area in the hospital just for people with disabilities.

Ted suggested that a separate area for PWLD would be better as hospital staff did not understand people with disabilities:

...it will help them even if they only come into hospital once to go to that special area... a proper ward and nurses who know what to do...if they put me on that ward it might have been better...someone trained to make an effort...I mean the doctor...asked me why it happens, why I pass out, I don't know...they ought to know that...if I was on a ward with nurses that understand that might not have happened...

(Ted, line 289-296)

There was a lack of awareness by nurses regarding the role of an acute liaison learning disability nurse whose role would incorporate supporting Kelly for hospital admission and surgery. Kelly had this support six months previously at the same hospital when she was preparing for the total hip replacement but it was not known about during her second visit in preparation for knee surgery:

...Yeah, we had a LD nurse then...I know she was very good and she organised everything but we haven't had it this time...

(Nat, line 79-81)

Sue believed that there were insufficient resources, both physical and human, to care appropriately for Alex in hospital:

... there's usually not enough hoists and usually they're not working either. Completely hopeless... completely hopeless and regarding someone reliable to look after him while I went to the loo or anything like that... again utterly hopeless they just don't understand, you know, you say to them, you need to watch his arms cos he'll get them caught....they put the cot sides up and he gets his arms caught in them and then you have another injury to deal with

(Sue, line 194-202)

For Kay, she did not have confidence in the hospital care as she saw different doctors at the hospital and not the doctor who had undertaken the surgery on her hip:

... sometimes I don't see the one that does my operation... I see someone else...I'm supposed to see the one who did my operation, not, not someone else...

(Kay, line 576-577)

Len did not experience this lack of confidence in the hospital system. He was in hospital for a relatively short period of time compared to the other participants who had many hospital experiences and longer lengths of stay than Len.

4.7.5 The vital support and valuing of carers

Kay, Sue and Kelly discussed the paramount importance of having the carers involved in the hospital care. Sue was the carer for her son, Alex in hospital although she felt undervalued by the hospital staff.

Sue stayed with her son in hospital and undertook the majority of his care, rarely leaving him. She was not often relieved of these caring tasks to have her basic needs met such as having food or adequate rest.

Sue did accept the offer to have a sleep on one occasion as she believed that the nurse would replace her and stay with Alex overnight:

... I was very grateful when this nurse said I could go and have a lie down and she said she would look after A, she said, I'm here to look after A...to completely look after him...

(Sue, line 368-370)

After this episode Sue felt very disappointed as the nurse did not stay with Alex all night as Sue had expected her to and she was very reluctant to leave Alex again after that, even to eat. The hospital staff did not support or care for Sue even though she was performing a vital role in caring for Alex full-time in hospital:

... no good God no, only for the loo, absolutely hopeless...if you want something to eat, heaven help you...

(Sue, 206-7)

There was a strong relationship between Kay and her mother as she helped Kay with fundamental care in hospital. This included the provision of clear communication regarding what was happening to Kay:

... so sometimes they have to tell my mom and then my mom tells me what it means...

(Kay, line 213)

Ted and Len did not mention this theme which was interesting as both lived alone and did not have a specific family or paid carer whereas Kay and Kelly had very strong family carers and Sue was the carer for Alex.

4.7.6 Incompetence of hospital staff

Sue and Ted both experienced issues that related to the incompetence of hospital staff caring for PWLD:

...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)

For Sue, there was a sense of indignation that the younger nurses particularly did not have the competence to care holistically for Alex:

The younger generation don't know anything at all and they're harsh...

(Sue, line 346)

The quotations from Ted and Sue served to illustrate that safe, competent person-centred care was not delivered.

4.7.7 Loneliness

Ted and Len discussed this theme which was interesting as both lived alone at home. They did not have a family/paid carer with them in hospital and they were the only males in the study. Ted was left for long periods without anyone checking on him in the hospital. Len did not want to go home and be alone as he was unable to get out of his upstairs flat for a period of time after his injury.

The impression was that Ted had always been on his own in hospital, even as a child:

...No-one has ever, ever stayed with me

(Ted, line 38)

For Len, there was a feeling of being lonely on discharge from hospital which he did not like:

...but then going home on your own, it's horrible...it's lonely...

(Len, line 131)

4.7.8 Fear of loss/dying

This theme was experienced by Sue only, who was the only carer interviewed as a participant. Sue was fearful that she would lose Alex and he would die if he stayed in hospital as she believed that the hospital care was detrimental to him. None of the other participants discussed this theme:

...I thought, my God, he's dying and so when the consultant came round and he was asking me if he had improved I said, yeah, yeah, lying through my teeth. He said, is he normally like this, totally unresponsive? Yes, yes, yes that's normally how he is, yes that's absolutely right, yes he's much better than he was um and er..I'll just take him home now and er...nurse him at home.. yes if you are sure he's much better that will be fine.., yes yes, oh...one of the carers from the college had said to me, if you need some help and so I rang him and said please just help me put him in the car so we can get out of this...so he came over and we did that and I got A home and got him on the loo so he could have a poo...just got him completely cleaned up and gave him some fluids and got him back on his feet again and within about 3 or 4 hours of coming home. He'd have died if he'd have stayed in hospital

(Sue, lines 401-414)

4.8 Summary

This chapter has presented the findings for each of the five participants in the study. Each participant shared their experiences of orthopaedic or trauma hospital care and this was presented as individual, idiographic accounts. Following this, a cross case comparison of the participants themes was undertaken, master themes were then developed and frequencies across participants noted.

All of the participants experienced 'communication challenges' and 'a lack of person-centred care' in hospital. The master themes, 'issues related to pain' and 'a lack of confidence in the hospital care' were experienced by four of the five participants. The master theme, 'the vital support and valuing of carers' was experienced by three of the five participants. The three participants that experienced this had very supportive carers involved in their hospital care. The master themes, 'incompetence of hospital staff' and 'loneliness' were represented across two of the five participants' accounts. Finally, the master theme 'fear of loss' was represented in one of the five participants' accounts.

Chapter five presents the discussion of the findings from this study in conjunction with existing literature.

Chapter Five Discussion

5.1 Introduction

This chapter provides a discussion of the findings in the context of PCC. The new knowledge that has been generated will be presented along with the impact and importance of this study for orthopaedic and trauma hospital practice. This latter aspect is particularly important given that 'Learning Disability' has recently been listed as a major priority for the NHS in England (NHSE, 2018c) and will be discussed throughout the chapter. NHS Improvement (NHSI) (2018) published standards that need to be met by NHS Trusts with the aim to improve the care of PWLD in hospital. These standards are supplemented by improvement measures or actions that Trusts are expected to take to make sure they meet the standards and deliver the outcomes that PWLD and their families expect and deserve. Furthermore, the NHS Long Term Plan (NHS LTP) (2019, p. 7) has agreed new, funded, action that the NHS will take to strengthen its contribution to prevention of health inequalities to ensure that, '*people with learning disability and/or autism get better support*'. Furthermore, it has been proposed that based on people's individual needs and choices, people identified as having the greatest risks and needs will be offered targeted support for both their physical and mental health needs, which include musculoskeletal conditions (NHSE, 2019).

5.2 Unique contribution to new knowledge

The research question was, 'How do adults with a learning disability describe their orthopaedic or trauma hospital experiences?' The participants shared their experiences via semi-structured interviews which produced valuable insights. This new knowledge was generated from a sample of PWLD who were very hard to reach and it enriches the understanding of the orthopaedic or trauma hospital experiences from the perspectives of PWLD and a family carer who shared experiences relating to her son who has a PMLD. The facility for highlighting unique perspectives as well as shared experiences is one of the cornerstones of IPA (Smith, 2004; Smith and Osborn, 2008).

This is the first qualitative study to explore the orthopaedic and trauma hospital experiences from the perspectives of PWLD. The contribution to new knowledge from the experiential accounts from PWLD provide evidence that within orthopaedic and trauma hospital care there was a distinct lack of person-centred care; there were serious communication problems within orthopaedic and trauma hospital settings; there was a lack of assessment and management of pain; the negative experiences included feelings of isolation and loneliness and a lack of confidence amongst PWLD in orthopaedic and trauma hospital care; the expertise of carers was not adequately tapped or acknowledged by hospital staff and a family carer feared that her son would die if he remained in orthopaedic trauma hospital care.

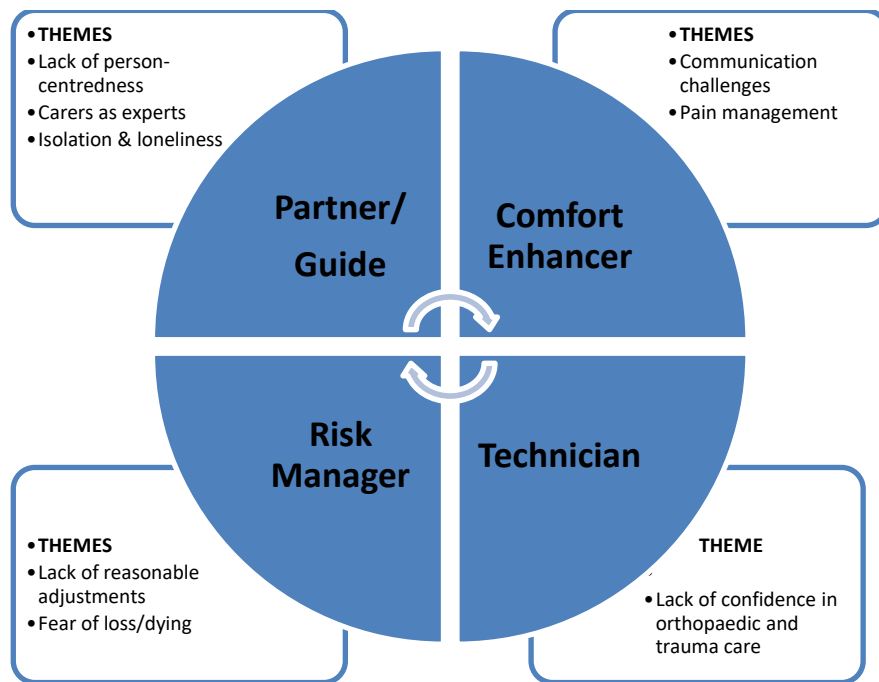
There were interconnections between the key findings which impact on each other. The lack of person-centred care impacted on the communication issues which

impacted on effective assessment and management of pain, isolation and loneliness which impacted on the confidence and trust the participants had in the orthopaedic trauma hospital system. The orthopaedic and trauma hospital experiences for the participants in the study fell below the expected care for any person.

5.2.1 A competency framework for orthopaedic and trauma practitioners caring for PWLD

The Royal College of Nursing (RCN) Society of Orthopaedic and Trauma Nurses (SOTN) (2005; 2012; 2019) developed a national competency framework for orthopaedic and trauma practitioners and the latest framework includes the requirement for reasonable and achievable adjustments to be made in orthopaedic and trauma practice for PWLD (RCN SOTN, 2019; Drozd and Clinch, 2016). The specialist role of the orthopaedic or trauma practitioner comprises of four domains; Partner/Guide, Comfort Enhancer, Risk Manager and Technician (Santy *et al.*, 2005, Drozd, Jester and Santy, 2007). These four domains of orthopaedic and trauma practice provide a foundation for current evidence-based care for all patients with the specific inclusion of PWLD (RCN SOTN, 2019, Drozd and Clinch 2016). Figure 10 shows these domains with the integration of the findings from the study.

Figure 10 The themes derived from the study situated within the domains of orthopaedic and trauma practice (RCN SOTN 2019)



The key findings from the study along with the current literature are discussed within the RCN SOTN competency framework (RCN SOTN, 2019).

5.2.1.1 Partner/Guide

The 'Partner/Guide' domain entails the building of a person-centred relationship to support patients to achieve optimal clinical outcomes. A primary function and goal is to assist patients, in partnership with the family, to gain a level of mobility and activity that meets their potential (Santy *et al.*, 2005).

5.2.1.1.1 Lack of person-centred care

McCormack and McCance (2010, p. 13) describe person-centredness as:

'An approach to practice established through the formation and fostering of therapeutic relationships between all care providers, people and others significant to them in their lives. It is underpinned by values of respect for persons, individual right to self-determination, mutual respect and understanding. It is enabled by cultures of empowerment that foster continuous approaches to practice development'.

Although the terms 'person-centred care' or 'person-centred practice' remain prevalent in health care literature, policies and codes of practice, this study found that orthopaedic and trauma hospital care was not person-centred for any of the participants. Ted experienced isolation in a side room for fourteen hours after surgery; he was aware that all patients should see a nurse after surgery yet he did not see a nurse for a significant number of hours. Ted did not request to be in a side room and he was concerned that everyone else had a nurse to check they were recovering satisfactorily post-surgery.

In a cross-sectional survey of 66,348 hospital patients and 2,963 inpatient nurses, Aiken *et al.* (2018) found that the patients' perceptions of care were strongly associated with missed nursing care, which in turn related to nurse staffing and hospital work environments. Other studies such as Aiken *et al.* (2014) and more recently, Griffiths (2019) linked the shortage of registered nurses in hospitals with the detrimental impact on the quality of care provided along with the increased risk of

mortality across all patients. This deficit in the workforce has been acknowledged in the NHS LTP (2019).

Ted had difficulty with expressive communication and a potential reason for being placed in a side room where he would not be easily observed, could be due to the challenges with verbal communication that he might present to the hospital staff or to other patients, and therefore he was separated. Furthermore, Ted believed that there was only one surgeon who was willing to try to correct his lower limb deformities to enable him to walk and he and his father had to move home to enable this to happen. Consistent with the present study, Read *et al.* (2018) agree that the current hospital system is not designed for individual care and there are potentially difficult experiences for disabled patients as their individual circumstances are not accommodated. However, the qualitative study undertaken by Read *et al.* included participants with different disabilities and did not focus specifically on PWLD.

During a consultation with an orthopaedic doctor, Kelly was upset when she was being considered for admission to a children's ward for her total hip replacement because she was a 32-year-old woman. The doctor did not know Kelly as a person who was involved in her local community in numerous ways including working as a teaching assistant. Over a decade ago, Goodrich and Cornwell (2008) highlighted the importance of seeing the person in the patient. An assumption was made by the doctor that Kelly was childlike as she has Down syndrome. Kelly attended this appointment accompanied by her father who was able to challenge this assumption and advocate for his daughter to be treated as an adult. Smith (2016) produced

clear guidelines for medical staff relating to good communication based on her own experience as a person with Down syndrome accessing health care.

Kay experienced a tense relationship with hospital staff as she did not understand the “long words” the staff used and she waited anxiously for her mother to arrive at the hospital to help her to get washed and dressed as well as to explain what was happening. That said, in the children’s hospital, Kay had a more positive experience and was more content as her mother was allowed to stay with her there. This situation changed, however when she transitioned to adult orthopaedic and trauma hospital care.

There has been an increased focus on health service delivery and outcomes for PWLD over the last five years, with publications post the response to the Winterbourne View Hospital Final Report (DH, 2012a) such as, ‘Transforming Care, Building the Right Support’ (NHSE, 2015a), aiming to embed service change in the community specifically and improving the quality of life for PWLD. Atkinson *et al.* (2013) developed The Health Equalities Framework (HEF) for PWLD and this offers PWLD and family carers a way of measuring general health equality outcomes. Prior to this, there were no adequate outcome measures to demonstrate the impact of service interventions on the health and wellbeing of PWLD and The Health Equality Framework (HEF) was developed to address this gap. It is based on five determinants of health inequalities set out by the Public Health Observatory for learning disabilities and can be linked to the NHS and Public Health and Social Care Outcomes Frameworks. Although the HEF is comprehensive, it is not specific

enough to measure the clinical outcomes for PWLD following orthopaedic and trauma hospital care. Patient Reported Outcome Measures (PROMS) are currently used to evaluate the clinical outcomes in orthopaedic hospital practice and Jester, Santy-Tomlinson and Drozd (2018) asserted that PWLD may have difficulty with the completion of the current format of the most commonly used PROMS in trauma and orthopaedic settings necessitating a consideration of reasonable adjustments if this information is to be captured accurately from PWLD. This is essential if PROMS are used as part of clinical assessment to make decisions about interventions and evaluation of progress because the information derived from PROMs must accurately capture the status of PWLD.

Registered Nurses have a professional responsibility to work in partnership with others to provide person-centred and compassionate care (NMC, 2018a). In particular, given the inequalities in health and healthcare for PWLD noted in chapters one and two as well as in the recently published NHS Long Term Plan (2019), they also have a duty to advocate on behalf of those they support, to promote and uphold human rights, and raise concerns when appropriate care is not provided (NMC, 2018a). Developing a person-centred practice culture, however, requires a clear understanding of what this involves along with a commitment from both commissioners and providers of orthopaedic and trauma hospital services.

5.2.1.1.2 The vital support and value of carers as experts

The participants who had significant carers, such as Kay and Kelly relied heavily on them for support whilst in orthopaedic and trauma hospital care. Although Sue was an expert carer by lived experience in knowing and caring for her son with a PMLD,

she felt conflict when she challenged staff regarding the inadequate care delivered to her son. Mencap (2012) concurs that families of PWLD have provided round-the-clock nursing care and that they were very concerned for their relative's wellbeing to leave their side in hospital because if they were not there, fundamental tasks such as feeding, providing drinks, washing and changing would not meet that person's basic needs. Tuffrey-Wijne *et al.* (2014a) also found a lack of support for carers of PWLD in hospital. However, an important contributory factor to the effectiveness of carer involvement was the degree to which staff understood the importance of carer expertise (Tuffrey-Wijne *et al.*, 2016). Expert carers are those who provide caring tasks based on knowing the person, using expert skills learned through caring at home as well as giving and expecting high standards of hospital care (Tuffrey-Wijne *et al.*, 2016).

Kay's mother and Kelly's parents as well as her paid carers were invaluable during their hospitalisations for orthopaedic care. They were expert carers because they knew and understood the person with the learning disability. The NHS LTP (2019, p. 42) recognises the value of carers and is aiming to encourage the national adoption of carer's passports which will identify someone as a carer to enable staff to involve them in a patient's care.

5.2.1.1.3 Isolation and loneliness

Len and Ted did not have family or paid carers with them in hospital and both lived alone at home. They were the only male participants in this study and Ted reported

feeling isolated in hospital when he was in a side room. Len emphasised how lonely he was when he went home alone with no support. He felt unable to go out or meet up with his advocacy group due to the boot on his lower limb and he felt lonely. It is interesting that Specht *et al.* (2018) found, in their qualitative exploratory study with patients who did not have learning disabilities, that the participants also experienced a lack of support once discharged home from a fast track/enhanced recovery/early discharge orthopaedic hospital care. Len was in hospital for two days with a fractured ankle which was immobilised in a special boot but felt alone at home as he remained indoors with his special boot on.

As far back as 1996, Lovett recognised the significance of relationships for PWLD and more recently, Barr and Gates (2019) acknowledged that everyone needs the support of other people throughout their lives although PWLD often lack this support from friendships and rely more on services. Len and Ted did not have support from family or paid carers and it is recognised that many PWLD lead lonely and isolated lives that can go unnoticed (Barr and Gates, 2019).

5.2.1.2 Comfort enhancer

The 'Comfort Enhancer' domain relates to the comfort enhancing practices, such as competence in the positioning of limbs and the assessment and management of pain to promote comfort for patients with orthopaedic conditions or injuries.

5.2.1.2.1 Communication challenges

There were serious problems with communication for all of the participants whilst receiving orthopaedic and trauma hospital services and to illustrate this some examples will be presented. Kay did not understand the terminology that hospital staff used and waited for her mother to arrive at the hospital to communicate with her so she could understand what was happening to her. The use of orthopaedic and trauma terminology and medical jargon is complicated and needs to be adjusted when communicating with all patients and especially PWLD who are likely to have difficulties with comprehension.

Whilst Ted's verbal speech was difficult to understand, he strived to make himself understood by using other strategies such as writing on a paper pad when others found it was difficult to understand him. Ted believed that he was given information that was not true relating to the decision to cancel the X-Ray of his nose after an epileptic seizure. The incident led to a lack of trust and confidence in the hospital team. A clear explanation that Ted could understand regarding the reason for this decision was lacking from the hospital team.

Kelly reported crying and screaming for the nurse to stop removing the surgical clips but the request was ignored. The potential ramifications of poor communication between health care staff and patients can lead to increased fear, anxiety, non-compliance with treatment and an increased risk of complications (McDonald, 2016). This could lead to a lack of trust in the nurse also.

Hospital staff communicated with Sue, the carer rather than with her son despite Sue stating her son could communicate by smiling for 'yes' and frowning for 'no'. Staff did not communicate with her son directly. Alongside this, there was conflict in the communication between Sue, the carer and hospital staff. The carers who were actively involved in the person's hospital care could have provided advice for the hospital staff regarding caring for the PWLD.

Although communication is known to be a specific area of difficulty for PWLD, in a study with participants who self-identified as disabled which included people with physical disabilities as well as learning disabilities and related to general hospital experiences across a number of specialities, the participants expressed concerns about hospital processes for receiving and sharing information about their care (Read *et al.*, 2018). People with disabilities wanted clear and understandable information and reported that this was not forthcoming at times. They spoke of their need for adjusted information, and their struggles in obtaining this, with one participant highlighting that hospital staff may not necessarily understand how to provide accessible information for disabled patients. The study recommended a need to adjust hospital practices to include time for personal communication and specific attention to the person with a disability in hospital (Read *et al.*, 2018).

Northway (2017) concurs that enhanced communication skills for health care practitioners are needed and should encompass the awareness of alternative and augmentative communication (AAC) systems when communicating with PWLD. This could help with ensuring that information is provided for PWLD in formats that are accessible to them and this can enhance their capacity to be actively involved in their

hospital care. A number of studies concur and recommend that health care students learn a specific form of augmentative and alternative communication (AAC) such as Makaton, which is used by more than 100,000 people in the UK (Gibson, 2007; McClimens *et al.*, 2012; RCN, 2013).

Bradbury-Jones *et al.* (2013) indicated that training in communication skills for use with PWLD had been found to be helpful in some of the literature they had reviewed. Furthermore, Mencap (2012) argue that hospital staff must be trained to overcome issues around communication in order to bring about the best outcome for the PWLD. Moreover, the new Accessible Information Standard (NHSE, 2018d) reinforces that PWLD need to be given information in a way they can access and understand and this is a disability related reasonable adjustment. Health care practitioners need to understand inclusive communication and how they can make reasonable adjustments to their communication style to meet the needs of PWLD (Barr and Gates, 2019).

It was elicited during four of the semi-structured interviews with the participants (Kay, Ted, Kelly and Sue) whether they had brought any information about themselves into hospital that could be shared with the staff. A 'Hospital Passport' was described to the participants. Len was asked about this during one of the group advocacy sessions. None of the participants in this study used a 'Hospital Passport' which would contain key information about the PWLD along with their communication needs and personal preferences. Hospital passports are one way of enhancing safety and person-centred care and need to be accessed and used as a basis for care planning (Northway *et al.*, 2017). Although these authors acknowledge that

further research is needed into the use and standardisation of hospital passports for PWLD, they are a quick reference guide to support the hospital staff in the delivery of person-centred care for PWLD. It was surprising that none of the participants had a hospital passport especially as two of the participants, Kelly and Kay, were receiving current orthopaedic and trauma hospital care.

In summary, the problem with communication for PWLD lies with the health care practitioner rather than the PWLD. Grace, cited in Doukas *et al.* (2017, p. 6) encapsulates this:

A person's ability to communicate is not dependent on their being able to master certain skills, it is dependent on our ability to listen and communicate responsively

5.2.1.2.2 Pain management

There was an interconnection with communication and pain as pain management relies on good communication. All of the participants who were patients experienced unmanaged pain in orthopaedic or trauma hospital settings. Pain is well known to be a prevalent symptom in people with orthopaedic conditions or injuries (Mackintosh-Franklin in Clarke and Santy-Tomlinson, 2014, p. 120). Furthermore, Pasero and McCaffery (2007) highlighted over a decade ago that orthopaedic surgery was considered to be one of the most painful because it involves significant muscle and skeletal tissue repair. The majority of the participants were able to report their pain verbally and it was shocking that they felt this was not managed effectively. It could be postulated that when PWLD verbalised their pain they were either not believed or

were ignored. The reasons for this need to be further investigated in orthopaedic and trauma hospital care.

Kay experienced severe pain and was crying because she was left waiting for extended periods for unforthcoming pain relief. Kelly felt relief from pain after her hip replacement but later reported crying and shouting for the nurse to stop removing her surgical clips due to the pain. Alongside this, she requested the presence of her parents during this procedure which was not actioned. It would seem that Kelly was not adequately prepared for this procedure which resulted in unnecessary pain and distress.

In a large quantitative cross-sectional survey conducted by Aiken *et al.* (2018) on patient satisfaction with hospital care in England, 7% of nurses reported that they lacked the time to complete necessary pain management. This self-reporting by nurses regarding pain management does not correspond with the findings from the majority of participants in this study who experienced unmanaged pain. Furthermore, 65% of nurses reported lacking the time to comfort or talk with their patients. This suggests that a high percentage of nurses may lack the time to assess patients for pain which would be conducted whilst talking to and comforting patients which concurs with the findings of this study.

Consistent with this IPA study, Webber, Bowers and Bigby (2010) also found that hospital staff did not treat pain in PWLD effectively. However, in their study, the

concern was expressed by carers of older PWLD rather than by the PWLD themselves and it was conducted in Australia with a hospital system that may differ to the UK. Conversely, Beacroft and Dodd (2010) found evidence that carers of PWLD in residential settings incorrectly believed that PWLD had a high pain threshold. This is particularly concerning for those PWLD who cannot verbalise their level of pain and other methods of pain assessment must be used as persistent physical pain has a significant impact on peoples' lives. Unrelieved pain is associated with a number of negative outcomes including depression, reduced quality of life, impairment of function and limiting daily activities (Main, 2019). In 2012, The Learning Disabilities Observatory highlighted issues related to pain recognition and management for PWLD who may not be able to express pain in a way that others easily recognise. The way in which individuals' express pain or discomfort should be documented and hospital staff require education to use this information and react appropriately.

Tuffrey-Wijne *et al.* (2016) add that PWLD may have challenging behaviours which might mask symptoms of pain; therefore, the importance of recognising 'unconventional' ways of expressing pain is essential. Moreover, Cooper *et al.* (2014) contend that if nurses are unaware of specific assessment tools for use with PWLD then pain may be missed and distress increased. There are tools to assist staff in assessing pain when PWLD cannot communicate verbally, such as the Disability Distress Assessment Tool (DISDAT) (Regnard *et al.*, 2003; 2007). This tool, used in conjunction with carers' knowledge and appropriate training, can be used to minimise unnecessary pain. Mencap (2012) in their report, 'Death by Indifference; 74 deaths and counting' concur that all staff caring for PWLD and

involved in pain treatment should receive training to overcome issues around communication, as well as drawing on the knowledge and skills of those who know the person.

An important aspect of an orthopaedic nurse's role is pain recognition, assessment and treatment (Hall and Gregory, 2016). Alongside this, Mackintosh-Franklin (2018) highlighted that within the orthopaedic and trauma setting, pain must be assessed and managed to prevent the ongoing and unanticipated consequences that poor initial management is now known to lead to a lifetime of chronic pain for many patients. Gregory (2017) was concerned that pain assessment and management in orthopaedic trauma hospital settings was poor particularly with elderly patients and people with cognitive impairments and attempted to establish if a specific pain assessment tool, 'The Bolton Pain Assessment Tool' (BPAT) was useful, practical and clinically feasible. The tool was tested with clinicians in four acute trauma units across the UK and Gregory (2017) concluded that the initial testing of the clinical feasibility of BPAT suggested that it was easy to use and helped to identify pain, but further testing of its reliability and validity was required. Nurses have a fundamental duty to relieve suffering, and the prevention of chronic pain through effective assessment and management of acute pain in the high risk orthopaedic and trauma patients must be prioritised (Mackintosh-Franklin, 2018).

A qualitative study by Vuille *et al.* (2018) which was undertaken in Switzerland, found that the discrepancies between patient's self-assessment and nurses' evaluation regarding pain intensity in the emergency department setting were common. The participants in the study did not have learning disabilities and were able to verbally

rate their pain which some PWLD may not be able to do. However, nurses underestimated patient's pain despite the use of tools such as the verbal numerical rating scale.

5.2.1.3 Risk manager

The 'Risk Manager' domain identifies the specific specialty and general risks or complications that need to be minimised for patients undergoing orthopaedic or trauma care. Alongside this, the potential risk of 'diagnostic overshadowing' must be understood to reduce or eliminate the potential risk of overlooking a life or limb threatening complication in PWLD. Diagnostic overshadowing is a term used to describe a situation where signs and symptoms are overlooked and assumed to be related to the person's learning disability.

5.2.1.3.1 Lack of reasonable adjustments

There is a legal requirement for hospitals to respond to the needs of individual disabled people by making reasonable adjustments, for example, by changing the timing or length of an appointment, or ensuring that a family member can be involved in a disabled patient's care (Equality and Human Rights Commission, 2015; MacArthur *et al.*, 2015). Despite the legal framework of the Equality Act (2010), it is known that there remain significant inequities for disabled people throughout the UK health care system (Tuffrey-Wijne *et al.*, 2014a; Tuffrey-Wijne *et al.*, 2014b; Sakellariou and Rotarou, 2017), along with delays in diagnosis and treatment for PWLD (Heslop, *et al.*, 2013; NHS Long Term Plan, 2019).

Read *et al.* (2018) suggest that when considering the reasonable adjustments needed by an individual patient, that person must first be identified as disabled, which may be a daunting process. Although it may not be obvious if a person has a mild learning disability on admission to hospital, Barr and Gates (2019) suggest that an individualised, person-centred assessment should take place for every person. There were identification and flagging systems in operation in some hospitals and these have been actively encouraged to identify PWLD (Tuffrey-Wijne *et al.*, 2014a). That said, even with identification and flagging systems in place it does not adequately ensure that a PWLD will have the care tailored to their needs (Hatton, Roberts and Baines, 2011; Kelly *et al.*, 2015; Sheehan, *et al.*, 2016).

A further area of concern is the hidden majority of PWLD who would not be identified via an identification or flagging system in hospital as they are not known to existing learning disability services. Read *et al.* (2018) argued that disability-related needs were often invisible or were ignored within the hospital system, and thus a major issue for disabled patients was the need to repeatedly advocate for themselves and explain their needs to staff. That said, PWLD may have more difficulty in advocating for themselves in a hospital setting due to their communication challenges as well as the inability of hospital staff to alter their communicative behaviour.

Regarding general hospital experiences for people without a learning disability, Ham and Berwick (2017) purported that the acute hospital environment is unfamiliar and on admission, patients lose their autonomy, their right to move, eat and drink at will, to sleep or wake up and to choose their own company. Moreover, Read and

Rushton (2013, p.1021) contend that PWLD are “*likely to need additional considerations within the healthcare context*”. A toolkit was developed to improve local health services for PWLD and workshops were delivered which aimed to improve the skills, knowledge, competence and confidence of nurses working within the local hospitals. Evaluation of the workshops demonstrated improved knowledge, skill and attitudes of hospital staff in relation to caring for PWLD.

5.2.1.3.3 Fear of loss/dying

Sue, the participant who was a family carer, believed that her son would die if he remained in orthopaedic trauma hospital care and she reported that she had to get him home as soon as possible.

Glover *et al.* (2017) identified that PWLD have an expected life expectancy at birth 19.7 years lower than the general population and the CIPOLD (Heslop *et al.*, 2013) highlighted that PWLD were dying prematurely. Consistent with this, Northway *et al.* (2018) found that most of the recorded deaths of PWLD occurred among those who were middle aged. Following the CIPOLD (2013), The Learning Disabilities Mortality Review (LeDeR) Programme was established and is the first national programme aimed at making improvements to the lives of people with learning disabilities. It has been developed to monitor and analyse the deaths of PWLD and is delivered by the University of Bristol, commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England. The LeDeR Programme collates and shares the anonymised information about the deaths of people with learning disabilities so that common themes, learning points and recommendations can be

identified and taken forward into policy and practice improvements. Although this is positive, many of the reported cases have not been analysed yet.

Northway *et al.* (2018) reported that PWLD are often cared for at the end of life in general hospital wards. Given that age and cause of death among this population differ from those of the wider population (Glover *et al.*, 2017) and that many of their deaths are unexpected (Heslop *et al.*, 2013), it may be that end of life in PWLD is not recognised on admission to hospital, which further highlights the need for good quality, reasonably-adjusted hospital care for PWLD.

Alongside this, PWLD may not recognise changes in their bodies which indicate serious illness or may be unable to articulate this (Barr and Gates, 2019). Another possibility is that PWLD who are deteriorating clinically are not detected and treated in a timely way to prevent further deterioration. This finding was unique to the carer participant. Jones *et al.* (2013, p. 1031) define a deteriorating patient as, ‘...one who moves from one clinical state to a worse clinical state which increases their individual risk of morbidity, including organ dysfunction, protracted hospital stay, disability, or death’.

Over the last decade there have been numerous Early Warning Score (EWS) systems in use to identify early recognition of clinical deterioration in a patient and then an expected rapid response within the hospital to prevent further deterioration. The Royal College of Physicians (RCP) (2012) introduced a standardised National

Early Warning Score (NEWS) system to enhance the reliability and this was updated with NEWS 2 (RCP, 2017) due to limitations of the initial NEWS system. Grant (2018) highlighted that there are limitations of the NEWS 2 system and there is a need for clinicians to know the patient and not rely solely on numerical scores. The RCP (2017) support the stance that NEWS 2 should be used as an adjunct to clinical judgement.

5.2.1.4 Technician

The final domain in the RCN SOTN competency framework is that of the 'Technician' which relates to the complex nature and management of the external appliances and devices that are used in the orthopaedic or trauma speciality, such as caring for patients with plaster casts.

5.2.1.4.1 Lack of confidence in orthopaedic and trauma hospital care

The technical components of caring for Alex who required support for all his needs was lacking in hospital as Sue undertook all aspects of her son's care including feeding, washing and bowel care because she felt the nurses did not have the knowledge or understanding to do this competently. This lack of trust, confidence and belief in the hospital staff to adequately care for her son with a PMLD who had a fracture to his tibia and fibula, a common injury, was extremely disappointing and contrary to the aims of the NHS which promotes high quality of care for all (DH, 2009a). Sue's experiences were from ten years ago and it is hoped that some of these experiences would not happen today, such as a lack of appropriate equipment for moving and handling Alex.

The lack of confidence in orthopaedic and trauma hospital care was evident amongst all of the participants except Len who was in hospital for a relatively short period following a fracture to his ankle which was treated in a plaster cast. Len experienced the hospital as noisy and cold but did not have a lack of confidence in the care he received as he was treated promptly for the injury he sustained. He did however believe that staff needed to understand that PWLD have 'rights'. Conversely, Ted experienced hospital staff who did not understand the needs of PWLD and he suggested that there should be a dedicated area in the hospital with staff that had been educated and trained to care for PWLD. However, this could lead to segregation of people again. During Kelly's pre-assessment for a subsequent operation on her knee at the same hospital where she had a hip replacement, it was evident that the staff were unaware of the learning disability liaison service that Kelly had received six months previously. Furthermore, Kelly felt very poorly due to constipation when she was discharged home which resulted in a negative and potentially serious situation. Kay felt that one of the hospitals she was in made mistakes with the operation on her hip because the metalwork that was inserted then had to be removed and she has had constant problems since then. Alongside this, Kay's self-reported pain was not acted upon by hospital staff which led to a lack in confidence in the orthopaedic hospital care. A lack of confidence in hospital care could potentially lead to a rise in anxiety levels for PWLD as well as reducing concordance and ultimately a reluctance to seek treatment when it is needed.

National survey data from the study undertaken by Aiken *et al.* (2018) suggested that patients' experiencing a hospitalisation in an NHS hospital in England had a high level of trust and confidence in Registered Nurses. However, it is highly unlikely that

PWLD would have contributed to this national survey unless adjustments were made to enable access to it. The findings of this study which demonstrated a lack of confidence in the orthopaedic and trauma hospital care by PWLD and a family carer of a person with a PMLD do not concur with the findings from this national survey.

Orthopaedic doctors assumed that surgery would be the best treatment for Alex's fractured tibia and fibula. However, they looked at the x-ray when they made this decision rather than Alex holistically. Sue, Alex's mother, was a veterinary surgeon and understood the type of fracture that Alex had sustained and she felt it would be more beneficial to treat conservatively in a plaster cast because Alex's bones were so weak and he could mobilise in his wheelchair. Alex was treated in a plaster cast although complications arose following discharge from hospital as the cast cut into the posterior aspect of his knee and this was not observed until damage had occurred.

5.3 Summary

The contribution of new knowledge arising from this study adds to the current evidence base about the orthopaedic and trauma hospital experiences of PWLD. Alongside this, the PWLD who participated in the study have had their voices heard. The idiographic nature of IPA offered a means of developing this understanding by the close attention to the individual participant's accounts which disclosed valuable insights for practice that may challenge orthopaedic and trauma hospital practitioners' everyday assumptions.

The primary aim of the study was to explore the orthopaedic or trauma hospital experiences of PWLD. The findings indicate that the majority of participant experiences were exceedingly poor in orthopaedic and trauma hospital settings. The fundamental needs of PWLD were not met in adult orthopaedic and trauma hospital settings. Further empirical exploration of the reasons for these failings is required. Addressing these issues might enhance the hospital experiences for PWLD, their health outcomes and ultimately avoid premature deaths. The next chapter will discuss the strengths and limitations of the study along with the recommendations for practice, education, policy and research.

Chapter Six Conclusion

6.1 Introduction

The previous chapter provided a discussion of the findings from the study. This chapter draws the study together by revisiting the aim of the research and the research question which was set out at the beginning of the thesis. A reflection on the study is provided. Alongside this, the strengths and limitations of the study, the unique contribution to knowledge that the study makes and suggested recommendations for education and training, orthopaedic and trauma practice, policy and further research are discussed.

6.2 The aim and objectives of the research

The aim of the study was to explore the orthopaedic or trauma hospital experiences of PWLD using semi-structured interviews.

6.3 The research question

The research question was, 'How do adults with a learning disability describe their orthopaedic or trauma hospital experiences? Although there had been some previous research regarding PWLD experience of hospital care there had not been any published studies related to the experiences of adults with learning disabilities specifically in orthopaedic or trauma hospital care. The findings of this study were based on the experiential accounts of five participants. The rationale for this study was that PWLD have a greater prevalence of musculoskeletal conditions and injuries

than the general population yet their orthopaedic and trauma hospital experiences were unknown.

This study was the first investigation into the orthopaedic or trauma hospital experiences of adults with a learning disability from a qualitative and phenomenological perspective using Interpretative Phenomenological Analysis. New and original knowledge has been generated from the experiential accounts of the participants. Furthermore, the researcher was from a non-learning disability background which adds to the unique contribution of knowledge specifically relating to the methodology of the study.

6.4 Reflections on the study

I have followed Driscoll's (2007) model of reflection to structure this reflection on the study which includes three phases: What? So what? Now what?

What?

It became clear to me that PWLD had not traditionally been involved as voluntary participants in research and their experiences of orthopaedic and trauma hospital care were not known. With shocking reports highlighting poor health care as well as avoidable and premature deaths of PWLD in hospital care, I believed that it was timely to undertake this study. It should be of concern to everyone associated with orthopaedic and trauma hospital care how a vulnerable group of PWLD describe their experiences.

From the beginning of the study it was important for me to look inward to clarify and attempt to remove personal and professional biases that could interfere with my ability to hear and acknowledge the experiences of the participants. As the mother of a PWLD, I had an experience of hospital care within a children's ward in 2016 and was aware how frightening this was for my child. This episode occurred before the interviews with the participants had taken place and I bracketed my own experience. My professional biases related to the potential for searching for good practices in orthopaedic and trauma hospital settings. Attempts were consciously undertaken to bracket these biases when preparing for the semi-structured interviews by developing open questions so that participants could describe their own experiences. That said, during the interpretive phases of the data analysis, my professional experiences were not bracketed as this was believed it could enhance the interpretation of the data in IPA. The study elicited rich data and answered the research question, 'How do adults with a learning disability describe their orthopaedic or trauma hospital experiences?'

So what?

It matters immensely how PWLD feel about their care in orthopaedic and trauma hospital settings because it has a direct impact on their clinical outcomes and their quality of life. However, it was very difficult to gain access to participants and a genuine concern was that this study would not take place due to a lack of access to PWLD. It was pivotal to build a relationship with the advocacy group managers who were both the facilitators and the gatekeepers to accessing PWLD as participants via their advocacy groups. Moreover, relationship building with the participants was a

vital component of the study. Time was important to build the relationship and therefore meeting the participant prior to the interview was essential to start this key process. All the participants shared their rich orthopaedic and trauma hospital experiences in order for their experiences to be known more widely. Although the PWLD were hard to reach and recruit to the study initially, it was very evident that they wanted their experiences known about and their voices heard which had a significant impact on me.

Person-centred care was the conceptual framework used throughout the thesis and IPA was considered a fitting approach due to its flexibility, creativity, in-depth focus on the individual participant along with my interpretation of the participant's orthopaedic and trauma hospital experiences. As stated earlier, the participants were people with whom a relationship had been built during the preparation and undertaking of the interviews and this has had a lasting effect. Boxall and Ralph (2011) suggested that researchers become more interested in the life of the participants even after the research project has finished. A year after one of the interviews, I received an invitation from a family carer to an official launch of a book in London that one of the participants had co-authored. Attendance was possible and meeting the participant again as well as her parents was fulfilling as the participant was walking very well and was so proud of her deserved accolades and fantastic achievement. Although I was unsure if the participant remembered me, it was gratifying to meet her again as well as her parents who were very interested in the progress of the study.

Many of the experiences the PWLD discussed were very poor and not person-centred. To fail to attend to the promotion of kinship, connectedness and kindness between staff and patients is to fail to address a key dimension of what makes people help others and can lead to appalling systemic abuses (Ballatt and Campling, 2011). An example of this systemic abuse was reported by Michael (2008) following inquiries into the extremely poor quality of hospital care and preventable premature deaths of PWLD. Ballatt and Campling (2011) discuss the powerful influence of the organisational culture on the attitudes, emotions and practice of staff. In their book entitled, 'Intelligent Kindness' they highlighted that the embodiment of kinship and its expression in the compassionate relationship between the skilled practitioner and the patient is central to the NHS and therefore reforming the culture of current healthcare is necessary.

Some of the underlying qualities required of the IPA researcher, as purported by Smith, Flowers and Larkin (2009), were open-mindedness, flexibility, patience, empathy and the willingness to enter into and respond to the participants world which I endeavoured to achieve during the course of the study.

What could I have been done differently?

It would have been more inclusive if I had worked alongside PWLD to produce the consent form, participant information sheet as well as the development of the questions for the interview (Herron, Priest and Read, 2015). A more inclusive approach involving PWLD in the design of the study would have required a longer

time period as well as funding that was not available (Walmsley and Johnson, 2003) but it would have strengthened the study. Furthermore, a pilot interview with a PWLD rather than a practice interview with an academic member of staff would have also enhanced the study. This could have improved my skills, confidence and competence and prepared me for the data collection process which was more complex with a PWLD. Sampson (2004) asserted that undertaking a pilot study to experience research and develop personal skills and abilities can make a significant contribution to the main study. Wray, Archibong and Walton (2017) agreed that a pilot study can be used effectively in qualitative studies to refine the final design, and provide the researcher with practical experience to enhance confidence and competence. Each participant was different in terms of their unique needs and abilities and each one required accommodation in a flexible and creative way during the data collection process. Herron, Priest and Read (2015) concur that engaging people through an individualised approach is important.

Traffic light cue cards, red, amber and green might have been useful to use during the interview to indicate if the participant wanted to stop the interview or ask a question, they could show the red card, amber if they wanted a longer period of time to think or green to start answering questions again. Tajuria, Read and Priest (2017) used a similar approach using Photovoice with PWLD although their participants were familiar with this system previously and this would need to be factored into the preparation time prior to the interview.

Furthermore, when consenting PWLD in future research, I would include that they may want to disclose their identity by co-presenting in the public domain. This would

be included in the discussion about the study and I would provide detailed information on the consent form along with gaining explicit consent to use their direct quotations from the interviews.

Now what?

The experiences of PWLD and a carer of a son with PMLD in orthopaedic and trauma hospital settings were very poor overall. The findings were confirmatory of other studies and it is therefore important to share these with the wider orthopaedic and trauma hospital teams.

The research process undertaken has been a rich and rewarding journey; it was a privilege to meet and get to know the participants as well as explore their experiences of orthopaedic and trauma hospital care. The importance of individualised, personalised health care for PWLD will be shared with current students to support a connected research and teaching informed curriculum for health care practitioners (Fung, 2017).

I have learnt a great amount from undertaking this study. Some of the challenges I encountered during the research process, for example, with the difficulty accessing PWLD as potential participants along with the limitations I am now aware of since completing the study have deepened my knowledge and skills in the application of real-life research. Moreover, I have enhanced my knowledge as a nurse and educator along with gaining knowledge and skills, capability and confidence as a qualitative, IPA researcher. More importantly, however, a deeper understanding has

taken place at a human level between each participant and myself, person to person, which has fuelled my determination to continue on this journey and advocate for change to improve person-centred, orthopaedic and trauma hospital care for PWLD.

6.5 Strengths of the study

A major strength of the study has been the inclusion of adults with learning disabilities as participants. Although the participants were hard to reach and it took a long time to gain access, their experiences have been captured.

The design of the study enabled PWLD to share their experiences of orthopaedic or trauma hospital care and the methods employed provided a detailed analysis of the experiences that the participants shared during the interviews. The findings extend understanding of the experiences of PWLD in orthopaedic and trauma hospital care.

The interviews were undertaken by a single researcher which ensured a consistent approach was maintained for each of the interviews. Meaningful engagement of the participants required careful preparation of the participants for the interview along with careful preparation of the researcher. Effective communication was of vital importance and 'learning to listen' very carefully as well as 'listening to learn' from PWLD was required (Lovett, 1996).

Kelly was supported by a familiar paid carer during the interview which was at her Father's request and Kelly's agreement. There were benefits to including a familiar person. However, there was also the risk that the carer may have conflicting

agendas, misplaced beliefs or an undue influence over the person (BILD, 2009). That said, the carer facilitated the communication between Kelly and the researcher and was a comforting and familiar presence for Kelly.

One of the participants, Sue, was a carer for her son who has a PMLD so her experiences reflect those of a carer rather than the person with a musculoskeletal injury receiving orthopaedic trauma hospital care. Although some of Sue's experiences were from ten years ago which may affect the recall of events, she was an advocate for her son. Mencap (2017) concur that people with PMLD, by the very nature of their personal barriers to advocate for themselves, require their families or carers to advocate for them.

The researcher undertook the IPA which ensured immersion in the data as recommended by Smith, Flowers and Larkin (2009). The researcher was a registered nurse with substantial experience in orthopaedic and trauma hospital care and having 'insider' status as an orthopaedic nurse enhanced the interpretative activity during the analysis of the research. Alongside this, both of the research supervisors undertook an independent analysis of three of the participants' transcripts and consensus was achieved.

Different stages of the study have been presented at national and local conferences. Moreover, two of the participants, Kay and Sue, have co-presented their experiences at conferences.

6.6 Limitations of the study

There were a small number of participants in the study although this is congruent with the IPA approach. The findings are tentative and it should not be assumed that similar findings would come from other participants in a similar situation.

Not all PWLD attend self-advocacy groups or will be in receipt of learning disability services therefore the sample recruited did not include the hidden majority of PWLD in the population. That said, the aims of the study were to illuminate the experiences of the participants in the study rather than to represent all PWLD who are not a homogenous group (Newell and Burnard, 2010).

The participants were interviewed after their orthopaedic or trauma hospital stay which may have implications in terms of their memory recall of the hospital experiences. The reported length of time since the orthopaedic or trauma hospital admission ranged from current hospital attendance to ten years ago. Interviewing PWLD after their orthopaedic and trauma hospital experience rather than during the hospitalisation was considered to be less distressing for the participants. Furthermore, although one of the participants had over 40 orthopaedic operations, he shared his experiences of other admissions too, for example, when he had his teeth removed. The interview schedule may have limited the exploration of some issues that the participants mentioned, such as problems with finding employment, as it focused on hospital care. Moreover, the participants who agreed to take part in the interviews may have had more health problems and more negative experiences of health care than other PWLD.

A pilot interview with a PWLD would have improved the study and strengthened the voices of PWLD. It would have enriched the interview schedule as well as increased the researcher's abilities and confidence.

6.6 Contribution to orthopaedic and trauma nursing knowledge

The study adds a valuable and unique contribution to knowledge in the area of orthopaedic and trauma hospital care for PWLD as their experiences have been illuminated and had not been studied previously. Alongside this, the underpinning conceptual framework of PCC was congruent with the methodology which adds to the body of knowledge.

The contribution of new knowledge to orthopaedic and trauma nursing practice has been aligned within the existing four domains of orthopaedic and trauma practice (RCN SOTN, 2019): Partner/Guide, Comfort enhancer, Risk manager and Technician (p.181-201).

6.7 Additional findings

Kay and Kelly recalled positive orthopaedic hospital experiences as children, but this changed when they received adult hospital services.

Kelly was constipated when she was discharged home following a total hip replacement. This fundamental aspect of care should be investigated prior to discharge home as constipation is a known risk, it is preventable and, more worryingly, can be fatal in PWLD (Coleman and Spurling, 2010; PHE, 2016c; Robertson *et al.*, 2017).

Although the study explored hospital experiences, there were findings that relate to primary care settings. For example, if Ted's epilepsy was better controlled in primary care, the number of seizures could be reduced with less risk of injuries that he could sustain during a seizure. Sue's son, Alex sustained fractures to his fingers and toes due to incorrect positioning or handling which suggests that further education and training is needed in primary care and residential settings.

6.8 Recommendations

These recommendations are tentative as they are based on a small sample and generalisation was never a goal of this study. That said, there are lessons that can be learnt from the sharing of the participants' experiences and their insights into the orthopaedic or trauma hospital services which could potentially influence the future delivery of person-centred orthopaedic and trauma hospital practice for PWLD.

6.8.1 Recommendations for future practice

The key recommendations relating to orthopaedic and trauma hospital practice, education and training, policy and further research are discussed. For the full list of recommendations, see Appendix 30.

6.8.2 Key recommendations for orthopaedic and trauma hospital practice

- Person-centred cultures need to be developed and embedded in orthopaedic and trauma hospital care.

- It is vital to find out how best to communicate with a PWLD through liaison with carers and other services as well as by asking for and reading hospital passports.
- The regular assessment and management of pain is needed for PWLD to enable administration of timely, effective and appropriate analgesia.
- To build a trusting relationship and to get to know and effectively support the PWLD and their carer, additional time is required e.g. preoperative ward visits or double appointments in clinics.
- Carers of PWLD need to be valued and supported in orthopaedic and trauma hospital settings because they are experts by lived experience.
- There should be close monitoring of PWLD for clinical deterioration in hospital as they may be unable to communicate their symptoms or may present in a different way to people without learning disabilities.

6.8.3 Key recommendations for education and training

Caring for PWLD should be included in orthopaedic and trauma education and should involve learning disability experts, i.e. PWLD, family and paid carers and learning disability nurse specialists. Northway *et al.* (2018) concur that to effect change and enhance hospital care for PWLD, staff need to be provided with appropriate educational preparation.

6.8.4 Key recommendations for policy

- Health policy frameworks need to outline and support the development and delivery of PCC for PWLD.

- Development of an organisational culture that actively supports staff development to provide clinically effective care for PWLD.
- Empowerment of PWLD and carers to assert their personal health care and communication needs.

6.8.5 Key recommendations for further research

Further research is needed to determine the impact of any changes to orthopaedic and trauma hospital practice, education and training and policies. The recommendations for further research include:

- Investigations into pain assessment and management for PWLD in orthopaedic or trauma hospital care.
- Investigations into the use of communication enhancement tools such as wordless books for PWLD related to orthopaedic and trauma hospital settings.
- A larger scale study exploring the orthopaedic and trauma hospital experiences of PWLD including research into staff knowledge and experiences of caring for PWLD.

6.9 Dissemination

The thesis is not the only outcome from the research study. Different phases of the study have been presented over the last few years at the RCN SOTN international conferences as well as at local conferences with PWLD who are part of the Wolverhampton Intellectual Disability Network (WIDeN). Two of the participants, Kay and Sue have co-presented their orthopaedic and trauma hospital experiences at conferences.

Some of the findings from this research have been used to underpin orthopaedic and trauma practice in the most recent national competency framework (Drozd and Clinch, 2016; RCN SOTN, 2019). A list of publications and conference presentations resulting from this study can be seen in Appendix 31.

6.10 Summary

This chapter has presented the contribution that this study makes to new knowledge along with recommendations for education and training, practice, policy and further research. The strengths and limitations of the study have been discussed. The experiences of the participants in this study provide a new perspective on orthopaedic and trauma hospital care which were very poor and raises ethical, legal and professional concerns. Given the ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (2006), it would appear from the accounts in this study and from parallel germane research that the basic human rights and person-centred needs of PWLD are currently being neglected, overlooked and unsupported. This is not an acceptable state of affairs as orthopaedic and trauma hospital care is failing a specific group of individuals.

Health care professionals in orthopaedic and trauma hospital settings are likely to care for a growing and ageing population of PWLD. The providers of orthopaedic and trauma hospital services must understand the individual needs of PWLD along

with supporting staff to develop person-centred cultures to care adequately for PWLD.

Mandatory training for NHS staff in learning disability awareness is currently being proposed by the UK government and this call to action by the government is warranted to address this poor level of hospital care for PWLD. The recently announced additional funding to the NHS provides a golden opportunity to address this and upgrade orthopaedic and trauma hospital care for PWLD.

The thesis finishes with a quotation from Ted to illuminate the positive and life enhancing impact that one health care professional made for him; there are individual staff who advocate for PWLD but this is not consistent or embedded in practice:

...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)

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Appendices

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Appendix 31: List of publications and conference presentations

Appendix 1:Table 2 The requirements for person-centred care
(adapted from the Health and Social Care Act, 2008)

<p>The care and treatment of service users must:</p> 	<ul style="list-style-type: none"> a. be appropriate, b. meet their needs, and c. reflect their preferences
<p>Activities that must be carried out</p> 	<ul style="list-style-type: none"> a. Carrying out, collaboratively with the relevant person, an assessment of the needs and preferences for care and treatment of the service user; b. designing care or treatment with a view to achieving service users' preferences and ensuring their needs are met; c. enabling and supporting relevant persons to understand the care or treatment choices available to the service user and to discuss, with a competent health care professional or other competent person, the balance of risks and benefits involved in any particular course of treatment; d. enabling and supporting relevant persons to make, or participate in making, decisions relating to the service user's care or treatment to the maximum extent possible; e. providing opportunities for relevant persons to manage the service user's care or treatment; f. involving relevant persons in decisions relating to the way in which the regulated activity is carried on in so far as it relates to the service user's care or treatment; g. providing relevant persons with the information they would reasonably need for the purposes of sub-paragraphs (c) to (f); h. making reasonable adjustments to enable the service user to receive their care or treatment; i. where meeting a service user's nutritional and hydration needs, having regard to the service user's well-being.

Appendix 2: Table 3: The key reports, legislation and policies from 2001- 2018

(adapted from The Open University Timeline of learning disability history, 2018)

Date and title of reports/legislation/policies	Key message from the reports/legislation/policies
2001 White Paper <i>Valuing People</i> . Revised Code of Practice (DfES)	Principles of rights, independence, choice and inclusion
2004 Mencap publishes <i>Treat Me Right!</i>	Summarises what is known about the health needs of PWLD and proposes changes to improve health care services which are failing PWLD. It confirms that the NHS has a poor track record in dealing effectively with PWLD.
2005 <i>Mental Capacity Act</i>	People with learning disabilities have the right to make their own decisions if they have the capacity to do so
2006 <i>UN Convention on Rights of Persons with Disabilities</i>	UK a signatory to this Convention which commits states to uphold human rights for disabled people.
2007 Mencap publishes <i>Death by Indifference</i>	This report exposed the fatal consequences of inequalities in NHS healthcare for people with learning disabilities.
2007b DH <i>Putting People First</i>	Department of Health's commitment to making individual budgets a choice for anyone receiving social care.
2008 Department of Health's report <i>Healthcare for All: The Independent Inquiry into Access to Healthcare for People with Learning Disabilities</i> .	Emphasised need for urgent change to improve grossly inadequate NHS healthcare.
2009 DH <i>Valuing People Now</i>	Re-iterated Valuing People's principles and urging more rapid implementation.
2010 <i>The Equality Act</i>	This replaced previous legislation related to disability and discrimination and includes a public-sector equality duty to have due regard to the need to eliminate disability discrimination.
2011 <i>Winterbourne View</i> Hospital scandal	BBC Panorama programme revealed widespread abuse by staff of people with learning disabilities.
2012 Mencap's <i>Death by Indifference: 74 Deaths and counting</i>	Highlighted the continuing critical inequalities in NHS health care for people with learning disabilities.
2013 <i>Confidential inquiry into premature deaths of people with a learning disability</i> (CIPOLD)	The quality and effectiveness of health and social care given to people with learning disabilities has been shown to be deficient in a number of ways. Despite numerous previous investigations and reports, many professionals are either not aware of, or do not include in their usual practice, approaches that adapt services to meet the needs of people with learning disabilities. The CIPOLD study has shown the continuing need to identify people with learning disabilities in healthcare settings, and to record, implement and audit the provision of 'reasonable adjustments' to avoid their serious disadvantage including premature deaths.
2015 <i>Mazars Report</i>	An independent investigation into the deaths of all service users who received Mental Health or Learning Disability

	<p>services at Southern Health Foundation Trust since April 2011.</p> <p>This report recommended that NHS England should ensure that learning from this review of deaths into people with a learning disability informs the National Learning Disability Mortality Review programme.</p>
<p>2017 <i>LeDeR Programme- Learning Disabilities Mortality Review</i></p>	<p>The persistence of health inequalities faced by people with learning disabilities has been well documented. People with learning disabilities die, on average, 15-20 years sooner than people in the general population, with some of those deaths identified as being potentially amenable to good quality healthcare. The Learning Disability Mortality Review (LeDeR) programme was established to support local areas to review the deaths of people with learning disabilities, identify learning from those deaths, and take forward the learning into service improvement initiatives. It is being implemented at the time of considerable spotlight on the deaths of patients in the NHS, and the introduction of the national Learning from Deaths framework in England in 2017.</p>
<p>2018 <i>The Learning Disabilities Annual LeDeR Report</i></p>	<p>The proportion of people with learning disabilities who died in hospital was greater (64%) than the proportion of hospital deaths in the general population (47%).</p> <p>As a result of the reviews completed, some actions have already been taken to improve service provision for people with learning disabilities, for example, strengthening discharge planning processes, and the provision of reasonable adjustments for people with learning disabilities.</p>
<p>2018 <i>The learning disability improvement standards for NHS trusts.</i> Published by NHS Improvement (NHSI)</p>	<p>Standards have been set by NHSI for NHS Trusts to deliver improved care for PWLD.</p>

Appendix 3:Table 6 An overview of the studies included in the review in date order

Title	Author(s) and year	Country of origin	Aim / Design/ Method	Sample and Sampling strategy	Response rate (%) and participant numbers (n=)	Limitations	Key findings
The experiences of adults with intellectual disabilities and their carers in general hospitals: a focus group study	Gibbs, Brown and Muir 2008	Scotland UK	Aim: To explore the hospital experiences of people with intellectual disabilities Method: Qualitative Grounded theory approach using focus groups Qualitative	Purposive sample	11 adults with intellectual disabilities 9 parents 5 paid carers	The participants were drawn from a limited geographical area of South East Scotland and locality specific effects cannot be ruled out. There may have been pre-conceived biases.	Five themes emerged showing that there was a need for education and training of hospital staff in the care of people with intellectual disabilities. The themes were: feelings of fear and anxiety, communication, practicalities of being in hospital, discrimination and negative comments and behaviour problems. There were high levels of health needs and health inequalities experienced by people with intellectual disabilities.
Hospital experiences of older people with intellectual disability: Responses of group home staff and family members	Webber, Bowers and Bigby 2010	Australia	To explore the hospital experiences of older people with ID living in group homes Qualitative Grounded theory In person and telephone interviews	The managers of 13 group homes. Managers each with 4-6 residents were contacted by telephone to request they take part in the study. The group homes were managed by 7 different disability organisations	55 people were interviewed 17 residents with ID (at first interview only) together with 17 family members 16 house supervisors from the home 11 accommodation managers and 11 staff from care facilities	Some people with ID were present during the interviews with family members although few participated in the discussion due to the severity of their impairment, frailty or communication difficulties so the data was drawn from family members and care staff.	Difficulties were experienced by people with ID in hospital settings. Family and carers used extensive strategies to improve hospital experiences. Hospitals are poorly designed to care for older people with ID

Title	Author(s) and year	Country of origin	Aim Design/Method	Sample and Sampling strategy	Response rate (%) and participant numbers (n=)	Limitations	Key findings
A small-scale investigation of hospital experiences among people with a learning disability on Merseyside: speaking with patients and their carers.	Dinsmore 2011	England UK	Aim: To generate recommendations for enhancements to the provision of hospital care to people with a learning disability in the Merseyside area. Semi-structured interviews Qualitative study	Purposive sample	(n=12) participants overall (n=2) participants with a learning disability (n=3) participants with a learning disability and their carer present (n=7) carers	The sample size is small and the findings should not be seen as representative of the wider learning-disabled population. Sample method used biases the study towards participants who have had particularly positive or negative hospital experiences and also towards service users and clients of learning disability charities and day centre. 3 were trustees of Mencap Liverpool. Some participants described experiences that took place more than 2 years ago exposing them to a risk of recall bias. Researcher was employed by Mencap Liverpool.	PWLD in Merseyside continue to face difficulties during hospital experiences as have been identified previously by national and international investigations. Eleven themes emerged from the data: Visibility of specialist learning disability nursing roles; Lack of awareness of provision of Annual Health checks; Placement of patients within hospital; Involvement of families and carers in the planning and provision of hospital care for PWLD; Responsibilities of patient after having left hospital; Provision of medication by nursing staff; Accessibility of complaints process; Provision of accessible 'Easy Read' information about conditions, treatments and relevant legislation; Lack of awareness of patient passports; Flexibility of health care routines; Perceived staff attitudes.

Title	Author(s) and year	Country of origin	Aim Design/Method	Sample and Sampling strategy	Response rate (%) and participant numbers (n=)	Limitations	Key findings
Interactions of people with disabilities and nursing staff during hospitalization	Smeltzer, Avery and Haynor 2012	USA	<p>Aim: To explore the experiences of people with disabilities in their interactions with nurses and unlicensed assistive personnel and their perceptions of the care they received during hospital stays.</p> <p>Method: Qualitative approach using focus groups</p> <p>6 focus groups across 3 sites</p>	Convenience	(n=35) in total: 5 participants had learning disabilities	<p>Focus group methodology</p> <p>Participants with learning disabilities "did not fare well in the focus group" (page 36)</p>	<p>Four themes were identified: poor communication on the part of nursing staff, compromised care, negative attitudes among staff, and participants' fears related to quality of care.</p> <p>The findings suggest the need for further research into the nursing care of people with disabilities during hospitalisation. Educational strategies to ensure that nurses and unlicensed assistive personnel have adequate knowledge about the needs of people with disabilities may help in augmenting the care provided to this population.</p>

Title	Author(s) and year	Country of origin	Aim Design/Method	Sample and Sampling strategy	Response rate (%) and participant numbers (n=)	Limitations	Key findings
Discrimination and other barriers to accessing health care: Perspectives of patients with mild and moderate intellectual disability and their carers	Ali, Scior, Ratti, Strydom, King and Hassiotis 2013	England UK	<p>Aim: To examine the extent to which patients with learning disability and their carers experience discrimination or other barriers in accessing health services, and whether health care experiences have improved over the last decade</p> <p>Method: A qualitative approach using semi-structured interviews</p> <p>Qualitative</p>	<p>Eleven sites in the UK were approached- community intellectual disability services, day centres and voluntary organisations</p> <p>Purposive sample</p>	(n=29) participants (14 patients and 14 carer dyads and one carer)	<p>Almost all the carers were female and were mainly informal carers</p> <p>The views of people with severe and profound ID were not included</p> <p>Interview schedule may have limited the exploration of other issues</p> <p>Participants that took part may have had more health problems and more negative experiences of health care</p> <p>Researcher's professional and personal background shaped the analysis and interpretation of the data</p>	<p>In over half the dyads, carers and patients with ID agreed with each other in the themes and accounts that were given. A number of patients felt that they were discriminated against or treated differently because of their intellectual disability. The themes that emerged from the data were :</p> <ul style="list-style-type: none"> Problems with communication Problems with accessing help Problems with how health professionals relate to carers Complexity of the health care system and lack of support for carers Substandard care of people with intellectual disability Problems with staff attitudes, knowledge and behaviour <p>There were examples of good practice and Improvements in services : - good communication skills, friendly and helpful staff and situations where both the patient and carer felt respected.</p>

Title	Author(s) and year	Country of origin	Aim Design/Method	Sample and Sampling strategy	Response rate (%) and participant numbers (n=)	Limitations	Key findings
The barriers to and enablers of providing reasonably adjusted health services to people with intellectual disabilities in acute hospital: evidence from a mixed-methods study	Tuffrey-Wijne, Goulding, Giatras, Abraham, Gillard, White, Edwards and Hollins 2014a	England UK	<p>Aim: This paper reports on the findings in relation to the following research question: 'What are the barriers to providing reasonably adjusted health services to patients with intellectual disabilities in NHS acute hospitals?'</p> <p>Method: mixed-methods This was a mixed-methods study in three stages, involving interviews and questionnaire surveys (July 2011– March 2013).</p> <p>Mixed methods</p>	The study was conducted at six NHS acute hospital trusts in England. The sites were purposively selected to cover a range of different sizes, demographic areas and models for accessing intellectual disability expertise	Data collected included staff questionnaires (n=990), staff interviews (n=68), interviews with adults with intellectual disabilities (n=33), questionnaires (n=88) and interviews (n=37) with carers of patients with intellectual disabilities, and expert panel discussions (n=42)	The number of carers and people with intellectual disabilities participating in the study was relatively small in relation to staff participants (although the sample size was large in comparison with existing studies, and saturation of data has been achieved). Sampling of patients and carers was facilitated by the Intellectual Disability Liaison Nurse (IDLN) or Intellectual Disability Lead at each study site, leading to sampling bias and a difficulty in accessing a sample of patients and carers who had no involvement from the IDLN. The research team had no access to a sample of patients who had not been identified or flagged as having intellectual disabilities.	<p>Hospital strategies that supported implementation of reasonable adjustments did not reliably translate into consistent provision of such adjustments.</p> <p>Good practice often depended on the knowledge, understanding and flexibility of individual staff and teams, leading to the delivery of reasonable adjustments being haphazard throughout the organisation.</p> <p>Major barriers included: lack of effective systems for identifying and flagging patients with intellectual disabilities, lack of staff understanding of the reasonable adjustments that may be needed, lack of clear lines of responsibility and accountability for implementing reasonable adjustments, and lack of allocation of additional funding and resources.</p> <p>Key enablers were the Intellectual Disability Liaison Nurse and the ward manager.</p>

Title	Author(s) and year	Country of origin	Aim Design/Method	Sample and Sampling strategy	Response rate (%) and participant numbers (n=)	Limitations	Key findings
The challenges in monitoring and preventing patient safety incidents for people with intellectual disabilities in NHS acute hospitals: evidence from a mixed-methods study	Tuffrey-Wijne, Goulding, Gordon, Abraham, Giatras, Edwards, Gillard and Hollins 2014b	England UK	<p>Aim: To</p> <ol style="list-style-type: none"> 1. explore the challenges in monitoring and preventing patient safety incidents involving people with intellectual disabilities 2. to describe patient safety issues faced by patients with intellectual disabilities in NHS acute hospital and 3. to investigate underlying contributory factors to these safety issues. <p>Method: mixed methods study</p> <p>Interviews, questionnaires, observation and monitoring of incidence reports</p> <p>Mixed Methods</p>	Sample 6 acute NHS Trusts in England.	<p>(n= 1251 in total)</p> <p>(n=990) clinical staff-questionnaires</p> <p>(n=88) carers-questionnaires</p> <p>(n=68) interviews with hospital staff (senior managers, nurses and doctors)</p> <p>(n=37) interviews with carers</p> <p>(n=8) Observation of in patients with intellectual disabilities</p> <p>(n=272) Monitoring of incident reports</p>	A relatively low number of carers compared to hospital staff in the study.	<p>One of the largest studies to date focusing on the safety of patients with intellectual disabilities in acute general hospitals. Staff did not always readily identify patient safety issues or report them.</p> <p>Hospitals lacked effective systems for identifying patients with intellectual disabilities within their service which made monitoring of safety incidents for this group difficult.</p> <p>The safety issues described by participants were mostly related to delays and omissions of care, in particular inadequate provision of fundamental nursing care, misdiagnosis, delayed investigations and treatment, and non-treatment decisions along with Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) orders.</p> <p>Acts of omission (failure to give care) were more difficult to recognise, capture and monitor than acts of commission (giving the wrong care).</p> <p>In order to improve patient safety for PWLD, the reasonable adjustments needed by individual patients should be identified, documented and monitored.</p>

Title	Author(s) and year	Country of origin	Aim Design/Method	Sample and Sampling strategy	Response rate (%) and participant numbers (n=)	Limitations	Key findings
Experiences of acute hospital services among people with mild to moderate learning disabilities	Howieson 2015	Scotland UK	<p>Aim: To explore the experiences of acute hospital services of people with a learning disability</p> <p>Method: qualitative approach using 2 focus groups</p> <p>Qualitative</p>	Paper does not discuss how participants were recruited	<p>(n=7) participants with mild or moderate learning disabilities</p> <p>Participants had accessed an acute hospital in the last 12 months</p>	<p>The study was small and undertaken in one part of Scotland, UK</p> <p>Strength- the focus groups were facilitated by an advocate and a researcher</p>	<p>Themes from IPA analysis were:</p> <p>Treat me right, with subordinate themes of: Valuing people, dignity, respect, and therapeutic relationships.</p> <p>Hidden in plain sight, with subordinate themes of: Accountability, staff attitude and vulnerability.</p> <p>Health care for all, with subordinate themes of: Inappropriate communication systems, inaccessible information and the environment.</p> <p>The findings resonate with current literature and add to the growing body of knowledge relating to acute hospital services and the needs of people with learning disabilities.</p>

Title	Author(s) and year	Country of origin	Aim Design/methods	Sample and Sampling strategy	Response rate (%) and participant numbers (n=)	Limitations	Key findings
Perceptions of Health and Healthcare of people with intellectual and developmental disabilities in Medicaid Managed Care	Gibbons, Owen and Heller 2016	USA	<p>Aim: To examine the perceptions of health and healthcare of people with intellectual and developmental disabilities receiving Medicaid Managed Care.</p> <p>Qualitative Method: Exploratory semi-structured telephone interviews</p>	<p>Sample: (n=23) participants with various level of intellectual and developmental disability</p> <p>Purposive sample</p>	23 participants volunteered	<p>Telephone interview with people with intellectual and developmental disabilities- who were verbal therefore excluded people with severe impairments</p> <p>Small study</p> <p>Study only included people in Medicaid Managed Care in USA- who self-identified as having an intellectual and developmental disability.</p> <p>It is unclear if the participants had experience in acute hospital care settings as primary care and specialist care is stated. However, the study was included as PWLD expressed what they valued and want from providers of health care.</p>	<p>Important implications for health care providers within the Medicaid Managed Care system in USA.</p> <p>The themes that emerged from the data were the importance of being treated with respect and dignity, the value of relationships with their health care providers, having medical staff who could communicate clearly, there was confusion around care coordination and a need for accessible information on care coordination.</p>

Title	Author(s) and year	Country of origin	Aim Design/methods	Sample and Sampling strategy	Response rate (%) and participant numbers (n=)	Limitations	Key findings
Being a Disabled Patient: Negotiating the Social Practices of Hospitals in England	Read, Williams, Heslop, Mason-Angelou and Miles 2018	UK	Aim: To understand disabled people's experiences of how they interact with, and are affected by, existing hospital practices Qualitative Semi-structured interviews	Convenience sample. Participants volunteered who self-identified as disabled	n=21	It is unclear how many participants had a learning disability in the study	Disability-related needs were often invisible despite the legal protections in place and ignored within the hospital system. A major issue for disabled patients was the need to repeatedly advocate for themselves and explain their needs to staff. Problems arise when things are designed in such a way that disabled people are forced to confront their difference, and to make that difference visible to others. This can become a problem in itself, resulting in disabled patients feeling guilty, anxious or frustrated. The Equality Act (2010) legislation, intended to mitigate or remove disabling practices seems to have had little impact on day-to-day hospital experiences.

Appendix 4: Table 9 A list of themes and subthemes arising from the initial codes with the supporting references

THEME1: Poor communication in hospital	
<p>Subthemes:</p> <ul style="list-style-type: none"> • Increased fear and anxiety due to poor communication • A lack of person-centred communication 	
Initial codes	Reference to the research studies
Poor communication with the person with a learning disability in hospital.	Dinsmore (2011); Ali <i>et al.</i> (2013); Gibbs, Brown and Muir (2008); Howieson (2015); Read <i>et al.</i> (2018); Webber, Bowers and Bigby (2010); Smeltzer, Avery and Haynor (2012); Tuffrey-Wijne <i>et al.</i> , (2014b)
Fear of having assistive devices taken away in hospital.	Smeltzer, Avery and Haynor (2012)
Poor communication about the PWLD between primary and secondary care. PWLD not identified or flagged so reasonable adjustments not made.	Tuffrey-Wijne <i>et al.</i> , (2014a)
Anxiety and fear increased in PWLD due to poor communication in hospital. Failure of hospital staff to communicate effectively with other staff regarding PWLD.	Dinsmore (2011); Webber, Bowers and Bigby (2010); Gibbs, Brown and Muir (2008)
Lack of hospital passports which could aid communication.	Dinsmore (2011)
Key information from carers not read by staff in hospital e.g. laminated information packages.	Webber, Bowers and Bigby (2010)
Not allowing time for the PWLD to process information and answer questions/failure.	Ali <i>et al.</i> (2013); Howieson (2015)
Inaccessible communication methods.	Howieson (2015); Read <i>et al.</i> (2018); Ali <i>et al.</i> (2013)
Failure to adapt communication to the needs of the patient	Ali <i>et al.</i> (2013)
Lack of consistency in doctors talking directly to PWLD in hospital.	Gibbs, Brown and Muir (2008)

THEME 2: Unsafe care	
<p>Subthemes:</p> <ul style="list-style-type: none"> • Lack of reasonable adjustments • Fundamental care omissions and mistakes 	
Initial codes	Reference to the research studies
Failure to make reasonable adjustments e.g. failure to use pictures or large print or easier read documents.	Ali <i>et al.</i> (2013); Howieson (2015) Tuffrey-Wijne <i>et al.</i> , (2014a; 2014b)
Failure to implement reasonable adjustments to minimise disruption to usual medication routines of PWLD in hospital.	Dinsmore (2011); Read <i>et al.</i> (2018)
Compromised care/lack of competence. Inappropriate early discharge from hospital. Lack of care regarding eating and toileting.	Webber, Bowers and Bigby (2010)
Inappropriate 'Do not attempt Cardiopulmonary Resuscitation' order	Tuffrey Wijne <i>et al.</i> , (2014b)
Substandard care of PWLD-comprising inadequate follow-up, incorrect medication, unnecessary investigations or investigations and treatments delayed or lacking, inadequate discharge arrangements, lack of support toileting.	Ali <i>et al.</i> (2013); Tuffrey Wijne (2014b)
Carers' knowledge disregarded/ Failure to heed carers' advice about the PWLD.	Howieson (2015); Webber, Bowers and Bigby (2010)
Inadequate pain assessment.	Webber, Bowers and Bigby (2010) Tuffrey-Wijne <i>et al.</i> ,(2014b)
Early discharge from hospital without being ready and care home staff unable to continue the level of care needed.	Webber, Bowers and Bigby (2010)
Lack of staff understanding and awareness of the needs of people with learning disabilities.	Read <i>et al.</i> (2018); Webber, Bowers and Bigby (2010); Gibbs, Brown and Muir (2008); Smeltzer, Avery and Haynor (2012)

THEME 3: Poor relationships with PWLD in hospital	
<p>Subthemes:</p> <ul style="list-style-type: none"> • Lack of caring and understanding for the individual PWLD • Perceived discrimination towards PWLD 	
Initial codes	Reference to the research studies
Poor staff attitudes and behaviours towards people with learning disabilities.	Dinsmore (2011); Howieson (2015); Gibbs, Brown and Muir (2008)
Dignity and respect lacking for people with a learning disability.	Ali <i>et al.</i> (2013); Read <i>et al.</i> (2018)
A lack of caring from hospital staff.	Webber, Bowers and Bigby (2010); Smeltzer, Avery and Haynor (2012)
Perceived discrimination due to learning disability.	Gibbs, Brown and Muir (2008); Webber, Bowers and Bigby (2010); Ali <i>et al.</i> (2013)
Need to be treated as an individual and receive personalised/individualised care.	Gibbons, Owen and Heller (2016); Read <i>et al.</i> (2018); Webber, Bowers and Bigby (2010)
PWLD left alone in hospital.	Webber, Bowers and Bigby (2010)
Fear of receiving inadequate/compromised care during hospitalisation and becoming more poorly.	Smeltzer, Avery and Haynor (2012)
Fear of getting lost in hospital by PWLD.	Gibbs, Brown and Muir (2008)
Issues with involvement of family carers in planning and providing hospital care.	Dinsmore (2011); Ali <i>et al.</i> (2015)
Desire for providers to listen, respect PWLD as individuals and human beings and address their medical concerns.	Gibbons, Owen and Heller (2016); Smeltzer, Avery and Haynor (2012)

THEME 4: Person-centred hospital experiences of PWLD	
Subtheme:	
<ul style="list-style-type: none"> Evidence of reasonable adjustments made in practice 	
Initial codes	Reference to the research studies
Good communication skills. Friendly and helpful staff. Incorporation of reasonable adjustments, such as longer appointment times.	Ali <i>et al.</i> (2013)
Nurses and doctors explained what was happening in a way that was understandable.	Howieson (2015)
Doctors listening, demonstrating concern and exhibiting patience.	Gibbons, Owen and Heller (2016)

Appendix 5: Semi-structured interview schedule

Welcome and background to the study. I will have easier read literature, symbols and pictures to explain and give to the participant prior to and during the semi-structured interview. I aim to create and maintain a relaxed and friendly environment.

Introductions

The researcher will go through the informed consent form again using easier read materials, symbols and pictures, allowing extra time for explanations and repetition prior to the interview. I will explain the researcher's role and the plan for the 30-60 minutes

Background information (to collect for context)

Age:

Sex:

Where do you live? (Town/County)

Who do you live with?

Questions

1. Have you been in hospital before?

Prompts:

Which hospital did you go to?

When was it?

Reason for hospitalisation/ broken bone/other injury/planned surgery?

When was this/months/years ago?

How long were you in hospital-days/weeks/months?

2. What was it like for you?

Prompts:

What was the ward like?

What did you like/dislike most about it/ the food in hospital/ were you able to move/eat and drink/get dressed/get to the toilet?

Did you have crutches (if lower limb affected)/cast on/sling (if upper limb affected)?

Did you have pain? What helped the pain?

What was good about the ward?

Were the staff helpful/kind/unhelpful/unkind, any examples?

Did you have the same person caring for you? Was it friendly/unfriendly, any examples? Did the doctors and nurses talk to you? Can you remember what they said?

What did they say?

3. What would have made your stay in hospital better?

Prompts:

What helped?

Did you feel happy/unhappy?

Did you feel safe/unsafe?

Cared for/uncared for?

Do you have any examples?

Did you feel well/ not in good health when you went home from hospital?

4. Have you been feeling well since your hospital stay?

Prompts:

is the bone fixed?

Do you have any pain from the surgery/operation/treatment now?

Can you do things that you like doing more/less since the operation/surgery?

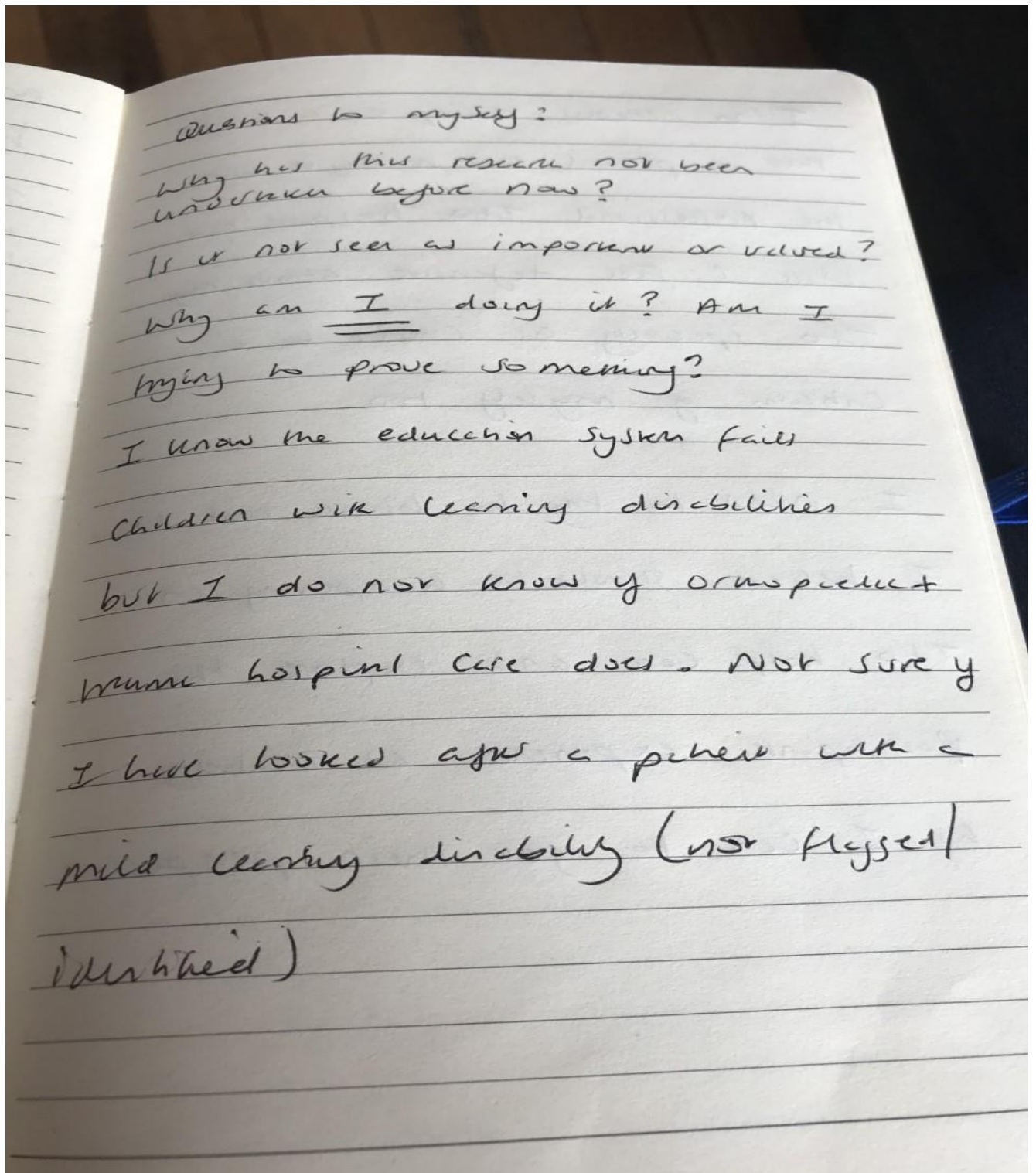
Did you have an appointment with the hospital after you went home?

Thank you for taking part.

When I listen/read what we've talked about, I might need to come back and talk to you again about some things, would that be ok?

Debrief- At the end of the interview the researcher will go through a debrief explaining again what the study is about and how the data will be treated and reported and will check that the person still wishes to take part. This will be based on the participant's level of communication and interaction and will be altered accordingly.

Appendix 6: Extracts from research diary



I'm nervous taking on a subject that is personal and mixing it with the professional Tto hospice care. Will I feel defensive about my Tto specialty or could be a criticism of myself too.

I need to try to block out what I believe should be happening in Tto hosp care and explore the participants experiences as neutrally as I can to get their perspective

Appendix 7: Letter to advocacy group managers



Mary Drozd
Professional Doctorate student
University of Wolverhampton
Faculty of Education, Health & Wellbeing
Institute of Health Professions
Walsall Campus
Gorway Road
Walsall
WS1 3BD
Email [REDACTED]
Tel [REDACTED]

Dear Sir or Madam

As part of my Professional Doctorate in Health & Wellbeing degree course at the University of Wolverhampton, I am proposing to conduct a research project into the orthopaedic and trauma acute hospital experiences of adults with a learning disability. The benefits of this research will be that the voices of adults with a learning disability who have experiences of being in orthopaedic or trauma hospital settings could inform future practice.

I am therefore writing to seek your permission to conduct this study in your Advocacy Centre in a quiet and private room with any willing members of your group who have experience of orthopaedic and trauma hospital care. I enclose a copy of a poster advertising the research along with a participant information sheet for your information.

I look forward to hearing from you.

Yours faithfully

Mary

Mary Drozd

Appendix 8: Recruitment poster

Would you like to be involved in research about your hospital experience?

Have you....

- been in hospital with a broken bone
- had surgery on a broken bone?



- I would like to hear your views about your hospital experience
- Please let the Manager of the Advocacy group know if you are interested so they can let me know. Thank you

Please see the information sheet that is attached for more information.

Thank you from



Mary Drozd

University of Wolverhampton

Faculty of Education, Health & Wellbeing Walsall Campus Gorway Road Walsall

Telephone [REDACTED] Email [REDACTED]

HEALTH STONES ISSUE 91, July 12th 2016

Welcome to the latest edition of Health Stones.

Requests

Research study- 'The Orthopaedic or Trauma Hospital Experiences of Adults with a Learning Disability in the UK'.

I am undertaking a Professional Doctorate in Health and Wellbeing at the University of Wolverhampton and I'm trying to find people with a learning disability who would be willing to share their story of what it was like for them in an orthopaedic or trauma hospital setting, either as an in-patient or an out-patient clinic setting.

Do you know someone that has been to hospital with a problem with their bones or joints like arthritis or broken bones or painful muscles? Do you know someone that might like to be share what it was like for them? The aim of the research study is to find out what was good and what could be better in hospitals from the viewpoint of a person with a learning disability. If you know of someone who has had a joint replacement or an operation on a limb or of someone who has been a patient on a trauma ward or to fracture clinic I would like to hear from you.

Full ethical approval for the study has been granted by The University of Wolverhampton.

For further information, please contact Mary Drozd on XXXXXXXXXX

Appendix 10: Extract from email questionnaire

Did you want a side-room or did you want to be with other patients?

To be honest I had a side room 1 time when I had my teeth out but the nurses didn't wipe any of the blood which was coming out of my mouth 14 hours in all.

When you say it was not nice in hospital, could you be more specific about what was not nice- was it the staff or the environment or being away from home?

It was a few things, It was boring in there and in the and it was not nice because when I trying to sleep even more at nights I was woke up every couple hours to only to have my blood pressure done

You mention sometimes the pain was awful. Did staff assess your pain or ask you about the level of your pain?

The nurses didn't ask about the pain that often

Did the staff/nurses give you painkillers regularly?

Not that often

Did the nurses/doctors/physios/ occupational therapists talk to you directly?

Yes / No because I was not always aware what was happening

If not, who did they talk to?

Sister Nurse / Doctors

When you mention that sometimes staff said things that didn't make sense, or not true, could you give any examples?

1. Like when I was in hospital last time because I hurt my self awful ,the A + E Doctor sent me to have a x-ray but when I sat down to wait for my turn 5 minutes later a man said to me come here and go back to the A + E department I said what about the x-ray he said they don't do x-rays on noses.

2. Also the ward Doctor came around and said they have to find out why I am passing out, but I have Epilepsy and no one even now after 40 years having Epilepsy no one have told me why I have Epilepsy.

3. Also some Doctors asked me when will I have a seizure, but how would I know that.

Did the staff use any communication aids like communication books, signs or symbols?

No

How did you communicate your needs to the hospital staff?

Talk to them or write it on paper

Did anyone stay with you in hospital?

No

If yes, did this help? How did it help?

What would have made your stay in hospitals better?

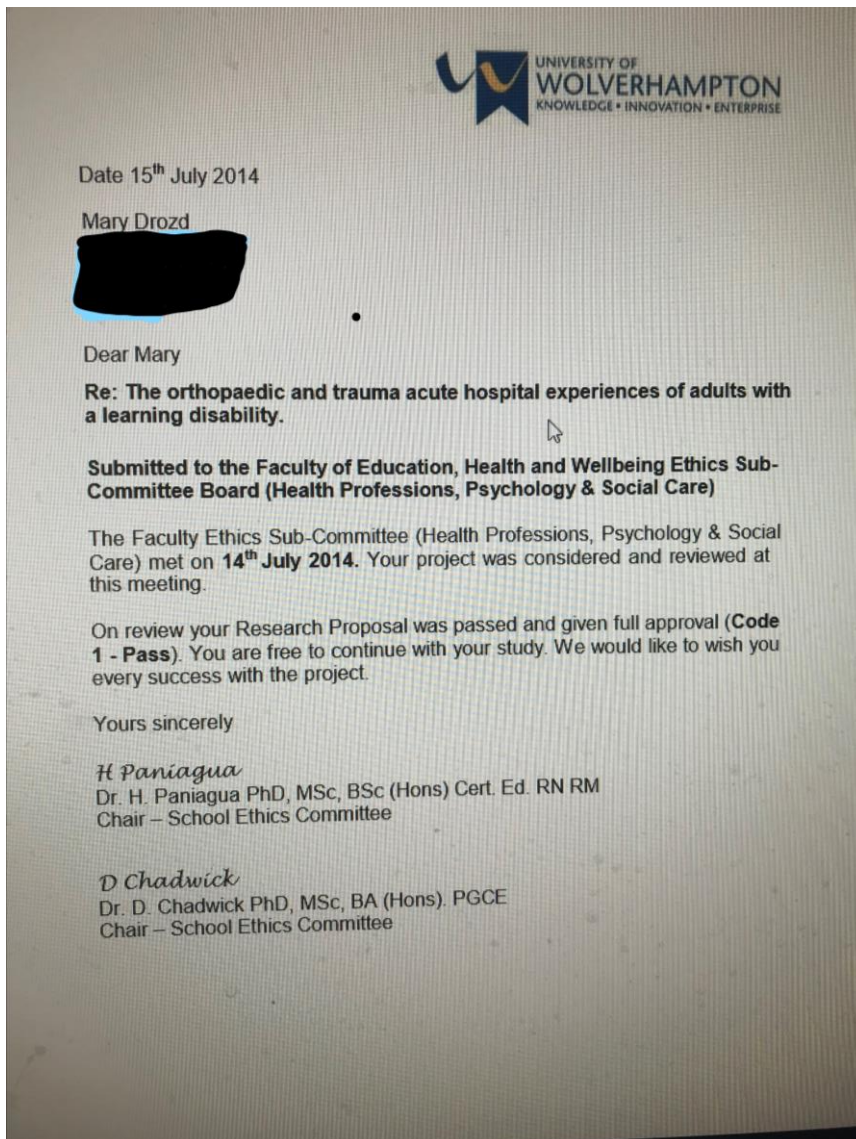
1 = Let the patients sleep at night and not wake them every 2 or 3 hours during the night

2 More things for the patient to do while in hospital.




Appendix 11 Table 71: Details of the participants in the IPA study

NAME	Gender	AGE	Elective orthopaedic or trauma hospital care	Surgical or conservative treatment	When
Kay	Female	25	Elective orthopaedic	Surgical: multiple operations and hospitalisations for hip surgery Conservative treatment for current knee and spine pain	3 years ago On-going hospital care
Ted	Male	45	Elective orthopaedic and trauma	Surgical: over 40 operations on lower limbs	1991 last planned orthopaedic surgery On-going hospital care for MSK injuries following epileptic seizures
Kelly	Female	32	Elective orthopaedic	Surgical: operation for SUFE Surgical: total hip replacement Currently awaiting knee surgery	Aged 14 February 2016 On-going hospital care
Len	Male	44	Trauma: Hit by a car at night whilst crossing the road: fractures	Conservative: fractured ankle treated in a below knee plaster cast and then a boot	"A long time ago"
Sue (Carer)	Female	Not known	Trauma: son Alex- fractures following accidents	Conservative: Plaster cast for fractured tibia and fibula; Fractures to fingers and toes treated with splints	10 years ago Not reported

Appendix 12: Ethics approval



Appendix 13: Easier read participant information sheet

  	<p>Study Title</p> <p>The orthopaedic and trauma hospital experiences of adult patients with a learning disability</p> <p>Invitation</p> <ul style="list-style-type: none">• You are being invited to take part in a research study• Ask me if there is anything that is not clear or if you would like more information <p>What is the purpose of the study?</p> <ul style="list-style-type: none">• I want to find out about your experiences of being in hospital so that I can share what is good and try to make things better <p>Why have I been chosen?</p> <ul style="list-style-type: none">• You may have been to hospital with a broken or painful bone or muscles. <p>Do I have to take part?</p> <ul style="list-style-type: none">• If you decide to take part you are still free to change your mind without giving a reason
-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------



What will happen if I decide to take part?

- If you decide to take part in the research, I will visit the Advocacy group you go to explain more about the study
- I will arrange a suitable room that is quiet and private. The interview will take between half an hour and an hour
- In the interview I will ask you questions about your experiences in hospital
- You can choose which questions you want to answer. The interview will be tape-recorded
- If you want to stop the interview you can at any time. Any decision you make will be respected
- I will check at the end of the interview to see if you are still happy to take part.

What are the potential benefits and risks of taking part?

- You will help me to find out how the staff in hospitals can help people with a learning disability
- There are no risks to you in taking part in the study, outside of those you would

experience in everyday life



Will my taking part in the study be kept confidential?

- Yes. All the information in this study will be kept confidential
- If anything is raised during the interview that indicates that either you or someone else is at risk of harm, then these concerns will be shared with the Advocacy Group manager

What will happen at the end of the research study?

- The findings of this study will be presented in a dissertation to the academic staff at The University of Wolverhampton
- The findings will be shared with hospital staff and nursing organisations
- You can have a copy of the findings from me Mary Drozd



What if I have a problem or concern?

- If you have a concern you should ask to speak to Mary Drozd or Darren Chadwick, Mary's supervisor who will do their best to answer your questions



- Mary can be contacted on telephone number [REDACTED]
- Darren can be contacted on telephone number [REDACTED]
- email Mary at [REDACTED]
- email Darren at [REDACTED]
- or by letter to
- Mary Drozd, University of Wolverhampton, Faculty of Education, Health & Wellbeing, Walsall Campus, Gorway Road, Walsall WS1 3BD
- Darren Chadwick, University of Wolverhampton, Faculty of Education, Health & Wellbeing, City Campus North, MH 024, Wolverhampton

Who has reviewed the study?

- The University of Wolverhampton, School of Health & Wellbeing Research Ethics Committee

Thank you for taking the time to read this information



Meanings of some words

Bones in your body



Orthopaedic....

Injury to bones, like a broken bone



Trauma.....

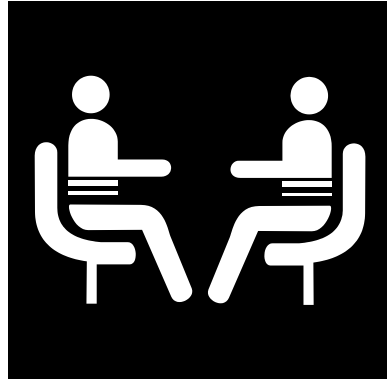
To find out what is good
in hospital and what needs to be better in
future

Research.....



A chat with the researcher, Mary, about
your experience in hospital

Interview.....



Appendix 14: Participant information sheet for family/paid carer

Study Title: The orthopaedic and trauma hospital experiences of adult patients with a learning disability

Invitation

- You are being invited to take part in a research study
- Before you decide it is important for you to understand why the research is being done and what it will involve
- Ask me if there is anything that is not clear or if you would like more information
- Take time to decide whether or not you wish to take part. Thank you for reading this

What is the purpose of the study?

- I want to find out about your experiences as a carer for a person with a learning disability who has been in an orthopaedic or trauma hospital setting (either for planned surgery on bones and joints or treatment such as surgery or plaster casts following injuries such as broken bones).
- I want to share what is good for adults with a learning disability in hospital (on orthopaedic or trauma wards/clinics) and try to improve areas of orthopaedic and trauma practice for people with a learning disability

Why have I been chosen?

- You are a family or paid carer for an adult with a learning disability who has been on an orthopaedic or trauma ward or hospital setting.

Do I have to take part?

- If you decide to take part you are still free to change your mind up until the interview is over and without giving a reason

What will happen if I decide to take part?

- If you decide to take part in the research, I will visit the Advocacy group that the person with a learning disability attends at an agreed and convenient time to explain more about it or arrange a telephone interview if this is preferable for you
- I will arrange a suitable room that is quiet and private in the Advocacy Centre
- The interview will take approximately 30 minutes

- During the interview you will be asked a series of questions about the orthopaedic and trauma hospital experiences of a person with a learning disability.
- You can choose to answer some or all of the questions asked. The entire interview will be tape-recorded
- If you want to stop the interview you can at any time. Any decision you make will be respected
- You must let me know at the end of the interview if you do not want the information to be used
- If you wish for the tape to be destroyed at this point then your wishes will be respected.
- After the interview you do not need to do anything else

What are the potential benefits and risks of taking part?

- Your input into this study will be of value to hospitals as by taking part you will help me to find out how the orthopaedic and trauma hospital wards/clinics can help people with a learning disability
- There are no risks to you in taking part in the study, outside of those you would experience in everyday life

Will my taking part in the study be kept confidential?

- Yes. All your personal information in this study will be kept confidential
- The notes of the interview will be stored safely
- Only the researcher and her supervisors working on the project will read the information
- If anything is raised during the interview that indicates that someone is at risk of harm, then these concerns will be shared with the Advocacy Group manager

What will happen at the end of the research study?

- The findings of this study will be presented in a dissertation to the academic staff at The University of Wolverhampton
- The findings will be shared with hospital staff and The Royal College of Nursing
- You can have a copy of the findings and published results from me, Mary Drozd

What if I have a problem or concern?

- If you have a concern you should ask to speak to Mary Drozd who will do her best to answer your questions or you can contact Dr Darren Chadwick, Mary's Director of Studies
- Mary can be contacted on telephone number [REDACTED]
- email [REDACTED]
- or by letter to Mary Drozd at University of Wolverhampton, Faculty of Education, Health & Wellbeing, Walsall Campus, Gorway Road, Walsall WS1 3BD
- Dr Darren Chadwick can be contacted on [REDACTED]
- email [REDACTED]
- or by letter to Dr Darren Chadwick at University of Wolverhampton, Faculty of Education, Health & Wellbeing, City Campus North, MH 024, Wolverhampton

Who has reviewed the study?

- The University of Wolverhampton, School of Health & Wellbeing, Research Ethics Committee

Contact for further information

- For further information regarding this study please contact:







Mary Drozd
University of Wolverhampton
Faculty of Education, Health & Wellbeing
Walsall Campus
Gorway Road
Walsall
WS1 3BD


[REDACTED]
Tel [REDACTED]

Thank you for taking the time to read this information.

Appendix 15: Consent form Easier Read

The orthopaedic and trauma hospital experiences of adults with a learning disability

		TICK
	The research has been explained to me	<input type="checkbox"/>
	I have been able to ask questions about the research	<input type="checkbox"/>
	I understand that I will talk about what it was like for me being in hospital	<input type="checkbox"/>
	I know I can stop the interview if I want to, before what I said starts being analysed	<input type="checkbox"/>
	My responses will be kept confidential	<input type="checkbox"/>
	The researcher will write about the findings but will not use my	<input type="checkbox"/>

	real name	
	I agree to take part	<input type="checkbox"/>

Signed: _____

Print Name: _____ **Date** _____

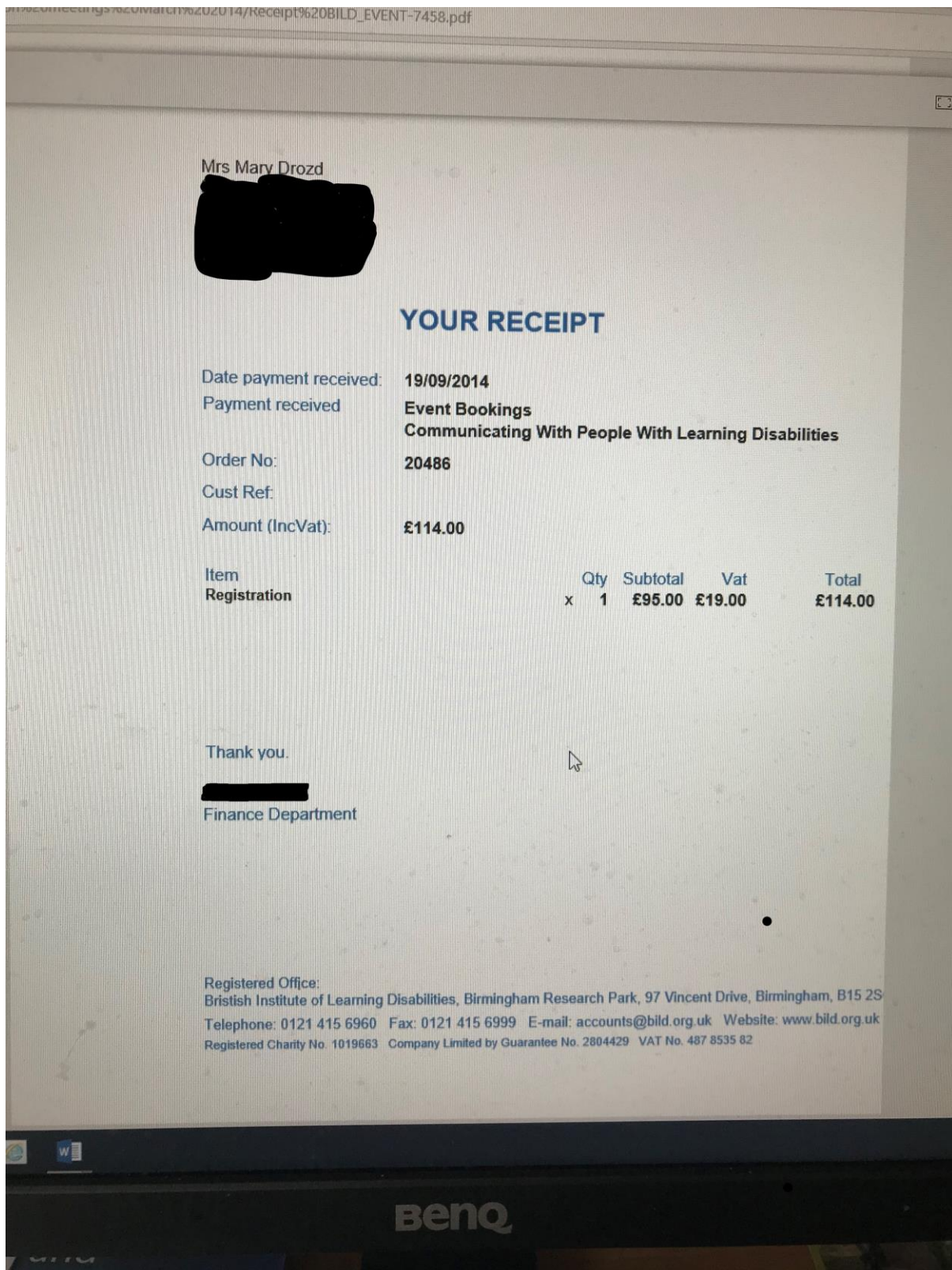
Witness details (if present): _____ **Date** _____

Researcher signature _____ **Date** _____

Appendix 16: Consent form for family/paid carers
The orthopaedic and trauma hospital experiences of adults with a learning disability

	initials
The research has been explained to me	<input type="checkbox"/>
I have been able to ask questions about the research	<input type="checkbox"/>
I understand that I will talk about what it was like for a person with a learning disability and myself as carer on an orthopaedic or trauma setting in hospital	<input type="checkbox"/>
I know I can stop the interview if I want to, before what I said starts being analysed	<input type="checkbox"/>
My responses will be kept confidential	<input type="checkbox"/>
The researcher will write about the findings but will not use real names only pseudonyms	<input type="checkbox"/>
I agree to take part	<input type="checkbox"/>
Signed	Date
PRINT NAME	
Researcher's signature	Date

Appendix 17: BILD study day



Appendix 18: Table 82: Details of the interviews

Names of participants	Interview method	Date of interview	Length of interview and contact time
Kay	Face-to-face 1:1	4 th May 2016	30 minutes
	Contact time in advocacy group after the interview	4 th May 2016	60 minutes
Ted	Email	13 th & 15 th June 2016	85 minutes
	Face to face: 1:1	17 th August 2016	
Kelly facilitated by Nat (carer)	Face-to-face 1:1	31 st August 2016	30 minutes
	Contact time, London for official launch of book	6 th September 2017	120 minutes
Len	Face-to-face 1:1	18 th October 7-9pm	24 minutes
		4 th October 7-9pm	Direct contact time in the advocacy group: 336 minutes
		20 th September 7-9pm	
Sue (Carer)	Telephone interview	16 th August 2016	45 minutes
	Face to face to present at RCN conference, Cardiff	8 th September 2016	45 minutes

Appendix 19: Reflection after an interview

I am now reflecting after the interview with Kelly who lives at home with friends and the support of a close family and carers. Kelly had a hip replacement six months prior to the interview and is awaiting surgery on her knee at the same hospital. Kelly's team leader, Nat, was present throughout the 30-minute interview.

How did I feel? I was slightly nervous as I had not met Kelly before. The preparation for the interview had been undertaken by Kelly's father and the carer over the weekend prior to the interview and Kelly was very well prepared. It was important to build a rapport with Kelly and her carer first and I was also aware that I had said the interview would be approximately 30-60 minutes and I did not want to take longer if they had plans for other activities that day.

What struck me was that Kelly was involved in many activities that she enjoyed but the pain in her knee was troubling her; she winced in pain a couple of times before the interview and the carer confirmed that Kelly had taken pain killers. Kelly was keen to have an operation to resolve this knee pain and knew the surgery was imminent.

Kelly is a 32-year-old woman and at one of the hospital appointments, she didn't like it when staff spoke to her carer rather than to her. This would upset me too. I was surprised that this still happens and then found myself guilty of doing this during the interview! Kelly shared a negative experience when she was going into a hospital previously where the doctor suggested that Kelly would go a children's ward. She very clearly told me she is not a child, she's an adult. Kelly does communicate very

clearly. Communication is not just verbal speech...her expressions and body language communicated so much too.

Before the interview, we chatted about her beautiful garden and Kelly loves gardening; she had grown the giant sunflowers and she was also involved with painting, drama, book clubs and she enjoys watching DVDs. Her favourite DVD was 'Finding Dory' which she had seen recently. Kelly also loves DVDs about animals but doesn't like scary movies. Kelly enjoys watching sport and cheering for Britain in the Olympics. Alongside this, she was very excited about her sister's imminent wedding as she was the bridesmaid. Kelly had worked in a school part-time too.

In hospital, Kelly really enjoyed having her visitors particularly her mum, her dad, her aunty and uncle and her friends who stayed during the day. They were very important to her and she used to 'facetime' her family and friends too while she was in hospital.

It wasn't always easy to understand what Kelly was saying verbally because her voice was slightly muffled at times and she seemed a little bit nervous to begin with. Although Kelly's father had prepared me via email for this, I felt uncomfortable when I couldn't understand what Kelly was saying during parts of the interview and occasionally, I looked to Nat, the carer for help. Perhaps I could have waited longer before doing this to allow Kelly to either expand on what she had said or I could have been honest and said that I didn't understand and ask Kelly to repeat her answer. I could have asked a similar question with different words. Kelly also looked to her carer for help at times during the interview as she said a few times, "help Nat" and Nat would rephrase my question so Kelly could understand it, which then enabled Kelly to answer it.

It might have helped if I had planned to stay longer or I could have done the interview in 2 parts, for example, a meeting first to enable Kelly and I to get to know each other and allay some anxieties as well as to enhance our preparation for the interview, and then another day to undertake the interview. I definitely feel that if I had met Kelly before the interview day it would have been more helpful, rather than conducting the interview on the same day that I met Kelly for the first time.

Kelly was happy to be involved in the research and her father said she had been involved in other studies too. Kelly had a hip replacement that has very successful as she said she was crying with pain before the hip replacement and now was walking independently. She remembered using the Zimmer frame after her hip replacement 6 months previously and Kelly was going into hospital again soon to have knee surgery. However, there was no liaison learning disability nurse this time and Nat, the carer, did have to ask to see the occupational therapist at the pre-assessment clinic to request equipment that would be needed at home after surgery. This made me wonder if this would have been missed if Nat had not been proactive which could result in a delayed discharge home after Kelly's knee surgery.

I was conscious after the interview, that Nat and I had spoken quite a lot during the interview. On reflection I do think a 2-part interview might have reduced this happening as I was aware afterwards that I really wanted more of Kelly's perspectives. That said, Nat was a great comfort and a reassuring presence for Kelly and myself during the interview and Nat certainly facilitated communication between Kelly and I during the interview.

Appendix 20: Example of transcription from an interview

Interview 5 Len 18th October 2016

This was the 3rd time that I had attended the advocacy group on a Tuesday evening session 7-9pm so the group had become more familiar with me.

Len wanted his friend, Fred, to join us. Fred is part of the group and the manager says they go everywhere together so he did support Len during the interview.

Venue: Advocacy Centre 7-9pm. Main hall with manager and other members in another area of the hall. Noisy at times as they were playing music and others were interested in what Len was doing.

Interview recording: 24 minutes

I is the Interviewer

Len is Len

Fred is Len's friend

The transcript notations used in the quoted extracts include the following:

... significant pause

[] material omitted

[for example]. Explanatory material added by researcher.

I: Thank you so much for agreeing to be involved in this research study

Len: that's OK, yeah

I: so I just want to get some background information, I have to ask if you don't mind telling me your age?

Len: er...would you believe er 44

I: thanks...

Len: all the 4's

I: all the 4's

Len: 45 next year, you know

I: You live in Birmingham, don't you?

Len: yes

I: do you live with other people or do you live alone?

Len: alone unfortunately

I: alone...that's fine

I: so...have you been in hospital before?

Len: yes been in loads of times

I: can you tell me about when you were in with a broken bone or...any problems with your bones?

Len: well...I got ran over ... I got ran over...by a car...obviously....and er...when I did it it was very painful...I got ran over by a car...I couldn't even move

I: was it your legs?

Len: yeah...yeah

I: and did you stay in hospital?

Len: yeah...yeah overnight unfortunately

I: and what was it like?

Len: horrible...what was it like...absolutely horrible...

I: why was it horrible, L?

Len: well...I couldn't go through the pain and the agony of it...

I: did they give you painkillers?

Len: yeah they did

I: did they help?

Len: a bit...

I: and you stayed in one night did you say?

Len: er...I think it was 2 nights I stayed in...yeah

I: and how long ago was it?

Len: ooh...ooh...it was a long time ago I think...I can't remember...it was a very long time ago...yes

I and what did they do for your leg?

Len: um...it had to be x-rayed obviously...to see which bones I'd broken...obviously

I: yeah

Len: it was 2 broken bones in my ankle and foot...unfortunately...it was very, very painful

I and that's what you remember, it being very, very painful?

Len: yeah...um...very, very, very painful, yeah

I: did you have an operation on it?

Len: erm...erm...not really ...just went and x-rayed it, x-rayed it really, you know

I: Did they put a cast on?

Len: I had to have one of those special boots put on

I: ah

Len: I had to have one of those special boots put on, didn't I?

I: ah

Len: unfortunately

Fred: you were in a lot of pain

Len: yes I was

I: how long did you have the boot on for, L?

Len: oh...for a while...till it healed up the bone...it was horrible...I could hardly go out to places neither when I did it...I had to be stuck in the flat all the time, didn't I...all the time basically...

I: what happened, L?

Len: A car went and knocked me over...knocked me down as I was crossing over a road...I was coming back from the disco on a Thursday night...it was a long time ago now that

I: yeah...can you remember what the ward was like?

Len: ...

I: was it busy?

Len: I suppose it was alright...the kind nurses...I had some nice kind nurses looking after me

I yes

Len: yeah

I: the nurses were helpful, were they?

Len: well some was and some wasn't

I: what made them helpful?

Len: ...

I: did they come to talk to you?

Len: yes they came to talk to me

I: did you have a side room or were you in a room with other patients?

Len: ooh...I think it was just a normal ward I think...there were other patients in it

I: yeah...anything you liked about that?

Len: um...I liked the food...well the food I had wasn't too bad I suppose really

I: so the food was OK, ...is there anything you didn't like about the ward?

Len: um...it was cold...and not too much privacy neither...noisy

I: noisy...was that at night time?

Len: yeah

I: were you able to get up and walk, L?

Len: well I couldn't walk on it on the first night

I: no

Len: I was tied to the bed unfortunately at the time

I: did the nurses help you; you know if you needed to get to the toilet...things like that?

Len: erm...oh I had one of those special things where you had...one of those special things that you put it into...I don't know what you call em

I: don't worry

Len: I had a special thing that they gave me

I: did you have crutches, L?

Len: crutches...no...crutches erm did I have crutches erm...no luckily not...I didn't have crutches no...I just had this special boot on...just had this special boot on which was an absolute pain in the arse

I: did you have to keep that on all the time?

Len: yes I did, yeah it was all sealed up properly and that, yeah

I: was that for a few weeks?

Len: yeah, yes...oh yes...probably would have been a few weeks or something like that...yes

I: did you go back to the clinic then?

Len: yeah, yeah I had to go back for check-up see...you know see how you was doing and...so yeah

I: you said the pain was really bad, terrible

Len: yeah

I: what would have helped or was there anything that helped the pain?

Len: ...sighs

I: I know you had a lot of pain and you had tablets...did anything else help or...

Len: no not really no...no not really no

I: the staff were kind, any examples of them being kind?

Len: ...

I: can you think of anything that showed they were kind?

Len: they were alright I suppose

I: did you have the same nurse caring for you or different ones?

Len: yeah different ones

I: was it friendly or unfriendly

Len: some didn't want to know

I: did you understand what was going on when you were there

Len: basically yes

I: what would have made your stay in hospital better

Len: getting better...but then going home on your own, it's horrible...it's lonely

I: did you feel happy or unhappy in hospital?

Len: felt both

I: what made you feel happy?

Len: ...

I: or made you feel unhappy?

Len: going home lonely then

I: yeah...so it was when you were going home?

Len: ...

I: did you feel well enough when you were going home?

Len: no

I: do you think the bones all fixed now, L?

Len: ...

I: fully mended or do you have any problems with that ankle?

Len: well, well erm...erm...not really...I still get aches and pains from it occasionally still...so yeah

I: which ankle was it, L?

Len: [points to it]

I: that left one?

Len: yeah the left one...yeah, yeah, yeah...it was the left one unfortunately

I: do you have any hospital appointments now, L?

Len: no, no fortunately not no...it's finished now yes...yes it's all finished now yes

I: was it at night that it happened?

Len: ...

I the accident?

Len: yes it was...it happened when I was coming back from a disco...

I: and you were walking on the pavement and about to cross the road

Len: yeah, yeah I was, yeah...and the car came out from absolutely no-where...he came out of like...he came out of like...and left me in the road for dead

I: did he stop?

Len: No no he didn't stop nor nothing

I: oh so what did you have to do?

Len: well I didn't have my phone on me at the time...I couldn't phone the ambulance at the time...I didn't have my mobile working at the time so I couldn't phone an ambulance...I had to more or less struggle back to the flat to phone for an ambulance

I: oh goodness...with a broken ankle

Len: yeah, yeah a broken ankle yes

I: oh dear

Len: up the stairs, yes

I: did you have to wait for long when you got to the hospital?

Len: well...

I: were you in A & E?

Len: unfortunately yes...yes unfortunately yes...unfortunately yes

I: did they explain everything to you in A & E?

Len: yeah they did

I: and they gave you painkillers there?

Len: yeah they did...yeah they did...they gave me painkillers and everything they did

I: how do you think they can make things better in hospital?

Len: erm...listen to what we say

I: listen to what you say?

Len: more about our rights

I: do tell me more...what specific rights should they know?

Len: that we're disabled

I: yeah

Len: and understand

I: did they have anything like this (showing a visual Hospital Communication Book)? that they used?

Len: no

I: no...would this help do you think?

Len: actually can I have that?

I: yes you can...this is free from the internet...was there anything like this in hospital?

Len: no they should do

I: would this have helped

Len: I think so yeah

I: what were you able to do in hospital?

Len:.. ...

I: were you able to watch television?

Len: no cos it was really, really noisy.... you know what hospitals are like, don't you?

I: yeah...is there anything else you would like to add?

Len: no

I: thank you so much for helping me with this study. What I'll do, I'll go away and I'll listen to the tape and type up what you have said and if there is anything that I haven't understood, would you be happy for me to come back if I need to ask a bit more?

Len: yeah

I: OK you've been wonderful. I'm going to turn it off now.

Appendix 21: Sample of exploratory notes & emerging themes

Extract from original interview	Exploratory notes
<p>: so...have you been in hospital before? Len: yes been in loads of times I: can you tell me about when you were in with a broken bone or any problems with your bones? Len: well...I got ran over , I got ran over...by a car...obviously...and er...when I did it it was very painful...I got ran over by a car....I couldn't even move I: was it your legs? Len: yeah...yeah I: and did you stay in hospital? Len: yeah...yeah overnight unfortunately I: and what was it like? Len: horrible...what was it like...absolutely horrible..... I: why was it horrible, L? Len: well...I couldn't go through the pain and the agony of it... I: did they give you painkillers? Len: yeah they did I: did they help? Len: a bit... I: and you stayed in one night did you say? Len: er...I think it was 2 nights I stayed in....yeah</p>	<p>Len has been in hospital previously. This time after a road traffic collision and he was a pedestrian.</p> <p>Horrible experience of being in hospital</p> <p>The pain was unbearable. How much pain relief did Len have and was it adequate for broken bones in his ankle and foot?</p> <p>painkillers helped slightly.</p> <p>In hospital for 2 nights, lives alone</p>

Appendix 22: Sample of Initial themes with quotations

Themes	Quotation
Pain	<p><i>...well...I couldn't go through the pain and the agony of it...Len line 36</i></p> <p><i>...yeah...um...very, very, very painful, yeah ...Len's line 52</i></p> <p><i>...they gave me painkillers and everything they did... Len line 178</i></p>
Loneliness	<p><i>...alone unfortunately...Len Line 21</i></p> <p><i>...but then going home on your own, it's horrible...it's lonely...Len line 131</i></p> <p><i>...going home lonely then...Len line 137</i></p>
Environment	<p><i>horrible...what was it like...absolutely horrible...Len line 34</i></p> <p><i>...it was cold....and not too much privacy neither...noisy...Len line 90</i></p> <p><i>...it was really, really noisy...you know what hospitals are like...Len line 200</i></p>
Abandoned after the accident	<p><i>...and the car came out from absolutely nowhere...he came out of like...he came out of like...and left me in the road for dead... No no he didn't stop nor nothing...Len lines 158-161</i></p>
Road traffic accident	<p><i>...well...I got ran over,... I got ran over...by a car...obviously....and er...when I did it it was very painful...I got ran over by a car....I couldn't even move...Len line 27-28</i></p> <p><i>...A car went and knocked me over...knocked me down as I was crossing over a road...I was coming back from the disco on a Thursday night...it was a long time ago now that...Len lines 68-70</i></p>
Feeling isolated at home	<p><i>...it was horrible...I could hardly go out to places neither when I did it...I had to be stuck in the flat all the time, didn't I...all the time basically...Len line 64-66</i></p>
Listening	<p><i>...listen to what we say...Len lines 180</i></p>
Disability rights	<p><i>...more about our rights... that we're disabled... Len lines 182-184</i></p>
On-going problem with ankle	<p><i>...well, well erm...erm...not really...I still get aches and pains from it occasionally still...so yeah...Len line 145-146</i></p>

Appendix 23: Sample of cluster of themes

Pain

Pain	<p><i>...well...I couldn't go through the pain and the agony of it...Len line 36</i></p> <p><i>...yeah...um...very, very, very painful, yeah ...Len's line 52</i></p> <p><i>...they gave me painkillers and everything they did... Len line 178</i></p>
On-going problem with ankle	<p><i>...well, well erm...erm...not really...I still get aches and pains from it occasionally still...so yeah... Len line 145-146</i></p>

Loneliness

Alone	<p><i>...alone unfortunately...Len Line 21</i></p> <p><i>...but then going home on your own, it's horrible...it's lonely...Len line 131</i></p> <p><i>...going home lonely then...Len line 137</i></p>
Feeling isolated at home alone	<p><i>...it was horrible...I could hardly go out to places neither when I did it...I had to be stuck in the flat all the time, didn't I...all the time basically... Len line 64-66</i></p>

Environment

Cold and noisy	<p><i>horrible...what was it like...absolutely horrible... Len line 34</i></p> <p><i>...it was cold...and not too much privacy neither...noisy...Len line 90</i></p> <p><i>...it was really really noisy...you know what hospitals are like...Len line 200</i></p>
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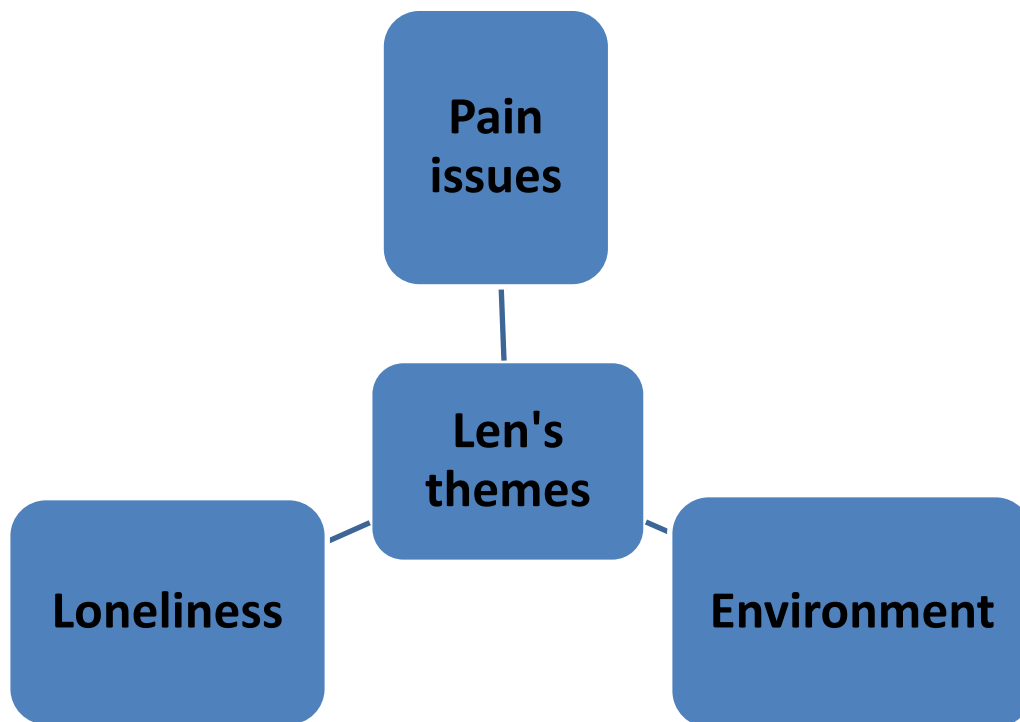
Communication

Listening	<i>...listen to what we say... Len lines 180</i>
Disability rights	<i>...more about our rights... that we're disabled... Len lines 182-184</i>

Appendix 24: Superordinate and subordinate themes for Len

PAIN	LONELINESS	ENVIRONMENT	COMMUNICATION
Subordinate themes	Subordinate themes	Subordinate themes	Subordinate themes
Pain	Alone	Cold and noisy	Listening
On-going problem with ankle	Feeling isolated at home alone	Lack of privacy	Disability rights

Further analysis and interpretation show the final superordinate themes for Len



Appendix 25: Table 93: A summary of Kay's themes

Superordinate theme	Subordinate themes	quotations
PAIN ISSUES	Anxiety about the hip pain	<i>... and they said it was growing pains... (Kay, line 26)</i>
	Pain assessment and management in hospital	<i>...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)</i>
	Living with pain	<i>... so every other couple of months...I end up having flare ups...where I can't get out of bed...I'm in a hell of a lot of pain ...pain...I can't move... and em... all they say is because my leg is so weak... so I have to have...I have to have a couple of days in bed... have stronger tablets... so its... it gets me down..... and it gets me down when I have these flare ups (Kay, line 306-317)</i> <i>... I'm still in a lot of pain... and erm... and it's affected other parts of my body now (Kay, line 430-432)</i>
CARER INVOLVEMENT	Help with fundamental care	<i>... I just stayed in bed until my Mom come ...but I didn't feel fresh, you know... waiting in bed looking (laughs) (Kay, line 414-418)</i>
	Trust as a pre-requisite for a therapeutic relationship	<i>... 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)</i> <i>...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)</i>
COMMUNICATION	Effective communication	<i>... em...I liked it at the children's hospital... and em...and I liked it at the orthopaedic hospital in []...yeah... em...there was more...em... they was more helpful...and they...they explained things...easier to me...they explained things...(Kay, line 187-194)...</i>
	Mother as translator for Kay	<i>...I found it hard to understand... erm... long words... (Kay, line 373).</i> <i>...but when I...but when I don't understand long words... so sometimes they have to tell my mom and then my mom tells me what it means... (Kay, line 220-226)</i>

Appendix 26: Table 104: A summary of Ted's themes

Superordinate themes	Subordinate themes	Quotations
LACK OF CONFIDENCE IN HOSPITAL CARE	Lack of continuity	<p>...every appointment I have is with a new doctor...what's the point in that...they ask me what's wrong, why don't they look at the report or ask the nurses, they must know what I come in with...in the end I walked out...(Ted, line 298-300)</p> <p>...I thought why does the doctor ask me each time what happened and I found out that the report is put away... it's all on the report but they can't find it... (Ted, line200-203)</p>
	Errors in hospital administration systems	<p>...they can't even put the right name on the computer properly... my surname, my second name...they put an S on it. They put the wrong number on my address also...they can't even put the right number... (Ted, line 205-209)</p>
	Belief of only one doctor	<p>...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)</p>
PROBLEMS WITH COMMUNICATION	Ineffective and unclear communication	<p>...some doctors asked me when will I have a seizure, but how would I know that? Email 13.6.16 at 21:22</p> <p>...some said things what made sense but sometimes they said things which were not true or not make sense. ...I was not always aware what was happening Email 13.6.16 at 21:27</p>
	Conflicting information	<p>...they said things which were not true..... he said they don't do x-rays on noses...Email 13.6.16 at 21:22</p>
LACK OF COMPETENCE OF STAFF	A need for additional and specific education and training of staff and a special facility	<p>... nurses and doctors are not trained to look after disabled people... most people in hospital don't have a disabled problem ... (Ted, line 261-264)</p> <p>hospitals ought to have special wards + clinics for the disabled people to be more happier + safer to be in so all the nurses are not only trained nurses but as well trained to know to cope with all sort of disabled problems like speech, hearing, learning problem, memory problems and more (Email from Ted,15.6.16 at 18:20)</p>
	Isolated and abandoned	<p>...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)</p> <p>...I had hit my head on the wall... but they left me there...(Ted line 173-175)</p>
	Pain assessment and management	<p>sometimes I had very awful pain... The nurses didn't ask about the pain that often... (Email from Ted,13.6.16 at 21:22)</p>

Appendix 27: Table 115: A summary of Kelly's themes

Superordinate themes	Subordinate themes	Quotations
FAMILY AND CARERS	Importance of family and carer support	<i>...I went last week with Dad and the doctor said... (Kelly, line 54)</i>
	Carer advocacy	<i>...Yeah, we had a LD nurse then...I know she was very good and she organised everything but we haven't had it this time... (Nat, line 79-81)</i> <i>...we asked the first nurse we saw...she didn't really know what we were talking about...I need to chase it up again... (Nat, line 85-86)</i>
COMMUNICATION	Communication with Kelly facilitated by carers	<i>I'm 32...and I'm not a child, I'm an adult (Kelly, line 291-293)</i>
	Use of technology to stay connected with family, friends and carers	<i>I used to facetime my Dad...and my Mom...and my Sister... (Kelly, line 212-216)</i>
PAIN	No more hip pain	<i>Nothing wrong with my hip... the pain has gone (Kelly, line 31)</i>
	Knee pain	<i>...my hip went...then my knee pain... (Kelly, line 45)</i>
	Abdominal pain	<i>When I had my hip operation...I was really poorly...sick...for a few days after...I was back at home and I feel sick (Kelly, line 185-187)</i> <i>It really hurt, the painkillers, they really constipated her really bad and I think the pain from that was worse than the hip... (Nat, line 230-231)</i>
	Distress from the removal of the clips from the hip wound	<i>...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>

Appendix 28: Table 126: A summary of Len's themes

Superordinate themes	Subordinate themes	Quotations
PAIN	Acute pain and management following the injury	<i>...yeah...um...very, very, very painful, yeah ...</i> (Len, line 52)
	On-going aches and pains in the ankle	<i>...well, well erm...erm...I still get aches and pains from it occasionally still...so yeah...</i> (Len, line 145-146)
ENVIRONMENT	An unwelcoming place	<i>...it was cold...and not too much privacy neither...noisy...</i> (Len, line 90)
	Listen to understand the rights of people with disabilities	<i>...erm...listen to what we say...more about our rights... that we're disabled... and understand</i> (Len, line 180-186)
LONELINESS	Living alone	<i>...but then going home on your own, it's horrible...it's lonely...</i> (Len, line 131)
	Isolation	<i>...it was horrible...I couldn't go out to places neither when I did it...I had to be stuck in the flat all the time, didn't I...all the time basically...</i> (Len, line 64-66)

Appendix 29: Table 137: A summary of Sue's themes

Superordinate themes	Subordinate themes	Quotations
PARTNERSHIP WITH THE CARER	The carer as expert by experience	<i>...again utterly hopeless they just don't understand, you know, you say to them, you need to watch his arms cos he'll get them caught...they put the cot sides up and he gets his arms caught in them and then you have another injury to deal with...(Sue, line 200-202)</i>
	Care for the carer	<i>...and I think the carers take on so much...you need to sleep too as you can end up exhausted at the end of it all so we need to take care of the carers too... (Sue, line 443-444)</i>
	Work with the carer	<i>...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)</i>
COMMUNICATION DIFFICULTIES	Communication with Alex	<i>...they had a go...um...and I explained to them all that... how he smiles for yes and frowns for no and that he understands everything that you are saying and stuff...yeah, they did have a little bit of a go but pretty ineffective really ... (Sue, line 425-428)</i> <i>...stop treating disabled people as if they are idiots... because they are not, they just don't communicate in the same way as we all do. So we assume that they can't hear, can't ...have no brain, have no thought, have no ... it's really frustrating... (Sue, line 435-441)</i>
	Communication with Sue	<i>... 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)</i>

NOT SEEING THE PERSON	Lack of advocacy by staff for Alex	<i>... and all this time they hadn't put support on it... (Sue, line 66)</i>
	Lack of fundamental care	<i>...he's peed and the pad was full and it was soaking wet, so he was, he was completely soaking...head to toes...and he was comatose. He was absolutely comatose, he didn't even recognise me... and so I... I... got hold of the nurses and really gave them a rollicking, I asked someone to come over and help me change everything, give him a sponge bath and got him cleaned up... (Sue, line 383-387)</i> <i>...they don't understand about giving enemas or anything, no common sense at all. Unless it's a drug, they don't know what the hell else to do...anyway I gave him an enema ...so that cleared that load of stuff... (Sue, line 348-350)</i> <i>...the nurse SAID that she would stay with him all night until I came back but she was nowhere to be seen... (Sue, line 419-420)</i>
	Lack of concern	<i>...gross isn't it? Compared then with my other son, I can take any number of his incidences...broken legs and stuff... um... so I can take one where it was a fairly comparable injury in fact due to his bike and he came off his bike and was in a heap...and he was screaming and he was like screaming and so I said stop screaming and tell me what's wrong...and he could tell me ... he could tell me what was wrong ... but he was treated straightaway...no question about, oh he's never going to walk on it...there was no question of anything like that at all...(Sue, line 215-235)</i> <i>...I thought, my God, he's dying and so when the consultant came round and he was asking me if he had improved, I said, yeah, yeah, lying through my teeth. He said, is he normally like this, totally unresponsive? Yes, yes, yes that's normally how he is, yes that's absolutely right, yes he's much better than he was um and er..I'll just take him home now and er...nurse him at home... (Sue, line 401-405)</i>
FEAR OF LOSS	Fear of death in hospital	<i>...He'd have died if he'd have stayed in hospital... He'd have died (Sue, line 414-416)</i>

Appendix 30: Recommendations from the study

Recommendations for education and training

- Trauma and orthopaedic education need to include learning disability experts, i.e. PWLD, family and paid carers and learning disability nurse specialists
- Annual mandatory education and training in caring for PWLD for all hospital staff
- A joint approach to reviewing pre and post registration education and training related to caring for PWLD in T & O settings
- Recognition of and valuing the PWLD as a person
- Implementation of reasonable and achievable adjustments for PWLD
- Need for hospital staff to enhance communication skills with PWLD
- Learning of Makaton and sign language for learning disability champions

Recommendations for orthopaedic and trauma hospital practice

- Develop and embed person-centred cultures in orthopaedic and trauma hospital care
- Active listening to PWLD and/or their carers
- Find out how every patient communicates through liaison with carers and other services
- Read and act on the information in the person's Hospital Passport
- Use the communication strategies that are known to support each PWLD
- Allow additional time and support for communication with PWLD
- Use pictorial resources such as The Hospital Communication Book and relevant picture books such as 'Books Beyond Words'
- Develop and provide easier read information about the processes within orthopaedic and trauma care
- Use valid and reliable pain assessment tools and resources where possible e.g. DISDAT tool
- Administer timely, effective and appropriate pain management for PWLD
- Give PWLD a choice regarding a side room or a bay with other people
- Do not isolate PWLD in hospital settings
- Consistent access to specialist learning disability liaison 24/7
- Additional support for PWLD offered if there is no family or paid carer with them in and out of hospital
- Open visiting for carers and friends
- Easy access to electronic equipment/social media for PWLD to connect with family and friends
- Additional time for hospital procedures to get to know and effectively support the PWLD and their carer e.g. preoperative ward visits
- Value the expertise of carers and provide facilities for them to be part of the hospital team
- Close monitoring of PWLD for clinical deterioration
- Minimise the risk of constipation
- Obtain regular feedback about hospital experiences from PWLD and/or their carers using appropriate/adapted methods

- Review PROMs to make them user-friendly

Recommendations for policy

The following are suggested recommendations:

- Health policy frameworks need to outline and support the development and delivery of PCC for PWLD
- Development of an organisational culture that actively supports staff development to provide care for PWLD
- Empowerment of PWLD and carers to assert their personal health care and communication needs
- Provision of skills training for PWLD and carers so they can assert their needs in hospital
- Enable PWLD and their carers to advocate for PCC
- There should be readily accessible, 24/7, learning disability liaison nurses to provide advice and support to patients and staff in orthopaedic and trauma hospital settings. This could include a helpline or liaison on-call service which will have financial cost implications that could be balanced against poor clinical outcomes for PWLD, increased length of hospital stays and readmission due to 'failed discharges home'.
- Regular assessment of the quality of care for PWLD in T and O settings against compliance with national competency frameworks such as RCN SOTN (2019)
- Identification and flagging systems to be developed so PWLD in orthopaedic and trauma hospital care are accommodated appropriately
- Promotion and valuing the recruitment of PWLD into research studies.

Recommendations for further research

Further research is needed to determine the impact of any changes to education and training, orthopaedic and trauma hospital practice and policy. The recommendations for further research include:

- Investigations into pain assessment and management for PWLD in orthopaedic or trauma hospital care
- Investigations into the use of communication enhancement tools such as wordless books for PWLD related to orthopaedic and trauma hospital settings
- Exploratory research is warranted into the use of early warning scores such as NEWS 2 with PWLD
- A larger scale study exploring the orthopaedic and trauma hospital experiences of PWLD
- Research is needed into staff knowledge and experiences of caring for PWLD
- Research evaluating the efficacy of orthopaedic and trauma hospital practice changes detailed above

Appendix 31: List of publications and conference presentations

Publications

Jester, R., Santy-Tomlinson, J., and Drozd, M. (2018) The use of patient reported outcome measures (PROMs) in clinical assessment. *International Journal of Orthopaedic and Trauma Nursing*. 29, p 49-53.

Drozd, M., and Clinch, C. (2016) The experiences of orthopaedic and trauma nurses who have cared for adults with a learning disability. *International Journal of Orthopaedic and Trauma Nursing*. 22, p 3-23.

Conference Presentations

Drozd, M., Chadwick, D., and Jester, R. (2019) abstract accepted for a concurrent session entitled, '*The experiences of orthopaedic and trauma hospital care from the perspectives of adults with an intellectual/learning disability in England, UK: An Interpretative Phenomenological Analytical (IPA) study*'. Royal College of Nursing International Research Conference, Sheffield Hallam University 3-5th September 2019.

Awarded a studentship to attend The Seattle Club Annual Conference on Intellectual and Developmental Disabilities held at the Shrewsbury Centre of the University of Chester on 3rd and 4th December 2018.

Drozd, M., Chadwick, D., and Jester, R. (2017) "*I'm not a child, I'm an Adult.*" *This is Kelly's Story*. Concurrent presentation. Royal College of Nursing (RCN), Society of Orthopaedic and Trauma Nurses (SOTN) International Conference. Chester, UK 14th November 2017.

Jester, R., Santy-Tomlinson, J., and Drozd, M. (2017) *The pleasures and the pains of using patient reported outcome measures in clinical assessment*. Concurrent session. Royal College of Nursing, Society of Orthopaedic and Trauma Nurses International Conference. Chester, UK 14th November 2017.

Drozd, M., Chadwick, D., Eggison, P., and Clinch, C. (2016) *What WE think about hospital care*. Wolverhampton Intellectual Disability Network (WiDeN) Conference. University of Wolverhampton. Plenary session. 16.9.16. Co-presented with a participant from the study (Kay).

Drozd, M., Chadwick, D., Eggison, P. and Clinch, C. (2016) *What do people with a learning disability say about orthopaedic or trauma hospital care?* Plenary Session. Royal College of Nursing (RCN) Society of Orthopaedic and Trauma Nurses (SOTN) International Conference, Cardiff 8.9.16. Co-presented with a participant from the study (Sue).

Drozd, M., Chadwick, D., Kozłowska, O., and Clinch, C. (2015) *What do nurses think about the care of people with a learning disability in orthopaedic and trauma hospital settings?* Plenary session. Wolverhampton Intellectual Disability Network (WiDeN) inaugural Conference, University of Wolverhampton 16.9.15.

Drozd, M. (2015) *A pilot study exploring orthopaedic and trauma nurses' experiences of caring for patients with a learning disability*. Concurrent session. RCN SOTN International Conference. Nottingham Conference centre, England, UK.

Drozd, M. (2014) *Experiences of adult patients with a learning disability in orthopaedic and trauma settings*. Concurrent session RCN SOTN International Conference. Brighton. Awarded 'The Best Paper'.

Drozd, M., Jones, S., and Bolton, J. (2014) *How YOU care for a person with a Learning Disability in acute hospital settings*. Fringe event. RCN Congress 18.6.14, Liverpool.

Drozd, M. (2013) An interactive Poster presentation Title- *'How do adult patients with a learning disability describe their acute hospital experiences?* RCN SOTN International Conference, Glasgow, Scotland.