

YOUNG HIP

An exploration into young patients' (≤ 50 years) expectations following primary total hip arthroplasty; An Interpretative Phenomenological Analysis study.

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ABSTRACT

Title: YOUNG HIP: An exploration into young patients' (≤ 50 years) expectations following primary total hip arthroplasty: An Interpretative Phenomenological Analysis study.

Introduction.

Total hip replacements (THR) are common operations performed in orthopaedics. Though initially developed to address hip conditions in older patients, demand in younger patients is increasing. Research in older populations informs current practice and it is unclear if outcome priorities important to older patients are similar in younger patients, or if younger THR patients consider other outcomes more important. Patient-reported outcome measures (PROMs), routinely used in clinical practice, aim to evaluate the success of interventions from the patient's perspective. However, these standard questionnaires may not account for differences in priorities across various demographic groups.

Aims

Young Hip's primary aim was to explore younger patients' (≤ 50 years) expectations and priorities when undergoing primary elective THR.

Methods

Four studies were undertaken: a systematic literature review (study 1), a Public and Patient Involvement (PPI) study (study 2), a bibliographic review (study 3), and a qualitative study (study 4). Study 1 highlighted the current absence of qualitative research on THR patients, the aim of study 2 was to reveal themes from the patient perspective not currently addressed by existing healthcare pathways, and study 3 underlined the minimal use of qualitative methodologies in research published in orthopaedic journals. These studies underscored the necessity and rationale for further exploration into the priorities of younger THR patients through qualitative enquiry. Therefore, study 4 utilised Interpretative Phenomenological Analysis (IPA) to examine the experiences of ten patients from a UK hospital. Semi-structured interviews were conducted at three timepoints: pre-surgery, six-weeks post-surgery, and six-months post-surgery. Data was analysed individually before cross-case analysis explored the similarities and differences between participants. Additionally, participants completed validated PROMs questionnaires at each timepoint, these results were compared with the qualitative data to assess whether PROMs accurately reflected the participants' experiences and concerns.

Findings

These findings suggest that younger patients face distinct psychological and social challenges that are often overlooked in standard care pathways.

Six superordinate themes were identified from the qualitative data in study 4; “I’m just constantly in pain”, “Giving up hope”, “Living a process that does not reflect me”, “This is not who I’m meant to be”, “My family didn’t sign up for this”, and “I can’t do anything”. Some themes emerged that are general regardless of patient age, such as pain (I’m just constantly in pain), and mental health challenges (Giving up hope). However, other findings, for example, perception of function (I can’t do anything), self-image, and identity (this is not who I’m meant to be) appear to be much more focussed and imperative to the younger patient than to the older patient.

Discussion

Studies 1-3 emphasised a critical need for research in this area, and the potential in using qualitative methodologies to further the understanding of what is important to younger THR patients. Study 4 expanded on this, highlighting aspects currently overlooked in younger THR patients such as self-image, psychological impacts, and the importance of functional recovery in relation to social and familial roles. Participants frequently expressed feelings of not fitting the typical patient profile for THR and reported difficulties in being heard by healthcare professionals. While PROMs provided some insights, they often failed to represent the full range of participants' concerns. A more personalised approach to care that includes patient-provider partnerships could help better meet the unique needs of younger patients.

Conclusion

Younger patients do not fit the expected THR patient profile meaning current care pathways do not always suit their needs. Developing a flexible THR care pathway that allows for more person-centred care for THR patients could help address issues raised by this study, more effectively supporting younger patient’s recovery.

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List of abbreviations

6M – Six Months
6W – Six Weeks
AB – Word in Abstract
ADL – Activities of Daily Living
AFTER - Ankle Fracture Treatment: Enhancing Rehabilitation
AVN - Avascular Necrosis
BAME - Black and Ethnic Minorities
BIBLIO - Preliminary guideline for reporting bibliometric reviews of the biomedical literature
BL - Baseline
BMI - Body Mass Index
CRAFFT - Children's Radius Acute Fracture Fixation
COVID19 – Coronavirus disease 2019
CQC – Care Quality Commission
DDH - Developmental Dysplasia of the Hip
FJS – Forgotten Joint Score
GIRFT - Getting It Right First Time
GP – General Practitioner
HHS - Hip Harris score
HOOS - Hip disability and Osteoarthritis Outcome Score
HRA – Health Research Authority
HUSH - Humeral Shaft Fracture Trial
IOM – Institute of Medicine
IPA – Interpretative Phenomenological Analysis
ISTC - Independent Sector Treatment Centres
LoS – Length of Stay
MH – Medical Subject Heading
MKUH – Milton Keynes University Hospital
NGT – Nominal Group Technique
NHS – National Health Service
NICE - National Institute for Health and Care Excellence
NIHR - National Institute for Health Research
NJR – National Joint Registry

NMC – Nursing and Midwifery Council
OPD – Outpatient Department
OHS - Oxford Hip Score
OA - Osteoarthritis
PCC – Person Centred Care
PIFU – Patient Initiated Follow-Up
PIO – Population Intervention Outcome
PIS – Patient Information Sheet
PPI – Public and Patient Involvement
PRISMA - Preferred Reporting Items for Systematic reviews and Meta-Analyses
PROMs – Patient Reported Outcome Measure
PT - Patient
QOL – Quality of Life
RA – Rheumatoid Arthritis
RCT – Randomised Controlled Trial
REC - Recreation
SA – Sexual Activity
SFCE - Slipped Capital Femoral Epiphysis
THA – Total Hip Arthroplasty
THR – Total Hip Replacement
TI – Word in Title
TKA – Total Knee Arthroplasty
TKR – Total Knee Replacement
UK – United Kingdom
WAX - Weightbearing in Ankle Fractures
WHO – World Health Organisation

Integrated papers

In line with the alternative formats of thesis outlined within BU's Research Degree Code of Practice, this thesis follows an integrated format, where two published research articles, and one article in preparation for publication, are integrated into the thesis. The table below provides the details of the included research articles, publication status, and location within this thesis. For co-authored publications, I am the lead author, and can confirm that I contributed over 75% of the substantive content of each article.

Paper	Reference	Chapter/section	Page numbers	Publication status
1	Mew, L., Heaslip, V., Immins, T., Wainwright, T.W. (2022) A Patient and Public Involvement Study to Explore the Need for Further Research into the Experience of Younger Patients Undergoing Total Hip Arthroplasty. <i>Journal of Patient Experience</i> . 9. doi:10.1177/23743735221083166	Chapter 3 Section 3.4	53-64	Published
2	Mew, L., Heaslip, V., Immins, T., Wainwright, T. (2023). What Is Important to the Younger Person (≤50 Years) When Having a Total Hip Arthroplasty: A Systematic Literature Review. <i>Orthopaedic Nursing</i> 42(4): 213-229, DOI: 10.1097/NOR.0000000000000955	Chapter 3 Section 3.3	35-51	Published
3	Bridging the Gap: Enhancing Orthopaedic Outcomes through Qualitative Research Integration	Chapter 4 Section 4.4	71-92	Accepted by Bone & Joint Open June 24

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Chapter 1. INTRODUCTION

1.1 Introduction to the Thesis

This chapter presents an introduction to the study as well as providing an overview of the structure of the thesis. It outlines the journey through initial research idea to final research question and presents a brief overview of the Young Hip study. The background and rationale behind the research question and the study's aims and objectives are detailed more thoroughly within Chapter 2.

1.2 Overview of total hip replacements (THR)

Total hip replacements (THR) are widely recognised as a cost effective and successful treatment for painful and limiting hip conditions in the older patient (Learmouth et al., 2007). Despite originally being an operation targeted at patients over 65 years of age, its use in younger patients is increasing (Kurtz et al., 2009). The hip is a ball and socket joint which is stabilised by a combination of the bony configuration and the complex muscles and ligaments surrounding it (Mirza et al., 2010). The anatomy of the hip is presented in Figure 1. The ball component consists of the femoral head which is surrounded by the acetabulum (the socket), this is shaped similar to a horseshoe and is situated within the pelvis (Radin, 1980).

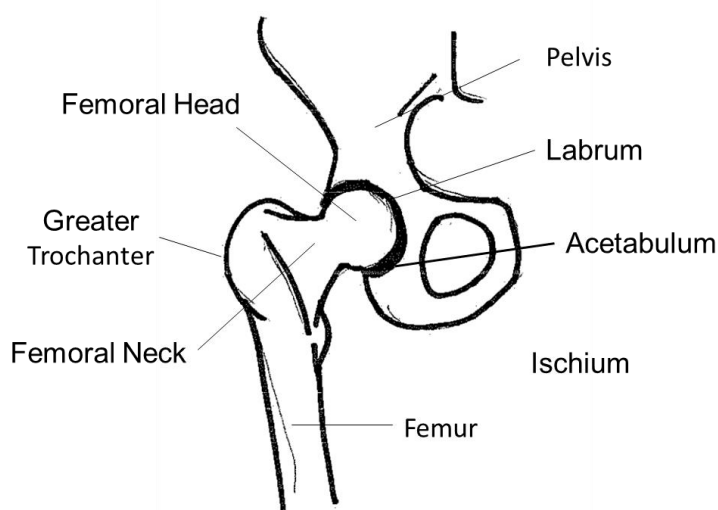


Figure 1. Simplified anatomy of the hip joint (illustration done by author).

The femoral head and acetabulum are primarily made from spongy trabecular bone which has some ability to be deformed without sustaining structural damage (Radin, 1980). This enables the joint to withstand the significant weight and pressure placed upon it by the body

by spreading the load across the joint. It is estimated that the human hip joint withstands, with cyclical loading, the equivalent of three - six times body weight per year (Nordin et al., 2001), this increases to seven - eight times body weight in sporting activities (Mirza et al., 2010). The hip joint allows for a wide range of movement, the three axes of hip joint movement include flexion-extension, abduction-adduction, and internal-external rotation (Baker and Bitounis, 1989) (see Figure 2).

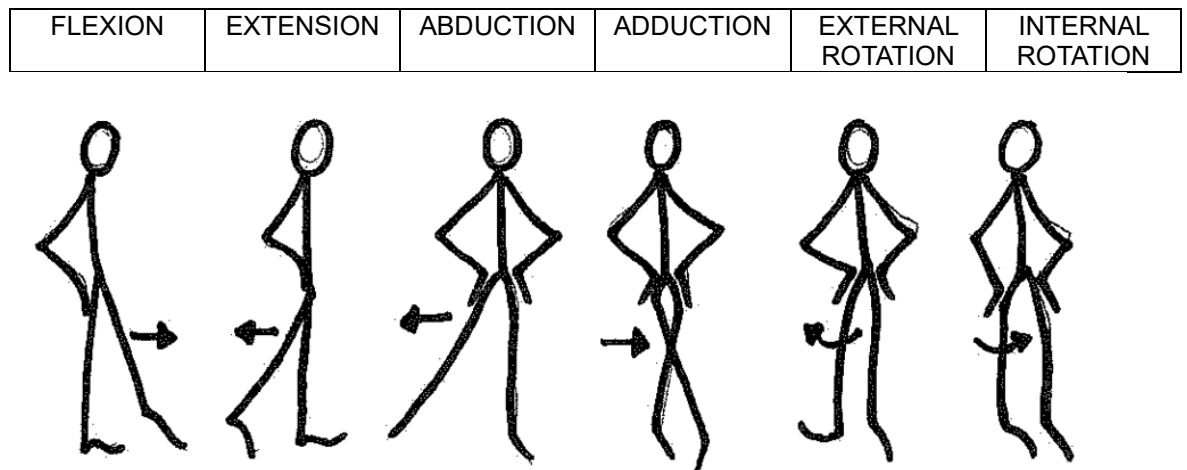
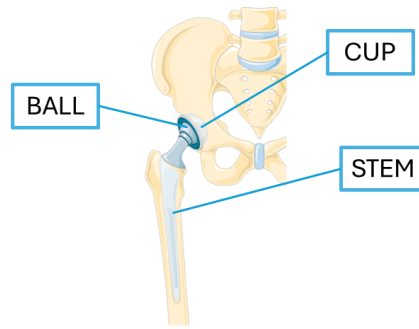


Figure 2. Movements of the Hip Joint (illustration done by author)

Due to both the range of movement required and the weight exerted upon the joint, the hip is considered as one of the more complex and essential joints in the human body (Baker and Bitounis, 1989). Thus, replacing this joint requires consideration of several certain unique design requirements to maintain the joint's ability to continue to fulfil its purpose.

The basic components of a total hip replacement are designed to replicate the bony anatomy of the hip. A metal or ceramic ball replaces the femoral head and is attached to a metal stem, this is inserted into the top of the femur for stability. A metal cup (usually titanium) with an inner plastic liner is attached to the acetabulum, this allows the prosthetic joint to rotate smoothly (Figure 3). This is a significantly simplified description of the components included with THR. In reality, there is a plethora of decisions including different materials, designs, and techniques currently available to orthopaedic surgeons when considering the best implant for their patient. However, a basic understanding of the evolution of the surgical procedure itself, and the development of the modern THR is presented in Section 2.3.



Janssen, O. (2019) Wikimedia Commons. Available at https://commons.wikimedia.org/wiki/File:Replacement_surgery_-_Total_hip_replacement_-_Smart_Servier.png. Image Accessed 04/10/2024.
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Figure 3. Simplified image of a total hip replacement showing the separate components of implant (ball, stem, and cup) (Jansenn, 2019)

1.3 Evolution and development of the YOUNG HIP study

Despite the growing numbers of younger patients undergoing THR, the patient information and education provided plus rehabilitation pathways remain primarily targeted at the older patient population who are more commonly associated with this procedure. It is unclear if the needs and priorities of the younger patient demographic are being addressed with these current care pathways. Previous research has not acknowledged or explored these concerns. To the researcher's knowledge, there is no qualitative study focussing exclusively on younger patients undergoing elective THR and very limited research including younger patients in qualitative papers exploring THR overall (see Section 3.3).

However, as was pointed out to the researcher by her orthopaedic consultant colleagues, identifying a lack of evidence does not mean there is further need for research in this area. To understand if there was a requirement for exploration into this area and if so, what questions were important to be addressed, a public and patient involvement (PPI) questionnaire was posted on social media in Spring 2020. This survey resulted in an overwhelming amount of feedback from younger patients suffering from lower limb musculoskeletal conditions, including conditions requiring THR. This feedback strongly presented a necessity for further qualitative research into younger patients undergoing THR (see Section 3.4).

Young Hip set out to address and explore the priorities and expectations of younger patients undergoing THR. The Young Hip study built upon the topics highlighted within the PPI survey to enable younger THR patients voices to be heard.

When assessing the success of an intervention in orthopaedic practice, clinicians and researchers use a variety of methods. These include, length of inpatient stay, infection rates, dislocations, and length of time a replacement joint lasts before requiring further intervention. To assess outcomes of orthopaedic interventions from the patient's perspective, healthcare professionals employ Patient Reported Outcome Measure (PROMs) questionnaires. PROMs are questionnaires made up of multiple-choice answers and numerical scales, the patient's answers contribute towards a scoring system which indicates any potential improvement or deterioration in their condition. However, PROMs typically used in assessing THR address only a limited range of functional activities and daily living tasks, confining the patient's voice to only those topics included in the PROMs (Hamilton et al., 2017). It is unclear if PROMs appropriately identify and consider the aspects of undergoing THR and recovery important to the younger patient. To address this uncertainty, PROMs were completed by each participant in the Young Hip study at the same time points that qualitative data was collected. The purpose of this was to compare the outcome measures used in clinical practice (PROMs) to the participants own voice and personal consideration of their recovery, and to assess if the PROMs gave an accurate representation of the participants opinion of their experience. Section 2.4.4 and Section 4.10.2 detail the variety of PROMs available in THR and consider potential concerns and limitations in their use.

1.4 Antecedents to the study

The focus of this research arose from my experience of working as a research nurse on a study exploring the effectiveness of bisphosphonate medication on patients suffering with avascular necrosis of the hip joint. Whilst involved in this project, I was surprised on the number of younger patients who were being identified and listed for an elective THR. I had always presumed that this was an operation targeted almost solely at an older population and was extremely rare in persons under retirement age. The numbers of younger patients I was witnessing undergoing this surgery indicated that this was by no means an accurate assumption. However, it appeared that though these patients were closer to my age and at my point of life experience, they were being treated and cared for in the same way and with the same perceived goals as patients over twice their age.

1.5 Structure of the Thesis

This integrated thesis is divided into eight chapters and includes two published papers and one paper accepted for publication in *Bone & Joint Open*.

Chapter 2 presents an overview of the current practice and evidence in hip replacement, including the history and development of THR. It presents the common conditions it is intended to address, current healthcare policies and NHS pathways, and the conceptual framework around patient-centred-care.

Chapter 3 focuses upon the younger patient population undergoing THR, it considers the current clinical perceptions are around younger patients. The chapter includes a published systematic literature review identifying and analysing qualitative research focusing on young THR patients. It proceeds to present a published public and patient involvement study that was conducted to understand if there was a requirement for further research into young patients undergoing THR and contributed to informing some aspects of the study design for Young Hip. The chapter concludes by outlining the aims and objectives of the Young Hip study.

Chapter 4 presents the methodological background of the Young Hip study; it includes an exploration of qualitative research methods in the trauma and orthopaedic research before continuing by describing the theoretical underpinnings of the study methods and the rationale and background of selecting an interpretative methodological analysis approach in conducting the research. The chapter then progresses to outlining and detailing the methods in conducting the study using the interpretative phenomenological analysis approach as described by Smith et al (2009). The findings of Young Hip are presented in Chapter 5.

Chapter 6 discusses the study findings within the current evidence base and healthcare pathways, it highlights and considers where contributions to current knowledge and introduction of new understandings can be identified.

Chapter 7 presents the reflections of the researcher and the challenges personally experienced when conducting the Young Hip study.

Chapter 8 presents the conclusion to the thesis along with recommendations to advance and develop practice, policies, and further research to ensure the voices of young THR patients are being heard and their priorities addressed.

1.6 Summary of chapter

This chapter begins by presenting a brief overview of the study evolution and its development in the very early stages, it then proceeds to describe the antecedents of the research. The chapter concludes by setting out the structure of the thesis, clearly explaining how it is presented.

Chapter 2. BACKGROUND

2.1 Introduction to chapter

To underpin the research undertaken in this thesis, this chapter presents an overview of the range of musculoskeletal conditions that can be treated with a total hip replacement. It explores and presents a brief history of the development of THR surgery and considers the perception of clinicians and the public of THR, as well as presenting the patient demographic that have a THR. The chapter continues by presenting the healthcare guidance and strategies that inform clinical practice. It concludes by presenting the conceptual framework of person-centred care within healthcare.

2.2 Reasons for surgery and various causes

Elective THR was designed to address a wide range of conditions of the hip joint. These conditions include but are not limited to osteoarthritis (OA), rheumatoid arthritis (RA), osteonecrosis or avascular necrosis (AVN), and childhood hip conditions. Though the aetiology of each condition differs, the presentation and symptoms can be similar, and these include pain and loss of function and mobility.

2.2.1 Osteoarthritis

OA is the most common cause of chronic hip pain and disability worldwide (Jotanovic et al., 2015) and the most common reason for surgical intervention in the form of THR (Ferguson et al., 2018). OA of the hip is defined as degeneration of the tissues of the hip joint, including hyaline cartilage, fibrocartilage, bone, and synovium (Hoaglund and Steinbach, 2001), and can be categorised into primary or secondary OA (see Table 1).

Table 1. Characteristics and causes of primary OA and secondary OA.

	Primary OA	Secondary OA
Characterisation	OA without identification of any pre-existing condition	OA resulting from underlying condition.
Aetiology	Largely unknown	Caused by pathological changes due to pre-existing conditions
Causes	Considered to be damage from repeated excessive loading and stress on the joint over time (NICE, 2020).	AVN, RA, trauma, sepsis, Pagets disease, and childhood conditions like developmental dysplasia of the hip (DDH) and slipped capital femoral epiphysis (SFCE) (Hoaglund and Steinbach, 2001).

This definition of primary OA as a wear-and-tear condition developing in persons as they age is presented by the majority of sources and is enforced by the prevalence of the disease in the middle aged or older population (Aigner et al., 2004). However, it is increasingly recognised that the explanation of general wear-and-tear with age is not always relevant to the younger person diagnosed with primary OA, therefore the aetiology of “Primary OA” is less clear and is the subject of ongoing research (Jotanovic et al., 2015; Ganz et al., 2008; Beck et al., 2005).

Regardless of the aetiology, there is no cure for OA. OA can affect any joint and requires ongoing management to minimise pain, continue physical activities, and maintain quality of life (NICE, 2020).

2.2.2 Rheumatoid Arthritis (RA)

RA is a multifactorial autoimmune disease in which the body’s immune system attacks the healthy joints and tissues (Zhang et al., 2017). The disease inflames the synovial lining in the joint and can cause pain, stiffness, swelling and loss of function and mobility in the joints (Burmester and Pope, 2017). Although the aetiology of RA is unknown, recent advances in medication and disease management can be used to slow the disease progress and delay the need for joint replacement (Myasoedova et al., 2010).

2.2.3 Osteonecrosis or Avascular Necrosis

Osteonecrosis (also known as AVN) is not a specific disease but the final common pathway of several conditions leading to bone death (Pavelka, 2000). The most common site of osteonecrosis is the femoral head, often occurring when the blood supply to the femoral head is decreased (Shah et al., 2015). This results from a variety of causes, including trauma, glucocorticosteroids, alcoholism, and connective tissue disorders. However, osteonecrosis can also be idiographic in nature and present with the absence of any associated risk factors (Lieberman et al., 2002). Early intervention (both non-surgical and surgical) can improve patient outcomes, however, almost 50% of cases in the hip require arthroplasty (Pavelka, 2000).

2.3 History and development of THR

THR is lauded as one of the major achievements in modern orthopaedic surgery in the 20th century (Markatos et al., 2020). The operation has completely revolutionised the treatment of a malfunctioning hip and is currently one of the most widely performed procedures in orthopaedic practice, with over 1 million THR completed every year worldwide (Ferguson et al., 2018). The advancement of implant technology and practice has been consistently

progressing since the introduction of modern THR, which was pioneered by Wiles (1957) and Charnley (1961), among others (Smith-Peterson, 1948), during the mid-20th century. However, for over 100 years prior to this, surgical techniques on hips have been attempted and developed. Knowledge of the history of THR can contribute to a greater understanding behind the reasons for patients undergoing THR, and factors contributing to surgeons' approaches and decision making within the operative process. Key developments in the evolution of THR are presented in the timeline in Figure 4.

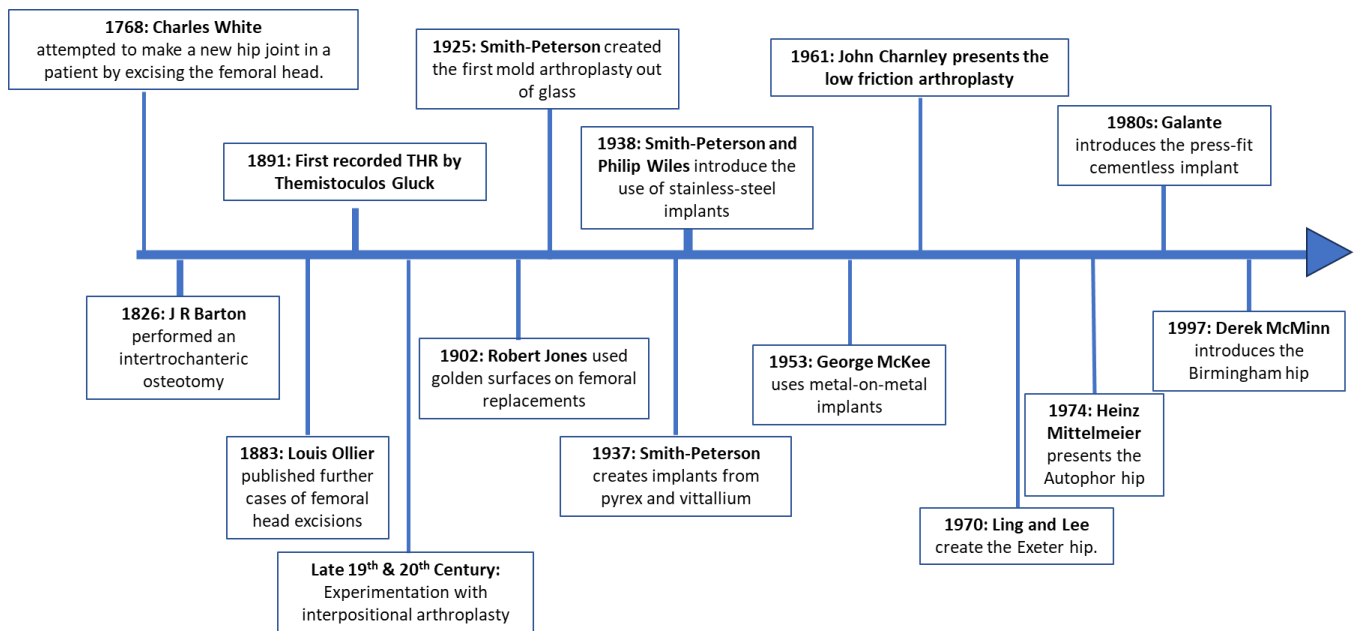


Figure 4. Timeline of the development of the modern THR

2.3.1 Early Techniques

In 1768 in Westminster Hospital, London, Charles White attempted to operate on a patient suffering from hip osteomyelitis. Using means and surgical techniques of the period, he excised the femoral head in an attempt to create a new hip joint in the patient, the intention being to create an early hip arthroplasty without implants (Markatos et al., 2020). In Philadelphia, in 1826, John Rhea Barton performed an intertrochanteric osteotomy in a 21-year-old patient with an ankylosed hip. Further cases of femoral head excisions for ankylosis were published by Louis Ollier in 1883 (Gomez and Morcuende, 2005).

The earliest recorded attempts of replacing the hip occurred in 1891 in Germany. Professor Themistocles Gluck used ivory implants and cement made of pumice, rosin, and plaster to replace the femoral heads and acetabulum of patients whose hip joints had been destroyed by tuberculosis (Gomez and Morcuende, 2005). Unfortunately, due to bone absorption these implants failed. In the late 19th and early 20th century, surgeons proceeded to

experiment with interpositional arthroplasty, this involved placing various tissues (fascia lata, skin, pig bladders submucosa) between articulating surfaces of the arthritic hip (Learmonth et al., 2007). In 1902, Robert Jones published the results of using golden surfaces to cover for missing parts in femoral head replacements (Jones and Lovett, 1929).

The American surgeon Marius Smith-Peterson created the first mold arthroplasty out of glass in 1925. Despite glass being a biocompatible material, it could not withstand the pressures going through the hip joint and shattered. In 1937, Smith-Peterson went on to introduce components created from pyrex and vitallium (a material invented by Venable and Stuck) (Smith-Peterson, 1948). Along with Philip Wiles from the Middlesex Hospital of London, in 1938, Smith-Peterson began to trial stainless steel, which is the current material of choice. This became the first total hip replacement that was fitted to the bone with screws and bolts (Smith-Peterson, 1948; Wiles, 1957).

George McKee was the first to use metal-on-metal prosthesis on a regular basis. In 1953, he used a modified Thompson stem (a cemented hemiarthroplasty used to treat neck of femur fractures) with a new one-piece cobalt-chrome socket as the new acetabulum. Though this prosthesis showed good survival rate of the implant, the method became unpopular in the 1970s due to local effects of the metal particles observed during revision surgery for prosthesis failure. (McKee and Watson-Farar, 1966).

Sir John Charnley, an orthopaedic surgeon working at Manchester Royal Infirmary is considered the father of the modern THR (Ring, 1971). In the early 1960s he designed and introduced the low friction arthroplasty. The low friction arthroplasty consists of three parts, a metal femoral stem (with a smaller femoral head than used previously, which reduces wear due to the smaller surface area), a polythene acetabular component, and acrylic bone cement (used regularly by dentists) to stabilise the implants (Charnley, 1961).

In 1970 in Exeter, Ling and Lee constructed and implemented an implant that could be firmly fixed to the bone using acrylic bone cement. This implant consisted of a tapered stem. This design was named the Exeter hip and is still routinely used today (Kingston and Walsh, 2001). In 1974, Hienz Mittelmeier, introduced an implant of a metal stem and a ceramic cup. This implant was named Autophor and is considered by many orthopaedic surgeons to be the most resistant and effective (Kingston and Walsh, 2001; Amstutz, 2000). Galante presented the press-fit implants in the 1980s, these prosthesis did not require the use of bone cement (Amstutz, 2000).

New innovations have emerged since the 1990s. Minimally invasive THR is becoming more frequently used, minimising blood loss, enabling faster rehabilitation and causing less damage to soft tissues (Learmonth et al., 2007). In 1997, Derek McMinn presented the Birmingham hip. This was the first modern metal-on-metal resurfacing hip implant; the

surgery was less invasive and consisted of a smaller implant to reduce damage to the soft tissues (Amstutz and Le Duff, 2015).

2.3.2 Present Day

With the introduction of robotic and computer assisted surgeries now revolutionising surgeries, these advances in technology will ensure the THR will continue to develop and improve.

The number of primary THR has historically increased annually in developed countries (Ferguson et al., 2018). Now, more than 95% of artificial hip joints survive beyond 10 years, and, despite Charnley's prediction, around 58% last beyond 25 years (Evans et al., 2019). However, as the number of successful operations has increased, techniques have become more standardised and the average age of those undergoing THR has reduced (Kurtz et al., 2009). Due to this, clinicians have become more aware of implant failure due to wear of bearings, thus there is now a variety of different bearings and techniques that can be combined to provide better outcomes, fewer complications, and longer implant survival rates (Amstutz and Le Duff, 2015). The implant type and technique utilised is selected by the clinician based on their experience and patient factors such as age, weight, levels of activity.

The National Joint Registry (NJR) was established by the Department of Health and Welsh Government in 2002 to collect data about hip and knee replacement in England and Wales (NJR, 2024). The purpose of this was to capture and analyse outcomes, trends, and patterns in joint replacements throughout the UK (NJR, 2024). The NJR is now the largest orthopaedic registry in the world with over 3.7 million records, with around 250,000 records submitted annually and growing in number year by year (NJR, 2024).

2.4 Current Care Pathways

2.4.1 Healthcare policy context

Continuous quality improvement has been a key strategic priority in the NHS since the 1960s. A variety of reformed policies and initiatives have been implemented over the decades to promote quality improvement (Darzi, 2008; Department of Health, 2010). The COVID19 pandemic reinforced the necessity for further strategic reforms in improving health and social care and addressing shortcomings and inequalities within the NHS (Coyle et al., 2021). The new structures and responsibilities across the NHS, introduced by legislation such as the Health and Social Care Act 2022, promote using the experience and learning from the COVID19 crisis to ensure the health and social care system can provide the greatest possible improvements to quality care and wellbeing (NHS England, 2022).

The consistent requirement of strategic reforms is in response to the broad variety of societal factors in the UK including: an aging population, new treatments, unhealthy lifestyles, technological advances, and patients' increasingly complex health needs, changing public expectations and increasing demand on services (Department of Health, 2014).

The strategic reforms implemented in the years throughout and after the COVID19 pandemic reinforce the key principle of the NHS Constitution (Department of Health, 2023) which specifies that the patient must be at the centre of everything the NHS does and pledges that all patients are entitled to appropriate care and treatment for them, meeting their needs and reflecting their preferences. Failure to adhere to this principle and the refusal to listen or place the patient at the centre of healthcare is a significant factor in the shortcomings and failings commonly identified in the NHS (Francis, 2013). All healthcare staff including nurses have a key role in putting people first, challenging discriminatory attitudes, acting as an advocate for vulnerable patients, and enhancing care by gathering feedback from a range of sources (NMC, 2018a).

Traditionally, the success or failure of orthopaedic interventions was assessed and reported by surgeons not the patients (Ashby et al., 2009). There remains significant potential for patients to possess a more integral role in healthcare processes and pathways. To optimise patient satisfaction and outcomes, it is essential that patient's views routinely feed into service provision (Edwards, 2002). Patients and service users who are empowered and have greater control in their own treatment and recovery experience better outcomes (Department of Health, 2001a; Jones et al., 2000; Larner, 2005).

2.4.2 National Institute for Health and Care Excellence (NICE) guidelines

The National Institute for Health and Care Excellence (NICE) are responsible for publishing evidence-based guidance on health and social care practice in England. The NICE guidelines are to aid health and social care professionals to prevent ill health, promote and protect good health, improve the quality of healthcare services, and to adapt and provide healthcare services (NICE, 2024b). These recommendations cover most patients with specific conditions or needs, or people in particular circumstances of situations.

The NICE Guideline covering primary THR was last updated on 4 June 2020, and provides evidence-based recommendations to guide decision making in caring and treating patients undergoing a primary joint replacement (hip, knee, shoulder) (NICE, 2020). The advice covers care before, during and after joint replacement surgery and is aimed at healthcare professionals, patients, patients' families and carers, and non- NHS services providing services to the NHS.

Notably, shared decision making between patients and healthcare professionals is the first recommendation on the NICE guidelines for hip, knee, and shoulder replacement. The recommendation states: “People have the right to be involved in discussions and make informed decisions about their care” (section 1.1. NICE, 2020). The guideline states that the patient should be provided with information about; what to expect before, during, and after surgery (including hospital stay, rehabilitation, and recovery period), preparation for surgery and ways to optimise their recovery, wound care, pain management, returning to work, and returning to usual activities (for example, sport, driving, and sexual activities).

2.4.3 Current treatment pathway

The “getting it right first time” (GIRFT) is a national programme first introduced to review elective orthopaedic surgery to address a range of observed and undesirable variations in orthopaedic practice (NHS, 2023). The NHS proceeded to apply this model throughout 40 different surgical and medical specialities. By addressing variations in the way services are run throughout the NHS, and sharing best practice between NHS Trusts, the GIRFT programme aims to improve patient care and outcomes and promote efficiency and cost saving (NHS, 2023).

The GIRFT recommended care pathway for THR was published in November 2022 and includes all aspects of the patient journey from initial presentation with symptoms to surgery to rehabilitation and follow up. Steps throughout the pathway are categorised into five timepoints; presentation and referral, triage and assessment, procedure, enhanced recovery, follow up. Each step includes key advice and recommendations for clinicians when guiding their patients through this pathway. A simplified example of this pathway is demonstrated in Figure 5, the full GIRFT pathway is included as Appendix 1.

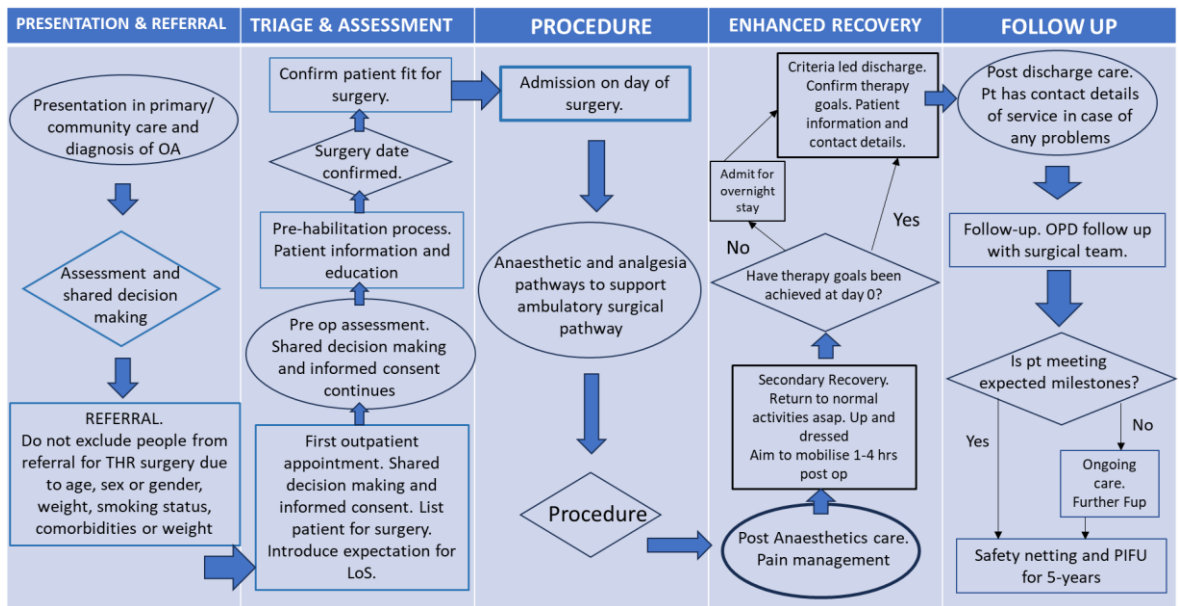


Figure 5. Simplified GIRFT Care Pathway for primary elective THR (NHS, 2023)

Shared decision making and ongoing informed consent (which requires patient and healthcare professionals to be clear and understand the complete diagnosis, full prognosis, and all treatment options (NICE, 2023) is an ongoing requirement throughout the pathway. Each step promotes patient information and education, and strongly encourages good and regular communication to manage patient expectations (NHS, 2023).

2.4.4 Patient Reported Outcome Measures (PROMs)

PROMs are questionnaires routinely used to measure the success of the operation from the patients' perspective (Larsson et al., 2019; Hamilton et al., 2017). There are a variety of types of PROMs designed and used for musculoskeletal hip conditions and THR (Falez et al., 2022). For example, Forgotten Joint Score (FJS), Hip disability and Osteoarthritis Outcome (HOOS), Copenhagen Hip and Groin Outcome Score, Oxford Hip Score (OHS) and the Hip Harris score (HHS). PROMs format utilises a scoring system based on the patient's answers to multiple choice questions to assess the patient's opinion about their hip and associated problems, it enables clinicians to quantitatively evaluate symptoms and functional limitations relating to a joint during a therapeutic process (Nilsdotter et al., 2003). The national PROMs programme was introduced to give a measure of the success of the outcome of hip and knee replacement (TKR) from the patient perspective and to provide an indication of the quality of care at the provider level. Initially introduced to address concerns expressed on the outcomes achieved in Independent Sector Treatment Centres (ISTCs) at that time (Browne et al., 2008), the collection of PROMs became standardised across all centres providing NHS-funded care for THR and TKR in April 2009 (Devlin et al., 2010). The PROMs currently used nationally in the NHS for elective THR patients is the Oxford Hip

Score (OHS). However, the best and most accurate PROMs to be used in young patients undergoing THR is a matter for debate (Falez et al., 2022). Evaluation tools such as PROMs were originally designed to assess the outcome of THR in patients over 65 years of age (Falez et al., 2022), with limited available research into the reporting of hip scores in younger adults (Walker et al., 2016; Eneqvist et al., 2018; Delasotta et al., 2012; Bryant et al., 1993). However, different PROMs are not always consistent with each other, and can give differing and contrary measures of success even when completed by the same individual (Bryant et al., 1993).

An aspect often criticised in PROMs is the potential risk of floor or ceiling effects (Conner-Spady et al., 2018). Floor and ceiling effects are identified if the PROMs questionnaire fails to demonstrate a worse score in patients who have clinically deteriorated or an improved score in patients who have clinically improved, for example, the patient initially achieves the best possible score and there is no scope on the scale to demonstrate further improvement, or patients have the lowest score possible and therefore have no room to detect further deterioration (Falez et al., 2022). If floor and ceiling effects are present, it indicates that extreme items are absent in the upper or lower ends of the scale, suggesting limited content validity (Terwee et al., 2007). This causes difficulty in distinguishing differences between those patients with the highest or lowest scores (Ackerman et al., 2021). Additionally, as changes cannot be measured in these patients, it limits the responsiveness and reliability of the PROMs (Falez et al., 2022). These effects can be a result of the PROMs design, or the disease or intervention been considered (Ackerman et al., 2021). Ceiling effects in particular have been reported in many of the PROMs used for hip conditions and surgeries, including the OHS, HOOS, the Copenhagen Hip and Groin Outcome Score, and the HHS (Wamper et al., 2010; Ackerman et al., 2021; Conner-Spady et al., 2018; Gandek et al., 2019). Despite these criticisms, PROMs do give a voice (however broad and limited) to patients that otherwise would be lost. NHS digital database contains the completed PROMs provided by NHS sites (NHS England, 2023). Clinicians and governing bodies can then access and use the information to inform decisions about patient care and quality enhancements. However, there are NHS sites missing from this database despite routinely providing THR for patients, thus even the limited patient voice presented by PROMs is absent for these areas.

2.5 Conceptual framework of person-centred care

The terminology of “Person-Centred Care” (PCC) is frequently cited in healthcare policies and practice (NMC, 2018a; NICE, 2024b). This approach to practice encourages the forming and fostering of therapeutic relationships between healthcare providers, people, and others significant to them in their lives, it is underpinned by values of mutual respect,

empowerment and understanding (McCormack and McCance, 2006). The benefits of PCC are recognised by the World Health Organisation (WHO) (2015) and is cited in a regulation in the Health and Social Care Act (2008). This regulation states that PCC is required to ensure people using a service have care or treatment specifically personalised for them. The Care Quality Commission (CQC) (an independent regulator of health and social care in England) state that PCC is a fundamental and essential requirement in hospital care, and states that each person must receive appropriate PCC and treatment based on an assessment of their needs and preferences (CQC, 2023). The fundamental requirements for PCC are illustrated in Appendix 2 (CQC, 2023).

This approach is not without challenges, however. The Nursing and Midwifery Council (NMC) (2018b) defines PCC as ensuring any treatment or care given to people is decided on by looking at what research has shown to be more effective. The NMC (2018b) goes on to recommend that both the nurse’s judgement and experience and the persons opinion should be considered when choosing the more appropriate treatment for that person. Balancing this duty of care to the person whilst maintaining a focus on working with the best evidence in healthcare decisions can be a significant challenge (McCormack et al., 2017). Promoting and maintaining the person’s identity as central to care decisions and maintaining that in the sense of who they are within the context of their lives is a key foundation in person-centred practice (Ross et al., 2014). The theoretical framework of PCC is demonstrated in Figure 6.

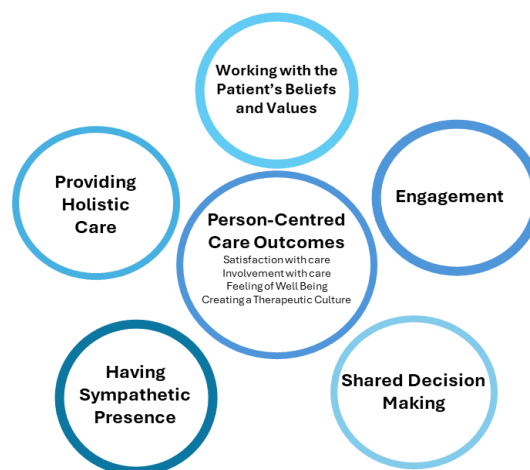


Figure 6. Person-centred care theoretical framework
(Figure designed by author adapted from Parlour et al., 2014).

A national strategy, Compassion in Practice (Department of Health, 2012), surrounds the values of PCC focussing on the “six Cs”: compassion, caring, courage, competence, communication, and commitment. It was introduced to promote a culture of compassionate caring by healthcare staff. The Young Hip study specifically addresses the actions identified

in this strategy by promoting and ensuring that the voices and experiences of patients are heard (Department of Health, 2012). The researcher's commitment to PCC is clearly demonstrated in the research question. The concept of PCC and the researcher's aim to adhere to it when providing care for this patient group was the inspiration for this research project.

2.6 Summary of chapter

This chapter presented a detailed description of the background and clinical significance of THR. It explained common hip conditions that commonly result in the need for THR. The chapter introduced the healthcare pathways and frameworks currently guiding healthcare for THR, and the methods by which patients own perceptions of post-surgical outcomes are currently measured. The chapter is a broad exploration into the care processes and considerations of THR over all patient populations, focus upon the current evidence base for younger patients undergoing THR will be presented in Chapter 3.

Chapter 3. TOTAL HIP REPLACEMENT IN THE YOUNGER PERSON

3.1 Introduction to Chapter

This chapter presents the systematic literature review undertaken to explore the current evidence base on the experiences of young THR patients in their own voice. The chapter continues by presenting a public and patient involvement study intended to inform the necessity of further qualitative research into young THR patients and to identify aspects important to this patient population that may not be addressed by the evidence currently available. The chapter concludes by clearly setting out the aims and objectives of the Young Hip study.

3.2 Perception of THR in patient population

3.2.1 THR in the younger population.

The National Joint Registry (NJR) records data from arthroplasty cases within the UK. It has been mandatory for NHS Trusts to submit information from all consenting arthroplasty patients since 2010 (NJR, 2024). By using the data published by the NJR, it is possible to clearly see the increase in demand in THR over recent years, the NJR also presents the increase in younger patients undergoing THR. The NJR reported 70,153 primary hip replacements in 2010, 4598 (6.5%) of these were in patients under 50 years of age (see Figure 7). In 2019, the total amount of hip replacements reported had risen to 102,797, with younger patients (<50 years) accounting for 6040 (5.8%) of these procedures (NJR, 2024). Both these numbers were predicted to keep steadily increasing year by year (Kurtz et al., 2009), however, the COVID19 pandemic in 2020 and 2021 resulted in the almost complete halt of elective operations such as hip replacements (Oussedik et al., 2020). The pandemic and ongoing pressures on NHS services is still causing a major impact on elective orthopaedic operations and patient waiting lists (Barrett et al., 2024). Despite this, in 2022 patients under 50 years of age accounted for 5304 (5.2%) records out of a total of 101,995 hip replacements (NJR, 2024). The increase in demand of THR in younger patients is evident and is predicted to continue to grow in the future (Kurtz et al., 2009).

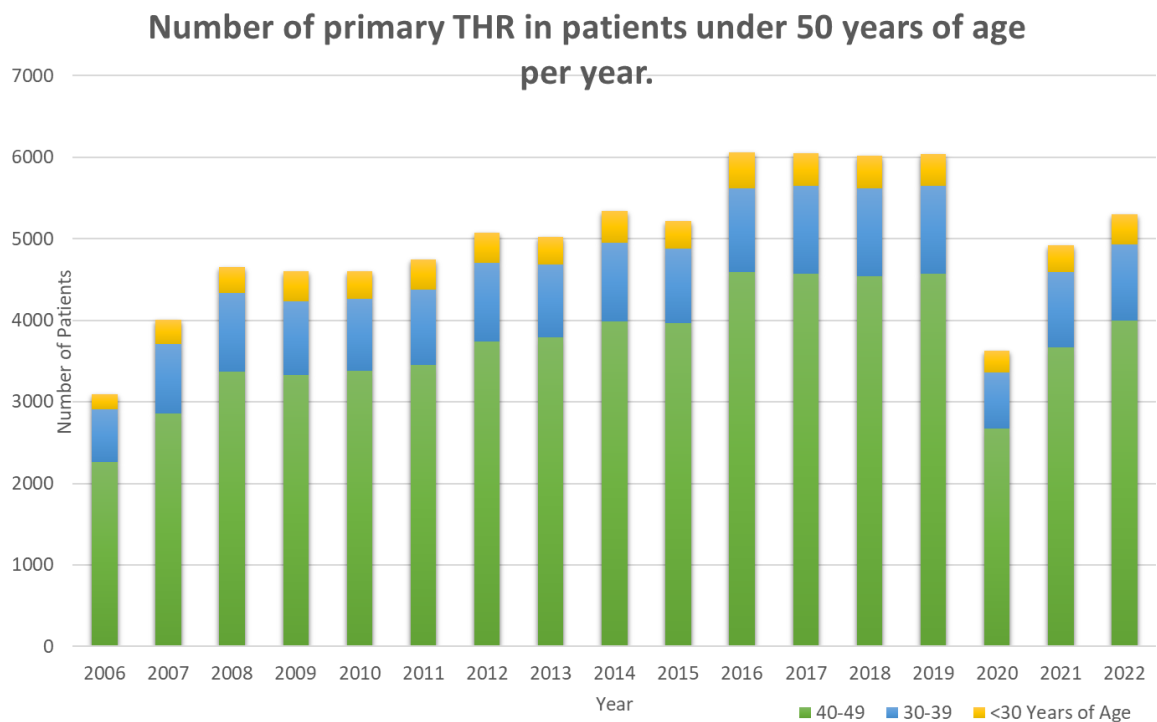


Figure 7. Graph showing increase in THR demand in patients under 50 years of age (graph by author)

3.2.2 Perception of the “young patient” in orthopaedic literature

There is a lack of consensus in the literature surrounding THR patients on the upper age used to define “young” patients. Some studies tend to enforce the upper age parameter at 60-65 years of age when studying young patients undergoing THR (Cowie et al., 2013; Mobasheri et al., 2006; Lie et al., 2000; Negm et al., 2022). 60-65 years of age was historically a common age for retirement from working life (Tilbury et al., 2014; Roebuck, 1979), society also implements financial concessions for persons over this age bracket (Boggatz et al., 2016; Walker, 2005; Vincent, 2003), imposing the perception of 60-65 as a timepoint of which old age commences. As discussed in Section 2.2.1, the most common cause of patients requiring THR is OA (Jotanovic et al., 2015). OA is a condition that often becomes more prevalent with age and is often diagnosed in patients over the age of 50 (Aigner et al., 2004; NICE, 2024a). The incidence of THR dramatically increases in the population aged over 50 years of age (NJR, 2024). This often results in the afore mentioned studies who have an age limit of under 60, presenting participant samples with a high percentage of participants within the 50 to 60 years of age bracket, and often grossly underrepresenting participants who are much younger (Negm et al., 2022; Cowie et al., 2013).

Alternatively, there is a large proportion of orthopaedic literature which studies young patients undergoing THR allocating the upper age parameter as 50 - 55 years of age (Kiran et al., 2018; Adelani et al., 2014; Delasotta et al., 2012; Stake et al., 2015). These are quantitative studies often exploring implant survival times, types of implants used, and patient participation in high levels of activity or sporting activities (Keeney et al., 2015; Malcolm et al., 2014; Adelani et al., 2014; Delasotta et al., 2012; Ritterman and Rubin, 2013; Navas et al., 2021). The topics studied within the literature focussing on the under 50s present an assumption in researchers and clinicians that patients within this age range are highly active sporting individuals, who due to this active lifestyle will wear the implant out much more quickly, subsequently requiring multiple further surgeries (Mason, 2008; Adelani et al., 2014; Munger et al., 2006). Though there has been evidence presented that heavily disagrees with this assumption (Clohisy et al., 2008), there remains a strong presupposition within the orthopaedic speciality that many young patients fit into this category (Hudak et al., 2008; Ritterman and Rubin, 2013; Kahlenberg et al., 2019).

3.3 Systematic Literature Review: What is important to the younger person (<50 years) when undergoing a THR.

A systematic literature review was conducted to explore current evidence and knowledge available in young THR patients. Primary importance in this literature review was placed on qualitative findings in the patient's own voice or opinions rather than quantitative methods more widely used (for example PROMs). This systematic review further demonstrated the absence of qualitative research derived from the patient themselves and compounded the necessity of the Young Hip study. The systematic literature review was published in *Orthopaedic Nursing* in July/ August 2023 and is included below in its entirety. The article below is published under copyright CC by-NC-ND 4.0.

What Is Important to the Younger Person (≤ 50 Years) When Having a Total Hip Arthroplasty

A Systematic Literature Review

Louise Mew ▼ Vanessa Heaslip ▼ Tikki Immins ▼ Thomas Wainwright

Total hip arthroplasties (THAs) are usually performed in older patients. Despite a growing number of THAs in younger adults, it is unclear whether they have similar priorities in recovery compared with their older counterparts. The purpose of this systematic review was to explore younger patients' priorities when undergoing a THA. Multiple databases were searched in September 2021 prioritizing qualitative data. This review was reported using the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) guidelines. Of 14,495 articles screened, nine remained for analysis. Four common themes were discovered: improving function and mobility; pain; relationships; and patient expectations and education. However, there was insufficient information to clarify whether these themes could be attributed directly to younger adults undergoing a THA. The absence of research on THA patients younger than 50 years results in the loss of the voices of these patients. Further research is essential to ensure their needs are identified, addressed, and met.

Introduction

RATIONALE

The objectives of total hip arthroplasty (THA) surgery are to reduce pain, increase function, and improve the patient's quality of life (QOL; Jourdan et al., 2012; Knight et al., 2011; Markatos et al., 2020). The U.K. National Joint Registry (NJR) reported that a total of 101,384 THAs were performed in 2019 (NJR, 2019). This number is predicted to increase year by year as the age of the general population increases (Kurtz et al., 2009). The mean age of patients undergoing a THA is 68 years (Ben-Shlomo et al., 2020), with the majority taking place in patients older than 65 years (Ben-Shlomo et al., 2020; Crowninshield et al., 2006). The incidence of THA in younger adults is increasing, similar to that for the overall population (Aalund et al., 2017; Kurtz et al., 2009). In total, 5,708 (5.6%) patients undergoing a THA recorded in 2019 were younger than 50 years and 14,376 (14%) recorded patients were between 50 and

59 years of age. This presents a significant increase from the numbers recorded in 2011, when 4,828 patients (6%) were younger than 50 years and 10,516 patients (14%) were between 50 and 59 years of age, from a total of 76,357 patient records (NJR, 2019). When considering THA in younger adults, many factors influence clinical advice, including patient activity levels, timing of surgery, fixation method, implant, and bearing-couple choice (Wang et al., 2016). Not only do these factors have an impact on implant longevity but they also influence the ease and likelihood of future revisions (Wang et al., 2016). Surgical attitudes toward THA in younger adults have become more positive throughout the years (Kumar et al., 2017). This could potentially be attributed to the increase in implant survival times and, by extension, reductions in planned revision surgeries

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Ethics Approval and Consent to Participate: HRA approval was not required for this study due to no identifiable or personal details being collected. This was confirmed by both the Health Research Authority and Milton Keynes Research and Development Department.

The authors declare they have no competing interests.

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enabled by use of new surgical techniques and introduction of modern bearing surfaces and implants (Kamath et al., 2012).

One method of measuring successful outcomes in clinical practice is through Patient Reported Outcome Measures (PROMs) (Larsson et al., 2019), which are completed by the patient to assess symptoms of pain, functional ability, and health status (Wright et al., 2000) and are standardized throughout patient populations to measure the success of interventions from the patient perspective (Larsson et al., 2019; Wright et al., 2000). Extensive attention has been given to research examining PROMs and expectations in older patients (Conner-Spady et al., 2014; Mahomed et al., 2002; Nam et al., 2015; Scott et al., 2019), and PROMs are widely recognized as an effective outcome measurement tool. However, scarce attention has been paid in examining potential differences in PROMs between the rapidly growing younger patient population requiring THA and their older counterparts (Malcolm et al., 2014).

Literature using qualitative research to inform orthopaedic practice is less common but informative (Gooberman-Hill et al., 2011). Through observation and interpretation, qualitative research strives to gain a deeper understanding of the behavior, experience, attitudes, intentions, and motivations of participants (Braun & Clarke, 2013). A qualitative approach is much more effective in exploring patient experiences (Rapport et al., 2013). The need to understand the psychological impact and experience of orthopaedic patients throughout their treatment and recovery was highlighted in previous studies exploring patients with hip fractures (Zidén et al., 2010), where qualitative methods identified many areas of importance to patients that were not evident in the existing outcome measures (Archibald, 2003).

Knowledge of the potentially differing needs of this patient group can support nurses to provide the best quality care possible. Nursing practice requires an individualized, holistic approach toward patients (Van Rooyen & Jordan, 2013). By listening to patients, exploring their experiences, and involving them and their families as healthcare partners, nurses can more effectively support and address the needs of this patient population (Janes & Serrant, 2018).

OBJECTIVES

Patient demographics such as age, gender, and preoperative QOL influence patient-reported outcomes (Aalund et al., 2017). Current knowledge and practice are heavily informed by the views of the predominantly older patient population that historically undergoes THA surgery. It is unclear whether outcome priorities and goals important to older patients are as important to younger THA patients or, indeed, if younger THA patients consider other outcome priorities more important than those currently measured using standard PROMs. The purpose of this systematic literature review was to explore young adults' priorities and concerns when undergoing a primary elective THA. The search explored studies focusing on the priorities identified by patients themselves.

Methods

This systematic review was conducted and reported in accordance with the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analysis) guidelines (Page et al., 2021).

REGISTRATION AND PROTOCOL

This systematic literature review is registered under the PROSPERO international register (Registration No. CRD42021279411).

INCLUSION CRITERIA

Studies were included if they included participants 18–50 years of age who had undergone a primary THA and used qualitative data or free-text reported outcomes. Studies were excluded if they utilized only standard PROMs in reporting outcomes or reported on the operative procedure only. This ensured that the topics assessed in the included studies were not limited to those addressed by the PROMs tool. Only articles published in the English language were included.

SEARCH STRATEGY

The literature review was based on systematic searches in multiple literature databases. The approach was adopted following a scoping exercise, which resulted in no other systematic review in this subject area.

The search terms were developed using the PIO search strategy (Akobeng, 2005). The PIO search strategy is considered appropriate for exploratory research questions focusing on qualitative research. Key words are divided into three categories: Population, Intervention, and Outcome (Jenson, 2019; Munn et al., 2018). Table 1 demonstrates the PIO search strategy used in this literature review and its relation to the inclusion/exclusion criteria.

Systematic searches were conducted using all possible combinations of the three categories of key words; these included words such as “total hip arthroplasty, priorities, expectations,” amongst others. A full list of included words can be found in Table 2. An example of the combinations of words used in the search strategy is demonstrated in Appendix A.

The searches were not limited by historical time constraints or geographical limitations. Forward citation searches and the reference lists of key full-text articles included in the review were manually checked by the researcher to identify any potential eligible studies.

SELECTION PROCESS

An electronic search took place using Cochrane, MEDLINE, AHMED, Emcare, CINAHL, Web of Science, Scopus, BNI, and EMBASE databases by the primary researcher. Studies reported empirical findings on the priorities and goals expressed by young patients (<50 years) when undergoing a THA. The consensus in the literature appears to classify “young patients” undergoing a THA as younger than 50 years (Crowninshield et al., 2006;

TABLE 1. PIO FRAMEWORK (EBSCO, 2019) AND INCLUSION/EXCLUSION CRITERIA

PIO	Inclusion	Exclusion
Population	Adult patients between the ages of 18 and 50 years, inclusive, who have undergone or are scheduled to undergo an elective primary THR.	
Intervention	Elective primary THR. All potential chronic health conditions resulting in the need for THR will be included.	THR used to treat traumatic fractures or dislocation of the hip joint. Literature exploring implant survivorship and revision surgeries, studies exploring surgical approaches or implant types, studies exploring the hospital inpatient stay and operative procedure only will be excluded.
Outcome	Eligible studies will include data gathered from the patient, either by qualitative methods or by free-text questions on standard PROMs.	Research that measures outcomes by exclusively using standard PROMs tools will be excluded.
Types	Qualitative, quantitative, and mixed-method studies are included if reporting qualitative data from the patient.	
Date range	No limit	
Geography	Worldwide	Note will be taken of studies in countries where the health service is comparable with the National Health Service.
Language	English text	Non-English text

Note. PROM = Patient Reported Outcome Measures; THR = total hip replacement.

Malcolm et al., 2014; Ravi et al., 2012). To be consistent with the literature classification, the systematic literature review enforced the upper age limit as 50 years. Primary observational studies with retrospective, cross-sectional, or prospective research design and randomized controlled trials were eligible if qualitative data were reported.

DATA COLLECTION PROCESS

Data collection was completed primarily by a single researcher; three separate researchers then reviewed the data collected to ensure all important aspects were included. Data collected in the participants' own words relating to the important aspects of their own recovery were sought and prioritized.

TABLE 2. KEY WORDS AND CATEGORIES USED IN DATABASE SEARCHES

Population	Intervention	Outcome
Young patient	Total hip replacement	Priorities
Young person	Total hip arthroplasty	Expectations
Middle age	THR	Importance
Less than 50	THA	Quality of life
	Hip prosthesis	Health priorities
		Perceptions OR Views
		Experiences
		Sport OR Exercise
		Sex OR Relationships
		Function OR mobility
		Pain

Note. THA = total hip arthroplasty; THR = total hip replacement.

DATA ITEMS

Articles selected for the review were analyzed to identify and capture data relating to the following: (1) study features, including study design and year of publication; (2) study population details, including number of participants and participant demographics; (3) data for outcome measures, including results and thematic findings; and (4) limitations, both limitations recorded by the study author and limitations in answering the question posed in this literature review.

REPORTING BIAS ASSESSMENT

All titles and abstracts were manually screened against the eligibility criteria to identify suitable studies. As part of the quality assurance process, 10% of rejected articles were independently reviewed by other members of the research team. Following this, the full text of any studies identified for potential inclusion was retrieved and examined against the eligibility criteria; 10% of the rejected articles at this stage were reviewed by the research team. Any disagreements were managed through discussion with all four members of the team until an overall consensus was reached.

Because of the variation in study designs included, the quality of studies was assessed using a tool developed specifically for conducting quality appraisal of mixed studies, the Mixed Method Appraisal Tool (MMAT; Hong et al., 2018). The MMAT was designed for the appraisal stage of systematic mixed studies reviews, for example, those that include qualitative, quantitative, randomized controlled trials, observational, and mixed-methods studies. This tool appraises transparency, recruitment, method of data collection, and outcome measurements using a "yes," "no," or "can't tell" scoring system, thus appraising

the quality of the studies as high, moderate, or low. The outcome of this assessment is presented in Appendix B.

METHOD OF ANALYSIS

In the studies using qualitative design, a three-phase narrative synthesis method was used as explained by Popay et al. (2006). These steps consist of developing the preliminary synthesis, exploring relationships in the data, and assessing the robustness of the synthesis product. The preliminary synthesis of the findings in the included studies occurred during the data extraction stage. The results of the studies were organized by identifying and describing textually, maintaining “text in context” (Sandelowski et al., 2013). This identified the findings and patterns within and throughout the included studies while maintaining context. Heterogeneity was examined by assessing differences and similarities within the context, outcomes, and mechanism of the identified studies (Linden & Hönekopp, 2021). This technique allowed the detection of any emerging themes across the studies in relation to the issues important to young patients when undergoing a THA.

Results

STUDY SELECTION

The database searches identified 14,495 records. These record titles and abstract were screened, and 313 records were assessed as being relevant to the review objectives; a further 4 studies were identified through reference lists and forward citations. Records were entered into Endnote, and once duplicates were removed, 214 records remained. In total, 182 records were excluded because of a lack of qualitative data or for relying solely on PROMs data to inform outcomes. Thirty-two full-text articles were screened against the inclusion and exclusion criteria, 18 articles were excluded for reporting no qualitative data, four were excluded for the participant age groups being older than 65 years, and one was excluded for having no hip-related data. The screening process resulted in identification of nine articles that satisfied the inclusion criteria for the final review. Figure 1 details the search and screening process in a PRISMA chart.

Search results fitting the inclusion and exclusion criteria were limited. All nine articles assessed as meeting the eligibility criteria had limitations in answering the objective of the literature review. The nine studies all involved patients younger than 50 years who had undergone a THA and incorporated qualitative data in the study design. However, each study was designed to answer a specific question and none of these aligned exactly to that posed in this article. No study focused on the outcome priorities of younger THA patients.

Eight studies used qualitative methods in their design, with one study using mixed methods (Lafosse et al., 2008). Lafosse et al. (2008) used postal questionnaires and included space for additional comments by the participant. No additional comments were reported fully within the article, however, nor attributed to specific patient ages.

Seven studies were retrospective in design, and patients were asked to record their data postsurgery

(Berg et al., 2019; Fujita et al., 2006; Goodman et al., 2020; Lafosse et al., 2008; Montin et al., 2002; Singh et al., 2020; Sjøveian & Leegaard, 2017), one study included preoperative interviews (Demierre et al., 2011), and one study covered the early recovery period—9 weeks from the day of operation (Strickland et al., 2017). Six studies used semistructured qualitative interviews at various timepoints through the patient journey (Berg et al., 2019; Fujita et al., 2006; Montin et al., 2002; Sjøveian & Leegaard, 2017; Strickland et al., 2017), and two studies utilized a nominal group technique (NGT). An NGT employs a highly structured group discussion format to achieve group consensus on a specific topic (Goodman et al., 2020; Singh et al., 2019). Singh et al. (2019) used this method to qualitatively explore patient perspectives on what constitutes hip or knee arthroplasty failure. Forty-two participants were divided into eight nominal groups; two of these groups consisted of participants younger than 45 years. However, the study did not identify how many of these had undergone THA surgery, as operations were recorded as “total knee arthroplasty (TKA) or THA.” The NGT was also used by Goodman et al. (2020) to explore patient perspectives of outcomes after TKA and THA. Goodman et al. (2020) added younger adults to the study after it was noted that the initial participant sample included an insufficient number of younger participants. As a result, two groups of participants younger than 45 years were added to the study. These groups totaled nine participants, with seven of them undergoing a THA.

Only three of the review studies exclusively explored participants undergoing a THA (Fujita et al., 2006; Lafosse et al., 2008; Montin et al., 2002); the other six articles also included patients undergoing a TKA, and in some instances revisions of joint arthroplasties in their Method and Results sections. These studies did not differentiate which joint was operated on within their findings, making it difficult to attribute any themes or findings to THA patient groups. All the studies used methods of thematic analysis when presenting their results. Findings were sometimes linked to individual participants, allowing some clarity on potential priorities for the population of interest in this review.

RESULTS OF SYNTHESIS

All nine studies included in the report consisted of THA patients. However, six of the nine focused on both THA and TKA patients. The nine studies covered a participant population ranging in age from 22 to 92 years and so were not targeted at the younger THA patient.

The nine articles included within this review contain a total of 14 confirmed THA participants reported as being younger than 50 years. Of the five studies (Berg et al., 2019; Demierre et al., 2011; Fujita et al., 2006; Goodman et al., 2020; Sjøveian & Leegaard, 2017) that reported the gender of the THA participants, eight participants younger than 50 years were male and six were female.

Four studies did not specify individual participant age and reported mean age and age range only (Demierre et al., 2011; Lafosse et al., 2008; Montin et al., 2002; Strickland et al., 2017). Singh et al. (2020) reported

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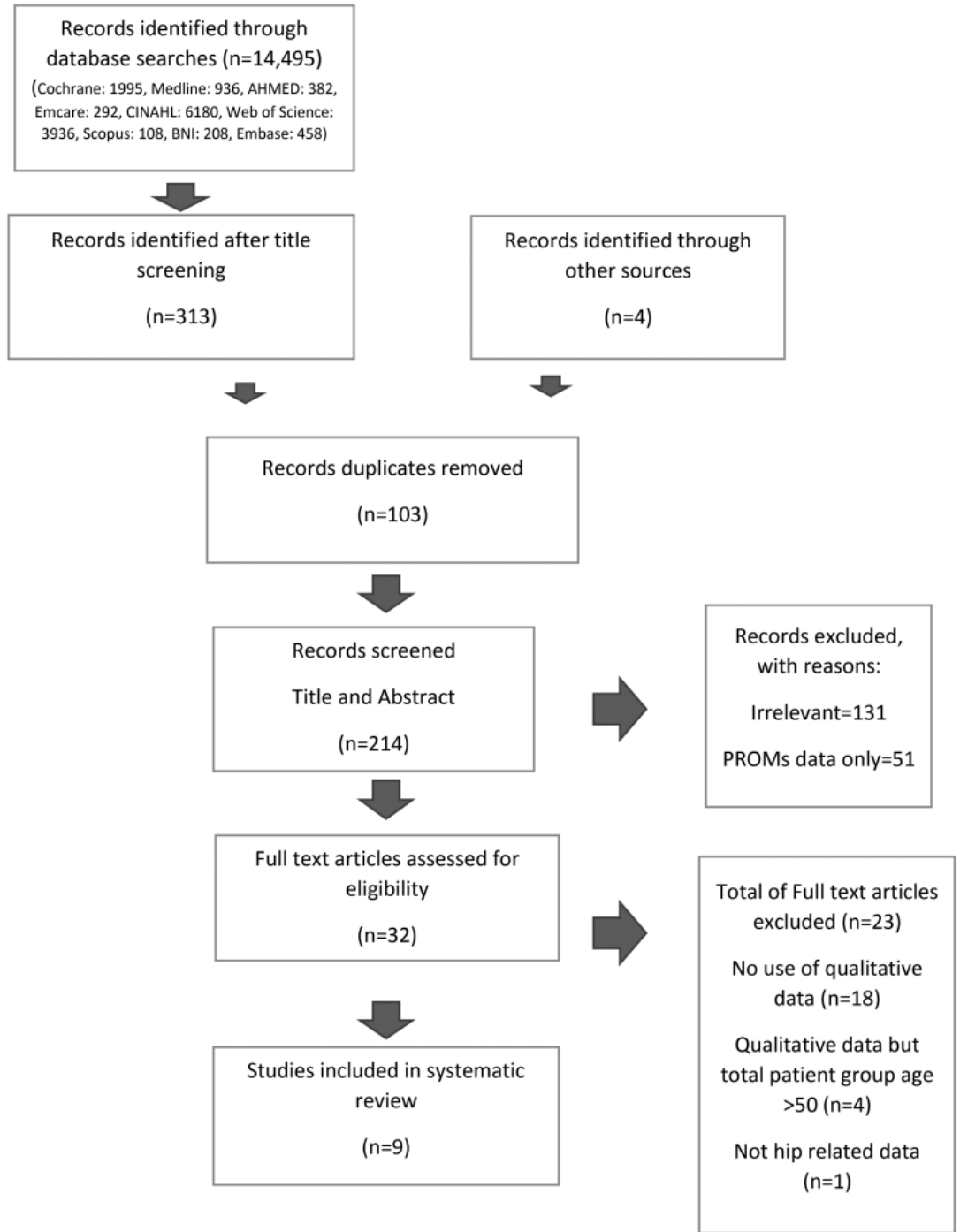


FIGURE 1. PRISMA chart detailing the search and screening process.

seven participants as younger than 45 years but did not differentiate between patients undergoing THA and TKA. Thus, it was not possible to calculate the average age of the total included participant sample relevant to this systematic review.

Use of the MMAT appraisal tool identified six studies as moderate to high quality and three as poor to moderate quality; however, the data could not be meta-analyzed because of the heterogeneity in outcome

measures and study aims. A summary of the quality appraisal of the included studies can be found in Table 3.

THEMES

Although unable to attribute specific themes to this review's patient demographic, four topics emerged as common themes in the included studies: (1) pain; (2) mobility and function; (3) relationships; and (4) patient expectations and education.

TABLE 3. CHARACTERISTICS OF INCLUDED STUDIES

Ref	First Author	Year	Place	Aim	Design and Methods	Sample Size	Average Age of Participants	Relevant Sample	Outcomes	MMAT Result
1	Lafosse	2008	Toulouse, France	To determine the significance of sexual difficulties in patients with chronic hip pain before and after surgery.	Observational study, retrospective postal questionnaires	135 THAs	Mean age: 51.8 years; age range: 22–65 years	Not specified	19% considered their sexual difficulties to be severe to extreme prior to surgery. This caused tension and unhappiness in relationships for 7% of participants.	Mixed-methods study assessment 1/5 Low quality (Appendix B)
2	Sjøveian	2017	Norway	What is the patient's experience of pain after discharge? How does the patient manage the rehabilitation process?	Qualitative study, retrospective semistructured interviews	12 total; 6 THAs	Age range: 45–83 years	1 THA	Patients experience varying degrees of pain in first 3–5 weeks after discharge.	Qualitative study assessment 5/5 High quality (Appendix B)
3	Singh	2020	New York	To determine the themes that define TJA failure from the patient's perspective. To assess whether these themes confirm the core set domains endorsed by the PROMs OMERACT.	Observational, qualitative, retrospective study, nominal group method	42 total; 21 THAs	Mean age: 66 years	$n = 7$, not specified if THA or TKA	When defining a failure of total joint replacement, the themes that ranked highest with participants were as follows: (1) pain; (2) adverse postoperative effects; (3) unable to resume normal activities or return to work; (4) little or no improvement in quality of life; and (5) early revision surgery	Qualitative study assessment 5/5 High quality (Appendix B)
4	Goodman	2020	New York	What results matter the most to a patient undergoing/having a knee or hip arthroplasty?	Observational, qualitative, retrospective study, nominal group method	45 total; 20 THAs	Mean age: 65 years	7 THAs	All participant groups ranked the same top three outcomes, though responses varied with age. The younger participant groups rated restored quality of life (including social life) as second in importance and improved function as third.	Qualitative study assessment 5/5 High quality (Appendix B)

(continues)

TABLE 3. CHARACTERISTICS OF INCLUDED STUDIES (Continued)

Ref	First Author	Year	Place	Aim	Design and Methods	Sample Size	Average Age of Participants	Relevant Sample	Outcomes	MMAT Result
5	Fujita	2006	Saga City, Japan	To describe OA patients' experience before and after THA to have a better understanding of patients' perspectives on THA.	Observational, qualitative study, retrospective semistructured interviews	20 THAs	Age range: 45–91 years	3 THAs	Participants reported the following: -Life restricted by pain and disability -Inferiority complex relating to disability -Difficulties with daily activities -Distress over body image	Qualitative study assessment 5/5 High quality (Appendix B)
6	Strickland	2017	Oxford, United Kingdom	To explore patients' perspective of surgery and early recovery when undergoing a lower-limb (hip or knee) arthroplasty.	Qualitative study, perioperative open semistructured interviews	30 total; 16 THAs	Age range: 45–92 years	Not specified	Reported themes consisted of the following: Improving function and mobility Pain Experiences of healthcare Support from others Involvement and understanding of care decisions Behavior and coping Fatigue and sleeping	Qualitative study assessment 5/5 High quality (Appendix B)
7	Demierre	2011	Lausanne, Switzerland	To explore the patient illness experience from the moment the decision is made to perform arthroplasty.	Qualitative study, semistructured interviews	24 total, 12 THAs	Mean age: 57 years	Not specified	Reported themes consisted of the following: Pain consequences generating limitations in functional, psychological, and social aspects. Ambivalence toward pain medication	Qualitative study assessment 5/5 High quality (Appendix B)
8	Berg	2019	Sweden	To explore patients' perspective and experiences of undergoing THA and TKA surgery within the entire fast track care process.	Qualitative study, retrospective semistructured interviews	24 total; 13 THAs	Age range: 44–85 years	1 THR	The importance of person-centered care. Focus on management of daily life, rehabilitation, and recovery. Uncertainty over whether the patient's progress was normal and questions over unfulfilled expectations.	Qualitative study assessment 3/5 (Appendix B)

(continues)

TABLE 3. CHARACTERISTICS OF INCLUDED STUDIES (Continued)

Ref	First Author	Year	Place	Aim	Design and Methods	Sample Size	Average Age of Participants	Relevant Sample	Outcomes	MMAT Result
9	Montin	2002	Finland	To explore the experience of THA patients of being a patient, care received, and of the healthcare organization.	Qualitative study, retrospective semistructured interviews	17 THAs	Age range: 22–79 years	Not specified	Reported themes consisted of the following: Pain, rest, and mobility were major physical experiences	Qualitative study assessment 2/5 (Appendix B)

Note: OA = osteoarthritis; PROMs = Patient Reported Outcome Measures; THA = total hip arthroplasty; TJA = total joint arthroplasty; TKA = total knee arthroplasty.

Pain

The experience of pain is reported as being diverse among participants in eight of the nine studies (Berg et al., 2009; Demierre et al., 2011; Fujita et al., 2006; Goodman et al., 2020; Montin et al., 2002; Singh et al., 2019; Sjøveian & Leegaard, 2017; Strickland et al., 2017). Differing degrees of pain and methods of coping between participants were a common theme. Pain control medication was reported as both a necessity and a curse. Demierre et al. (2011) stated analgesics were viewed as necessary to maintain an acceptable QOL. Participants' concern with the amount of pain medication they were taking preoperatively was evident; seven of the nine studies (Berg et al., 2009; Demierre et al., 2011; Fujita et al., 2006; Goodman et al., 2020; Singh et al., 2019; Sjøveian & Leegaard, 2017; Strickland et al., 2017) reported a decrease in required pain medication postsurgery as an important outcome to the participant. Strickland et al. (2017) and Demierre et al. (2011) discovered that participants viewed pain as part of the disease and accepted it as part of the recovery process. A THA participant (40 years old) described his concerns surrounding long-term use of pain medication; he was aware of the negative consequences and potential side effects that regular, long-term use of pharmaceutical analgesics could have.

I do not know if I'll ever be able to stop (taking) medication. I know also that the drugs I take, the pain relievers, are not without any negative consequences on my health either. Well for now, it works for me. But I know I would not take them my whole life. (Demierre et al., 2011; p. 553)

Sjøveian and Leegaard (2017) used qualitative semistructured interviews to explore THA and TKA patient experiences of pain after discharge from hospital. This study was primarily focused on aspects of pain and rehabilitation in the immediate postoperative period and therefore information regarding priorities and other experience was not addressed. The study included one participant younger than 50 years, and no direct quotations or results were directly linked to this individual in the study reports.

Mobility and Function

Function and mobility were common concerns reported in the included studies, although often merged with other aspects of the participant experience. Fujita et al. (2006) reported the limitations of function and mobility directly influenced participants' ability to fulfill their role, either professionally or socially. This was echoed by Demierre et al. (2011), who reported that the inability to perform usual roles due to restricted function and mobility caused feelings of guilt and resulted in negative implications on participants' psychological well-being. The study stated that participants often attempted to hide their difficulties to avoid feelings of being "handicapped and stigmatized" (Demierre et al., 2011, p. 552). Three articles (Fujita et al., 2006; Demierre et al., 2017; Strickland et al., 2017) reported that an improvement in QOL due to recovery of function and mobility in the joint was a key theme in participants' recovery priorities

and expectations. Singh et al. (2020) stated that improving function, mobility, and QOL were reported by participants as one of the chief purposes for undergoing surgery. The younger participants in the studies by Singh et al. (2020) and Goodman et al. (2020) ranked improving QOL (including aspects of social participation) much higher in importance than the older participant groups. Although exercise and sport were not highlighted as a theme from the nine included articles, one 40-year-old male reported missing physical exercise: “It has been since two years that, that I cannot go and run into the forest, what I do like very much, to go and pick mushrooms, or hike into the mountains” (Demierre et al., 2011, p. 553).

Relationships

Sjøveian and Leegaard (2017) identified that support from family members was crucial in participants’ recovery, whether through practical means or as emotional support. Strickland et al. (2017) Demierre et al. (2011), Montin et al. (2002), and Berg et al. (2019) named this support as a key factor; they also identified patient frustration due to the need to rely on others and feeling like a burden to friends and family. The younger groups in Goodman et al. (2020) reported feeling concerned that their friends and family would fail to understand their experience of chronic pain and disability. Lafosse et al. (2008) explored the impact on intimate sexual relationships and found that 19% of study participants reported hip pain having a significant effect on sexual activity, in turn, causing stress and tension in their relationship. Women were affected more than men in this regard and often took longer to commence sexual activity postsurgery than the male participants. A 40-year-old male was quoted: “Even with my wife, it is not easy in bed; I cannot do all these things anymore. So I tell myself, I am still young, I still want to enjoy life” (Demierre et al 2011, p. 553).

Patient Expectations and Education

Optimizing patient expectations and education was a common priority across the research. The younger nominal groups in Goodman et al. (2020) considered this topic as a high priority. An important part of holistic and patient-centered care is meaningful participation of patients and their families in decisions regarding their own care (Institute of Medicine, 2001). Strickland et al. (2017) Demierre et al. (2011), and Berg et al. (2019) highlighted the patient’s desire to be involved in their own care and included in surgery decision-making. They concluded that shared decision-making between the patient and the clinician is imperative in developing an effective partnership between the surgeon and the patient. Montin et al. (2002) reported that knowing what the patients themselves consider the most important aspects of their care was crucial when supporting patients undergoing a THR, though did not elaborate further on this statement.

A short one-sentence quotation from a 44-year-old woman referring to the decision being made for surgery was featured: “I was terrified. Because just that day I didn’t have so much pain. I thought, he won’t believe me” (Berg et al 2019, p. 3).

As this is the only quotation or information attributed to this participant, we were left without any further clarification into her experience.

Demierre et al. (2011) found that the lack of control in the logistics of the surgery process—for example, waiting lists, timings, and potential for cancellations—negatively affected participants’ psychological and emotional well-being. Four studies (Berg et al., 2019; Demierre et al., 2011; Lafosse et al., 2007; Sjøveian & Leegaard, 2017) cited insufficient information from healthcare professionals regarding what to expect from recovery, prompting participants to seek information from other sources. Participants in Berg et al. (2019) reported comparing their rate of improvement and rehabilitation with that of others perceived as being in similar situations on social media. Berg et al. (2019) acknowledged that these sources could sometimes provide misleading information, resulting in unrealistic expectations.

REPORTING BIASES

With the uncertainty that the information available applies to the patient population of interest for this review, it is impossible to definitively address the question in this systematic review. Research utilizing PROMs and clinical and radiological outcome measures are frequently used (dependent on the author’s position) as evidence that THA operations either satisfy or do not satisfy patient outcome priorities and needs. This systematic review demonstrates that no study to date has asked younger adults about their THA priorities and goals. Patient voices have become lost behind clinicians’ and other healthcare professionals’ assumptions of what constitutes a successful outcome; these assessments are too often based on the priorities, goals, and needs of a significantly older patient population undergoing the same intervention.

Only one of the studies included took place within the United Kingdom (Strickland et al., 2017), two studies took place in the United States (Goodman et al., 2020; Singh et al., 2020), one in Japan (Fujita et al., 2006), one in Sweden (Berg et al., 2019), one in Finland (Montin et al., 2002), one in Norway (Sjøveian & Leegaard, 2017), one in France (LaFosse et al., 2008) and one in Switzerland (Demierre et al., 2011). Each of these countries has a different healthcare system, and this affects participants’ experience of their illness and surgery, potentially affecting the data collected. Fujita et al. (2006) acknowledged that the wait for THA in Japan may be much shorter than that in other countries; consequently, the participant population in that study may not be representative of those in other countries, where longer waiting lists mean patients live with their symptoms for a significant period.

The retrospective method used in seven of the studies can also cause limitations on data collected. Retrospective interviews rely on participant memory of the experience, and memories can be unintentionally altered over time (Friedman & Winstanley, 1998); priorities that were important to participants at the time of the experience may not feel significant when retrospective interviews are conducted. Berg et al. (2019) recognized that the single

retrospective interview 3 months postsurgery made it difficult for the participants to explore the full experience in depth. It is advisable that future research in this field take place during the diagnosis and treatment journey as opposed to retrospectively.

Notably, the researchers of the nine studies do not address their own bias or preconceptions on the subject. The analysis of qualitative data requires interpretation by the researcher. The concern is that the researcher's interpretation of a subject may be influenced by their experience and opinions, resulting in the introduction of bias (Cresswell & Cresswell, 2018) or, worse yet, invalid findings (Pathak et al., 2013). Qualitative research is sometimes criticized for this perceived lack of subjectivity; however, these criticisms are unwarranted if study weaknesses are adequately addressed and the limitations of the findings identified (Howard & Davis, 2002). The nine studies included in this literature review do not give any insight into the researchers' personal or professional experiences or how they addressed the potential for bias.

CERTAINTY OF EVIDENCE

The included studies focused on different aspects of patient experiences with THA. All contained potentially relevant information regarding younger THA patient priorities and experiences; however, a significant constraint to effective evaluation of this information and the studies' findings is the failure of some included studies to attribute findings to specific age categories and/or to differentiate between THA and TKA patients.

Discussion

Although there is an absence of qualitative research on younger THA patient priorities, there is extensive literature available on the patient priorities that clinicians and researchers assume is important to this patient population. These general themes include return to work, sports and leisure activities, sexual activity, and caring responsibilities for young families. These topics are generally considered relevant to this age group (Borg et al., 2017; Kurtz et al., 2009; Malcolm et al., 2014; Tilbury et al., 2014); therefore, it is reasonable to assume they would also apply to the patient group in question.

It is estimated that between 15% and 45% of patients who undergo a THA are of working age (Kuijter et al., 2009; Tilbury et al., 2014). Hip conditions requiring THA are associated with decreased physical function, increased missed workdays, possible loss of employment, and subsequently reduced household income (Li et al., 2006). The annual cost of work-related musculoskeletal disorders is calculated by estimating both financial cost and "human cost" and is difficult to assess (Health and Safety Executive, 2018). Individuals experience the impact of the costs of ill health on their QOL, whereas the employer and society deal with the effects on loss of productivity and an increased need for healthcare, rehabilitation, and compensation (Bhattacharya, 2014; Bieleman et al., 2011; Sharif et al., 2016).

Employment has been shown to be important for both physiological and psychological well-being (Cook et al., 1982; Linn et al., 1985; Ross & Mirowsky, 1995); working has significant benefits on mental, emotional, and physical health, not to mention the financial benefits (Gignac et al., 2004; O'Brien & Feather, 1990; Waddell & Burton, 2006). Loss of employment can create an increased burden on both patients and their families (Tilbury et al., 2015). An early return to work following surgery has potential health benefits in addition to socioeconomic benefits (Baker et al., 2020).

In this synthesis, younger adults identified the negative impact on their social QOL as an important concern. Social isolation and the avoidance of social interaction due to chronic hip conditions are explored throughout the literature but are focused on the older patient (>65 years; Cattan et al., 2005; Iredell et al., 2004; Siviero et al., 2020). The results presented in this article indicate that this is a concern across all age groups and not exclusive to the older individual.

The impact of THA surgery on sexual activity appears to be little considered or understood by clinicians (Coradazzi et al., 2013; Dahm et al., 2004). Research on this topic suggests that THA is known to significantly affect sexual activity, whether through anxiety regarding specific positions or pain (Coradazzi et al., 2013; Klit, 2014). More than half of participants included in studies attributed their sexual difficulties directly to their chronic hip pain and disability (Currey, 1970; Issa et al., 2017; Todd et al., 1973). Total hip arthroplasty has a beneficial effect on sexual activity in younger adults, with this improvement being more frequently reported by women (Baldursson & Brattström, 1979; Lafosse et al., 2008; Meyer et al., 2003; Stern et al., 1991; Todd et al., 1973). The literature overwhelmingly supports clinicians discussing sexuality with hip surgery patients and suggests that education and further information on sexual activity postsurgery may decrease pain and facilitate self-awareness, self-confidence, and improved body image; this, in turn, can promote positive sexual health (Meiri et al., 2014).

Of the themes identified within the nine studies, several findings in this systematic review are also recognized and explored within wider literature on THA; these topics are relevant to all age groups and not exclusively specific to the younger patient and are presented in the following text.

In this synthesis, the effect and experience of pain and the loss of function and mobility emerged as dominant themes within the patient experience. The literature on THA endorses this finding. Indeed, THA was initially designed primarily to address low mobility and symptoms of pain in elderly patients (Charnley, 1961). Surgeons perform THA to address a variety of conditions, such as osteoarthritis, osteonecrosis, inflammatory arthritis, and congenital deformities (Adelani et al., 2013). These conditions and disabilities occur in differing frequencies within all age groups, and the primary symptoms experienced are widely reported as pain and limitation of function (Keeney et al., 2015). Consequently, inclusion of these themes within included studies was expected.

Current literature generally accepts that younger adults may engage or wish to engage in high activity levels postoperatively (Clohisy et al., 2008; Kinkel et al., 2009; Malcolm et al., 2014), although it is important to acknowledge that this generalization has varying levels of applicability to specific medical conditions (Keeney et al., 2015). Participation in exercise and sport is reported to be one of the least fulfilled expected outcomes after THA (Jourdan et al., 2012; Malcolm et al., 2014; Nilsson et al., 2003) and one of the more common reasons for dissatisfaction with a prosthetic joint (Mannion et al., 2020). Yet, it is one of the higher rated expectations in younger adults (Jourdan et al., 2012; Mancuso et al., 2009). A large number of younger adults return to recreational or impact sport after THA (Keeney et al., 2015; Prokopetz et al., 2012). It is not unreasonable to conclude that a younger person may aspire to higher functional outcomes than older patients, who may be willing to accept lower attained functional scores (Judge et al., 2012).

It is acknowledged that patients' concerns after THA differ significantly from the views of the clinician and that patients often feel their needs and views are underappreciated (Jourdan et al., 2012; Kinnaman & Mabrey, 2006). Our results indicate that shared decision-making between the patient and the clinician, and the active involvement of the patient in their care, can avoid this misalignment and enhance the therapeutic relationship between the surgeon and the patient.

Conclusion

This systematic review highlights the absence of quality qualitative data relating to the priorities and expectations of young adults when undergoing a THA. The necessity of further qualitative research in this field is evident. Without exploring these patients' own perceptions of their experience and priorities, we cannot be confident that the literature is not just presenting what clinicians and researchers assume is important to this patient population. As a result, orthopaedic nurses and other healthcare professionals may be uncertain that they are addressing patient needs and providing holistic, individualized, and patient-centered care. Further research is essential to identify what outcomes and expectations are important to young adults when undergoing a THA and how best to meet their priorities.

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APPENDIX A. SEARCH STRATEGY

Details an example of searches that will be used: MEDLINE advanced search October 3, 2021

1	MH "Hip Prosthesis"
2	MH "Arthroplasty, Replacement, Hip"
3	MH "Health Priorities"
4	MH "Quality of Life"
5	TI (Prior* OR Expectation* OR Importan* OR Goal* OR sport* OR exercise* OR sex OR pain OR function OR mobility OR relationship* OR perception* OR experience* OR view*) and AB (Prior* OR Expectation* OR Importan* OR Goal* OR sport* OR exercise* OR sex OR pain OR function OR mobility OR relationship* OR perception* OR experience* OR view*)
6	TI (middle age*) AND AB (middle age*) OR TI (less than 50) AND AB (less than 50)
7	TI (young patient*) AND AB (young patient*)
8	TI (qualitative OR phenomenolog*) AND AB (qualitative OR phenomenolog*)
9	S1 OR S2
10	S6 OR S7
11	S3 OR S4
12	S5 AND S9
13	S5 AND S9 AND S10
14	S8 AND S13
15	S8 AND S12
16	S5 AND S8 AND S9
17	S9 AND S10 AND S11

Note. AB = word in abstract; MH = Medical Subject Heading; TI = word in title.

APPENDIX B. MMAT ASSESSMENT TOOL: SCREENING QUESTIONS

Ref	First Author	Year	Citation	SQ 1. Are There Clear Research Questions?	SQ 2. Do the Collected Data Allow to Address the Research Questions?	Mixed Methods/Qualitative
1	Lafosse	2008	Sexual function before and after primary total hip arthroplasty	Yes	Yes	Mixed methods
2	Sjoeveian	2017	Hip and knee arthroplasty—Patients' experiences of pain and rehabilitation after discharge from hospital	Yes	Yes	Qualitative
3	Singh	2020	When has a knee or hip replacement failed? A patient perspective	Yes	Yes	Qualitative
4	Goodman	2020	Patients' perspectives of outcomes after total knee and total hip arthroplasty: A nominal group study	Yes	Yes	Qualitative
5	Fujita	2020	Qualitative study of osteoarthritis patients' experience before and after total hip arthroplasty in Japan	Yes	Yes	Qualitative
6	Strickland	2017	Early recovery following lower limb arthroplasty: Qualitative interviewing with patients undergoing elective hip and knee replacement surgery. Initial phase in the development of a patient-reported outcome measure	Yes	Yes	Qualitative
7	Demierre	2011	The long and painful path towards arthroplasty: A qualitative study	Yes	Yes	Qualitative
8	Berg	2019	Fast-track program of elective joint replacement in hip and knee—Patients' experiences of the clinical pathway and care process	Yes	Yes	Qualitative
9	Montin	2002	The experiences of patients undergoing total hip replacement	Yes	Yes	Qualitative

MIXED-METHODS ASSESSMENT

Ref	First Author	Year	5.1. Is There an Adequate Rationale for Using a Mixed Methods-Design to Address the Research Question?	5.2. Are the Different Components of the Study Effectively Integrated to Answer the Research Question?	5.3. Are the Outputs of the Integration of Qualitative and Quantitative Components Adequately Interpreted?	5.4. Are Divergences and Inconsistencies Between Quantitative and Qualitative Results Adequately Addressed?	5.5. Do the Different Components of the Study Adhere to the Quality Criteria of Each Tradition of the Methods Involved?	Comments
1	Lafosse	2008	Yes	No	No	No	No	Unsolicited comments not reported or attributed to particular patients

QUALITATIVE METHODS ASSESSMENT


Ref	First Author	Year	1.1. Is the Qualitative Approach Appropriate to Answer the Research Question?	1.2. Are the Qualitative Data Collection Methods Adequate to Address the Research Question?	1.3. Are the Findings Adequately Derived From the Data?	1.4. Is the Interpretation of Results Sufficiently Substantiated by Data?	1.5. Is There Coherence Between Qualitative Data Sources, Collection, Analysis, and Interpretation?	Comments
2	Sjøroevian	2017	Yes	Yes	Yes	Yes	Yes	Study focused on pain and rehabilitation retrospectively and little focus was accorded to priorities and goals moving forward.
3	Singh	2020	Yes	Yes	Yes	Yes	Yes	No separation between THA and TKA in nominal groups, so not clear if there was a difference between responses based on joint.
4	Goodman	2020	Yes	Yes	Yes	Yes	Yes	Not clear on what participants had TKA or THA, no separation of results, so unclear if any differences between the procedures.
5	Fujita	2006	Yes	Yes	Yes	Yes	Yes	Eligibility criteria excludes other diagnosis—Not representative of all patients undergoing a THA.
6	Strickland	2017	Yes	Yes	Yes	Yes	Yes	Age range is from 45 years upwards, unknown how many participants were younger than 50 years, or if those younger than 50 years were hip or knee operations. Age not identified as being a specific factor in certain themes. Quotations from participants not linked to their age or surgery site (i.e., hip or knee).
7	Demierre	2011	Yes	Yes	Yes	Yes	Yes	Small sample size did not differentiate between pathology and diagnosis; revision surgeries included in sample size. THA and TKA included in the sample.
8	Berg	2019	Yes	Can't tell	Can't tell	Yes	Yes	One quotation attributed to THR patient younger than 50 years. No other themes sorted by specific age group or surgery site.
9	Montin	2002	Yes	Yes	Can't tell	No	No	Limited reports of raw data, no reports of participant ages. No recognition of researchers own bias and assumptions in limitations.

Note. THA = total hip arthroplasty; THR = total hip replacement; TKA = total knee arthroplasty.

3.4 Public and patient involvement in the initial stages of planning Young Hip

As presented in the previous section (chapter 3.3), the subject of younger patients undergoing THR has scarce and limited prior qualitative research, thus the voices of the patients are grossly absent within the current evidence base. There was a risk that when planning Young Hip, the researcher could focus the study on what they assumed would be important to patients rather than what patients themselves considered priorities. Because of this concern the researcher opted to undertake a public and patient involvement (PPI) study to ask the proposed study population whether the study was required and the topics it should include. The intention was to also use this initial PPI study to inform the design and methods of Young Hip, however, this PPI study was initiated in April 2020, coinciding with the first Coronavirus (Covid19) lockdown in the UK. This meant that the methods of delivering this research to potential participants were significantly limited. Due to social distancing and lockdown requirements, the PPI study was required to take place as an online survey advertised primarily through social media platforms. Due to the limitation in possible methods the resulting influence the PPI study had on informing design and methods of Young Hip was more restricted than intended. Regardless, the findings uncovered from the PPI study were invaluable in guiding the researcher in addressing topics and aspects within the Young Hip patient interviews that otherwise may have been missed. The public and patient involvement study was published in *The Journal of Patient Experience* in March 2022 and is presented below in full.

A Patient and Public Involvement Study to Explore the Need for Further Research into the Experience of Younger Patients Undergoing Total Hip Arthroplasty

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Abstract

Background: Total Hip Arthroplasty (THA) is one of the most commonly performed operations in orthopaedics. It is an operation usually performed in older patients, however the need for THA in younger patients is increasing. There is a lack of literature examining whether current recovery pathways address the specific needs of younger patients. Public and Patient Involvement (PPI) is a core aspect of good research practice and is recommended throughout the research process, including the formulation and refinement of pertinent research questions. Therefore, the explicit aim of this PPI study was to collect qualitative data from patients on the feasibility and requirement for further research into the experience of younger hip arthroplasty patients. **Methods:** Qualitative data was collected via an online questionnaire that was advertised on social media, requesting the input of anybody who had experienced a lower limb musculoskeletal injury or condition before the age of 50. The survey asked the respondents to describe their experiences and reflect on their priorities and goals throughout their recovery. **Results:** There were 71 respondents, of which 90% were female, with an average age of 43. Qualitative responses identified many concerns that were issues that could be translated across all patient ages. However, other priorities were raised that are not always recognised as important when measuring successful outcomes after a THA. Furthermore, many respondents described not feeling listened to by clinicians or treatment options not being sufficiently addressed and explored. Multiple respondents reported being told they were too young to have anything serious or that nothing could be done until they were older. **Conclusions:** The responses to the survey indicate that current care pathways are not fulfilling the needs and priorities in younger patients. Further research is required to explore these priorities and goals in more depth in order to understand how healthcare professionals can address them.

Keywords

Patient Experience, orthopaedics, Total Hip Arthroplasty, rehabilitation, Public and Patient Involvement, PPI

Plain English Summary

To understand if healthcare delivery is meeting patients' needs, we need to ask those patients what their needs are. This is particularly true when the clinical treatment, such as hip arthroplasty, is typically required by an older population but is increasingly used in patients of all ages. To understand the needs of younger patients undergoing a lower-limb total joint replacement, a survey was posted online asking for responses from people under 50 years of age, who had a hip, leg or foot injury or condition. The respondents reflected on their priorities and goals throughout their diagnosis and recovery and on whether they felt these needs had been met by healthcare staff. The responses described areas of dissatisfaction in the care received and highlighted a need for more research into

the aspects of recovery important to them as individual patients. Any lower limb injury or condition will have an impact on a

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patient's quality of life and affect their daily activities. Therefore, common themes in experiences and recovery priorities may emerge in the responses regardless of the body part affected. The outputs of the survey have influenced the development of the research question and the design of a planned future study. Using PPI in this way ensures the planned research is user-led. This makes certain that researchers and healthcare professionals are addressing the aspects important to the patient as opposed to what clinicians or researchers consider a priority.

Background

Total Hip Arthroplasty (THA) is a common operation performed in Orthopaedic Surgery. The National Joint Registry (NJR) within the United Kingdom (UK) reported that a total of 101,384 THAs were performed in 2019 (1). This number is predicted to increase year by year as the age of the general population increases (2). Although most of these operations are performed on older patients, the demand amongst younger patients' is increasing (2–5). For example, 5708 (5.6%) of the patients undergoing THA recorded in 2019 were under 50 years old, 14,376 (14%) of the recorded patients were aged between 50 and 59 years of age. This presents a significant increase from the numbers recorded in 2011, when 4,828 patients (6%) under 50 and 10,516 patients (14%) between 50 and 59 years, from a total of 76,357 patient records (1). However, the current care pathways used are traditionally based on the needs of older patients (>65 years), and little attention has been paid to the potential differences between them and the growing younger population requiring THA (2,5,6).

The National Institute for Health and Care Excellence (NICE) (7) provides guidelines for clinicians and professionals caring for patients recovering from THA. The recommendations specify that additional rehabilitation support is only indicated in patients with additional needs, such as dementia and cognitive impairment. Younger patients are not included in this category, despite their rehabilitation needs potentially being more complex than that of the older patient population usually associated with THAs (5,8,9). Further research into the goals and priorities of these younger patients is essential to ensure they are met and supported.

Patient Reported Outcome Measures (PROMs) are routinely used after treatment to measure the success of the operation from the patients' perspective (10–12), and Enhanced Recovery Pathways are used to prepare patients for surgery and to expedite recovery and discharge from hospital (13–15). There is a lack of literature examining whether these measures and pathways are effective with younger patients and whether they completely address factors important to them in their recovery. The expectations of a successful post-operative outcome, in terms of function and mobility, are much higher for the younger patient from both a patient and surgeon perspective (8,16). However, standard PROMs have revealed that long term outcomes of THA are worse in younger patients compared with older patients (17). Factors such as sex, age and pre-operative quality of life all appear to influence patient-reported

outcomes (17). In addition, the way a successful outcome is measured is unclear (18–20), and there is little agreement and high variability between patients' and surgeons' opinions (8,21–23).

Evidence recognises that surgeons and patients often differ in their assessment of health priorities, symptom status and surgical outcomes (8,22,23), leading to concern that some outcomes important to the patient may not be considered or addressed. Surgeons' expectations appear to be significantly associated with joint related clinical data and radiological assessments, for example, positioning and survival of the implant, alleviation of pain and function of the joint (5,21,24). In contrast, patients seem to rate expectations on criteria that are mainly psychological and non-joint related, such as ability to participate in recreational activities and effect on mental wellbeing (8).

Incorporating patients into research improves the relevance and quality of results and can demonstrate methods of adopting research findings into practice (25,26). Clinicians have expertise on the illness or disability, but patients experience the daily impact of living with the health condition (27–29). It is therefore practical to "ask the experts" when identifying the factors to explore and the outcomes to assess (28). Just because a proposed research question is *scientifically* relevant does not necessarily mean that it is important from the patient's perspective (29).

Public and Patient Involvement (PPI) has become a core aspect of good research practice and is increasingly recommended in the design, conduct and dissemination of health and social care research (30). PPI in research is often defined by three levels of involvement: consultation, collaboration or user-led research (31). Though the method of PPI selected depends on many factors with each research study, user-led research is arguably the more effective and highest level of involvement (32). The method of user-led PPI was utilised in this study. This approach incorporates the inclusion of patients and the public in all aspects of the research cycle (30), beginning with the research topic to be explored and the design of the research question. Identifying the lack of literature in the field of younger patients' priorities when undergoing a THA does not automatically reinforce the assumption that there is a need for it. Nor does it confirm that a proposed clinical research question will cover the necessary topics. Thus, it is essential that patients are given the opportunity to identify the issues, questions, and objectives they want exploring. This helps enforce the relevance and usefulness of the future research results (33). The themes identified in the PPI responses can be used to ensure the appropriate topics are addressed in the study, optimising the relevance of the results. The PPI survey results are reported using the GRIPP2 reporting guidelines. These guidelines are recommended as a way of promoting transparency, quality and consistency of PPI work ensuring it is based on best practice (34).

Aim

The survey's primary objective was to determine the necessity of further research in the area of younger people undergoing THA. It was also intended to inform and support the design of a qualitative research project exploring the goals and priorities of the younger patient (aged 50 years and under) undergoing a THA. Although there is a recognition of a lack of research or literature, there is also little evidence indicating the potential need for it. Without asking the patients what priorities they have throughout their recovery and whether they personally feel they were addressed, there is a risk that the proposed research could be irrelevant (31). Using PPI ensures that the research addresses the issues important to the relevant patient population and may identify areas for exploration previously unconsidered by the researcher (33,35).

Methods

The purpose of this study was to inform the requirement for the proposed research topic and influence the design of a future research study. A survey was developed which asked respondents to describe their experience related to their expectations, priorities, and outcomes throughout their treatment journey from injury and diagnosis to rehabilitation and recovery. The survey questions were open ended giving the respondent complete control of the topics and issues they described. For clarity, questions divided the patient's journey into three periods (1. Diagnosis and initial treatment, 2. Rehabilitation stage of recovery, 3. When returning to function) with an additional section available for further comments. The survey as presented to the respondents can be seen in Appendix 1. The survey was directed at anybody who had experienced a lower limb musculoskeletal injury or condition before the age of 50 years old rather than carers or family members. The survey was deployed through Survey Monkey and shared on the social media platforms, Twitter and Facebook.

The survey asked respondents to explain what their own goals and priorities were throughout their treatment and recovery. A loose time period guide was provided, and respondents were asked to feedback their own experiences at that point. To clarify the different journey periods, there were prompts and key words such as "diagnosis", "treatment", "rehabilitation", "relationships" amongst others. These "prompt words" were provided in order to invite respondents to discuss potentially sensitive or uncomfortable topics they may not have felt were necessarily important to the researcher (36), for example the effect the injury or condition had on their sexual activity or relationships. Using virtual surveys is preferable to face-to-face or group situations for collecting information about sensitive topics, as participants can disclose intimate details without feeling uncomfortable (37).

It was unclear how many respondents the survey would attract via social media platforms. Due to this, the survey was designed to be relevant to anyone who had suffered a lower limb injury or condition when they were under 50 years of age. The aim was to collect a sufficient level of responses to identify common themes and goals important to the specific age group of 50 years and younger. Inviting individuals who had suffered an injury or condition on any lower limb significantly increases the relevance of the questions to a wider portion of the population. The survey's goal was to influence the design of a proposed research question exploring the specific priorities experienced by individuals undergoing THA. As the survey was designed purely to inform the design of the main study and future research question, the answers provided by the respondents were not going to be extensively analysed nor used to make recommendations on future practice. Any person under 50 years who has lived through or currently suffers with a lower limb injury or symptoms will have experienced some impact on their quality-of-life daily activities. Therefore, their experiences and individual priorities in their recovery may emerge as a common theme throughout the responses no matter the body part affected. Consequently, targeting the survey at all people experiencing any injury or condition of any lower limb was a justifiable approach that maximised the potential number of relevant responses.

The survey was initially advertised through Twitter and Facebook via local groups and through persons associated with Milton Keynes University Hospital and Bournemouth University sharing the link on their individual profile. This was extended to support groups for individuals pre- and post-lower limb joint replacements. As responses were submitted it became clear that many of the respondents were Caucasian females and therefore, not representative of the relevant patient population. In order to target a more diverse group of people the survey was advertised on social media groups for Black and Ethnic Minorities (BAME) Healthcare workers and University Students (with permission from the administration teams of these groups). It was also advertised on support groups for patients suffering from Avascular Necrosis (AVN), as this condition is known to present in patients living with Sickle Cell Disease (38). Sickle Cell Disease is a condition more common in certain ethnic groups, predominantly in people of African descent, but also Hispanic-Americans and people of middle Eastern, Asian and Indian descent (39). These efforts were ineffective, however, with no increase of responses from ethnic minority groups.

In addition, the survey link was also posted on numerous arthroplasty support groups on Facebook including: Young Hip Replacements (UK); Hip Replacement group for Active people; Avascular Necrosis Support - UK group; Musculoskeletal Disorders Forum; Knee Surgery Support Group; Sickle Cell Disease; BAME Healthcare Professionals UK; and Avascular Necrosis Young Support Group

The survey was reposted two weeks after the initial posting. As these were groups for people seeking support and advice in these fields, the author was conscious that despite the groups' administrations approvals, over-frequent reposting could overshadow posts by members seeking help and advice as per the group's purpose. It could also become irritating to members who had no interest in the survey, or those who had already completed it.

Other social media platforms were considered before selecting Facebook and Twitter as the most useful platforms to use. Facebook is reported to be the most popular social media platform worldwide with a reported 2.5 billion active monthly users (40). The only other comparable platform is YouTube which does not lend itself to this type of survey advertisement. However, due to the volume of responses collected through Facebook and Twitter, it was unnecessary to broaden the survey scope to encourage further responses. The practicalities of a single researcher working through the responses and time constraints limited the quantity of contributions possible to accept.

Results

The survey attracted a high level of response. It was initially posted online on social media platforms on 22/04/2020. By 11/06/2020 there were 71 completed responses. The responses were all from the patients themselves as opposed to family members or carers. A potential saturation of data was indicated in the later responses as no new themes were emerging. Consequently, the survey was closed after 71 responses.

The mean age for respondents was 43.4 years (median age 44, interquartile range 39-49) with the mean age at the start of symptoms as being 31.8 years (median age 31, interquartile range 24 - 44). Participant's current ages ranged from 17 to 61, with their ages at the start of symptoms stated as "from birth" to 52 years. Out of 70 respondents (this question was skipped by one participant), 90% were female, and 10% being male. 65 respondents described themselves as white or Caucasian, 2 respondents were Asian or Asian-American, 3 described themselves as another race and 1 participant declined to answer. Respondents were not directly asked what their diagnosis was, nor did they have to specify the limb affected. Of those responses that did describe the injury or condition, 22 were hip conditions, 8 were knee conditions and 3 were ankle conditions. 38 respondents did not specify the limb affected.

52.1% of respondents described pain and loss of function as a major concern. Frustration and dissatisfaction with the explanation of the diagnosis was cited by 63.4% of respondents, along with 45.1% reporting they had not felt listened to, or that their concerns had not been addressed by clinicians. There were also frustrations expressed by 46.5% of respondents over how long their recovery had taken. Exercise and recreational sports were considered important to 40.8% of participants and 38% described sexual activity and intimate

relationships as a priority. These themes will now be explored further.

Pain and loss of mobility and function were identified by 37 respondents in the section relating to initial diagnosis and treatment. Over half of respondents (n=45) also described feelings of frustration and dissatisfaction with the explanation of the diagnosis and reasons for their condition. The information given by healthcare professionals was described as inadequate and difficult to understand.

"I was put in a class of people who were 30+ yrs older than myself who were also getting joint replacements" "I know that my recovery, my needs, my physio, all of it was different since I was more mobile" "I wish that providers wouldn't lump us into the same category as others getting the same thing." Respondent 16

32 respondents described not feeling listened to by healthcare professionals, feeling that treatment options were not sufficiently addressed and explored. Age was identified by several individuals as a potential reason why clinicians potentially came across as dismissive or unbelieving. Multiple respondents reported being told they were too young to be suffering from anything serious or that nothing could be done until they were older.

"After countless doctors telling me they didn't know what to do with my condition at my age, I finally found one that said it will continue to get worse and there is nothing to be done but manage symptoms until I'm old enough for a replacement."

Respondent 10

"Was told it would just be a muscular problem as I was "too young for it to be anything serious". Respondent 31

29 respondents (40.8%) reported being eager to return to exercise such as running or high impact sporting activities. The ability to return to sport and exercise (regardless of clinical recommendations or level of sporting activity) was identified as a high priority throughout the survey by multiple respondents. Frustration was expressed regarding differing recommendations by different clinicians on when to return to exercise and what level of exercise was advisable post-surgery. This inconsistency of advice was reported by 29 survey respondents (40.8%) and was identified as a significant reason for the anxiety and nervousness they experienced when regaining function and undergoing rehabilitation.

"The hip consultant agreed that I could run. My physio wouldn't let me start running because they didn't understand the differences between my risks and the risks for the elderly." Respondent 15

“Consultant said I would be able to run again and altered his treatment accordingly, Physio disagreed.” Respondent 60

“As a keen sportsman, surprised to find that different doctors had range of attitudes as to expectation of resuming “before” activities.” Respondent 48

“Felt advice could sometimes send mixed messages” Respondent 32

One participant was frustrated that when measuring functional recovery, it was the standard PROMs that provided proof of a successful outcome, as opposed to the patient’s own specific goals.

“The hip specialist just wants to know that I can walk “50 metres unaided” and sit/ stand. These are great but I wanted more.” Respondent 15

Practical considerations emerged further down the recovery journey. Aspects such as returning to work or regaining the ability to drive increased in importance to many respondents in the latter questions. 33 respondents felt that recovery was taking far too long for their injury and that the potential time frame had not been fully explained by healthcare professionals.

“My expectations for the speed of recovery were unrealistic.” Respondent 57

“Was told 6 months should be back to normal. It actually took 18 months.”

Respondent 70

The negative impact on patients’ mental health of undergoing a THA at a younger age featured strongly throughout the responses and was regularly highlighted as not having been addressed or discussed by clinicians.

“Effects on mental health etc should be given more focus. Perhaps more so in younger patients who have potentially lost a large part of their future.” Respondent 6:

“I don’t feel the mental health side of this is considered at all.” Respondent 39

The primary issue identified in the final section (addressing any further information the respondent may want to provide) centred on relationships and sexual activity. Over a third of participants (n=27) described this as a priority. Several respondents described feelings of embarrassment and a lack of confidence when engaging in sexual activity with their partner. These feelings were not limited to the functional aspect or positioning but also related to body confidence and feeling limited in their sexual ability.

“My body shape has changed significantly due to surgery. When I see myself in the mirror, I don’t recognise my body, it feels like a stranger.” Respondent 2

“It was embarrassing. Bedroom activity was difficult. I felt embarrassed at the lack of function of my hip at that time.” Respondent 38

Concerns regarding pain and the risk of dislocation of the hip joint were also expressed by multiple respondents. Participants recognised that this issue was also having an adverse effect on their partner and many respondents expressed that their injury and symptoms had had a negative effect on their relationship.

“It essentially ruined my marriage being in pain for so long.” Respondent 20

“I am single and won’t date, because I am a burden at this point.” Respondent 10

In addition to sexual relationships, other relationships were also impacted. Those with young families described being unable to play with their children on the floor, or to take part in activities together. 1 respondent expressed her upset at being unable to take her son to his primary school and being reliant on others for this task.

“I feel like a bad mother.” Respondent 29

Participants expressed concerns over potential future pregnancies and how their hip condition may adversely affect this.

“I gave up trying to have a 2nd child as all sex had stopped 2 years prior to the op and also post op.” Respondent 20

“I don’t have children due to fear of what pregnancy could do to my body.” Respondent 39

The responses indicated a frustration with the expectations of a poorer outcome of clinicians and healthcare staff compared to the patient’s own individual goals. 20 respondents believed that it had been their own determination and persistence outside of the professional care provided, sometimes in direct contrast to the professional advice, that had achieved their desired outcomes.

Participants felt “let down” or as if they “had been left to get on with it”.

“I was encouraged to go on disability. I did not find this reasonable.” Respondent 10

“I was put into a (physiotherapy) group with 8 senior citizens. I felt unseen and not understood at all.” Respondent 15

"Basically left to my own devices." Respondent 71

Different themes emerged throughout the survey, as individuals described their journey through initial diagnosis and treatment to rehabilitation and recovery. New concerns and goals were identified and increased in importance to the respondent, whereas previous concerns became less of a priority. The reason for these changes, whether the previous concern had been resolved or alleviated, or why other priorities had become more prominent is not explored in this survey. The graph in Figure 1 is a visual representation of the numbers of respondents highlighting linked themes.

Discussion

Many immediate concerns (for example, pain, mobility, and function) identified in the survey were issues that can be translated across all patients, regardless of variables such as age and gender. There were other priorities described that are not always recognised as important objectives when measuring successful outcomes in patients undergoing a THA. The primary goals of a THA are pain relief and improvement of mobility (8,41). These themes were amongst the most common identified by the respondents in the section relating to initial diagnosis and treatment, and are concerns and issues commonly experienced in patients undergoing THA across all age groups and patient populations. However, it is important to consider the potential differences between what the younger person considers necessary for a good quality of life compared with the priorities of an older patient. For example, younger patients often require the ability to work, to care for young children or dependents, or desire a more active lifestyle in terms of exercise and other physical activities (8). The effect that symptoms of pain, mobility and lack of function in the joint can have on these different considerations of the younger patient are not addressed in the current literature and clearly needs further exploration.

The impact on exercise and sport featured as one of the more prominent concerns in the survey responses. There is some literature exploring the topic that participation in exercise and sport is one of the least fulfilled expected outcomes after THA (5,8,42), yet it is one of the higher rated expectations in younger patients (8,42). What a younger person wishes to achieve in functional outcomes may, understandably, be different to that of an older patient, for whom a lower functional ability may be perfectly acceptable (43). A significant number of younger patients return to recreational or impact sport after THA (39,44). Some even wish to return to a sport not recommended by clinicians (8). A young person with an isolated condition of the hip would be reluctant to substantially limit important parts of their life, thereby causing a considerable deterioration of lifestyle (45–48). The survey responses reinforce these findings. Respondents describe the inconsistency of advice regarding exercise between professionals as a major obstacle in their recovery. Some clinicians advised no exercise or recommended

considerably less than the patient expected or wanted. Other clinicians had fewer concerns in that area and were confident that the patient would regain their desired ability. The variation between clinicians' advice on sporting activities after THA is acknowledged frequently within the literature and is recognised as a potentially significant factor in managing the expectations of the patient (49,50). Equally, the expectation of some clinicians that the younger patients would "bounce back" and recover quicker than older patients was a common theme. The literature reports evidence that clinicians often have higher expectations of speed of recovery in a younger patient than that of an older person (8,10). Respondents reported feeling considerable pressure to recover faster and meet to these expectations. Young patients undergoing THA often recorded lower levels of function, activity and mobility post operation, despite clinician's higher expectations. The assumption that a younger patient should experience successful outcomes is inaccurate (5,50).

The negative effect on respondents' emotional and mental health in addition to feelings of losing independence featured strongly throughout the responses, but was an especially prominent topic in the final two questions. Within the scope of the survey, it was impossible to explore the reasons behind this effect on the patient's mental health satisfactorily, however, it is widely recognised that the impact on younger patients' mental health pre and post injury or diagnosis can be enormous (5). The negative effect on employment, quality of life, sleep and social life is well known (9) and could be potential factors. Though a large majority of patients successfully return to work after recovery (44,51,52), a considerable number are forced to work fewer hours than previously (52). Employment and exercise are important for both physiological and psychological well-being (53,54). The possibility of being unable to return to the same level of employment could create a feeling of increased burden on the patient's partner or family. The considerable pressure and impact on the patient's mental health caused by this, amongst other factors, cannot be ignored. Depression and anxiety can, on average, be far more debilitating and severe in a 20-year-old than that in a 63-year-old (5).

There is limited data available supporting the proposition that undergoing a THA significantly affects sexual activity, whether through pain or anxiety regarding positions (46,55). There is evidence in the literature that this topic can cause much anxiety and insecurity in patients, but it is often unaddressed by clinicians during appointments (56–58). It was not specified in the responses if patients had broached this subject in appointments. However, the issue was of significant concern for many respondents, and participants claimed it had not been addressed or discussed satisfactorily with clinicians at any point between diagnosis and rehabilitations.

Though some topics highlighted in the responses were anticipated (for example, pain, function, mobility), others were unexpected. Body confidence and self-image were previously unconsidered areas when exploring this subject. The

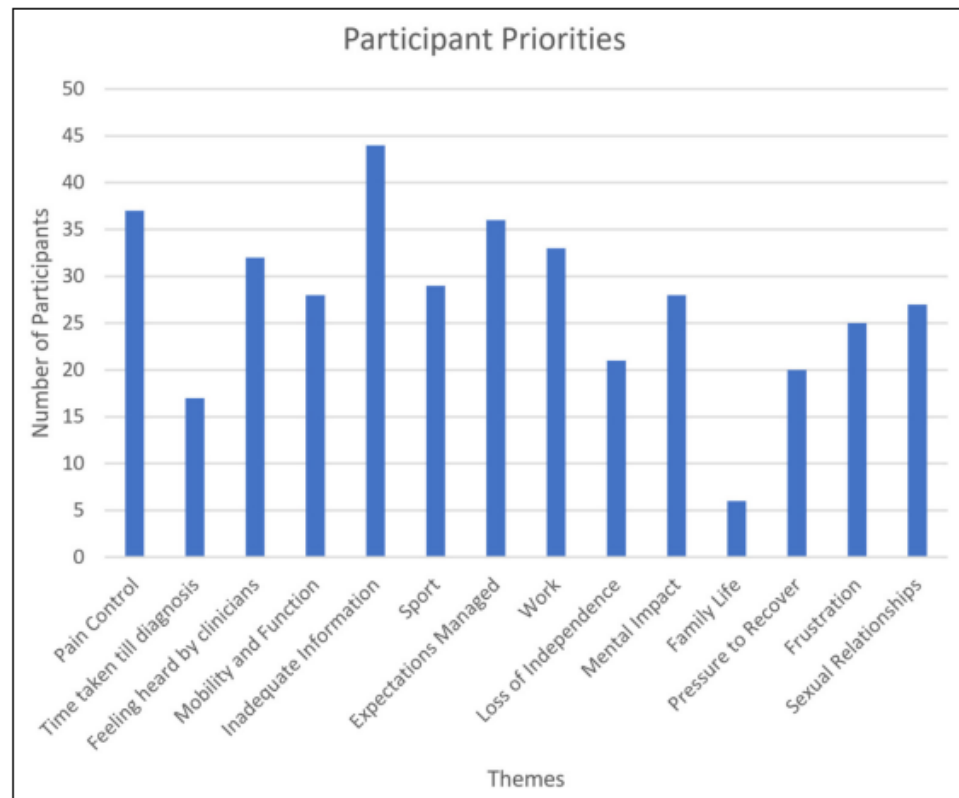


Figure 1. This graph shows the number of participants that highlighted common themes within the survey.

reported increased pressure to recover, whether from clinicians, family and friends, or themselves was also unexpected. The design of the future research project will incorporate the common themes reported in the PPI work into any study interviews to ensure they are addressed by the patient if relevant.

Though the study results are not being used to directly inform practice or intended to be generalisable across the wider population, it is important to identify and highlight the limitations of the survey and study.

Interestingly, despite the larger population of female respondents compared to male, there did not appear to be any significant differences in their experiences. The priorities and issues identified were similar throughout and not influenced by gender (with the exception of pregnancy and childbirth). Regardless of this, due to the inequality of male representation there is potential that some concerns specific to men have not been identified.

The lack of ethnic and cultural diversity in respondents may limit the broadness of the data. Despite the overall high response rate, numbers of respondents from black and ethnic minorities were low. Efforts to include a more diverse population in this PPI work were ineffective. This could lead to an omission of an important topic when exploring proposed the future research. The issue of underrepresentation of ethnic minorities is identified as a

common problem throughout healthcare research (59) and is certainly not unique to this project.

The method of using an online survey was largely influenced by real world constraints. The emergence of the Coronavirus 2019 (COVID19) pandemic and the implementation of a lockdown across Britain occurred during the initial planning stages of the PPI. The initial intent was to secure patient involvement by use of paper questionnaires in the outpatient department, or by inviting appropriate patients to participate in face-to-face focus groups. COVID19 safety concerns and the policies the National Health Service (NHS) put in place to protect patients, staff and the public on hospital grounds rightly prevented these ideas becoming anything more than suggestions. On-line surveys are not without their limitations. Completing the survey on-line limited the depth and detail into which topics could be explored. The information provided by respondents and the amount of detail revealed was completely dependent on the individual. The survey also had no time constraints on how long ago the injury or diagnosis had occurred. People's memories can be unintentionally altered (60), and priorities that were important to the individual at the time of the experience may not now feel significant. This indicates that proposed future research in this field should take place during the patient's diagnosis and treatment journey as opposed to retrospectively. The wording of questions in a survey comes with

added considerations and the way a respondent interprets the question can influence the answer they provide. If the wording is unclear or confusing the respondent may either decline to answer or provide what they believe to be the “correct answer”. For example, the answer they believe the questioner would like to hear or one that agrees with other respondents (61,62). This survey attempted to avoid this issue by using open-ended questions, allowing respondents to make the decision about a response to give. Due to the pandemic’s impact on face-to-face interaction, the options for collecting responses were limited; however, advertising the survey via social media also limited the target audience to those that used these social media platforms. It is recognised that this method of advertisement excludes individuals who do not have access to these platforms or choose not to use them.

Conclusion

The aim of the PPI is to generate findings to inform on the design of a qualitative research project exploring the goals and priorities of younger patients undergoing and recovering from a THA. Data collected from this survey strongly indicates the necessity of further research into this area and patient group. The PPI findings will help focus the study on the issues important to the relevant patient population and frequently uncovered areas of knowledge, previously unconsidered by researchers (36,63). The feedback obtained will influence the topics addressed in the planned semi-structured, informal interviews between the researcher and participants. Current research has not sufficiently explored the priorities and goals of younger patients undergoing THA and it has been identified that clinicians and patients can differ in their idea of successful recovery (8). This PPI study ensures that issues addressed within the proposed future research are not based on the researcher’s or clinicians’ assumed areas of importance (prior to PPI feedback) and explore the participants own individual concerns.

Using an online survey for this PPI had numerous positive aspects in facilitating access to a wide population group. Respondents could complete the survey at a time and place convenient for them, with no need for consideration of extra travel or timings. It is uncertain how the world will adjust after the COVID19 pandemic or if COVID19 will be something that needs taking into consideration indefinitely. Remote methods of incorporating PPI into research may be required in order to ensure appropriate patient involvement in the design and delivery of high quality, relevant, patient-centred research. The simplicity of the survey set up and the large response rate demonstrate the practical benefits of this method.

Appendix

1 Survey advertised on Social Media as was presented to participants.

Feedback from Young People (50 years and under) with Musculoskeletal injuries or conditions.

Why we need your feedback.

My name is Louise Mew and I am a Research Nurse in the NHS, I am trying to discover the priorities and goals in the recovery of young people with a MSK lower limb injury or condition.

What is a MSK lower limb injury or condition?

It is a chronic or acute musculoskeletal problem to the lower part of the body, including the hip, knee, pelvis or ankle. This could be the result of an injury or another illness or condition.

Why do we need your help?

We are asking any young person (50 years or under) who has a lower limb injury or condition, about what concerns we, as healthcare professionals should be addressing if we are to improve patient care and recovery.

What will we do with your survey results?

We will use your results to highlight any common themes in patient priorities and use these to inform and design a full research study exploring the priorities and goals in younger patients undergoing lower limb orthopaedic surgeries, for example total hip replacements. All answers are anonymous and no identifiable information is necessary. Any identifiable information provided will be anonymised and not stored.

1. **During your initial treatment, (whether in-hospital treatment, GP treatment or other healthcare settings). What were your priorities and goals in working towards your recovery? Were there any areas in your treatment in which you felt these were not addressed?**
This question relates to the initial diagnosis, expectations of recovery, pain management, operation or other treatments.
2. **During the rehabilitation stages in your recovery (mental and physical support, including physiotherapy and occupational therapy). What were your priorities and goals in working towards your recovery? Were there any areas in your treatment in which you felt these were not addressed?**
3. **When returning to function, (expectations for return to work, driving, sport and other hobbies). What were your priorities and goals in working towards your recovery? Were there any areas in your treatment in which you felt these were not addressed?**
4. **Is there anything else you would like to tell us (e.g. personal experiences, effect on relationships and sexual activity?)**
5. **ABOUT YOU?** It is important that we know a little bit about you so we can ensure we have collected the views of a wide range of people with different

experiences. However, you do not have to provide the following information.

6. **Are you Male or Female?**
7. **What is your age?**
8. **How old were you at the time of injury/ onset of symptoms?**
9. **What is your ethnic group?** please select from options below:

White or Caucasian
 Black or African American
 Hispanic or Latino
 Asian or Asian American
 Another race

Availability of Data and Material

The datasets analysed during the current study are available from the author on reasonable request.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.



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Ethics Approval and Consent to Participate

HRA approval was not required for this study due to no identifiable or personal details being collected, no vulnerable groups being approached and the study using social media and not an NHS trust to identify potential participants. This was confirmed by both the Health Research Authority and Milton Keynes Research and Development Department.

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When considering the large quantity of literature using quantitative methods focusing on younger patient's undergoing THR, the absence of qualitative data highlighting this patient populations' own voice on their experiences and opinions is starkly noticeable. It is evident by the limited research available, and the voices of the participants featured in the public and patient involvement study that further research and exploration into younger THR patients is essential. The PPI study highlighted significant aspects of patient care that were unaddressed by healthcare professionals and current care pathways. It uncovered priorities and important concerns that are not even considered in previous research or clinical practice, for example: body image, awareness of their young age in comparison to the usual expected older patient profile for THR.

The PPI study also highlighted the importance of using open ended questions to allow participants to describe topics important to them and to avoid only focusing on areas healthcare professionals assume to be important. The findings from this PPI study were used to inform the main qualitative study by incorporating the themes identified into the informal interview schedule ensuring participants were given opportunity to address them if relevant. Furthermore, the use of open-ended questions was undoubtedly beneficial within the PPI study, it enabled participants to offer a variety of information that would otherwise not have been requested. This heavily contributed to the decision to employ a semi structured interview method in Young Hip to allow participants to describe topics important to them and to avoid only focusing on areas healthcare professionals assume to be important. The PPI study also confirmed that the Young Hip data collection process was required to be in an interview format rather than an online survey. There were many responses within the PPI study that the researcher would have been eager to explore in more detail, however, the methods of data collection used made this an impossibility.

The systematic literature review failed to identify any qualitative studies focussing on the experiences of patients aged 50 years and younger, who are undergoing THR. The PPI study highlighted the necessity of exploring this topic to better understand the patient's lived experience in their own words, enabling clinical practice to improve care and better support patients' needs.

3.5 Aims and objectives of the study.

3.5.1 Aims

- To identify and explore the priorities and expectations of a younger patient (≤ 50 years) undergoing a primary elective THR.

3.5.2 Objectives

Primary Objective

- To identify the priorities and expectations of the younger patient (< 50) when undergoing a THR and explore if these priorities are being addressed in current healthcare pathways?

Secondary Objectives

- To assess if current methods of measuring outcomes from the patient's perspective in clinical practice (PROMs) address the priorities and expectations highlighted within the qualitative findings.
- To consider and assess the use of qualitative methods in trauma and orthopaedic research and its potential value to healthcare practitioners working in trauma and orthopaedics.

3.6 Summary of chapter

This chapter highlighted the growing population of younger patients undergoing THR within the NHS, it presented the perception of young THR patients in clinical practice and considered if these assumptions were accurate. The chapter proceeded to identify the gap in qualitative knowledge and evidence around THR in the younger patient by detailing the comprehensive systematic literature review completed at the initial stages of the research journey. It then continued by presenting the PPI study set up to inform the need for further research in this area by asking the patients themselves. The chapter concluded by presenting how the Young Hip study aims to address this gap in the literature by exploring the lived experience of the young patient (≤ 50 years) undergoing a THR and assess if the priorities and expectations identified within the findings are addressed in current clinical practice. The chosen methodological approach and the methods used to undertake this research will be presented and described within the next chapter.

Chapter 4. METHODOLOGY AND METHODS

4.1 Introduction

This chapter explores the theoretical underpinnings around the methodology utilised in the research. It explains the reasoning behind selecting a qualitative approach to answer the research question and explores the epistemological and ontological positioning of the study. The chapter then explores the traditional approach to research within the speciality of trauma and orthopaedics. It features the paper “Bridging the Gap: Enhancing Orthopaedic Outcomes through Qualitative Research Integration”, (accepted for publication by *Bone and Joint Open*) which highlights the scarcity of research using qualitative methods published in clinical orthopaedic journals and demonstrates the benefit of the inclusion of qualitative research in promoting person-centred care in trauma and orthopaedic practice. The chapter proceeds to review different qualitative methods before presenting the rationale of why an IPA approach was the best approach for the Young Hip study. The chapter then continues, introducing IPA and its position, approach, and process of analysis. The rationale for using semi structured interviews as the method of data collection is explored as well as sample size. The impact and influence of the experience and knowledge of the researcher and their clinical role could have on the study is examined and considered.

The chapter then progresses detailing the methods employed in participant recruitment, data collection and analysis, and identifies ethical issues and concerns that were identified through the study. It considers the appropriate methods to address the study aims and objectives. The chapter concludes by exploring how transparency and rigour of the research were ensured to facilitate credible and dependable results.

4.2 Research Design

4.2.1 Qualitative Research

This study sought to explore the priorities and goals of younger patients undergoing a THR. Exploratory research’s primary purpose is to discover new information and to gain a better understanding of the concept or issue being studied (Given, 2008, Bourgeault et al., 2010). Qualitative research explores the full nature of the phenomenon under study, in this case priorities and goals of young people having a THR rather than concentrating on one factor alone (Polit and Beck, 2012).

Merriam (2002) defines a basic qualitative study as one seeking to discover and understand a phenomenon, a process, the perspectives of the people involved, or a combination of these. Braun and Clarke (2013) further elaborate by stating that qualitative research puts

emphasis on meanings rather than cause and effect, they detail that the approach captures the complexity, disorderliness, and ambiguity of the real world. Qualitative approaches are especially suitable within exploratory research when attempting to understand both the experiences of the participant and the context in which these are located (Robson, 2011).

As presented in Sections 3.2 to 3.4, there is a large volume of research which utilises PROMS to identify a successful outcome for the patient. PROMs use numeric scales and closed questionnaires making them largely quantitative in nature. However, quantitative methods are ill suited to exploring the subjective experiences of individuals. They are unable to capture complex human experience and cannot provide detailed insight into how individuals experience, interpret and make sense of phenomena such as pain, stress, and illness (Crossley, 2000). Therefore, a qualitative method was considered the most appropriate to provide a deeper understanding of the patients' experiences when undergoing a THR. The open and exploratory nature of the research question lends itself to a qualitative approach as it enables collection of in-depth data required to fully explore participants' individual experiences. As qualitative methodology also enables participants to generate their own responses and ideas (Braun and Clarke, 2013) it enables a broader account than may be captured using a quantitative method. The use of a qualitative approach was guided by Patient-Centred Care (PCC) (see Section 2.6). Smith et al., (2009) states that humans are essentially sense-making beings, and it is important to consider their reflections and attempts to make sense of their own experiences. It is therefore imperative to recognise each participant as a unique individual, with their own personal history and personalities. This is congruent with PCC.

4.2.2 Epistemology and Ontology

When considering the research method appropriate for answering this question it is necessary to understand the underlying philosophical tradition in which this research sits. Philosophies are typically credited as the foundation of research (Cresswell, 2013), indicating the ontological and epistemological standing of the research. Ontology is concerned with reality and the scientific study of being (Bryman, 2004), whereas epistemology is the philosophy of knowledge and how we come to know something (Krauss, 2005). Ontology and epistemology are interconnected and ultimately result in a holistic view of the knowledge and the researcher's relation to it. Research paradigms are a set of common beliefs and agreements shared by scientists on how to address and understand problems (Kuhn, 1962) and can be referred to as ways scientists respond to the ontological, epistemological, and methodological questions within research (Scotland, 2012). Research paradigms can be categorised into positivism, interpretivism, post-positivism, critical theory (ideology), constructivism and pragmatism (Elshafie, 2013; Tracy, 2013; Rehman and

Alharthi, 2016). When considering the position of the study on the research paradigm a wide range of approaches were explored, however only those relevant to this study will be explored in this chapter.

The main objective of the research was to enable the participants voices to be heard. It was therefore imperative that the participant was placed in the centre of the research, enabling findings to be grounded in their experiences. A constructivist paradigm is an approach that asserts people construct their own understanding and knowledge of the world by their own experiences and their reflection on their experiences (Honebein, 1996). The epistemology of constructivism states that individuals generate knowledge and understanding through interaction between their ideas and their experiences (Mogashoa, 2014). The constructivist's primary goal is to rely as much as possible on the participant's view of the issue under study and interpret the meanings the participant attaches to their experiences (Cresswell and Cresswell, 2018).

Interpretivist paradigm is based on the idea that social reality is not singular or objective but rather shaped by human experience and social contexts (Yanow and Shwartz-Sheal, 2006). The interpretivist researcher's access to reality can be obtained through social constructs such as, language, consciousness, and shared meaning (Aliyu et al., 2014), implying it is how the individual interprets their experience of the phenomena that reveals the whole truth. The interpretivist paradigm assumes that there are socially constructed multiple realities of the same social phenomena and not one single "truth" (Rehman and Alherthi, 2016). It requires the effort to understand how the phenomena are experienced and interpreted by those directly involved or influenced (Bunniss and Kelly, 2010). The best "fit" therefore, appeared to be situated in the interpretivist/constructivist paradigm as the epistemological basis of the project. My wish to understand and represent the priorities of these younger patients reflects an interpretivist position, whilst exploring their situation through their own perspective and interpretation of their experiences locates this work within a constructive paradigm.

4.3 Research in Trauma and Orthopaedics

4.3.1 Tradition of research in trauma and orthopaedics

Over recent decades, trauma and orthopaedics has seen an upsurge in clinical research capability and capacity (Brohl and Schreiber, 2017). Though the trauma community has always been active in research, the speciality has lacked the research culture and infrastructure evident in other clinical areas of study, (e.g. cancer). Previously, research was reliant on individual investigators and study centres, and the absence of collaborative research networks resulted in a rarity of large-scale studies (Holcomb, 2017). Thus, clinical

practice was often based on relatively weak evidence, findings from other conditions (Brohl and Schreiber, 2017), clinicians' personal experiences (Freedman, 1987), and surgical tradition (Moseley et al., 2022). This lack of ethical frameworks and regulations led to some surgical products and techniques being widely introduced with limited prior investigation (Perry et al., 2014).

The culture of research between medical and surgical specialities is very different, and a strong research culture results in research success (Perry et al., 2014). Within the UK, introduction of large research-focussed organisations such as the National Institute for Health Research (NIHR) and implementation of the Research Governance Framework (Department of Health, 2001b) have highlighted the importance of scientific research and developed the extensive infrastructure required to provide high quality surgical research (Perry et al., 2014; Howard and Davis, 2002). For healthcare research to fulfil its purpose, it needs to meet the clinical priorities and needs of patients, musculoskeletal research has been accused of failing at this aspect in the past (Buchbinder et al., 2015; Bourne et al., 2018). To address this and to continue securing funding for research, trauma and orthopaedic researchers have initiated extensive efforts to incorporate public and patients in the inception, design, conduct and dissemination of studies (Gwilym et al., 2021). The James Lind Alliance Priority Setting Partnership was developed to use public and patient involvement to identify and prioritise research questions important to the patients themselves. This method of research prioritization has resulted in many large multi-centre randomised controlled trials (RCT), for example, Humeral Shaft fracture trial (HUSH), WHITE 8 COPAL Cement, Weightbearing in ankle fractures (WAX), Children's Radius Acute Fracture Fixation (CRAFFT), Ankle Fracture Treatment: Enhancing Rehabilitation (AFTER).

The need for surgical research in Trauma and Orthopaedics, particularly in the form of randomised controlled trials (RCT) is undoubted, however, there is a risk that in the pursuit of evidence considered scientifically based other research approaches could be excluded (Howard and Davis, 2002). Surgical research overwhelmingly reflects a discipline of quantitative research and evidence, qualitative research remains limited and uncommon within the literature (Johnson and Waterfield, 2004). However, in clinical practice, qualitative methods are used continuously. Clinicians and healthcare professionals use and incorporate qualitative methods every time a diagnosis is reached. The patient presents with symptoms that are discovered through the qualitative methods of data collection and analysis (Howard and Davis, 2002).

4.3.2 Attitude to qualitative research

The medical mindset encourages clinicians to think in terms of cause and action and to value concise numerical data from large scale trials, qualitative research is considered as

“hopelessly subjective”, “unscientific” and hard to publish (Johansson et al., 2003). It is estimated that only 3-18% of trials incorporate qualitative research (O’Cathain et al., 2013). Traditional concepts of reliability and validity are addressed differently in quantitative and qualitative research approaches (Shenton, 2004; Ritchie et al., 2013), and the distrust of qualitative research within the profession could be related to the perception that qualitative methods are unable to produce useful and valid findings (Sandelowski, 1997; Hammarberg et al., 2016). In addition to this, participant sample sizes in qualitative research tend to be smaller due to the volume of data generated through qualitative methods. Smaller sample sizes are often perceived as a weakness in clinical research, in quantitative research, the number of participants is dictated by the quantity of cases the researcher assesses as necessary to give a statistically valid result that can be generalisable across the population. This usually requires a large number of cases (Staller, 2021). The analysis of qualitative data also requires interpretation. Despite the use of a theoretical framework, the concern is that the researcher may introduce bias at this point, resulting in the findings of the research becoming invalid. This invites criticisms of an alleged lack of rigour in data collection and analysis resulting in claims of subjectivity and poor generalisability (Burns and Grove, 1997). By criticising qualitative research for these reasons, the true purpose of qualitative research is being ignored. Generalisations are not the purpose of this methodology (Howard and Davis, 2002). Qualitative research is intended to explore and gain insight into reasons for people’s behaviour, to define what is important to them and identify how people feel or experience different events (Goberman-Hill et al., 2011). It allows clinicians and healthcare practitioners to reflect on their personal and professional beliefs and to improve their clinical practice (Johnson and Waterfield, 2004). That is not to say that issues of validity and reliability should be ignored, however, providing these concerns are addressed adequately, and the limitations of the findings are identified, criticisms become unsustainable (Howard and Davies, 2002).

4.3.3 A place for qualitative research in trauma and orthopaedics

In recent years, there has been an increase in incorporating qualitative methods in Trauma and Orthopaedic research. Qualitative research is identified as important in promoting recruitment and retention of participants in trauma and orthopaedic research, the purpose of many qualitative methods is to explore what more can be done to engage and inform patients to maximise recruitment into the RCT (Toye et al., 2016; Perry et al., 2014; Rapport et al., 2013; O’Cathain et al., 2013). This purpose is undeniably important, however, to marginalise the purpose of qualitative methods into how it can benefit quantitative research can completely ignore the valuable contribution qualitative methods can make towards evidence-based practice in trauma and orthopaedic Surgery. Trauma and orthopaedic practice involve a multifaceted understanding of pain, disability and health that progresses

beyond a biomedical approach. Qualitative methods incorporate an awareness of the patients biological, psychological, and social contexts, and in turn provides the important foundation for patient centred care (Klem et al., 2021; Pelzang, 2013). It presents the opportunity to add a new dimension to interventional studies that cannot be obtained by numerical data or measurement of variables (Pathak et al., 2013). The need to understand the psychological impact and experience of traumatic injuries and their recovery was highlighted in studies exploring patients with hip fractures (Ziden et al., 2010), where qualitative methods identified many areas of importance to patients that were not evident in the existing outcome measures (Archibald et al., 2003). When these additional factors are not considered and only quantitative approaches are used, practitioners and clinicians gain a limited view of the interacting aspects that play a role in treatment outcome. To understand and effectively treat the complex social and physical facets of health and disease, research methods must go beyond the scope of quantitative data and experimental models in order to explore the complexity of human behaviours (Hammell, 2001).

The development of trauma research and the increasing number of large trials means there is an urgent need to include qualitative approaches within this speciality (Gooberman-Hill et al., 2011). Trauma and orthopaedic research must ask the “right” questions and assess areas important to both the patient and the healthcare professional. Without identifying these questions and areas, research findings become meaningless and difficult to implement in practice. Qualitative research is an essential tool available to trauma and orthopaedic practitioners when exploring the meanings and complexities behind the phenomena’s that are observed in research findings and clinical practice (Beaton and Clark, 2009). Essentially, all aspects of a condition and treatment must be explored and investigated so as to provide the most optimal solutions for healthcare professionals and patients.

4.4 Bridging the Gap: Enhancing Orthopaedic Outcomes through Qualitative Research Integration

To highlight the underuse of qualitative methods in trauma and orthopaedic research, a bibliographic review was undertaken to identify the amount of research using qualitative methods published in the top-rated trauma and orthopaedic journals as per impact factors and scimago ranking (SCImago, n.d.). Both impact factors and scimago rankings calculate the number of times selected articles are cited within the last few years and are universally used to measure the importance of a journal. The higher the impact factor or scimago ranking, the more highly ranked the journal (Sharma et al., 2014). The article was accepted

for publication in June 2024 to the *Bone and Joint Open* and is presented in its entirety below.

The Bone & Joint Journal



This is the Author Accepted Manuscript.

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Bridging the Gap: Enhancing Orthopaedic Outcomes through Qualitative Research Integration

Journal:	<i>The Bone & Joint Journal</i>
Manuscript ID	BJJ-2024-0659
Manuscript Type:	Original Article
Keywords:	Qualitative, Bibliometric review, Person Centred Care, Qualitative Methods

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Bridging the Gap: Enhancing Orthopaedic Outcomes through Qualitative Research Integration

Abstract

Objective

The evidence base within trauma and orthopaedics has traditionally favoured quantitative research methodologies. Qualitative research can provide unique insights which illuminate patient experiences and perceptions of care. Qualitative methods reveal the subjective narratives of patients that are not captured by quantitative data, providing a more comprehensive understanding of patient-centred care. The aim of this study is to quantify the level of qualitative research within the orthopaedic literature.

Method

A bibliometric search of journal's online archives and multiple databases was undertaken in March 2024, to identify articles using qualitative research methods in the top twelve trauma and orthopaedic journals based on impact factor and SCImago rating. The bibliometric search was conducted and reported in accordance with the Preliminary guideline for reporting bibliometric reviews of the biomedical literature (BIBLIO).

Results

Of the 7201 papers reviewed, 136 included qualitative methods (0.1%). There was no significant difference between the journals, apart from Bone and Joint Open, which included 21 studies using qualitative methods, equalling 4% of its published articles.

Conclusion

This study demonstrates that there is a very low number of qualitative research papers published within the trauma and orthopaedic journals. Given the increasing focus on patient outcomes and improving the patient experience, it may be argued that there is a requirement to support both quantitative and qualitative approaches to orthopaedic research. Combining qualitative and quantitative methods may effectively address the complex and personal aspects of patients' care, ensuring that outcomes align with patient values and enhance overall care quality.

Introduction

A central tenet of healthcare is the use of evidence-based research to inform clinical practice (1). Continual development and research are necessary to improve care quality and optimise outcomes for service users. Clinical research methods can be divided into two main categories, quantitative and qualitative (2) (see Table 1). Quantitative research collects numerical data and analyses it using statistical methods, producing objective, empirical data that can be measured and expressed to test hypothesis, make predictions, or identify patterns (3). Qualitative research collects non-numerical data such as words or images. It explores subjects' experiences, opinions, or attitudes (4).

Table 1. Quantitative vs Qualitative Research. What are the differences?

	QUANTITATIVE RESEARCH	QUALITATIVE RESEARCH
PURPOSE	Answer "how many/much" or "how often" questions.	Answer "why" questions.
DATA TYPE	Number/ statistical results.	Observations, words, symbols etc.
APPROACH	Measure and Test. Fixed and Universal, "factual".	Observe and interpret. Dynamic and subjective.
ANALYSIS	Statistical analysis.	Grouping of common data/ non-statistical analysis.

Both methods are required in research when exploring multi-faceted and complex questions surrounding patient care and understanding the impact care provided has on individual patients and the broader patient population (5). Despite recognising the value of qualitative approaches in specific areas, clinical research in trauma and orthopaedics overwhelmingly utilises quantitative methods (6). Incorporating both quantitative and qualitative methodologies is vital within trauma and orthopaedics. These two approaches are distinct in the types of questions they seek to address (7). For instance, quantitative methods (such as randomised controlled trials) (RCTs) are powerful tools to assess the effects of interventions and treatments. However, critical limitations arise when such studies exclusively rely on quantitative methodologies, as they overlook the subjective experiences of patients undergoing these interventions and can fail to gauge their perceived success (8). These specific research inquiries can only be effectively tackled through qualitative methodologies. Qualitative research diverges from quantitative by drawing upon patients' narratives, opinions, and emotions as primary data sources. This approach enhances the pertinence and robustness of findings while pinpointing practical ways to implement findings in clinical practice (9; 10). To establish a culture of evidence-based practice in the field, it is imperative to recognise that both quantitative and

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3 qualitative research traditions make indispensable contributions (11). These two methods are
4 complementary, and their combined application is essential to enable comprehensive explorations
5 and enhancements of all dimensions of care quality.
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9 Orthopaedic research has been criticised regarding its alignment with the clinical priorities and needs
10 of patients (12; 13). In response, there has been concerted efforts to involve public and patients in the
11 inception, design, execution, and dissemination of research, exemplified by initiatives like The James
12 Lind Alliance Priority Setting Partnership (14) and research funders such as the National Institute for
13 Health Research (NIHR), which emphasise the need to actively involve patients and public in research
14 design and conduct (15).
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19 Despite these advancements, qualitative studies are scarce in prominent orthopaedic journals. It may
20 be argued that qualitative methodologies, to a certain extent, remain largely overlooked or considered
21 relevant only to nursing and allied professional-related roles and topics. To explore this, a
22 comprehensive bibliometric search took place to identify the amount of qualitative research published
23 in orthopaedic journals.
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29 This bibliometric search was conducted and reported in accordance with the Preliminary guideline for
30 reporting bibliometric reviews of the biomedical literature (BIBLIO) (16).
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34 **Methods.**

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36 A comprehensive bibliometric search occurred in March 2024, by two independent researchers. The
37 top 15 orthopaedic and sports medicine journals from 2023 were identified, according to a
38 combination of the Thomson Reuters impact factor and Scimago Journal ranking (17) (Table 2). Each
39 journal's full online archives and databases, CINAHL, Cochrane, and PubMed, were searched using the
40 search terms "qualitative, qualitative approach, qualitative methods". The search included all
41 available published papers in the journals, regardless of date published. The searches were not limited
42 by historical time constraints or geographical limitations. The decade each eligible article was
43 published was recorded to enable a comparison between decades and identify if there is an increase
44 in numbers of qualitative research published over time. All included journals published articles in
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56 **Table 2 Included top Orthopaedic and Sports Medicine Journals based on impact factor and Scimago rating**
57 *(listed by Scimago ranking).*
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	Impact Factor	Journal Title	Scimago Journal rating
1	18.6	British Journal of Sports Medicine	1

2	7.1	American Journal of Sports Medicine	3
3	4.6	Bone and Joint Journal (Br) and Bone and Joint Open	5
4	4.435	Journal of Arthroplasty	7
5	4.33	Arthroscopy - Journal of Arthroscopic and Related Surgery	8
6	4.578	Journal of Bone and Joint Surgery	9
7	7	Osteoarthritis and Cartilage	10
8	3.8	Knee Surgery, Sports Traumatology, Arthroscopy	11
9	3.925	Acta Orthopædica	17
10	5.853	Bone and Joint Research	18
11	4.16	Spine Journal	19
12	4.837	Clinical Orthopaedics and Related Research	38

The Journal of Sport and Health Science, Sports Medicine, and the Journal of Cachexia, Sarcopenia and Muscle were excluded from the results (see table 3) as the qualitative research they included were unrelated to the trauma and orthopaedic speciality.

Table 3. Journals excluded from search.

	Impact Factor	Journal Title	Scimago Journal rating
13	9.8	Sports Medicine	2
14	8.9	Journal of Cachexia, Sarcopenia and Muscle	4
15	13.077	Journal of Sport and Health Science	6

The title and abstract of search results from each journal were manually screened against the eligibility criteria (Table 4). The full text of studies identified for potential inclusion were retrieved and examined against the eligibility criteria.

Eligible studies included qualitative approaches or methodologies at any point in study processes. Literature reviews and editorials/opinion pieces using or discussing qualitative research were also identified. There was no restriction on method of qualitative approach, nor when it featured within the study. The qualitative methodology could be used for initial study design or within the main body of study data collection.

Table 4. Eligibility Criteria

Inclusion Criteria	Exclusion Criteria
Article focussed on Trauma and Orthopaedic Surgical Specialities.	Articles focussing on other clinical specialities.
Research using a qualitative methodology or approach at any point in the study process, including, nominal group, focus group, open ended questionnaire, interviews, data collected in participants own words.	Research solely using PROMs as a form of participant feedback data.
Research using either patients or clinicians or healthy volunteers in participant sample.	
Systematic literature Reviews, scoping reviews, editorial, opinion articles using or discussing qualitative research or qualitative methods.	

Notably, the word “qualitative” often had different meanings. For example, some papers used the term “qualitative methods” when describing subjective clinical assessments of an injury, imaging, or anatomy. Systematic literature reviews frequently used the term qualitative methods to describe analysis of search results by researchers. These alternative meanings of “qualitative” meant each journal initially identified large lists of articles including the search terms. Further investigation and reading of full text were needed to ensure the results were accurate.

The objective was to identify the number of published articles using or discussing qualitative methods or approaches. It was not to conduct a quality appraisal of the results, therefore, with the exception of the decade it was published, no additional data was extracted.

Results.

The 12 Orthopaedic and Trauma journals identified 7201 articles containing the search terms. After titles and abstracts were screened, 169 records were assessed as potentially eligible. These full articles were screened against the eligibility criteria, resulting in 23 systematic literature reviews, 10 editorials or opinion pieces, and 136 research studies using qualitative research methods in the study process (see Table 5).

A PRISMA style chart (18) clearly demonstrates the search process (Fig 1).

Figure 1. PRISMA chart presenting the search process and results from the Trauma and Orthopaedic Journals.

Table 5. Breakdown of search results from each orthopaedic journal and the percentage of qualitative research published within the journals published articles.

Journal title	Total number of published articles identified in search.	Number of articles identified from each journal archive search	Qualitative Research papers published	Systematic literature reviews/ Editorial or Opinion articles	Percentage of Qualitative Research in Journal
British Journal of Sports Medicine	9474	826	17	16	0.34%
American Journal of Sports Medicine	11685	798	5	0	0.04%
Bone and Joint Journal	16550	233	7	1	0.04%
Bone and Joint Open	513	61	21	0	4%
Journal of Arthroplasty	10762	802	7	0	0.06%
Arthroscopy - Journal of Arthroscopic and Related Surgery	12792	541	9	0	0.07%
Journal of Bone and Joint Surgery	28523	1223	17	4	0.07%
Osteoarthritis and Cartilage	16335	1110	14	3	0.10%
Knee Surgery, Sports Traumatology, Arthroscopy	8641	486	7	1	0.09%
Acta Orthopædica	8885	147	2	0	0.02%
Bone and Joint Research	870	95	5	1	0.60%
The Spine Journal	14522	652	10	3	0.08%
Clinical Orthopaedics and Related Research	13907	227	15	4	0.13%
Totals	153459	7201	136	33	

Articles including qualitative methods accounted for 0.1% of published articles out of the catalogue of work published by listed journals. Research studies using qualitative methodologies accounted for 0.08% of published articles within the included journals. In addition, 0.02% of published articles

mentioned qualitative research within the paper. Bone and Joint Open included the greatest number of studies using qualitative methods, out of the available articles identified within their archives, 21 (4%) of these included qualitative methods.

In the decade 2000-2009, 0.07% of published papers included qualitative methods in the journals, this rose to 0.14% between 2010-2019 (see Table 6, figure 2). The current decade is shown to predict the biggest increase so far as the volume of qualitative research since 2020 already exceeds the previous decades data at 0.4% (Fig.3). However, it is important to note that along with the increase in qualitative research, there has also been marked increase in articles published overall. The ability to publish articles online in addition to paper copies resulted in over 15000 more papers in the named journals in 2010-2019 compared to 2000-2009.

Table 6. Number of articles including qualitative methodology published by decade in trauma and orthopaedic journals.

	1900-1969	1970-1979	1980-1989	1990-1999	2000-2009	2010-2019	2020-to date	Total
British Journal of Sports Medicine	0	0	0	0	11	14	8	33
American journal of Sports Medicine		0	0	0	0	3	2	5
Bone and Joint Journal	0	0	0	0	0	1	7	8
Bone and Joint Open							21	21
Journal of Arthroplasty			0	0	1	4	2	7
Arthroscopy - Journal of Arthroscopic and Related Surgery			0	0	0	3	6	9
Journal of Bone and Joint Surgery	0	0	0	0	7	10	4	21
Osteoarthritis and Cartilage				0	2	6	9	17
Knee Surgery, Sports Traumatology, Arthroscopy				0	0	4	4	8
Acta Orthopædica	0	0	0	0	0	2	0	2
Bone and Joint research	0	0	0	0	0	5	1	6
The Spine Journal					0	11	2	13
Clinical Orthopaedics and Related Research	0	0	0	0	0	1	18	19

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Fig. 2. Number of qualitative research in orthopaedic journals by decade.

The overall scarcity prompts questions about the prevalence of qualitative methodologies in orthopaedic research: Are they underutilised? Are the research questions not conducive to qualitative inquiry? Alternatively, is there unconscious bias against publishing qualitative research in orthopaedic journals, suggesting that clinicians may believe that qualitative research methods are more suited to be published elsewhere?

Discussion

Nursing and allied professional research hold strong traditions of using qualitative methods (19). The role of the nurse and allied professionals is synonymous with a holistic view of the patient and family and is underpinned by theories that are congruent with qualitative methodology (20). This rationale implies qualitative research is common within nursing and allied professional journals and why qualitative methodologies are associated with these more “caring” and holistically focussed disciplines. The medical and surgical mindset encourages clinicians to think in terms of cause and action, valuing concise quantitative results, qualitative research is sometimes considered “hopelessly subjective”, and “unscientific” (21). The quality of qualitative research has also been acknowledged as

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3 inconsistent in the past (22), which may have contributed to the perception of it being less valuable
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5 than quantitative methods (23). A holistic understanding of patient well-being extends beyond a
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7 biomedical model in all healthcare specialities, not least in trauma and orthopaedics. Acknowledging
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9 the intricate interplay of a patient's biological, psychological, social, and economic circumstances is
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11 crucial for fostering a genuinely patient-centric healthcare environment and should be prioritised in
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13 every healthcare discipline (6; 24; 5). As presented in the results, Bone and Joint Open included by far
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15 the highest number of publications featuring qualitative methods amongst the listed journals, Bone
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17 and Joint Open was first published in 2020 and is dedicated to publishing high-quality clinical papers
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19 across a range of healthcare disciplines (25). By actively encouraging other healthcare professions to
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21 submit their research to Bone and Joint Open, the journal can include studies from those disciplines
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23 that have a strong history of using qualitative methods within their research. Importantly, though
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25 research using qualitative methods are evident in nursing journals and have increased overall over
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27 time, the rates across journals fluctuated considerable, and the number of publications using
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29 qualitative methods were not as high as what could be assumed (19; 22).

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35 A challenge lies in quantifying the impact of perceptions of care quality on patient outcomes and
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37 experiences. The National Health Service (NHS) has integrated research and evidence-based practice
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39 as core strategies to enhance patient care. Therefore, it is essential to evaluate whether current
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41 research initiatives align with the priorities and concerns of the patients themselves. The merit of
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43 research findings and their scientific validity, often gauged through quantitative methods, may not
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45 always reflect the values and necessities perceived by patients (26). The Institute of Medicine's (IOM)
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47 2022 (27) framework conceptualizes quality care as a complex construct comprising six dimensions:
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49 safety, effectiveness, timeliness, patient-centeredness, equity, and efficiency (Figure 3). These
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51 dimensions are guidelines for health professionals when considering how to holistically improve
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53 standard of care provided through research and practice development endeavours.
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Fig. 3. Institute of Medicines (IOM) six dimensions of quality care.

Evaluating the Measurement of Quality in Orthopaedic Practice

Improving quality across all dimensions necessitates a collaborative, multi-disciplinary approach that synergizes patient perspectives with clinical acumen. In the context of elective hip and knee replacements, the success of these procedures has historically been gauged by the longevity and reliability of implants and rate of revisions (28; 29; 30). Over time, assessments have expanded to include readmission rates, mortality, and hospital stay duration, thereby furnishing a broader perspective on patient recovery and informing the evaluation of surgical wait times and criteria (31; 32). However, these traditional metrics emphasise outcomes that may be more relevant to health professionals, potentially overlooking the patient's subjective experience.

To address this, in 2009 the NHS introduced patient-reported outcome measures (PROMs) for individuals undergoing these procedures (33). This initiative, aimed at enhancing patient choice and transparency, seeks to incorporate the patient's voice as a critical dimension in evaluating care quality. However, the PROMs typically employed in assessing joint replacements are limited in scope, addressing only a narrow spectrum of functional activities and daily living tasks, and reporting results using quantitative numerical methods. Moreover, they are prone to a 'ceiling effect,' where the most active individuals' capabilities may not be fully captured (34). Alternative approaches, such as physical performance tests and activity monitoring devices, are gaining traction in recovery protocols, offering more nuanced understandings of functional ability, and sometimes revealing disparities with PROMs data (35; 36).

Without considering patient experiences from their perspective, it remains unclear whether PROMs or functional tests adequately reflect aspects of recovery that mean most to patients or if they predominantly address healthcare professionals' preconceptions. Qualitative research has been instrumental in uncovering patient priorities not apparent in existing PROMs (37; 38), indicating

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3 significant divergence between quantifiable health outcomes and the patient-perceived quality of
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5 care. This raises fundamental questions for healthcare providers: How can we ensure patient-centred
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7 care when the outcome measures may not fully capture what is genuinely significant to patients?
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11 Considering the IOM's framework for measuring care quality (28), the methodologies employed in
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13 trauma and orthopaedics capture five of the six dimensions. Routine data collection on complications,
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15 infection rates, readmissions, and mortality rates underscore the dimension of safety. Waiting times
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17 for surgeries serve as proxy for timeliness. Analyses by national programs like Getting It Right First
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19 Time (GIRFT) (39) and the Atlas of Variation (40) address equity by identifying disparities in care
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21 delivery and evaluating the value of healthcare for populations and individuals. Data on hospital stay
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23 lengths and insights from GIRFT contribute to efficiency metrics. Implant survivorship data, catalogued
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25 on the National Joint Register in the UK (41) and PROMs, provide insight on effectiveness from clinical
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27 and patient standpoints. However, despite the extensive research and literature on these themes, the
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29 one dimension that appears to be underrepresented within trauma and orthopaedic journals is
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31 person-centred care, which is vital to the holistic measurement of healthcare quality.
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39 **Fostering Patient-Centred Research in Trauma and Orthopaedics**

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42 Person-centred care is pivotal for focusing on care, support, and treatment aspects important to
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44 patients, families, and caregivers (42). To deliver this effectively, it is crucial to discern its key
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46 components directly from a broad and representative range of patients without relying on
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48 presumptions. Qualitative research methodologies are particularly suited to unearth these insights
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50 and are especially useful for ascertaining viewpoints from groups of patients whose voice is seldom
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52 heard. Within hip and knee arthroplasty pathways, one example could be related to age. Current
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54 practice is influenced by the predominantly older patient demographic who undergo the operation.
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56 However, it is unknown if the outcomes and goals valued by this group align with those of the
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58 increasing number of younger patients undergoing hip replacements (43).
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Mixed-methods research, marrying quantitative and qualitative approaches, offers a comprehensive understanding of the applicability of treatments and the patient experiences therein (44). Large-scale studies like SCIENCE (45) and CRAFFT (46) have integrated qualitative sub-studies to capture patient narratives beyond standardised follow-up, enriching our understanding of patient and family experiences. However, this approach is marginalised to patients involved in a RCT and excludes the experiences of those receiving standard care not involved in research.

Nonetheless, the intrinsic value of qualitative research in providing nuanced insights into patient experiences and the multi-faceted nature of care is gaining recognition (4) and as identified in the results, there is an increase in qualitative research published over recent decades. One domain which values qualitative research is examining strategies to enhance patient engagement and maximising recruitment into trials (47; 48; 8; 49). While the necessity for surgical trials is uncontested, an overemphasis on what is deemed 'scientifically' rigorous could marginalise alternative research approaches (50). By framing the role of qualitative research to supplement quantitative studies, it overlooks its broader possible contributions to evidence-based practice in Trauma and Orthopaedics. It is incumbent upon research communities to acknowledge and integrate the rich insights offered by qualitative research to ensure that healthcare's evolution continues to be based on the pillars of scientific rigour and embodies the essence of person-centred care.

This bibliometric review has limitations, the multitude of medical and surgical journals available mean that it is impossible to search every archive, therefore, the examples of qualitative orthopaedic research that undoubtedly feature in non-orthopaedic journals are not included within this search. The purpose of this article was to highlight the absence of qualitative research within the orthopaedic specialty; therefore, the featured journals were speciality journals. It is difficult to ascertain how underrepresented qualitative research is in these journals as the actual volume of qualitative research being conducted relative to quantitative research is unknown, neither are rates of submission, review, and acceptance of qualitative research compared with non-qualitative research. It could be

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quantitative researchers greatly outnumber qualitative ones, however, the amount of qualitative research published in orthopaedic journals is so minimal, there implies some other contributing elements. Further research is required in exploring the factors and circumstances of publication rates within orthopaedic journals, and the journal publication policies that guide editorial decisions.

Conclusion

This review seeks to substantiate the indispensable role of qualitative research methodologies in trauma and orthopaedics, underscoring their potential to unveil patients' nuanced experiences and expectations, which often remain unseen by quantitative data alone. A more holistic and empathetic understanding of patient outcomes and satisfaction can be achieved by embedding qualitative methods within trauma and orthopaedic research. This approach complements quantitative methods and enriches them, providing a comprehensive picture that is crucial for truly patient-centred care. The imperative to integrate these methodologies is further amplified by the increasing demand that patient voices and narratives guide clinical decisions and personalise care. Thus, the paucity of qualitative studies in prominent orthopaedic journals is not just a gap in research but a missed opportunity to enhance the quality and relevance of orthopaedic practice.

Advocating a shift towards greater inclusion of qualitative research in orthopaedic journals may require addressing inherent biases and misconceptions about the value of qualitative data. As the field progresses, it is crucial to promote a balanced research paradigm that recognises the symbiotic relationship between qualitative and quantitative methodologies. This balance may allow for a more robust and nuanced exploration of patient care, ensuring that outcomes reflect the complexities of individual patient experiences and lead to more effective clinical solutions. Therefore, the research community must champion this cause, fostering an environment where qualitative research is not only conducted but also published and valued on par with quantitative studies. This paradigm shift is key to advancing a more patient-centred approach in trauma and orthopaedics, enhancing both the science and the humanity of patient care.

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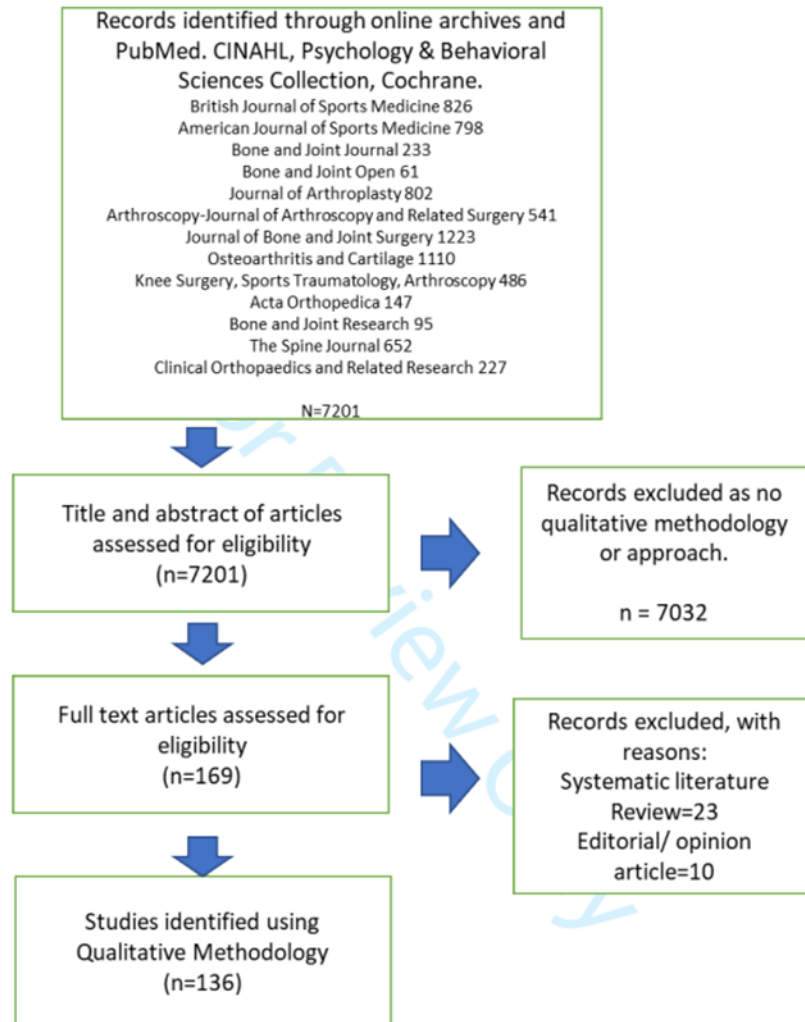
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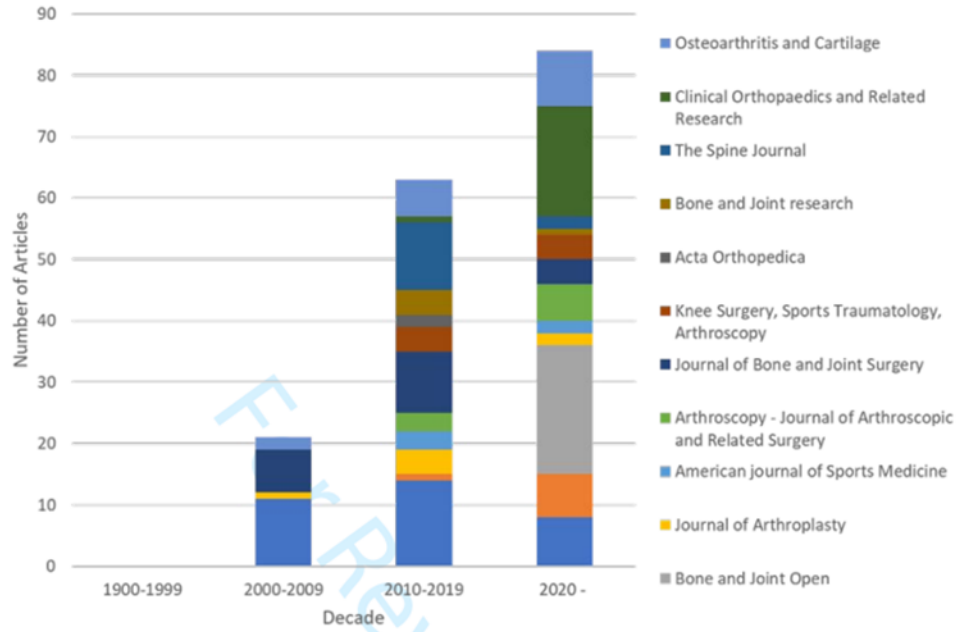
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Figure 1. PRISMA chart presenting the search process and results from the Trauma and Orthopaedic Journals.



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Fig. 2. Number of qualitative research in orthopaedic journals by decade.



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Fig. 3. Institute of Medicines (IOM) six dimensions of quality care.



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The bibliographic review was expanded, and a further search took place in August 2024 including the original search terms plus “interview, focus group”. Though some journal highlighted an increased number of search results, on further investigation, these additional results did not include qualitative research or methods, therefore, this second search did not impact any results or alter the findings of the review.

4.5 Qualitative Methodologies

A range of qualitative approaches were explored when considering the most appropriate method for the intention of the research. The most prominent approaches available are: Grounded Theory, Narrative Analysis, Discourse Analysis, and the Phenomenological approaches (Cresswell and Cresswell, 2018). As discussed below these methods were discounted based on aspects that were not congruent with the research aim.

Grounded theory focusses on constructing themes from qualitative data to develop theories on that topic. Through ongoing recruitment of participants, it uses theoretical sampling techniques in which these theories are tested and evolved (Glasser and Strauss, 1967). Grounded theory explicitly seeks to establish claims for the broader population and usually requires larger sample size (Morse and Field, 1996). The research aim was to understand the lived experience of the individual participants, it did not strive to develop a theory or seek to generalise findings over a broad population, thus, Grounded Theory was in direct contrast to the ideographic nature of the research question. Narrative Analysis explores the story and experience of an individual within a social backdrop (Hyden, 1997). The researcher analyses the structure of the account as presented by the narrator and does not deconstruct the story into themes (Reissman, 1993). Narrative analysis is primarily effective on the exploration of a single participant’s experience, this is not congruent when collecting data from multiple participants and exploring the emergent themes within the data both within individual participants experiences and within the whole group data set. Discourse Analysis takes this further by examining the role of language in describing and constructing the participant’s experience (Paltridge, 2012; Harper, 2006). The research question of what is important to the younger person when undergoing a THR focuses on the topic and the participant’s understanding and reflection of their experience. By focusing only on the language used could result in important data relating to the content being lost.

4.5.1 Phenomenology

Phenomenology aims to describe experiences as they are lived by participants (Langridge, 2007). Phenomenology is both a philosophy and a research method used frequently by qualitative researchers (Caelli, 2000). Phenomenology is essentially the study of a phenomena, which could be an event, situation, occurrence, experience, or concept

(Neubauer et al., 2019). The phenomenological approach aims to describe, understand, and interpret the meanings of experiences of human life through focusing on a concrete, experiential account, grounded in everyday life (van Manen, 2016; Langdrige, 2007). There are many different interests and emphases amongst phenomenologists, but what they all have in common is that they strive to explore what the experience of being human is like (Smith et al., 2009). The two main phenomenological approaches are descriptive and interpretative. These two traditions are distinctly different in their theoretical philosophical underpinnings which greatly influences how they are used as a research method (Biggerstaff and Thompson, 2008).

Descriptive phenomenology is the traditional approach and is closely connected to Edmund Husserl's (1859-1938) philosophical tradition. Husserl described phenomenology as the study of phenomena as it appears through consciousness and introduced the concept of the "life-world" or lived experience (Husserl, 1931). He explained knowledge stems from conscious awareness and the mind is directed towards objects, he termed this intentionality (Husserl, 1931). Reality is subjective as every person has his or her own reality, therefore every person's unique perception of their lived experience is explored (Finlay, 2011). Husserl emphasised the importance of returning to the actual living world in which people are experiencing the phenomena in everyday situations (Giorgi, 1985). To arrive at an understanding of human consciousness and experience, Husserl stated that research must be carried out with a subjective and unprejudiced perspective to allow the phenomenon to present itself so it can be precisely described and understood (Valle et al., 1989). To achieve this, Husserl described the strategy of bracketing and phenomenological reduction (Moran, 2000). Husserl's original meaning of phenomenological reduction is that of a technique that endeavours to separate the effect culture, tradition and society may have on the phenomenon in question, to explore the "true" phenomenon (Stumpf and Frieser, 2008). Schutz (1970) explained that Husserl's method not only separated the outer world from the research but also the individual consciousness, it aimed to eliminate all pre-conceived notions, judgements, and assumptions. The process of phenomenological reduction in Husserl's phenomenology defends the validity and objectivity of the research from the potential self-interest of the researcher (Koch, 1995).

A student of Husserl, Martin Heidegger emphasised differences between their philosophies (Smith et al., 2009). Heidegger was interested in interpretation rather than description, thus introduced interpretative phenomenology and developed the hermeneutic approach (Dowling, 2004). He argued that understanding is not only a method of knowing but as a mode of being, a fundamental characteristic of our "being" in the world (Heidegger, 1962). Phenomenological reduction was vehemently rejected by Heidegger, who argued that prior understanding and experience increased the value of interpretation (Moran and Mooney,

2002). Heidegger saw the researcher as a pivotal part of the research, whose ability to interpret the data relied on their previous knowledge and experiences (Dowling, 2004). In interpretive phenomenology, it is impossible to ignore the researcher's judgement and influence.

4.5.2 Hermeneutics

Hermeneutics is the art and science of interpretation or finding meaning, traditionally it was an entirely separate body of thought from phenomenology (Dowling, 2004, Reid et al., 2005). However, the philosophical traditions of Heidegger and the philosopher Hans-Georg Gadamer (1900-2002) combined the interpretative phenomenological concerns of the part and the whole with the hermeneutic focus of the history and the context of the phenomenon (Gadamer, 1960; Sloan and Bowe, 2014). The focus in hermeneutic phenomenology is towards revealing seemingly small details in experiences that maybe taken for granted, with the goal of creating meaning and understanding reality (Lavery, 2003). During data collection, the researcher also pays close attention and strives to interpret other additional sources of information, such as body language or facial expressions. In hermeneutics these unspoken, unconscious or hidden meanings are perceived to exist within the phenomenon under study alongside what is verbally conveyed. Thus, this body language also requires the perception to interpret (Lavery, 2003).

When considering the two phenomenological traditions, both descriptive and interpretive approaches would have been appropriate for use, as both focus on the lived experience of the participant. However, it was whilst exploring the traditions and history of phenomenology that I came across interpretative phenomenological analysis as an approach.

4.5.3 Interpretive Phenomenological Analysis (IPA)

IPA is a qualitative, hermeneutic phenomenological approach that despite growing popularity in many academic disciplines is still relatively new in nursing research (Finlay, 2011). First proposed by Jonathon Smith in 1996 as an experiential approach in psychology, IPA offers an accessible and adaptable approach enabling the researcher to reach, hear and understand the experiences of participants. Researchers using IPA are especially interested in what happens when a lived experience takes on a specific importance to the individual such as a significant event (Smith et al., 2009). When people are focused on an experience of something important in their life, they reflect on the significance of what is occurring and IPA research attempts to engage with these reflections (Smith et al., 2009). There are three theoretical commitments underpinning IPA, phenomenology, hermeneutics and idiography (see Figure 8). This chapter will explore each of them and the influence they have on the chosen approach.

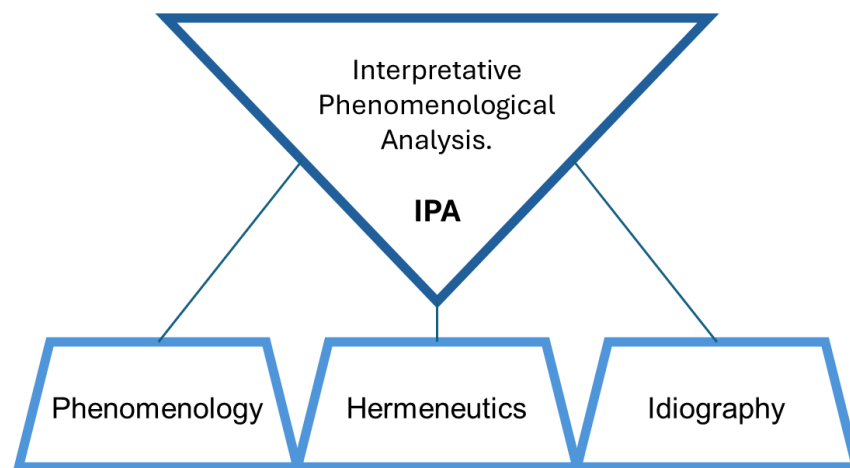


Figure 8. The philosophical and theoretical underpinnings of IPA

4.6 Interpretive Phenomenological Analysis (IPA)

4.6.1 Phenomenological influence on IPA

The phenomenological underpinnings of IPA are based on a combination of the philosophies of Husserl, Heidegger, Merleau-Ponty and Sartre. Merleau-Ponty (1908-1961) described an embodied nature of human's relationship to the world (Moran, 2010). He suggested that the body was not an object in the world, but as a means of communicating with it (Langer, 1989). In IPA, this view is critical, ultimately the researcher can never share entirely the participants experience, as their experience belongs to their own unique embodied position in the world (Smith et al., 2009).

Jean-Paul Sartre (1905-1980) was concerned with the effect encounters with others had on our view of the world, the world does not belong exclusively to any one person and peoples' perception of the world is largely influenced by the presence of other and their own agendas (Sartre, 1956). Sartre also developed the concept of nothingness, he argued that things that are absent are as important as those that are present in defining who we are and our perception of the world (Sartre, 1948).

IPA sees the collective contribution of each of the philosophers discussed as complementary to each other as opposed to in competition. Each subsequent philosopher added to Husserl's original concept to create a mature, holistic, and multi-faceted phenomenology (Smith et al., 2009).

IPA was developed as a phenomenological methodology to holistically explore the multi-dimensional response that individuals can have to a major experience in their lives. Smith et al., (2009) stated that humans are physical and psychological beings, they do things in the world, they reflect on what they do, and those actions have existential consequences.

This experience could be anything perceived as important to that individual. A major surgery, such as a THR is likely to be viewed as an important event and experience. Thus, a holistic phenomenological approach like IPA is particularly apt for this study. IPA's commitment to explore, describe, interpret, and situate the participant's sense of their experience makes it the ideal choice of methodology to use in researching younger patients' priorities when undergoing THR. By enhancing and developing on interpretive/ hermeneutic phenomenology, the IPA approach explores all the multidimensional aspects of the participants experience. In combining an empathetic and questioning approach, the IPA researcher attempts to understand by both, trying to see what the experience is like for someone, and by analysing, illuminating, and making sense of the situation (Smith et al., 2009).

In healthcare research it is difficult to justify using the traditional philosophical meaning of phenomenological reduction. Descriptive phenomenology uses strict bracketing approaches to obtain a true unbiased description of the raw data (LaVasseur, 2003). As an adult nurse who has worked in trauma and orthopaedics for over a decade, in addition to being of that age group being explored, the researcher was very aware that they had assumptions and theories on what would be discovered, whether consciously or subconsciously. They recognised that they may have difficulty in bracketing their fore knowledge when conducting research activities. This along with other arguments already presented was a crucial reason for selecting IPA over other phenomenological approaches. Making sense of the participants narratives require the researcher to interpret the information using their own experiences and knowledge (Smith, 2004). The methods of bracketing and its place in IPA is explored later in this chapter.

4.6.2 Hermeneutic influence on IPA

Hermeneutics is a major theoretical underpinning of IPA (Smith et al., 2009). IPA researchers only claim to access a version of the experience that the participant makes sense of through their narrative account, and do not attempt to produce an objective account of the phenomenon (Smith and Osborn, 2008). The researcher is making sense of the participant making sense of their experiences, this is known as a "double hermeneutic". As such, the researcher is required to use their own knowledge and experience when understanding what is being described, Smith (2004) refers to this as the "biographical presence" of the researcher. Finlay (2011) suggests the researcher intuitively seeks deeper interpretations by probing between the lines of surface meanings. Adopting an approach which emphasises reflexivity is essential in addressing this, (Finlay, 2008). The hermeneutic cycle model which references the dynamic relationship between the "part" and the "whole" relates at many levels of the dynamism of interpretation and reflection. Smith et al., (2009)

detail that in relation to IPA, the “part” relates to the encounter with the participant, (for example, participant interview) and the “whole” to the researcher’s reflection and interpretation of the participant’s experience incorporating the researcher’s knowledge and experience (see Figure 9). Because of this process, the researcher using IPA has a central role in the analysis and interpretation of the participant’s experiences (Smith et al., 2009). This process takes a circular form, continuously repeating with each new participant and researcher encounter.

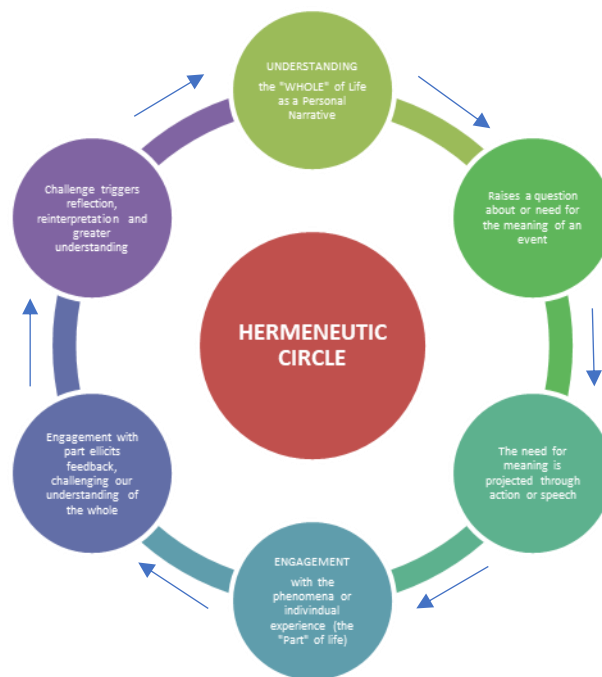


Figure 9. Diagram of the Hermeneutic Cycle (Figure drawn by author adapted from Smith et al., 2009)

A combination of phenomenology and hermeneutic insights are both necessary in IPA. Without phenomenology, there would be nothing to interpret, without hermeneutics, the phenomenon would not be seen (Smith et al., 2009).

4.6.3 Idiographic influence on IPA

Idiography is the third major influence upon IPA. An idiographic approach focuses on the individual and on the unique personal experience of human nature (Noon, 2018). IPA demonstrates the idiographic approach in the sense of detail and depth of analysis and in also aiming to understand how a particular experience is understood by a particular person, in a particular context (Smith et al., 2009). IPA explores in depth each individual’s unique experience, it then details similarities and differences between participants, this then develops any general claims that present themselves through the analysis (Smith and

Osborn, 2008). Idiography does not avoid generalisation but utilises a different way of establishing it (Harre, 1979). Warnock (1987) and Goethe (1988) illustrate this by stating that exploring deeper into the particular can help us uncover the aspects of the phenomena that are universal. Smith et al., (2009) explain that, while findings discovered through IPA may have limited generalisability, they do possess a transferability which may reveal something interesting, useful, or important about the phenomenon.

This section has described IPA, its theoretical underpinnings and why it was felt the most apt choice for the research method in this study. However, IPA is not without its critics. IPA is accused of lacking standardisation and being riddled with ambiguities (Giorgi, 2010). It has been criticised for being over descriptive and lacking in interpretive nature (Hefferon and Gil-Rodriguez, 2011). There are questions around whether IPA can accurately capture the experiences and their meanings rather than opinions of it (Hefferon and Gil-Rodriguez, 2011). This implies concerns that should the participant or researcher not possess the communication skills necessary to communicate the nuances of their experiences, findings will be incomplete or inaccurate. These criticisms have been rejected as elitist by the large quantity of publications that outline IPA's theoretical, methodological, and philosophical underpinnings (Smith, 2011), for example Snelgrove and Lioffi, (2009); Biggerstaff and Thompson, (2008). IPA's main purpose is to gain insight into an individual's lived experience, it uses narratives, discourse, and metaphors etc, to achieve this (Brocki and Wearden, 2006). It also strives to understand the cultural position of a person's experiences by using hermeneutic, idiographic and contextual analysis, therefore, Smith (2011) argues that if the researcher is aware of these criticisms but takes care to collect rich and exhaustive data from participants, then these concerns are baseless.

4.7 Reflexivity and bracketing with IPA

Reflexivity refers to the "tacit" or assumed knowledge of the researcher undertaking the project (Saks and Allsop, 2013). The researcher may not necessarily be conscious of their preconceptions beforehand. But the complex way they unpack the relationship between interpretation and fore understanding when using an IPA approach may potential uncover a more robust and cyclical reflexive bracketing (Smith et al., 2009).

At its core meaning, bracketing is a scientific process where a researcher suspends or puts aside their own opinions, judgements, and assumptions during the interview process. This enables them to objectively explore the phenomenon being investigated (Given, 2008; Rolls and Relf, 2006). When bracketing is referred to in phenomenological research it is usually in relation to the process of reflexivity on the part of the researcher (Dowling, 2005). There is no single set of methods for undertaking bracketing (Gearing, 2004; Wall et al., 2004)

and the technique of bracketing can be problematic and inconsistent in a hermeneutic phenomenological approach (LaVasseur, 2003), where it is acknowledged that the researchers pre-understanding cannot be discounted (Koch, 1995). Giorgi (2011) argued that there is no step of bracketing in IPA. However, it is important to recognise that no-one has better knowledge and experience than the participants themselves regarding their lived experiences and perceptions (Tufford and Newman, 2010). An awareness of reflexivity is required, in IPA as with all research methods, to ensure the research findings are as close as possible to what the participant means (Chan et al., 2013; Smith et al., 2009).

My background as a trauma and orthopaedic nurse had potential to bias the interpretation of the participants experiences. In order to address this, I approached each encounter with participants or the encounter with the data with an open mind. To incorporate reflexivity when exploring the participants experiences, I took steps to bracket my preconceptions to discover meaningful ways to interpret the participants' experiences without imposing my values as recommended by Smith et al., (2009). Prior to entering each patient encounter and beginning any analysis or interpretation of the data, I recorded any assumptions or preconceptions I identified that I believed influenced my perceptions. Recording these concerns allowed me to begin the encounter with an awareness of topics that may require further clarification if identified by participants, it also highlighted areas I needed to avoid imposing on the participant. An extract of these reflexive recordings is demonstrated in Appendix 4. After the participant encounter, I again recorded my thoughts and considerations, this allowed me to reflect and explore my thoughts on the encounter before moving on to the next interview process. The recording of these preconceptions and reflections continued throughout the interview, transcribing, and analysis process. Finlay (2002) explains that this awareness assists in unravelling instances in which the participants and researcher share understandings and ones in which they diverged. The researcher should guard against the assumption that the participant shares their concerns and perceptions, failing to do this may result in missing the points where there are differences (Finlay, 1998).

When considering how to manage my own preconceptions and assumptions, I found Gadamer's philosophy offered a solution. Gadamer explained the way previous knowledge and assumptions may be organised is through the fusion of horizons (Vessey, 2009). This process involves the researcher recognising their foreknowledge, preconceptions and assumptions that may influence the interpretative process, these aspects create their horizon which at this point limits how far they can see. The new understandings present in the data adapt and change this horizon; therefore, a fusion of horizons occur between the participant and the researcher (Walsh, 1996). This concept fits in with the hermeneutic circle, as this fusion of horizon takes a circular motion with no end (Vessey, 2009). The

researcher embraces a new understanding, which is again, adapted and changed when encountering another horizon and so on. Although IPA does not specifically mention the concept of fusing horizons, it is very similar to the argument that when attempting to uncover and come close to the participant's experience, the IPA researcher should be willing to adapt and alter their views in light of the participant's data (Larkin et al., 2006). Smith and Eatough, (2007) describe the process of reflexivity in IPA in the concept of a circle, the researcher with all their previous experience and preconceptions starts at one point of this circle, the researcher then moves towards the encounter with the participant on the other side of the circle. During this movement, the researcher attempts to acknowledge their preconceptions and move the point of focus from them to the participant. After attending closely to the participant's experience, the researcher then continues around the circle to the initial start point where the data gathered is analysed. The researcher is now irretrievably altered because of the patient encounter. Importantly, the researcher may not be aware of their own preconceptions or assumptions in advance, so reflective practice and a cyclical approach to bracketing is essential (Smith et al., 2009).

Smith and Eatough, (2007) also recognise the need for an awareness of the researcher's own perceptions and conceptions in the analysis stage of the research. Analysis has typically been described as an iterative and inductive cycle, the strategies that are flexibly incorporated into this cycle include a process of reflexivity and reflection (Smith et al., 2009).

4.8 Ethics

Ethical approval was granted by London – NHS Chelsea Research Ethics Committee (Ethics reference 20/PR/0858) and Bournemouth University (Ref 34876) on 13th January 2021 (see Appendix 5). However, ethical approval does not reduce the responsibility to ensure that the research process remains ethical throughout the process of conducting the research, and this is detailed below.

4.8.1 Informed Consent

Valid informed consent is fundamental when carrying out any research activity at any stage of the research study (Jefford and Moore, 2008). It ensures information regarding the study has been effectively communicated and understood by the participant, decisions about participation are voluntary, potential benefits and risks to the participant are understood, and the participants capacity to provide informed consent is recognised (Health Research Authority (HRA), 2018). Each participant was given a participant study information sheet (PIS) (Appendix 6) detailing reasons why the study was being conducted, what was expected of them as a participant, and how the data generated would be used. It was made clear that consent to participate was completely voluntary and declining to participate would

not affect their medical care or legal rights in any way. A participant consent form (Appendix 7) was completed by the participant prior to any study procedures being initiated. To ensure the participant fully read and understood the consent form, they were required to initial a box at the end of each listed statement to demonstrate they had read and understood the statement. The form was then signed by the researcher involved in the consent conversation. Informed consent is recognised by the HRA (2018) as an ongoing process therefore verbal consent was checked and recorded in medical notes at each stage of the study process. Participants were informed they were free to withdraw participation at any time without being obliged to give a reason or their care being affected. Participants could withdraw by contacting and informing the researcher. Unless the participant explicitly withdrew their consent for data already collected to be used, any data collected up until the time of withdrawal was retained by the research team and anonymously included in the final analysis. This was made clear in the participant information leaflet.

Any contact with the participant was recorded in their medical records to ensure transparency and accuracy throughout. A GP letter (Appendix 8) was also sent to the participants GP surgery to inform them that the patient was participating in a research study, permission to send a letter to their GP was requested on the study consent form (Appendix 7).

4.8.2 Confidentiality and anonymity

The aspect of confidentiality was discussed both verbally with each participant as well as provided in the Patient information Leaflet. To ensure confidentiality, all identifiable data was stored on password protected drives and computers accessible only to the researcher. All research staff involved in the study were bound to comply with the requirements of the Data Protection Act (1998) and the General Data Protection Regulations (GDPR) (Gov, 2018) with regards to the collection, storage, processing, and disclosure of personal information and will uphold the Act's core principles. These two legislations set out how personal information and privacy should be managed within research (Wilms et al., 2020). All identifiable information was removed from the data at the point of transcription as each participant was given a pseudonym (Nursing and Midwifery Council (NMC), 2018a) which was then used throughout data transcription and the rest of the research process. All the participants were aware through the participant information sheet that the researcher would be sharing the findings more widely.

Completed consent forms and completed Hip Disability and Osteoarthritis Outcome Scores (HOOS) were filed in the Young Hip Site file, which was held in a secure, locked filing cabinets within a restricted area at the hospital where the researcher worked. Identifiable

data was kept separately from the outcome data (both paper and electronic). No identifiable information was shared with other persons at any point.

4.8.3 Role Conflict between Researcher Role and Nurse Role

Separating the role of the researcher and the role of the nurse was an initial concern. It is difficult to ignore nursing knowledge and experience and enter the research field as a completely impartial researcher, whose main role is gathering data (Ashton, 2014). As a nurse employed by the hospital where the participants treatment was taking place, I was often unavoidably linked to the treating team in some participant's view, and questions were sometimes posed to me which caused a role conflict. It is recognised that information provided by the nurse-researcher could potentially influence participants' responses or discourage participants openly sharing information (Baxter and Jack, 2008). However, refusing to answer health-related questions also has the potential to adversely affect the interview and directly contraindicated my professional obligations under the NMC (2018a). The rapport and trust established between the participant and researcher may be damaged if the participant perceives the researcher as being unwilling to discuss their concerns or offer advice (Dempsey et al., 2016). Reflecting on this, I incorporated the advice advocated by Britten (1995) deferring requests for further advice or answers until the end of the interview and if there was a need for further intervention then the participant was referred to another healthcare professional. In this way I attempted to separate my roles without affecting the interview or relationship. I also took care to approach and discuss informed consent with the participant as a researcher and not in my clinical role as a nurse. It was important to separate these roles, no matter how difficult, at the point of recruitment. It was unjustifiable to use the role of the nurse at this stage, then change identity once the study commences (Dowling, 2006).

Being perceived as part of the clinical team was also concerning in the aspect of the perceived imbalance of power between treating clinicians and patients. This power imbalance has been explored and analysed in multiple journals and is widely recognised as a concern in healthcare and a barrier to successful nurse-patient or doctor-patient relationships (Koeck, 2014; Henderson, 2003; Tobiano et al., 2016). The feelings of vulnerability, which illness and disability can create in patients, along with the perceived greater knowledge and influence on care healthcare professionals possess, cause an inequality and power imbalance in the relationship between the two (Tobiano et al., 2016). Several participants asked me directly if what they divulged would be shared with the surgeon or clinical teams and were sometimes initially wary of describing negative aspects of their care. I took time to reassure them of complete confidentiality and attempted to separate myself from the care team when conducting research activities. When interviewing

face to face I did not wear my nursing uniform. I also ensured I was never involved with their direct care. These methods, I believe, contributed to the successful, trusting, and collaborative relationship between myself (the researcher) and participants, as evident by the discussions facilitated and the sensitive topics the participants independently addressed within the interviews.

4.9 Study Sample

4.9.1 Inclusion and Exclusion Criteria

As IPA is an ideographic approach, participants are selected on the basis that they can offer the researcher a particular perspective on a phenomenon. The phenomena under exploration were young patients' experiences of undergoing a primary elective THR. All patients who met the inclusion and exclusion criteria for the study (Table 2) were approached to participate. A screening log recorded all patients approached, along with reasons documenting why they were not included if the patient provided them (Appendix 9):

Table 2. Inclusion/ exclusion criteria

<u>INCLUSION CRITERIA</u>	<u>Rationale</u>
Patients aged 18-50 years.	Consensus in the literature appears to classify "young patients" undergoing THR as under 50 years, therefore the upper age limit was enforced as 50 to be congruent with the current literature available.
Scheduled to undergo a primary elective THA in the next 12-18 months. Patients were still eligible if they had previously had a THA in the opposing hip)	All potential chronic health conditions resulting in the need for THA were included. Patients undergoing THA to treat traumatic fractures or dislocation of the hip joint were not eligible. This is due to the stark difference between patient pathways and experience prior to surgery.
Able to provide informed consent.	Participants had to have capacity to understand and consent to study procedures.
<u>EXCLUSION CRITERIA</u>	
Under 18 years of age Over 50 years of age	See Inclusion Criteria Above
Undergoing a revision of THR in the index hip.	The study objective was to explore the lived experience of the patient undergoing a primary THA. Comparison between previous index hip surgery and experience of the revision may affect expectations and prioritised outcomes.
Unable to provide informed consent or participate in study interviews.	See Inclusion Criteria Above
Unable or unwilling to complete follow up interviews.	See Inclusion Criteria Above

4.9.2 Recruitment

As a single centre study, all research activities took place at a large district general hospital. Potential participants were identified through orthopaedic clinic lists with the surgeon identifying potential participants and referring them to the Chief Investigator. Patient posters (Appendix 10) advertising participation in the study were also advertised in clinical areas and patient waiting rooms with clear contact information displayed. Once identified and confirmed as potentially eligible to participate, the study was introduced by the clinician or clinic nurse. If the patient was happy to be approached, the Chief Investigator then contacted the patient, either in clinic or via telephone to provide more information. If the patient was interested in potentially participating, the researcher provided them with the Study Patient Information Sheet (PIS) (Appendix 6) and read through the PIS as required. The participant had as much time as necessary to read through the information and ask any questions they may have; it was made clear to the patient that they were able to take the PIS home to consider and discuss with family and friends if required.

4.9.3 Sample Size

The determination of sample size is a consideration for any researcher regardless of research topic (Blaikie, 2018). Quantitative and qualitative approaches require very different sample sizes and sampling strategies. Shaw and Holland (2014) explain that there is no sense in attempting random or probability sampling in qualitative research. Participants in qualitative studies are often chosen purposefully, because they represent typical or extreme cases, or because they cover a range of cases to demonstrate as much variation as possible (Shaw and Holland, 2014). The strategy of purposeful sampling is to select the best, relevant, informative, and detailed data available, this can be then analysed and used to gain insight and understanding in the research subject (Emmel, 2013; Yin, 2011).

Although optimal sample size in qualitative research can divide opinion, many scholars agree that the research project proposed will be the primary influence on the sample size required. Morris (2006) explained that the type and purpose of the research, the resources available and the questions being asked will impact the underlying rationale in qualitative research. Guetterman (2015) concluded that topic, discipline, methodology and population were important when considering sample size. In IPA Smith et al., (2019) assert there is no "right answer" to the question of sample size as the focus in IPA should remain on detailed accounts of the individual experience. Therefore, it is more important to ensure the complexity of human phenomena is being explored in a meaningful and detailed way than fulfilling a recruitment target. To ensure all aspects of the participants' experiences were

given this consideration, each participant was interviewed at three different timepoints of the patient journey, which is detailed further in Section 4.9. Smith et al., (2009; 51) state “the issue is quality, not quantity”, noting it is more difficult to meet the requirements in IPA with a larger sample than a sample that is too small (Smith et al., 2009).

At the recruiting hospital there were ten participants fulfilling the inclusion and exclusion criteria between January to December 2019. In determining sample size, consideration was given to practicalities such as, time constraints of the PhD programme, research activities being conducted by a single researcher and the potential number of participants willing to participate and who complete follow up. The initial target for recruitment was assessed to be six – seven participants.

The appropriate number of participants to include in the study was changed part way through recruitment due to circumstances around elective surgery waiting lists and national events, namely the COVID19 pandemic. There was concern recruited participants may not undergo the replacement in the timeframe initially predicted, hence, the recruitment target was increased to be more certain that post-surgery data could be collected. Questions surrounding sample sizes are not unique to this project and are recognised as a major debate amongst qualitative researchers (Guetterman, 2015). Staller (2021) explains that this reassessment of adequate sample size is common in qualitative research, and reflexive qualitative researchers will often revisit the question of adequate sample size throughout the research project.

Due to the nature and purpose of the study, a homogeneous sample was required rather than a random or representative one, study participants were required to have a meaningful association with the research question. A purposeful sampling strategy was utilised as the study purpose required participants to be undergoing a THR. The sample comprised of 10 patients scheduled to undergo elective primary THR (see Table 3). The sample consisted of both male (n=5) and female (n=5) participants, the youngest participant was 28 and the oldest was 50 years old, the mean age of participant was 35.6 years, and the median was 39 years of age.

To maintain confidentiality whilst also recognising the participants as individual human beings, fictional pseudonyms have been given to each participant. However, to avoid confusion to other staff members within the clinical setting, when documenting in participant’s medical records, a study number was also assigned, for example MKH001, MKH002. The number was primarily for use within the clinical care setting and will not be used to refer to the participant within this thesis. The participant will be known by the pseudonym throughout the study.

Table 3. Biographical details of the participants

Claire (MKH001) is a 40-year-old married mother of 3 boys, her youngest is in primary school. Claire has scoliosis and subsequently began experiencing symptoms in her hips at the age of 7. After some initial reluctance to investigate her symptoms by clinicians, she was diagnosed with severe OA. She has been waiting for a hip replacement for approx. 5 years and has had numerous cancellations, some at very short notice.

Diane (MKH002) is a 50-year-old lady with osteoarthritis of the hip. She has 2 teenage daughters and lives with her husband. She is currently unable to work due to her hip pain and has been experiencing hip symptoms since 2018. Diane has struggled with her weight for many years and finds it difficult to lose weight without being able to exercise. She loves to garden and enjoys walking her three large dogs, who she acknowledges can be a handful.

Annie (MKH003) works as a carer in a nursing home. She is 49, a married mother of 3 boys and also has an older stepdaughter. Her youngest son is 13. She was diagnosed with osteoarthritis approx. 3 years ago. Annie is very passionate about her job and her family, though she does not need to work for financial reasons, her job is her independence and vocation. She takes great pride in her work and her role.

Patrick (MKH004) is a 46-year-old married father of an 8-year-old daughter. He has a very manual job with long hours. He was diagnosed with osteoarthritis approx. 4 years ago. Patrick is the sole wage earner in his household. Patrick struggled to make the decision of whether to undergo a THR. He described the effect his hip had on his life as inconsistent, with the pain levels fluctuating from mild to extreme over periods of time. He All these factors made his decision to undergo surgery complicated and even up to the morning of his operation, he was second guessing and doubting his decision. Multiple treatment options had been tried prior to making his decision, Patrick perceived the operation as a last resort to help resolve his symptoms and enable him to function.

Fran (MKH005) is 50 years old. She lives with her partner. Fran runs her own business and spends most days on her feet at work. She has osteoarthritis but avoids pain killers where possible, preferring alternative therapies. She makes a significant effort to maintain a positive outlook throughout her life. Due to the waiting time for surgery currently involved in the NHS, Fran's partner changed his employment to a job with health insurance and benefits. This enabled Fran to expediate her operation, though she still experienced a wait of over 10 months between decision for surgery and THR.

Rob (MKH006) is 38 years old. He started having problems with his hips whilst in the army in his 20s. He was recently diagnosed with avascular necrosis. Rob lives with his partner and works as a tradesperson in a very physical role. Though his employer is understanding to Rob's condition, Rob is aware of the limitations caused by his hip in his job role. Rob's passion is going to the gym and keeping physically fit, something he has been unable to do due to his hip.

Chris (MKH007) is a schoolteacher and is 33 years old. He lives with his girlfriend and was diagnosed with osteoarthritis in 2019. His operation has already been cancelled once. He enjoys playing football as part of a team and plays drums in a band. His hip condition prevented him from participating in these activities and he sorely misses them.

Zoe (MKH008) is 36, she is married and lives with her husband and 3 young children. She works in retail. Zoe has been under review by the orthopaedic consultants for 13 years after an injury whilst on holiday. She had regular appointments and x rays every 3 months to monitor her condition. She was diagnosed with osteoarthritis in 2008. She has been requesting a THR for several years but has experienced reluctance from the surgeons due to her age. Due to the waiting time for surgery, Zoe opted to transfer her care to a specialist orthopaedic hospital nearby as she believed this would expediate the process.

Henry (MKH009) is married with a toddler and another baby on the way. He is 36 and works in sales, which involves a lot of driving. He has bilateral avascular necrosis in the hips and secondary osteoarthritis in the left hip. Henry has had musculoskeletal issues in his hips throughout his childhood, however, he admits that though he struggled with his mobility when he was younger, his hip condition has never prevented him living his life until now. As Henry has private health insurance through his work, he opted to have the THR in the private sector due to NHS waiting times.

Scott (MKH010) was diagnosed with rheumatoid arthritis when he was around 19 years old. He is now 28 years old and has regular treatments in hospital to manage his condition. His hip condition started deteriorating a few years ago. Over the last year his hips have now started significantly affecting his quality-of-life, culminating in the decision to undergo a THR. He lives with his girlfriend and their small dog and works full time in a supermarket.

4.10 Data Collection

4.10.1 Rationale of Semi Structured Interviews

The use of semi-structured interviews in this study was selected for a variety of reasons. Semi-structured interviews or semi-standardised interviews are the predominant choice of interview format in qualitative research (Flick, 1998). Semi-structured interviews are often

the chosen method for the IPA researcher for good reason – the real-time interaction between the researcher and participant provides major flexibility when exploring the lived experience (Smith et al., 2009). Hardwick and Worsley (2011) explain that this type of interview provides a structure through questions constructed around key themes yet is flexible in allowing the interviewer or participant to digress from the schedule to explore details relevant to the research aims. IPA aims to set up the interview as an event which enables a discussion of relevant topics, this then allows the research question to be answered by analysis of the data (Smith et al., 2009). To facilitate a relaxed and comfortable environment, the researcher is advised initially to develop some rapport with the participant (Elmir et al., 2011). Smith et al., (2009) cautioned that if the participant does not feel at ease with the researcher, and that rapport is not established, then that can prohibit good data.

Braun and Clarke (2013) have suggested that the relationship between the participant and researcher inevitably affects participants self-disclosure and the depth of the experiences they are willing to share. The interviews had the potential to address private and sensitive topics of the participant's life, this made the establishment of a trusting relationship between participant and researcher especially integral (Murray et al., 2003). Efforts were made to build a good rapport with each participant prior to, and throughout, the interview process. Participants were invited to ask questions of the researcher before any contact, this included before the consent process and at each timepoint interview (baseline, six-weeks after surgery, then six-months after surgery). By completing the informed consent process at a different time to the baseline interview, it ensured the participant had already had contact and communication with the researcher prior to the interview in which potential sensitive discussions would occur. This attributed to the participant's feeling comfortable to share their stories and experiences, it was clarified to the participants throughout that there were no right or wrong answers. In addition to this, participants were reassured that any information they provided would be anonymised and their identity kept confidential.

The interviews took place at three timepoints in the participants treatment journey (see Figure 10), baseline (before the operation), six weeks post-surgery and again at six months after surgery. The longitudinal aspect of the study and interview timepoints was employed due to evidence that the recovery and rehabilitation can continue to improve until around six months (Allyson-Jones et al., 2007).



Figure 4. Time points of Interviews

For the novice IPA researcher (which I believe I am), Smith et al., (2009) advise the development of an interview schedule or guide when engaging in research interviews. He explains an interview schedule requires the interviewer to explicitly consider what they expect to cover in the interview and to plan for any potential difficulties, such as: covering sensitive topics or complex questions. They also advocate that the more reserved participant may prefer and feel more comfortable with a more structured approach (Smith et al., 2009). When I considered my interview schedule (Appendix 11) I was influenced by Smith et al., (2009)'s guidance on interview schedules and question types and also the themes identified in the PPI study (see Section 3.4) The interview guide was used in a flexible way when adapting question order and language, this allowed a more open exploration of participants perspectives and experiences and enabled participants to raise other issues I may not have anticipated. Key topics to consider, highlighted in the PPI study, were noted in the interview schedule as potential areas to request more detail on if the participant mentioned them.

Smith et al., (2009) note that questions should be descriptive, narrative, structural, contrasting, evaluative, circular, and comparative, in order to assist the researcher to holistically explore and understand the experience from the participant's perspective. These aspects are not essentially combined in each question, but instead, where appropriate, should be included in various questions in one interview (Smith et al., 2009). The interview schedule followed a simple chronological format, enabling participants to reflect on their experiences to date and consider their goals moving forward. I began each encounter with a descriptive and narrative question, conversation began quite readily as participants began with answering the open-ended question about their experiences and journey up to that point. This question in baseline interviews was "Please can you tell me about your experience with your hip up to today?" in the 6 week and 6-month interview, this question was changed to "How are you? How is the hip?". This opening question often set up the content for the remainder of the interview, with participants later making references to concerns they had initially identified as central to their experience. I included structural aspects by asking them to describe their day-to-day life and incorporated contrasting and comparative approaches when discussing how their life had changed from pre hip symptoms or how they felt it differed currently to others of their age. The participants feeling

and concerns were explored by using evaluative questions and circular questions were included when exploring how the participant perceived other attitudes and behaviour towards their hip.

The questions did not focus upon specific topics in isolation but combined them in various questions throughout the interview as advised by Smith et al., (2009). Broad, open questions with prompts were used to elicit more information about the participants experiences (Smith et al., 2009). Participants were encouraged to continue discussing their experiences by non-verbal, visual prompts such as nodding and smiling (in face-to-face and video call interviews) and encouragers such as “yes”, “go on”, “mmmm” and “really” (in telephone interviews). Though the informal interview structure was available to the researcher at each interview, the researcher often found that points and aspects noted in the schedule were discussed spontaneously by the participant when asked to talk about their experiences with their hip condition and its progression.

In some instances, it may be that the interview moves completely away from the schedule and instead follows the participants preferred course. These tangents in conversations occurred regularly during interviews for the Young Hip study, particularly in the baseline interviews. Smith et al., (2009) advocate interviewing as a method in IPA, precisely because it allows the researcher and participant to engage in a dialogue, this dialogue can facilitate the modification of the initial questions in light of participant responses and encourages the researcher to investigate and explore any interesting topics that arise.

The PPI study demonstrated priorities and goals could change and evolve over time (Mew et al., 2022). The interviews occurred at a time and place convenient to the participant. Due to the COVID19 pandemic restricting face to face appointments a large majority occurred remotely via telephone. The effect on location of interviews on data collection has been subject to much discussion. Face-to-face interviews have traditionally been viewed as the gold standard in qualitative healthcare research methods (DiCicco-Bloom and Crabtree, 2006; Saarijarvi and Bratt, 2021). Importantly, despite its favoured position, face-to-face interviews can present disadvantages when compared to other methods (Opdenakker, 2006). A summary of these advantages and disadvantages between interview techniques can be found in Table 4.

Table 4. Comparison of Interview Techniques in Qualitative Research

	ADVANTAGES	DISADVANTAGES
FACE TO FACE INTERVIEW (Opdenakker, 2006).	<ul style="list-style-type: none"> - Synchronised in time and space. - Can create safe and comfortable atmosphere. - Body language and facial expressions are visible. 	<ul style="list-style-type: none"> - Time consuming - Need to travel. - Safety risks
TELEPHONE INTERVIEW (Hershberger and Kavanaugh, 2017)	<ul style="list-style-type: none"> - No geographical concerns - Less technology dependent - Less time consuming due to no requirement to travel 	<ul style="list-style-type: none"> - No visibility for non-verbal communication
VIDEO CALL INTERVIEW (Kruwel et al., 2019)	<ul style="list-style-type: none"> - No geographical concerns - Body language and facial expressions are visible. - Cost Effective 	<ul style="list-style-type: none"> - Technology dependent - Requires technological literacy
ONLINE CHAT/ EMAIL (Hershberger and Kavanaugh, 2017)	<ul style="list-style-type: none"> - No geographical concerns - Provides participant with time to reflect on answer before replying. 	<ul style="list-style-type: none"> - Requires technological literacy. - Confidentiality

The digitalisation of healthcare services rapidly being incorporated by healthcare providers means that digital encounters are quickly becoming more common throughout the health service, either through telephone clinics with clinicians or video call appointments with physiotherapists. The COVID19 pandemic expedited these methods being implemented more widely (Van Bulk et al., 2020). Social distancing, travel bans, and other restrictions necessitated alternative methods throughout healthcare. These restrictions also impacted data collection methods in qualitative research and prompted researchers to quickly explore alternative methods available when conducting research (Saarijarvi and Bratt, 2021). As addressed in the PPI study (Section 3.4) online surveys were utilised to collect data, however, due to the level of measurement and interpretation required in IPA methodology, the online survey or email approach was dismissed when considering the method for Young Hip. The advantages of face-to-face interviews cannot be discounted and when the participant opted for that method it was much preferred by the researcher. However, due to convenience, time, and travel constraints, in addition to concerns surrounding social

distancing and infection risks, telephone and video calls were often the preferred method chosen by the participants.

Braun and Clarke (2013) caution that the research process can be influenced by potential meanings attached to the locations of said interview. A previous negative or upsetting experience that occurred in a location could limit the participants willingness to interact or influence their mood and relationship with the researcher. Unfortunately, a hospital can often be the location of a traumatic and negative experience. When the participant did opt to meet face-to-face in the hospital, care was taken to reduce the risk of this influence. Interviews did not take place directly before or after meetings with the surgeons or other healthcare providers directly associated with the participants care, in addition to the reflexivity and awareness of the researcher's positionality in the study and clinical environment explored in Section 4.7, the researcher wore civilian clothes to disassociate herself with the participant's care providers.

It is important to consider that qualitative research often depends on people's memories when describing past experiences (Barusch et al., 2011). Memory, as a concept, is rarely described or considered in qualitative publications but is recognised as complex and subjective with no agreed theory to explain it or how it works (Blakey et al., 2019; Baddeley et al., 2015). Cohen et al., (2010) asserted that people remember areas that are significant to them, this is contested by Blakey et al., (2019) who argue that when participant's memories are explored in qualitative interviews, they are socially constructed and co-constructed, with dialogue between researcher and participant affecting the memories being reported. Jedlowski (2001) elaborates on this by contending that the context in which the past is reported can also cause it to be presented differently. In addition, Baddeley et al., (2015) suggest that recall is imperfect, and a memory is modified each time it is recalled (Young-Rojahn, 2013). Leading questions were strongly avoided throughout the interviews as they can potentially create false memories (Laney and Loftus, 2013). However, the position adopted in this study was that it was acceptable for qualitative research to value experiences and feelings over alleged accuracy of memory (Blakey et al., 2019). IPA primary objective is to explore and make sense of the participants' sense of their experiences (Smith et al., 2009). The experiences the participants discussed was true to themselves and their own lived experience, therefore, how they interpreted that memory and experience was the primary interest of the study.

Baseline interviews lasted between 25 mins - 85 minutes, with 6-week and 6-month interviews being frequently shorter, lasting between 7 minutes – 40 minutes. Details of the interviews can be found in Appendix 12. The duration of the interviews was completely influenced by the participant themselves and the detail and depth they wanted to provide. In accordance with the principles of IPA, the researcher approached each participant

interview with sensitivity, a non-judgemental attitude, flexibility, and patience to capture the richness and complexity of each participant's meaning making (Eatough and Smith, 2006. Smith et al., 2009. Finlay, 2011). A personal thank-you card was posted to each participant at the end of study participation.

4.10.2 Patient Reported Outcome Measures (PROMs).

To address the secondary objective of assessing if current methods of measuring outcomes from the patient's perspective in clinical practice address the priorities and expectations highlighted within the qualitative findings, I was required to consider the usual methods in which patient outcomes were measured within the clinical setting. As presented in Section 2.4.4 patient reported outcome measures (PROMs) are patient questionnaires routinely used to measure the success of the operation from the patients' perspective (NHS, 2023). There are a variety of PROMs considered appropriate and relevant to THR patients (Nilsson et al., 2003; Lyman and Hidaka, 2016). The standard PROMs currently used nationally in the NHS for elective THR is the Oxford Hip Score (OHS), however, within the study setting, the Hip disability and osteoarthritis outcome score (HOOS) (Appendix 13) is routinely used for younger THR patients, usually led by surgeon preference. The HOOS is also known as a validated and highly reproducible score specifically appropriate for young adults (Ackerman et al., 2021; Kuijpers et al., 2020). Study participants were requested to complete the HOOS at every interview timepoint. The HOOS is a patient-administered self-report questionnaire intended to evaluate symptoms and functional limitations related to the hip. It is designed to be user friendly and self-explanatory and should take 7 to 10 minutes to complete (Nilsson et al., 2003).

The HOOS includes 40 items categorised into 5 subcategories.

1. Pain (10 items with a total score of 40 points)
2. Symptoms and stiffness (five items with a total score of 20)
3. Activities of daily living (17 items with a total score of 68)
4. Function in sports and recreational activities (four items with a total score of 16)
5. Quality of life (four items with a total score of 16)

To answer the questions, 5 standardised Likert-boxes are used (no, mild, moderate, severe, and extreme). A score of 0 - 4 is calculated for each item, the score is calculated using the HOOS scoring calculator utilised in the hospital as part of standardised care (Orthotoolkit.com, 2024). The score does not correlate to the number of Likert boxes per

item. A normalised score is calculated for each subscale with 0 indicating extreme symptoms and 100 representing no symptoms.

With the data collected through the responses to the HOOS, I was able to compare them to the participants' voice in the qualitative data. I was then able to assess and consider if the participant's HOOS scores accurately represented the qualitative findings for each individual, at each timepoint.

4.10.3 Transcription of Interviews

Each interview was recorded and then transcribed verbatim by the researcher. To allow for full immersion into the data, the researcher did her own transcribing as recommended by Smith et al., (2009). The following transcript notations were used, "..." indicated a significant pause, [] indicated the participants words were lost (usually due to phone signal), explanatory material for these occurrences were included and attempts were made to request the repetition of this information without interrupting the participant's flow, but the initial phrase and words used were lost. Capital letters were used when the participant emphasised the words loudly and italics were used for non-verbal communication, for example, tears, sighs, laughs. An example of a patient transcript is presented in appendix 3. As already stated, a reflective diary was maintained to record the researcher's initial thoughts after each interview and throughout the study (appendix 4) ensuring reflexivity throughout the research process.

4.11 Analysis

As an approach to analysis, IPA values individual case analysis before moving on to a more general analysis across the data set focusing on convergence and divergence between cases (Smith et al., 2009). IPA is committed to the detailed analysis of the investigated phenomenon (Eatough and Smith, 2006) and embeds the phenomenological epistemology of focusing on people's everyday experiences to gain an understanding of the phenomenon being studied. The coding in IPA is referred to as "descriptive" and "conceptual" comments. There are two types of theme development in IPA. Subordinate themes develop from emergent themes, these are then consolidated into categories of superordinate themes (Smith et al., 2009).

The aim of the data analysis in this study was to focus on understanding the context and complexity of the data rather than to identify frequency or attempt to generalise. This required the researcher to have detailed and prolonged engagement with the recordings and transcribed texts to immerse themselves within the data and the participant's experience.

4.11.1 Six Steps of IPA Analysis

When conducting the analysis of the data I followed the 6 steps of IPA data analysis (Smith and Eatough, 2007).

The six stages of IPA are:

1. Reading and re reading the interview transcripts.
2. Make initial notes to systematically capture observations.
3. Develop emerging themes for each case.
4. Search for connections across emergent themes for each case.
5. Move onto the next case.
6. Look for patterns across data.

These steps are described in more depth below from Smith et al., (2009):

I. Reading and re reading the interview transcripts:

To ensure the participant becomes the focus of the analysis, this step involves immersing in the original data. The analysis process began with listening and then re listening to the entire interview recording without interruption. Notations were made on initial thoughts, feelings, tone of participant etc after the interview itself, then after listening to the recording. The transcript was then read through twice as I recalled participants' tone and methods of expressing themselves. This method allowed the me to become as "intimate as possible with the account" as suggested by Smith (2004). This enabled an establishment of a sense of the whole data prior to breaking down the transcript paragraph-by-paragraph and line-by-line. Decontextualising text (reading paragraphs backwards, sentence-by-sentence) was frequently undertaken as advised by Smith et al., (2009) to ensure the I got close to what the participant was saying, rather than what I thought they were saying.

II. Make initial notes to systematically capture observations:

This is the most detailed stage of the analysis. The researcher keeps an open mind and notes anything of interest within the transcript. These notes highlight specific ways in which the participant speaks, thinks, and understands about an issue. There are no rules about what is noteworthy, the aim is purely to produce detailed and rich comments on the data. A set of core comments, possessing a clear phenomenological focus, and are close to the participant's explicit meaning are likely to present at the core of the narrative. These are the points at which the participant describes key aspects important to them. From these, I endeavoured to develop more interpretative notation, focusing on how and why the

participant has these concerns. This involved the language used by the participant, the context of their concerns and identifying abstract concepts to understand patterns of meaning in the data. The notations were divided into three processes with different focuses, these were: Descriptive comments describing the content and subject being discussed, linguistic comments exploring the specific use of language and conceptual comments focussing on engaging at an interrogative and conceptual level. As I read through and emersed myself in the data, similarities and differences emerged within the topics and themes discussed within the transcripts. It was important for me to consider what each word, phrase or sentence meant to me as well as what it meant to the participant. The aim of descriptive comments is to describe content, it is very much taking things at face value and highlighting aspects that structure the participants recollection of the experience. Linguistic comments involved pauses, laughter, repetition, tone, fluency, or hesitation. Metaphors were particularly important as a linguistic tool to link descriptive comments to conceptual ones. Whilst making conceptual notations it was important for me to draw on my own perceptions to uncover the meaning of key events for the participant. It often took on an interrogative form and encouraged further questioning of the data. The interpretation is always legitimate if it is inspired by and tied to the original data. However, it was essential to remember the analysis is primarily about the participant, not myself. I used my own knowledge and experience to help make sense of the participant.

The transcripts were printed within a three-columned table, with the full transcript in the left margin. The central column allowed comments considered important and consequential in the data to be noted next to the relevant part of the transcript (see Appendix 14). The right margin was for possible emergent themes (this step will be detailed in the next step). Smith et al., (2009) insists that there are no rules about what is noteworthy, the aim is to produce detailed and rich comments on the data. Preliminary comments and impressions were added to and expanded on as reading and re reading took place. Efforts were made to consider what each word, phrase or paragraph meant to me in addition to what it meant to the participant. As recommended in IPA analysis, descriptive comments were noted in normal text, linguistic comments in italics and conceptual comments were underlined (Smith et al., 2009). I drew on my own perceptions and experiences to uncover the meaning of key events for the participant when making conceptual notations. By using myself to make sense of the participant, the conceptual comments noted encouraged me to further consider and question the data and the participants' meanings.

III. Develop emerging themes for each case:

In this step I endeavoured to map connections and patterns between notations. This involved moving away from the full transcript and working primarily with the initial notes.

Emergent themes were noted in the right-hand column of the table. These were derived from the notations in the central column and the context of the data in the left column. The themes discovered reflected primarily the original words of the participant but also the interpretation of the researcher. Though not initially considered, a dimension of emotion was identified in each of the participants data set. Particularly empathetically felt themes were identified based on the frequent emotional language and behaviour demonstrated by the participants such as tone of voice when describing feelings of frustration and physical signs of distress (i.e., sobs) when explaining the how they were feeling in their situation. This additional perspective was useful when judging particularly strongly felt themes. The themes that were beginning to develop were discussed with the supervisors, who independently read over several transcripts to judge if they agreed with the themes identified and the methods of analysis used.

IV. Search for connections across emergent themes for each case:

Thus far the themes identified were arranged in a chronological order. This step aimed to develop a map of how they appear to fit together. Although presenting recommendations of different techniques to facilitate this, Smith et al., (2009) encourages the researcher to develop their own innovative ways of exploring the analysis in this step. This stage of the analysis was carefully recorded, and the methods used were documented in a research diary.

Each participant's data was vast and involved a large volume of emergent themes and notes. I used several techniques derived from the work of Smith et al., (2009) when searching for connections across themes within each participants data. Themes were arranged in a chronological order, an initial process of theme clustering then occurred. This essentially involved linking the emergent themes with superordinate themes for each individual participant. A clear relationship was established between emergent and superordinate themes. This stage involved rigorous and detailed interpretation throughout casting and re-grouping of themes, along with frequent re-examination and re-engagement with the source data. A sample of this stage of analysis is presented in Appendix 15. The primary strategies used are presented in Table 5.

Table 5. Techniques used to search for themes (Smith et al., 2009, p 96-99)

TECHNIQUE	DESCRIPTION
Abstraction	Putting “like with like” to create a superordinate theme.
Contextualisation	Constellations of themes around a particular life event or key moment for the individual.
Subsumption	Emergent theme is highly significant/ recurrent and “lifted” to the status of superordinate.

a. Abstraction

The method of abstraction was a primary strategy used throughout this process. Abstraction is described by Smith et al., (2009) as one of the more basic forms of identifying patterns between emergent themes, it involves putting like with like and developing a new name for the cluster. An example of the method of abstraction in grouping emergent themes taken from the analysis of Claire’s transcripts is demonstrated in Table 6.

Table 6. Abstraction leading to the development of a superordinate theme

SELF IMAGE
<ul style="list-style-type: none"> • Body Confidence • Self Esteem • Sex appeal • Self-worth • Others’ perception of her • Perception of disability • Feelings of being a burden • Feelings of guilt

b. Contextualization

This method was useful when exploring the connections between emergent themes relating to a contextual or narrative element within the transcript. The participants narrative shaped the transcript, therefore key or critical “events” can be dispersed throughout the transcript. Highlighting constellations of themes relating to these particular narrative moments enabled me to identify important themes that related to specific events or contexts within the participant’s interview. For example, within Claire’s transcript there are many key moments of reflection: the inconsistency of advice between healthcare professionals, the recurring cancellations of the surgery, the breakdown of relationship between herself and the surgeon. It was reasonable for me to organise the emergent themes relating to the initial

experience of healthcare up until surgery in terms of the temporal and contextual moment that they are located.

c. Subsumption

Though similar to abstraction, this analytical process operates by an emergent theme itself being promoted to super-ordinate status by helping to bring together a series of related themes. This can be demonstrated by Table 7, where the emergent theme of “Pain” becomes a super-ordinate theme and brings together a several other related themes.

Table 7. Subsumption leading to the development of Pain being classified as a super-ordinate theme

PAIN
Pain Control Pain Medication Side effects of medication Different types of pain Effect on sleep

In this example, the analytical method of numeration was also considered, as the theme of pain and its effect on the participant was mentioned frequently throughout the transcripts. Numeration takes the frequency of which the theme appears in the transcript into account. I was reluctant to use numeration as a primary analytical tool, Smith et al., (2009) expressly warn that numeration is not the only indicator of a themes importance and should not be over-emphasized, a very important theme, which unlocks a further set of meanings to the participant, may only be referenced once. However, in some circumstances as demonstrated in the example above, using numeration was useful in reinforcing the importance of an emergent theme and its development to a super-ordinate theme.

d. Polarization

Polarization involves exploring oppositional relationships between themes by focussing upon differences rather than similarities. Though not used frequently, I did use this method when exploring aspects discussed by participants at both pre- and post-surgery timepoints. For example, in Claire’s transcripts, the deep depression and significant impact on her mood caused by living with her hip condition can be set against her euphoria and positive outlook post-surgery.

As advised by Smith et al., (2009), a graphic representation of the structure of the emergent themes was created in a table. This enabled me to observe the gestalt that emerged through the analytic process, allowing me a more detailed understanding of the findings for each

individual participant. Table 8 demonstrates the organisation of the emergent themes taken from Claire's transcripts.

Table 8. Organisation of Emergent Themes from Claire's Transcripts

THEMES
Experience of Healthcare
<ul style="list-style-type: none"> • Lack of control in own healthcare and treatment plan • Relationships with HCP – inconsistency of treatment • Therapeutic Partnership • Lack of information • Expectations • Adapting to implant.
Self Image
<ul style="list-style-type: none"> • Body Confidence • Self Esteem • Sex appeal • Self-worth • Other's perception of her • Perception of disability • Feelings of being a burden • Feelings of guilt
Psychological consequences of hip condition and surgery.
<ul style="list-style-type: none"> • Self-imposed Isolations • Avoidance of situations. • Mourning and grief • Depression <> Positive changes in mood post-surgery
Relationships
<ul style="list-style-type: none"> • Pressure to recover • Pressure to function • Independence • Control over own life • Working role • Contributing to society • Dependence on others to function • Comparing herself to others • Parent Role • Partner Role • Daughter Role
Pain
<ul style="list-style-type: none"> • Pain Control • Pain Medication • Side effects of medication • Different types of pain • Effect on sleep • Controls everything

To assist in organising the large amount of source data available, a word file was opened for each emergent theme and transcript abstracts (with the extracts page and line number) relevant to that theme were pasted into it. These word files were then stored in a file labelled by the super-ordinate theme title. Initially this process was completed for each interview transcript individually, when each interview was completed, themes expressed at multiple timepoints were grouped together with a clear indicator of the interview timepoint they appeared at. In this way, the chronological order was maintained and the relevant context in which themes appeared was evident.

V. Move onto the next case

This involves moving and repeating the process with the next participant's transcript. It is essential to (as much as possible) bracket the ideas discovered in previous participants accounts. This is congruent to IPA's idiographic commitment. When analysing the transcripts in this study, the researcher ensured that a sufficient period passed between the analysis of each case. This was so the researcher emerged themselves within each participant account with an open mind and as clear as possible from the previous cases. Once analysis had been completed to this level, all of the other cases were considered using the same steps.

VI. Look for patterns across data

In samples larger than six participants, Smith et al., (2009) recommend identifying recurrent themes across the data set. This can be considered a method of enhancing the validity of the findings. I was conscious to make a considerable effort to retain an idiographic focus on each individual's voice whilst presenting claims for the larger group.

The final step consisted of identification of connections between cases and modifying or re-framing existing themes identified in each case (Smith et al., 2009). I endeavoured to undertake this step without losing touch with the individual lived experiences of participants or detracting from captured individual, ideographic experiences, and unique themes. Here the focus moved to eliciting shared experiences, comparing, and contrasting between participants, exploring patterns and connections, and where apparent highlighting general themes and combining them across cases. The outcome of this was a cross-case analysis highlighting similarities and differences between experiences (Smith et al., 2009; Smith and Osborn, 2015). Using this extended process of analysis and interpretation, a detailed narrative emerged of the experiences of young patients undergoing total hip replacement. This stage transforms the findings from an idiographic to nomothetic level of interpretation between and across cases, from particular to shared, descriptive to interpretative, on an individual and group basis. This process demonstrates working across the hermeneutic

circle from individual to collective, idiographic to nomothetic elements. An example of this step of analysis is presented in Appendix 16.

Further analysis and interpretation continued during the process and in the context of the cross-case analysis. This included re-organisation of some themes and refinement of theme titles. Through re-reading the full interview transcripts, critical evaluation, and close reference of the full data set of each participant led to some themes been re-prioritised and some re-labelled. This was usually applicable where there was a repetition of points or when, on re-reading, as a whole, some aspects appeared less relevant. Another element of double hermeneutic is evident in this process, with narratives representing the whole and themes being the parts, resulting in a revised “whole” interpretation.

When using IPA in studies of a larger sample size, Smith et al., (2009) cautioned that the analysis of each case cannot be as detailed as that in smaller participant studies, instead the emphasis may be to assess the key emergent themes for the whole group. By illustrating the group level themes with examples from individual participants enables this group level analysis to adhere to IPA (Smith et al., 2009).

When seeking to identify the main themes and findings across the cases, measuring recurrence across cases enabled me to highlight the key group themes within the data. Smith et al., (2009) advised there was no standard rule on what counts as recurrent, and the decision should be made by the researcher and the pragmatic concerns surrounding the study. In *Young Hip I* concluded that for a theme to be considered recurrent, at least half of the participants must have identified it within their interviews. This measurement enabled important themes expressed at more of a specific level to be included along with those themes discussed at a broad level that appear in more instances in the interview transcripts. There were also instances where one theme had been expressed by all participants within a subcategory, for example, the theme of sexual activity and intimacy had been highlighted as a priority for all female participants yet had not been raised as a concern by male participants. Thus, setting the threshold of recurrence at half the participants expressing a particular theme ensures the inclusion of themes particularly relevant and important to a smaller subset of participants. The recurrence of superordinate themes and sub-ordinate themes is demonstrated in appendix 16. Despite a prevalent theme being considered recurrent, the themes still held considerable variation between participants. Frequently participants discussed and manifested the super-ordinate themes in differing ways, themes could be expressed and evidenced throughout the interviews in a variety of ways and contexts. To address this, Smith et al., (2009) highlights the importance for the IPA researcher to constantly negotiate the relationship between convergence and divergence, commonality, and individuality.

4.12 Rigour of the study

Trustworthiness is essential in demonstrating the quality of qualitative research (Williams and Morrow, 2009). The researcher is accountable to the broader research community and the study participants, and as such the study methods and findings should commit to the three dimensions of trustworthiness: integrity of data, clear communication of findings and a clear balance between subjectivity and reflexivity (Williams and Morrow, 2009).

No specific criteria of assessing validity of qualitative research have been applied to IPA, however, Smith et al., (2009) recommend using the approach presented by Yardley (2000: 2007: 2017). This approach requires the researcher to assess the research from four broad perspectives: credibility and sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance.

4.12.1 Credibility and sensitivity to context

Simply put, credibility ensures the data produced is valid and a true representation of the participant's experience and perspective. Prolonged engagement with the participant and the transcripts is identified as a successful method in ensuring credibility (Yardley, 2017; Morse, 2015; Lincoln, 1995; Guba, 1981). This approach consists of being present long enough to build trust and rapport with the participant. This results in more rich data, more information is revealed, therefore, the data is more valid (Given, 2008). In this study, I ensured that all participants were given as much time as they wanted in their interviews. Some interviews lasted 90 minutes in total, whereas others were significantly shorter. The time taken in the interview within this research was completely dependent on the participants' wishes. I also took time to visit the participant on the ward on the day of their planned surgery. This was not part of the participant's clinical care, but a way of promoting a trusting relationship and comfortable rapport between the participant and researcher. Regular meetings with the supervisors were also scheduled to minimise bias and facilitate the development of the study.

Yardley (2000) details reflexivity and awareness of the balance of power is essential considerations for the researcher when committed to context sensitivity. These processes and strategies in place to minimise these aspects were explored and detailed earlier in Section 4.7.

4.12.2 Transferability, transparency, and coherence

The principles of IPA are committed to examining how people make sense of their major life experience (Smith et al., 2009), this was in coherence with the exploratory research question. The analysis and presentation of the data and findings evidenced commitment to

this approach in accordance with IPA and patient centred care. The data analysis process is rigorously documented and provided in Appendix 4 and Appendix 14 to 16. Rich description of participant data and responses, in addition to accurate recording of the interpretation of the research, facilitates an easier evaluation of transferability and indicates if the research findings may be applicable in other contexts (Guba, 1981; Lincoln, 1995). Importantly, phenomenology is not always applicable in developing generalised claims (Van Manon, 2016), to enable this, the reader needs to be able to work through the findings to the theories and understand how the researcher has arrived at the resulting interpretations (Yardley, 2000). Detailed documentation of the analytic process facilitates this.

4.12.3 Dependability, commitment, and rigour

Dependability asks the question; would similar findings be produced if someone else also undertook this research (Yardley, 2000; Lincoln and Guba, 1985). The researcher endeavoured to explicitly describe their methods and the research processes. There was a commitment of compliance to the principles of IPA and patient centred care and producing a systematic idiographic analysis of the data. Rigour is determined by the thoroughness and robustness of the study, and it is important to demonstrate this (Tobin and Begley, 2004). The detailed descriptions of the study processes and the examples of analysis methods and narrative extracts included in the appendices could be used in repeating the study. Morse (2015) argues replication of a qualitative inquiry is unnecessary and undesirable, however, to ensure rigour it was important that the steps undertaken could be followed.

4.12.4 Confirmability, impact, and importance.

Confirmability refers to the confidence the reader has that the findings of the study are true and congruent to the participants' narratives instead of potential researcher bias (Yardley, 2017). The detailed documentation on the research processes can be used to establish confirmability. The recording of the research decisions made when considering the research design and method are also appropriate in evidencing confirmability.

This study explored the priorities and goals of young patients undergoing total hip replacement. Due to the increasing numbers of younger patients undergoing THR (NJR, 2019) along with the lack of literature identified in this field, it was important to undertake this inclusive study.

4.13 Summary of chapter

This chapter has presented the methods chosen to undertake this study and explained the rationale behind the decisions. It considers and explores the quantitative research methods traditionally used in trauma and orthopaedic research and the benefit qualitative research would have in addressing some of the gaps in knowledge within the current evidence base. Additionally, it has explored the theory and methodology underpinning IPA and the reasons it was selected as the research approach. The chapter has also detailed the analysis process and has addressed the reflexivity of the researcher. The next chapter will present the findings identified and explored in the Young Hip study.

Chapter 5. FINDINGS

5.1 Introduction

The Young Hip study uses an IPA approach to explore the experiences and expectations of young patients undergoing THR. The study includes ten participants aged between 28-50 years old. This is considered a large number of participants for an IPA study (Smith et al., 2009). When presenting findings of an IPA study involving larger sample sizes, Smith et al., (2009) recommend focusing on the key emergent themes for the whole group as opposed to more detailed analysis of each individual case. Therefore, I have presented the findings from the ten participants under six superordinate theme headings. To enable the group level analysis to adhere to IPA, individual patient examples will be used to illustrate the group themes (Smith et al., 2009).

After careful analysis of the interviews using an interpretative phenomenological approach (Smith et al., 2009) six superordinate themes were identified.

1. Living a process that does not reflect me.
2. I'm just constantly in pain.
3. Giving up hope.
4. This is not who I'm meant to be.
5. My family didn't sign up for this.
6. I can't do anything.

In addition, subordinate themes are categorised under the superordinate themes to provide clarity into the vast amount of data provided from the interviews (see Figure 11).

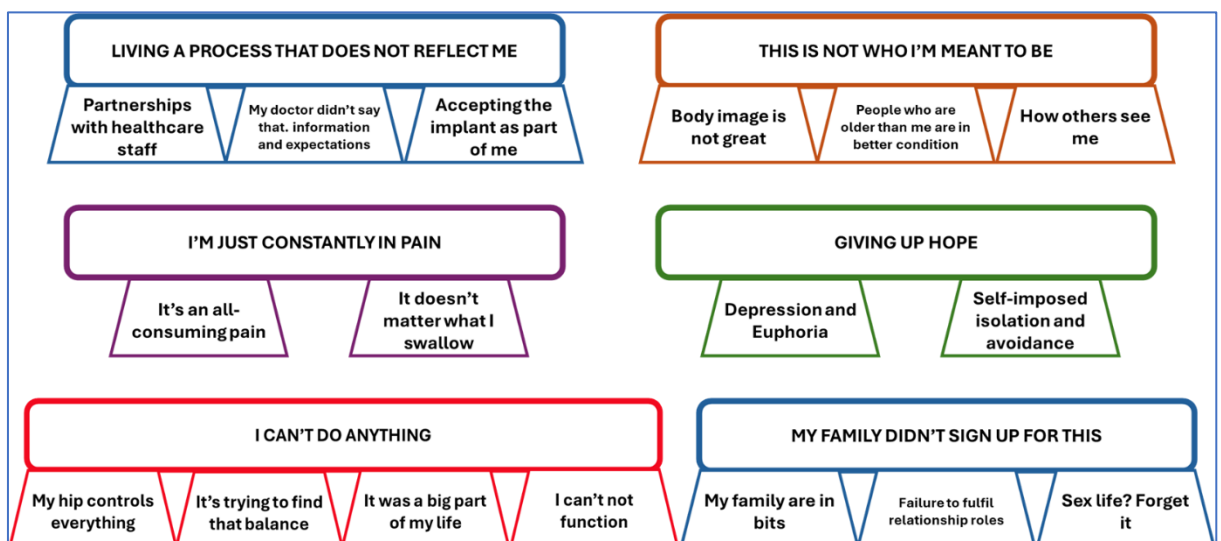


Figure 11. Superordinate themes and corresponding subordinate themes

Excerpts from all 30 interviews will be used to illustrate the identified themes and illuminate the participants' voices. Remaining true to the IPA approach, interpretation was then justified by direct quotations. This method also enables identification of some ideographic detail within the superordinate theme and illustrates the complexity of the participants' experiences (Smith et al., 2009). These quotations are taken directly from the transcripts and are presented in italics to clearly identify the participants voice as separate to the interpretation. Alongside this, the researcher's reflections will be interspersed through the text to provide transparency and understanding of how the interpretation was reached.

Although the themes interlink, each one contains sufficient unique information to separate them from each other. However, the lived experiences narrated by participants often featured information that could apply to more than one superordinate theme simultaneously. Smith et al., (2009) identify that in studies with larger sample sizes, participants may manifest the same sub-ordinate themes in different super-ordinate themes. The same sub-ordinate and super-ordinate themes may look very different in how it is portrayed across the participants, Smith et al., (2009) recommend the researcher maintain a constant negotiation on the relationship between convergence and divergence, commonality, and individuality.

Table 9 lists the six superordinate themes and their included subordinate themes. The table also demonstrates the participants (identified by their pseudonyms) whose interviews in which these themes occur.

Table 9. Identified occurrences of superordinate and subordinate themes in participant data.

Themes	Claire	Diane	Annie	Patrick	Fran	Rob	Chris	Zoe	Henry	Scott
LIVING A PROCESS THAT DOES NOT REFLECT ME.	Superordinate theme addressed by all 10 participants									
Partnerships with healthcare staff.	x	x	x	x	x	x	x	x	x	x
My doctor didn't say that: Information and expectations.	x	x	x	x	x	x	x	x	x	x
Accepting the implant as part of me.	x	x	x	x	x	x	x	x	x	x
I'M JUST CONSTANTLY IN PAIN.	Superordinate theme addressed by all 10 participants									
It's an all-consuming pain.	x	x	x	x	x	x	x	x	x	x
It doesn't matter what I swallow.	x	x	x	x	x	x		x		x
GIVING UP HOPE.	Superordinate theme addressed by all 10 participants									
Depression and Euphoria	x	x	x	x	x				x	x
Self-Imposed Isolation and Avoidance.	x	x	x	x	x	x	x	x		
THIS IS NOT WHO I'M MEANT TO BE.	Superordinate theme addressed by all 10 participants									
Body image is not great.	x	x	x	x	x	x	x	x	x	x
I've got people who are older than me in better condition	x	x		x		x	x	x	x	x
I wouldn't be happy..... I'd feel disabled	x	x	x	x	x	x	x	x	x	
MY FAMILY DIDN'T SIGN UP FOR THIS.	Superordinate theme addressed by all 10 participants									
My family are in bits.	x	x	x	x	x	x	x	x	x	x
Sex life? Forget it.	x	x	x	x	x		x	x	x	
Physically fit super dad.	x	x	x	x				x	x	x
I CAN'T DO ANYTHING.	Superordinate theme addressed by all 10 participants									
My hip controls everything	x	x	x	x	x	x	x	x	x	x
It's trying to find that balance,	x	x	x	x	x	x	x	x	x	
It was a big part of my life	x	x	x	x	x	x	x	x	x	x
I can't not function	x	x	x	x	x		x	x	x	

The themes all featured in each timepoint, though the participants perception of these themes shifted marginally, there was no clear distinction between priorities and goals important to the participants at pre-surgery, six-weeks post-surgery and six-months after operation. Therefore, this chapter presents the data from the interviews as a whole rather than divided into the different time periods. Each participant quotation is clearly labelled with the timepoint where it occurs (see key below), along with the line number where it can be found in the transcript:

- BL – Baseline Interview.
- 6W – Six weeks after surgery.
- 6M – Six months post operation.

5.2 Living a process that does not reflect me.

Although the participants' experience of healthcare varied widely, aspects considered important to them regarding what contributed to successful outcomes were very similar. Whether these aspects had been perceived and experienced in a positive and therapeutic way or as a negative recollection were extremely diverse. Participants described a mixture of positive and negative reflections on events and timepoints whilst accessing healthcare services and communicating with healthcare professionals.

The analysis of the data produced rich but vast amounts of data in this theme. The findings evident in this subordinate theme were divided into three subthemes: Partnerships with healthcare staff, My doctor didn't say that: Information and expectations, and Accepting the implant as part of me.

5.2.1 Partnerships with healthcare staff.

The relationships between the participant and the orthopaedic doctors were reflected upon by all ten participants, these relationships focussed not only on the consultant responsible for their care but also the registrars and healthcare professionals working alongside them.

The relationships between the participant and the surgeon had a significant influence on the participant's experience of the diagnosis through to treatment and the recovery.

Scott was diagnosed with rheumatoid arthritis when he was around 19 years old, however over the last year the pain and limitations in function in his hips have started significantly affecting his quality-of-life, culminating in the decision to undergo a THR. Scott expressed his relationship with the orthopaedic consultant as a partnership, in that decisions were made on his treatment jointly by them both.

I treat it as “we” because obviously I make decision because it's for me and I'm the one dealing with it, but then I took on board their expertise and knowledge so it's a “we” (Scott, 6W. Line 97).

One of these decisions was to prolong the time before making the decision to operate as long as possible.

We've just been trying to prolong having replacements all along this time (Scott, BL. Line 25).

Scott clearly felt comfortable and confident in this decision because he had been involved in the decision-making process and therefore felt he had some level of control in the management of his own condition.

Unfortunately, post-surgery, Scott did not experience the same support in his aftercare. He felt unsupported by the physiotherapist, whom he found unhelpful. Scott felt as if he was having to instigate communication in scheduling appointments and assessments. He described a perception of a lack of interest in his rehabilitation from the physiotherapist.

I got discharged from physio probably about...a while ago, they were not really helpful at all ... he was like should I discharge you? And I was like...err well fine, do you not want to come and see me to make sure I'm doing this? So, I just like gave up, I didn't feel he was particularly supportive no. He didn't help (Scott, 6M. Line 33).

The feelings of working towards a shared goal and their priorities being considered and heard were clear in both Fran and Rob's interviews. They identified a positive and trusting relationship with their surgeon. Though Rob acknowledged there had been delays and cancellations in his treatment, this does not appear to have had any significant negative effect on him, nor his relationship with his surgeon with whom he expressed confidence.

The surgeon made me feel very confident, you know, that I was with the right person, and I believed them as well when they said it was going to change my life for the better (Rob, 6W. Line 71).

Fran's relationship with the consultant surgeon was also extremely positive, she evidently had a lot of trust in the surgeon and respected his judgement as highlighted by the excerpt below.

Dr X has obviously worked really hard (Fran, 6M, Line 12).

The consultant personally contacted her several times to update her of the treatment plan ensuring Fran felt involved throughout.

Consultant is really good, they messaged me privately, and was like “oh I’m really sorry I had to cancel”, they’ve been really good (Fran, 6M. Line 76).

Additionally, there was a clear partnership and evidence of shared goals between them.

They say, yeah...well what do you want to happen? and I said, well just take the pain away, they said, okay let’s take the pain away (Fran, BL. Line 97).

The wait between decision for THR and surgery date was extremely long, which led Fran to opt for private treatment (surgery) by the same consultant. The strength of the positive therapeutic relationship between the consultant surgeon and Fran is evident as she chose to remain under his care despite transferring healthcare settings. She then chose to continue to be treated by him for her subsequent surgery on the contralateral hip.

In contrast, Claire’s healthcare journey was particularly difficult, she had experienced musculoskeletal symptoms from childhood. Because of these symptoms, Claire had been in regular contact with a variety of orthopaedic consultants and professionals throughout her life, and these interactions throughout her childhood set a blueprint of the type of relationship and power dynamic Claire perceived to be present between herself and healthcare professionals.

When Claire first started exhibiting symptoms at seven years old, the GP she saw informed her parents that Claire was pretending to be unwell.

when I was 7, I woke up one morning and I couldn’t get out of bed, I was literally, my legs just didn’t work, and my Mum thought I was trying to get of going to school, even the GP that came round said oh she’s like faking it. Until I literally nearly fell down the stairs because I was like I am not faking it, my legs do not work. And I ended up in hospital for 6 weeks because I had a viral infection on my left hip. (Claire, BL. Line 95).

This feeling of not being listened to and ignored by healthcare professionals has continued throughout her life. When symptoms developed specifically in her hip, Claire repeatedly told clinicians that her hip was causing the problems. Despite this, she expressed that for four years she was ignored and dismissed by healthcare staff who tried to link her symptoms to other causes.

I kept saying it’s not my back, it’s my hips and they were like no we need to do several spinal fusion because of the scoliosis, it must be like referred pain, you’re used to that, and I was like no I’m telling you it’s my hips, then they said no its fibromyalgia and erm and then I kept saying no its my hips my hips (Claire, BL. Line 10).

When Claire eventually had an x ray on her hip, she was diagnosed with severe osteoarthritis (OA) and the clinician immediately recommended a THR. Within six months

the surgery had been scheduled. Unfortunately, due to other factors it was assessed that her case would prove to be “too complicated” for that clinical setting, so she was transferred to a different consultant at a different NHS hospital.

I had to go back, sort of go through my case again with a new surgeon (Claire, BL. Line 30).

Claire was crushed when the situation repeated itself in the second NHS hospital. At the eleventh hour, the nurse contacted Claire informing her that her case was too complex for their hospital.

they said, oh we've had a meeting about you today...they said that we've just been looking at your case and we've decided that looking at your case that you're too complicated for our clinic (Claire, BL. Line 34).

This comment of being “too complicated” was set to become a continuing theme throughout Claire’s healthcare journey. Decisions about Claire’s treatment were made without her input or opinion. She felt completely powerless and that she had no control in her care or treatment. After this second cancellation, no further plans were put in place for any ongoing treatment, Claire felt completely abandoned with no idea of what would happen next.

So, I said, “Well what do I do”, and rather, it was a pain specialist nurse, and rather than actually tell me she started to talk about Oxycontin and getting off oxycontin, and how dangerous it was... she went “oh just wait a few days and go and see your GP I'll send an email to them” and then she just hung up, that was it (Claire, BL. Line 42).

After this, her GP referred Claire to the orthopaedic consultant at the local general hospital. However, this transfer of care was not as simple as Claire expected. The new consultant recommended a different treatment plan to the operation advised previously.

when I saw the consultant, I'd obviously waited another 4 or 5 months again, so when, and I'd thought they was going to look over all the records, look over all the x rays, the notes and go, right, I'll transfer you to my hospital, and then I'll put you on the surgical list. So, when they didn't do that, (Line 353).

I couldn't understand why if I needed it before...how come now...I'm starting again as if I'd come in and gone, ouch, my hips a little bit sore (Claire, BL. Line 362).

Although Claire expressed respect for the consultant’s experience and reputation, she did not view her relationship with her consultant as a partnership and dreaded appointments and interactions with them.

They either make me cry or I just like end up barely saying anything to them and staring at them because I think, are you going to make me cry this time? (Claire, BL. Line 269).

I was so scared, so I said, well I'm not going then, I'm not going, I was like I'm not going there on my own, I can't (Claire, BL. Line 383).

This breakdown in communication and the absence of trust between Claire and the consultant had a significant impact on Claire's mental health and experience prior to surgery. Claire felt unheard and that her priorities and needs from treatment were being unacknowledged and ignored. This in turn prevented Claire from confiding her full vulnerabilities and concerns, limiting any open and trusting communication.

and I'm still stuck in bed, still crying, and I still can't sleep, and I still can't. And then they said, oh perhaps your mental health isn't strong enough to deal it the surgery, and I was like, are you for real? My mental health is bad because of the pain, the only way to get out of the pain is to have the surgery, and it was like none of that mattered (Claire, BL. Line 368).

I have had my guard up about them (Claire, BL. Line 323).

Reflexive Account

Dated 17/03/2021.

Claire's first interview was extremely emotional. This was the first interview I did for this study, and due to my inexperience, I was less emotionally prepared than at subsequent interviews and had no idea of what to expect.

Although I was aiming to remain impartial, I could not help but be compassionate to Claire's experience and feel disappointed in the actions of the healthcare providers described in the transcript. I also struggled to associate her experience with the consultant with the same consultant I knew on a professional level. It was important that I separate my feelings and own experience completely from Claire's so as not to impose my own views in the analysis. It was also imperative to separate myself from the consultant in Claire's eyes and reassure her that this was an anonymous and confidential conversation that would not be relayed back to the clinicians. This was essential in promoting trust and confidence in our relationship as researcher and participant.

Henry had a different experience as he had no interaction with his consultant surgeon at all prior to the operation.

*I haven't even met ***** yet (Henry, BL. Line 106).*

Henry opted to have the surgery at a private hospital very soon after the decision for surgery had been made, primarily due to the waiting time on the NHS because he had access to private healthcare through work.

I've got to be a bit selfish for myself because I am so glad that I'm probably going to get the operation in 3 months whereas it was probably going to be 10 months (Henry, BL. Line 109).

The importance of relationships between patient and clinician were not unique to the consultant, as similar interactions and scenarios with other members of the healthcare team were described.

Diane attended multiple appointments but rarely saw the consultant who would operate on her. Instead, she was reviewed by a junior doctor. Diane was told repeatedly that they were unable to operate because of her Body Mass Index (BMI) being over the threshold for surgery, she felt there to be a reluctance to help her and a lack of empathy from the clinicians.

I was just thinking, they're going to send me away again, I'm going to have to suffer again (Diane, BL. Line 97).

Diane's weight was an aspect that was focussed upon by multiple healthcare professionals. Diane began having problems with her hips around 10 years ago. It appeared to her that there was a reluctance to investigate or treat any conditions, instead blaming her symptoms on her size, faulting her for being overweight. This significantly affected the trust and confidence Diane had in the clinicians treating her.

I went to her (GP) one day, I said, 'look, it's getting me down now, there's something wrong with my leg', and she just kept blaming everything on my weight and she didn't do nothing, I had no x rays, no MRIs, no nothing (Diane, BL. Line 31).

Relationships with healthcare professionals impacted on participants throughout all three interview timepoints: baseline (pre-surgery), 6-weeks post operation, and 6 months post-surgery. These were not only encounters between themselves and healthcare staff, but also family and friends' experiences with clinical professionals in the same hospital.

Patrick recognised that he held a very negative view of the hospital due to previous encounters for both him and his partner, where he felt they had not been treated appropriately or effectively.

I've not had the best experience I don't think of this hospital, her mum was pretty much put in a room and told that she was going to die and that was that, just left to die, erm you know, friends of ours have lost children in childbirth here, erm, yeah its...I've tried to come in and see my wife and being refused entry (Patrick, BL. Line 134).

Post surgery, Patrick felt dismissed by the junior doctor in his follow up appointments in the consultant's clinic.

He really didn't seem to have a clue, erm about my notes, didn't really want me to be asking any questions...but it was as if he just wanted me out the door really (Patrick, 6M. Line 225).

Patrick described feeling as if the doctor he saw had no interest in his ongoing care, the clinician viewed Patrick's case as a good outcome because of the almost complete resolution of pain and the absence of any major complications. In Patrick's view, the doctor did not display any interest in Patrick's own opinion of his recovery and did not give any indication of personalised care towards Patrick's individual needs.

I don't really get the feeling from any of the guys that I've spoken to that they fully understood my personal notes, they're looking at it in a very black and white stance, so there is two understandings of my life (Patrick, 6M. Line 221).

Participants described their journey from diagnosis to operation as a "fight" for surgery. Participant's felt they had to "battle" to make their voice and priorities heard.

I had to fight to get the operation (Zoe, 6W. Line 196).

I had to really push... push for, you know to get here now, erm it wasn't, you know, I'd go in... once or twice it was like, oh you've got arthritis there's nothing we can do it's fine (Chris, BL Line 44).

The participant's age was identified repeatedly throughout the interviews as a factor and an influence on the way healthcare professionals made decisions on their care and treatment.

I'm not waiting to have this done because it's "oh no just wait until you're older" (Henry, BL. Line 162).

...they kept saying, no, we'll give it a bit more time because of your age, you're only young, you'll need a replacement in 10 years, I was like, I don't care about 10 years, I want my life now (Claire, BL, Line 356).

Chris had initially been put on the waiting list for THR in 2018. Frustratingly, he was removed from the waiting list after his first pre-operative assessment due to some abnormal blood results. The assumption made by clinicians on these results was that Chris was drinking alcohol too much which Chris vehemently denied.

obviously straight away they thought that I was drinking too much, like they said you've got to stop the drinking (Chris, BL. Line 77).

Chris was never given any detail of why this assumption was made by clinicians; however, he believed his age (33 years old) may have contributed to their perception.

I don't go mental like 20 pints every weekend or something like that (Chris, BL. Line 78).

After, further investigation, Chris was diagnosed with a fatty liver, and after some apprehension to operate by his consultant, he was put back on the waiting list for surgery.

I think I actually got my liver scanned again and then they decided oh no it's fine, 30 percent of the population have, in England have fatty liver, it's not going to affect your operation. So, they put me back on the list and then that's where I am now (Chris, BL. Line 83).

Throughout this early process leading up to surgery, Chris remained confident that a THR was the right treatment decision for him.

... it felt like a reluctance at times when I'd speak to them, but I knew that it was the right thing for me to do (Chris, BL. Line 85).

Although, reasons for this perceived reluctance were never explained by the clinicians, Chris believed that his age was the clinicians' primary concern. Despite this, Chris maintained a positive relationship with his surgeon, believing that they were acting in his best interest and despite the long wait and the indecision around his liver result, concluded that this had all occurred because it was necessary to investigate and proceed to surgery with caution. He admitted that the assumption on his alcohol intake had been frustrating but claimed he understood why this had been considered.

I think it was because of my age and they're probably a little bit apprehensive to do... to give, you know a hip replacement to a 33-year-old (Chris, BL. Line 50).

Participants were also acutely aware that they were considered young for this operation.

I don't think I'll be the first 35-year-old to have a hip operation but I'm assuming it's more for the older person, when you look online it always says like 60 ages on... I mean not ideal, obviously I thought, well I'm too young to have one (Henry, BL. Line 167).

after 2 years, 3 years of it, I got fed up because the pain wasn't going and they were telling me that's what it was, so I gave up, went back again...I again I've been on and off the records, them telling me I was too young to have anything done (Zoe, BL. Line 27).

When doctors agreed to place Zoe on the elective surgery waiting list, her relief was overwhelming, she described it as feeling like she had won a battle.

all I get told is you're too young... to be simply told there's nothing we can do, you've just got to live like this until you're in your...50, 55 whatever, that's a long bloody time... I did come out and I did cry with relief, it felt like I'd won a battle, someone has finally said yes (Zoe, BL. Line 172).

Due to consistent delays and postponements of operation dates, Zoe opted to transfer to a nearby specialist orthopaedic hospital to undergo surgery. Zoe described a particularly upsetting interaction with a receptionist when Zoe requested a follow up appointment.

*I'm battling now for aftercare...She was a right nasty little ***** on the phone in **** ..just horrible. She was horrible, I actually came off the phone and I was crying (Zoe, 6W. Line 198).*

Imbalance of power was a recurrent topic. Claire believed that if she complained about the surgeon or displeased them in some way the surgeon would withdraw treatment.

if they're rude I will tell them, and I said, no, no because then they'll kick me off the list or they'll punish me somehow (Claire, BL. Line 388).

The perception of power and control was paramount to participants. Though many described it as inevitable, the idea of having no control of their treatment and being completely powerless was an uncomfortable experience.

then they were strapping me in a chair and then you are waking up, that feels horrible, they could've done anything (Henry, 6W. Line 122).

Though participants recognised the idea that the clinicians were “doing anything” to them as illogical, the concern that they would have no awareness or no control in the situation was evident. Both Patrick and Henry described the operation itself as a very brutal and forceful procedure.

when you really think about the operation, it's really brutal what they do, having your ball socket off, then re attaching it then smashing the other bit into there (Henry, 6W. Line 125).

I'm finding this whole principle of having a...booking yourself in to have somebody dislocate your joint, cut the top of your leg off, then stick a metal shaft down inside it and screw a cap to inside it, and all of that just bizarre (Patrick, BL. Line 154).

The perceived brutality of the surgery and the power imbalance between patient and surgeon, particularly in the operating theatre itself, stressed the paramount importance of a positive trusting partnership between participant and healthcare staff. Participants were desperate to feel supported and heard and reacted positively to feeling that they were working with clinical staff towards shared goals and priorities. Unfortunately, some participants felt they were at a disadvantage in comparison to other patients needing THR because of their younger age. They believed they had to “fight” to be heard and be offered the same treatment as their older counterparts. They had to “battle” to have an equal voice. It is important to acknowledge that separate participants often described completely different experiences and relationships with the same orthopaedic consultant.

5.2.2 My doctor never said that: Information and expectations.

Sufficient and consistent information throughout the healthcare experience was a common aspect that participants cited as being essential to a positive healthcare experience. It enabled participants to manage their expectations adequately. Unfortunately, this information was often insufficient and inconsistent resulting in unrealistic expectations. A

stark example of insufficient and inconsistent information centred on the waiting time for surgery that was expected by some participants.

Fran's expectations on waiting time for surgery she felt was poorly managed as the consultant stressed the severity of her condition leading her to perceive there to be some urgency for the surgery. Despite being informed the waiting time to be six to eight weeks, Fran experienced a significant wait for her THR. When she contacted the hospital, several months later having not heard anything further, she was booked in for a pre-operation nursing assessment and her hopes were raised that the surgery would take place imminently.

you're quite a severe case, bone on bone, there's no cartilage left at all between my hips on my left hips, and on my right quickly deteriorating as I'm using that a lot more than my left hip, but erm, yeah, I'm hoping anyway in the next 6 to 8 weeks there'll be some kind of action (Fran, BL. Line 115).

I was whisked away for a pre-op probably...first couple of days in November, erm on the promise that it would probably be in the next 2 weeks, erm yeah, right, it was definitely not in the next 2 weeks (Fran, 6W. Line 9).

Fran expressed that she had felt this pre-surgery appointment had been booked to placate her with no intention of booking her on for surgery.

I went up for that pre-op, but I now realise that that pre-op was just to shut me up (Fran, 6W. Line 72).

Diane had a similar experience with her expectations of time between decision for surgery and operation date. After the decision for THR had been made, things appeared to be organised very quickly.

a couple of weeks later I actually had my pre-op, it got me, I was like bloody hell, I got all excited thinking any time within the next three months hopefully...I was getting a bit...like thinking, oh my god, it's going to happen, and it was like, building my hopes up just a little bit (Diane, BL. Line 104).

Unfortunately, the wait for a surgery date was extremely long and difficult for Diane.

I contacted admissions about a month ago and said, can you tell me roughly how far I am down the list I am, and she said, oh you are quite far down on the list, I wish I'd not made that call (Diane, BL. Line 221).

A significant influence on participants expectations of recovery after surgery came from individual prior experience. Participants shared various success stories that they had heard through friends and family of successful joint replacements.

I do know people that have had a hip replacement and they're back on the football pitch playing football (Annie, BL. Line 267).

There is someone at work who's had a double hip replacement, and they told him not to do any sports...the physio, he said he knew some guys had gone back and played rugby with it (Henry, BL. Line 101).

This included personal experience of recovering from other types of operations or watching older family members undergo and recover from joint replacements. In addition, participants' expectations were more optimistic due to their younger age, they presumed they would recover at a faster pace than their older relatives.

My mum had her knee replaced and was told it would last her 10 years, my mum's now over 10 years on it and it's as good as new, my mum's more active than me, my mum works more hours, walks like 6 miles a day and it's still as good as it was when it was first done (Zoe, BL. Line 158).

My mum...gosh her first hip was back in 1993, so yes...that enabled her to walk again properly, oh bless her, she's 87 bless her, she gardens, still carries on rides a bicycle, still does all sorts of stuff (Fran, BL. Line 124).

These reflections affected the participants perception of what should occur during rehabilitation.

I didn't realise how fragile my body would feel after, you know, I thought I'd be up and walking like normal, within a week, you know, listening to all the old people that I've met who had had it (Rob, 6W. Line 11).

Hopes and expectations of outcomes were discussed at length, Chris and Claire both declared expectations of outcomes that were more guarded than and balanced than other participants.

I'm not naive enough to know my hips going to be 100%, because of all the other factors, I know that's not going to be the case (Claire, BL. Line 249).

sort of to live a normal life again without feeling in pain like walking, and been able to do certain things, I know there are certain things I won't be able to do, but you know, doing sport again (Chris, BL. Line 163).

Other had high expectations and hopes of outcomes.

I've got a couple of close friends that have had their hip, and they're like, "Diane, you'll be a new woman once you've had it, you know", and that's good to hear because I can't wait for that day, I really can't wait (Diane, BL. Line 168).

I've put an awful lot of hope into this hip giving me my life back (Patrick, BL. Line 10).

Assumptions of outcomes and expectation of recovery were not solely focussed on the participants expectations, healthcare professionals also assumed the participants would have positive outcomes due to their age. This negatively affected the care and treatment received after surgery. Zoe was not given any follow up or physiotherapy appointments after discharge from hospital.

They said it's because I'm young and because at nine days after surgery I was doing really well they didn't book me in for any follow up or for any physio... they said because I'm young and because of that I would bounce back quicker, so they weren't worried about providing physio (Zoe, 6W. Line 42).

This turned out to be inaccurate and Zoe initially struggled significantly in her recovery.

The recovery from the operation is horrendous, I'll be honest with you, the first, at least 4 nights at bedtime, my husband had to help me get my legs up into bed and you know, the whole he had to help me to the toilet and everything, I just sat in the bed and cried, like what the hell have I done, what have I done? (Zoe, 6W. Line 87).

Participants also reported that information and advice on care and treatment was also inconsistent between healthcare professionals, making it very difficult for them to be confident in their treatment, recovery, causing significant anxiety. For Rob, this manifested as another consultant contacting him to voice disagreement with the initial consultant's assessment.

I had to wait ages and then the surgeon called...another surgeon, and they were like, "you have seen your hip? I don't know why you're getting this done" (Rob, BL. Line 61).

For Annie this inconsistency related to pain management; she was informed by a pharmacist that her consultant had prescribed inappropriate medication.

I went to the chemist the other day, he was like, I can't give you this because you're taking Gabapentin and you shouldn't be taking the two, and I was like, my doctor never said that (Annie, BL. Line 75).

The "My Mobility App" was referenced by multiple participants as a source of information and guidance. This was recommended by the hospital when the decision for surgery was made. Though information on the app was described as useful, Scott claimed that its other functions for ongoing care were insufficient.

we were worried about it bleeding and stuff like that and it had a function on it, we can message the ward, but no one got back to me for over a week (Scott, 6W. Line 163).

Zoe felt the app was not updating and progressing at the same rate she was. The app continued advising the same five exercises for several weeks, there was no progression to further, more challenging exercises, nor was there any guidance to increase the time spent exercising. The app remained stagnant in its information. Zoe felt that she was capable of more than the app was advising her to do but was cautious of progressing too fast and causing herself harm.

I've got a little app on my phone now but, as I said five exercises, nothing's changed (Zoe, 6M. Line 32).

When seeking information on their situation and rehabilitation, participants used other patients progress as a benchmark of what stage of recovery they should have achieved. Expectations amongst participants were that recovery and rehabilitation would be quicker than their older counterparts because of their age. Henry believed that his age would positively impact his recovery time and would expediate his rehabilitation.

I've spoken to loads of people, different things involved, obviously I'd like to think because of my age it will be quicker, because you know I am younger, I am fairly healthy you know (Henry, BL. Line 146).

...maybe because I'm a lot younger, I thought, I'll have it, and then I'll just get up and walk out (Henry, 6W. line 99).

This grossly contributed to participants frustration and anxiety of their progress, both Diane and Patrick observed other older patients on the ward immediately post-surgery and were starkly aware of other patients increased ability to function and mobilise in comparison to themselves.

I felt like I was a week behind everyone else, they would have had the same operation at the same time (Patrick, 6M. Line 61).

...in the hospital there was an old lady opposite, and she was perfect the next day (Diane, 6W. Line 66).

Several participants highlighted significant concerns on the slower than expected progress in the initial post operative period and the negative impact this had upon their mood and their perception of their own progress.

I was a bit worried that it was a bit slow (Henry, 6W. Line 19).

... it completely addled my brain, I thought I was actually useless, I was going backwards, nothing was changing (Zoe, 6M. Line 193).

The slower than expected rehabilitation process had a significant impact on Patrick's mood. Patrick experienced fluctuating symptoms with his hip and deliberated for some time on

whether surgery was the correct treatment option for him. Due to this uncertainty pre surgery, there may have been some underlying feelings of regret at undergoing the THR.

...the frustration of...you know, how long it was actually taking for the leg to be usable and things like to going up the stairs, one step at a time, you know, after that sort of third week started really kind of...really playing on me (Patrick, 6W. Line 25).

Rehabilitation advice after surgery was scarce and unclear, Zoe felt that the purpose of the support and information given was solely to expediate her discharge from the ward rather than regain her function in the long term.

...recovery wasn't really explained at all, there was no, "this is what to expect at this point and this is what to expect at that point", erm it was more kind of, "let's get you up and walking" for discharge (Zoe, 6W. Line 37).

This lack of information led Diane became confused with her progress; she was unsure of the rate of her improvement and oscillated between feeling it to be too slow or too quick.

...am I making it worse or am I doing it good, you know, you just don't know what you're doing with yourself half the time (Diane, 6M. Line 72).

The need to protect the hip was highlighted regularly throughout the transcripts, either to prevent dislocations or extend its longevity and postponing future surgeries. Participants were cautious of overdoing exercise or moving in a way that could cause damage.

I don't want to go out and just fall over on it, and it get dislocated...I think you just need to be a little bit careful on it (Henry, 6W. Line 128).

I need to protect it, I don't...I want this to work. I don't want it to dislocate then always having problems again because then I'm back to square one (Scott, 6W. Line 135).

Insufficient aftercare and lack of support was an all-too-common experience. Lack of information regarding what to expect and lack of routine contact with healthcare professionals fostered feelings of isolation and abandonment in participants. It also contributed to participants being much more hesitant to progress in their own rehabilitation due to concern that they may cause harm to the new hip.

Participants identified the care pathways; assessment tools, and support practices used by the clinicians were very much focussed on the older person. This was very isolating and frustrating for many participants, who felt like their individual needs were not being addressed.

... with the questions and things like that, erm you know, do you have a carer? Do you live alone? you know what I mean, on the checklist and everything else you know...feels like it's more targeted at someone much older (Rob, 6W. Line 58).

The whole process is definitely geared towards the old people, you know... there's no consideration for us younger people who want to be part of the world, and do things, and still have to go to work, and have kids to run round, there's no consideration for us (Zoe, BL. Line 238).

Chris was the only participant who attended the pre pandemic care pathway of Joint School. Though he explains he found the information helpful, he was very aware of the difference in age between himself and the other attendees.

It was informative, nobody else my age there, erm...but yeah, I didn't realise it was...yeah, I was the youngest there (Chris, 6W. Line 151).

The combination of insufficient and inconsistent information led to participants seeking advice and information elsewhere, sometimes from inaccurate or unchecked sources, such as: unofficial websites and social media.

... obviously, I'm just like googling things, can I bend down? Can I do that? (Diane, 6W. Line 155).

Due to the COVID19 pandemic and the restrictions on social contact, usual care pathways were unavailable, Zoe felt this was a factor that negatively affected her experience and left them feeling isolated and unsupported.

It might be different if you could meet up once a week and have a chat with other people who are going through the same thing and be like "hey yeah that happened to me," or "this happened to me" and we're on the same level, it's very much that I'm doing this on my own (Zoe, 6W. Line 62).

Without access to a physical support network, Zoe sought other ways of seeking support from others living through the same experience, such as online forums to connect with other young people who had undergone THR.

I know you shouldn't compare yourself but that's all you do, you compare yourself to err...there's a Young Hips group online on Facebook, you compare yourself to how well everyone else is doing (Zoe, 6W. Line 53).

Zoe identified that social media was not an appropriate source of information to use as users choose what content they share, often resulting in misleading or inaccurate information.

You've got this...wealth of information, probably 90% of it is not true (Zoe, 6W. Line 171).

You only see the things they want you to see, you only put the good stuff on (Zoe, 6W. Line 60).

No participants relayed any experiences of THR failures or discussed any potential negative outcomes; they had not allowed themselves to consider that this treatment option would fail, and they would potentially end up in a worse condition.

5.2.3 Accepting the implant as part of me.

Adapting to the implant was a theme described by all ten participants. Annie and Zoe found accepting the implant and adapting to the new joint simple and easy.

The actual joint itself, I would've never known. I never feel like that doesn't feel like me or mine or whatever (Annie, 6W. Line 90).

It actually feels like part of me... people have said like you get a heavy kind of feel, and it doesn't really feel like part of you, but it feels more me than what was in there before (Zoe, 6W. Line 15).

Patrick, Chris, and Scott struggled to wrap their head around it, perceiving the implant as a foreign and rudimentary object.

It's the fact that it's going to be this chunk of something else in me... I don't want to feel like I've got a shard of metal in me, I don't want to feel...I want to feel as normal as I can (Patrick, BL. Line 159).

you can feel it's not real as opposed to bone (Chris, 6W. Line 32).

Reflexive Account

Throughout the analysis, I was struck by the harsh language Patrick, Chris and Henry used when describing the implant. In particular, Patrick used words which described the implant as a very rough, clumsy, and harsh object, He uses the words “chunk” and “shard” which imply a heavy, solid, or sharp item. The impression is that the implant to Patrick is an alien, foreign object, completely separate to him.

Patrick's resentment of requiring a THR is evident through the language he uses in describing the implant. He has focussed his negative thoughts on the implant itself rather than on his situation. Though his perception of the THR had softened slightly at his 6-week and 6-month interview, he still considered it as a separate part of him, one that he had limited control over. It would have been very interesting to follow up Patrick after the 6-month timepoint to see if he had ever reconciled himself to the implant and accepted it as part of him.

5.3 I'm just constantly in pain.

One of the primary objectives of a THR is to relieve pain in the patient (Markatos et al., 2020). Therefore, it can be no surprise that the experience of living with pain was highlighted and frequently expressed by all ten of the participants as a major impact. The aspects attributed to pain and its effect on each individual's life was varied and multi-faceted between participants. Resolution of pain was identified by each participant as a significant priority and key reason for undergoing the surgery, however, the ways the participants all detailed the lived experience of pain, and its management was extremely diverse.

The analysis identified a super-ordinate theme of Pain which compiled of two subordinate theme categories; It's an all-consuming pain; and It doesn't matter what I swallow.

5.3.1 It's an all-consuming pain.

The topic of the pain experienced before their surgery was not limited to the pre surgery interview alone but frequently reflected upon throughout all three timepoints. The pain experienced before the operation had a significant impact on the participants life and was clearly something they could not dismiss as being in the past.

Pain before surgery was constant, extreme, "all-consuming" agony. It took over everything, completely overwhelming their lives. Zoe, Claire, Annie, and Diane were unable to concentrate on anything else other than the agony radiating from their hip.

It's an all-consuming pain, every movement (Zoe, 6M. Line 172)

I'm just constantly in pain, it doesn't matter what, you know I could have a headache, but the hip would be more priority over the pain (Diane, BL. Line 41).

Pain pre-surgery was so severe that it completely impacted every part of participants' life. Mobility, ability to sleep and mental health were identified as areas significantly affected directly by severity of pain.

It's mainly sleep, I can't sleep on it, that's the worst thing, so I never ever get enough sleep, so I'm just tired all the time (Rob, BL. Line 30).

It's that thing, if you're in pain you can be quite snappy (Patrick, BL. Line 112).

Pain was usually the first symptom to present itself to the participant, indicating there was a problem in the hip. Annie initially dismissed and tolerated the pain in the hope it would just go away.

I kind of dismissed it for some time thinking, oh maybe I've just pulled a muscle, or you know, but it was getting to the point where I was like, no...it's more than that, I think (Annie, BL. Line 24).

Annie was reluctant to admit that the pain could be an indication of a more severe issue, she was too young, too active, so she attempted to block it out and carry on with her life despite it.

For Henry, initially the pain only presented after exercise. The severity of the pain had now increased to a constant agony. This point was when many participants sought help, when the pain could no longer be excused or tolerated.

It's gone from the days where it would only hurt if I had done quite a bit or considerable walking, but now it hurts even sitting down, lying down at night, it hurts all the time now (Henry, BL. Line 35).

Patrick also experienced this gradual progression, he became used to the pain, to the point where his ability to cope with the pain increased beyond other people who did not have this experience.

Obviously, the pain is a steady progression, so as it gets worse, you know in a kind of way you kind of get used to it so it's never quite as bad as it actually could be if it had not been such a gradual progression in the first place (Patrick, 6M. Line 117)

I'd been kind of living with it for so long, erm, and you know without trying to blow my own trumpet or anything, I deal with pain quite well (Patrick, 6M. Line 112).

Patrick explained that before surgery, his pain levels were variable, however, when he did experience pain in his hip, he described the pain as “*like someone is sticking a knife in my hip every time I step then I'm happy to have my leg cut off*” (Patrick, BL. Line 94).

I can go days without really been in much pain if I'm not doing very much, or I can be in excruciating pain for days in a matter of minutes depending on what and how long I'm doing it (Patrick, BL. Line 15).

Being “used” to the pain was a common description evident in the transcripts, Rob explained that didn't know any different and had forgotten what it was like to have no pain.

I'm just always in pain, I don't know any different, do you know what I mean (Rob, BL. Line 18).

Prior to surgery, participants often made conscious decisions to avoid activities that caused them pain.

If I can kind of avoid it, if I can stay in my seat more and not run around and not, kind of do anything strenuous then I can get by (Patrick, BL. Line 100).

I just couldn't because it would be too painful...erm...I suppose the only thing I would make excuses for...I just wouldn't go for walks (Chris, 6W. Line 95).

This aspect of avoidance and self-imposed isolation will be explored in more detail further in the theme “giving up hope” (see Section 5.4).

When the decision was made to undergo THR, all participants had already surpassed the point of being able to tolerate the pain and carry on with their lives. The intensity and persistent nature of the agony served as a significant factor in their resolve to undergo surgery. The expectation that post-operative pain was unavoidable after surgery was accepted without question and considered much more acceptable than their current torture.

When describing the type of pain experienced post operation compared to the pain experienced pre surgery, Zoe had a different perception of this post-operative pain than that she experienced before THR, though almost equal in severity, the pain after THR had a clear end point. It was the type of pain to be tolerated and overcome with time, rather than the never-ending agony experienced pre-surgery.

The pain that you have, pre-surgery and post-surgery, I would say they are the same kind of intensity in different ways. One pain you've got which is pre-surgery which is all consuming all the time, it doesn't matter what you do, you can't get rid of the pain, the other pain after surgery is also, I can't get rid of this pain, but I know this pain is going to go, so it's kind of working through it (Zoe, 6M. Line 200).

Patrick had significant concerns around post-surgery pain relief. Due to a back condition, he was unable to receive spinal anaesthetic. He was apprehensive that the pain relief provided would not be effective in managing the pain in the immediate post operative period.

...because I've had spinal surgery, they can't give me the spinal block, so they are going to put me to sleep and then by all accounts it's paracetamol and ibuprofen which doesn't do shit really (Patrick, BL. Line 164).

Pain control whilst an inpatient after THR had been a significant problem.

...because I couldn't have the spinal block they gave me the morphine drip, I was so out of it...you'd come round, and your pain would kick in again because you haven't pressed the button for however many hours, you press it then you knock yourself out again, it's just this repetition that I found difficult to deal with (Patrick, 6W. Line 190).

Reflexive Account

Dated 30/5/21.

When commencing the Young Hip study, my expectations had been that the relief of pain would be a significant priority in all participants. Patrick surprised me, his description of pain experience was unlike any of the other participants. Though he suffered with extreme pain in his hip, it was not constant, and the levels were more variable.

Because of this I spent time focussing on Patrick's transcripts and his pain experience to ensure I was interpreting the effect his pain had on him as true and individually focused on him rather than diminishing it in comparison to other participants' experiences.

For Patrick it was extremely important to him to be perceived as a controlled, strong individual. The admission of unmanageable pain would contraindicate this desired persona. Like with his admission of the effect his hip had on his mental health, the admission of his experience of pain was starkly informative by its presence rather than any great detail attributed to it.

Once the initial post operative pain had passed, the relief of pain was highlighted as a successful outcome.

It's just great, I'm not in any pain, I don't take any painkillers (Annie, 6M. Line 49).

It puts a smile on your face because it's like I've waited so...I suppose I've forgotten about like ...having the feeling of just having no pain in that...in this hip (Chris, 6W. Line 42).

Rob and Chris both discussed pain less frequently than the other participants, reflecting on it more as a limitation and its effect on their ability to function more than it being a significant issue on its own. Describing the relief of the pain as a weight demonstrates how much of a physical and mental toll the pain had been, and how much it had impacted on aspects of their life they had not considered pre surgery.

...didn't really realise how much pain I was in and how uncomfortable I was getting because I was limited to where I could move my legs, and then it affects that leg and then it affects you mentally and then after you have had it done, it's like a... yeah, massive weights been lifted (Chris, 6W. Line 78).

I suppose like a weight off your shoulder, I don't know, I don't know how to describe it unless you've had it (Rob, BL. Line 103).

Unfortunately for Diane and Fran, the surgery did not provide the complete resolution to pain they had hoped for. However, the continuing pain they described post-surgery could be attributed primarily to other areas than that of the operated hip.

The pain is intense, very intense, the pain...erm, it's probably the worst pain I've ever been in (Fran, 6M. Line 25).

I feel that I haven't become pain free yet, when I wanted to be, no...don't get me wrong, the pain like the bone pain, because of the arthritis, that's gone, but it's like, it's been replaced now with my knee (Diane, 6W. Line 43).

Both Diane and Fran believed complete resolution of pain was something they may never experience. Pain was something now to live with and tolerate.

Literally being pain free, but I don't know if that exists anymore, yeah, you just...I know you've got to live with certain things (Diane, 6M. Line 102).

5.3.2 It doesn't matter what I swallow.

Taking regular analgesia became part of the daily routine, without these medications participants were completely incapable of functioning. Medication was absolutely necessary to keep going and living their life.

My 4 hours are up, my painkillers are wearing off, I need to go and take the next lot of tabs because I've started to feel really uncomfortable (Annie, BL. Line 311).

I've found that if I just keep taking the meds, I can keep taking pain killers all day so function more (Patrick, 6W. Line 99).

Pain medications were viewed as a necessary evil, participants were reluctant to rely on them too much but at the same time needed them to address the severity of pain they were in. Several participants expressed that the pain medication prescribed by the doctor were ineffective at relieving the hip pain completely.

I just keep taking tablet after tablet (BL. Line 39) it doesn't matter what I swallow, it doesn't do nothing (Diane, BL. Line 61).

They cut the edges; they don't take away the pain completely (Zoe, BL. Line 311).

However, when participants requested help with managing their pain medications and attempting to reduce them, they found limited support from healthcare professionals.

It got to the point where I went to the GP to see about my medication and she said, well what do you expect me to do? (Claire, 6W. Line 479).

Pain relief is going awful as well, you know I'm not getting any of that properly (Diane, 6W. Line 16).

Annie had found little support and experienced contradictory advice between healthcare professionals on appropriate pain medication. This caused significant anxiety and a reluctance to take prescribed analgesia. Unfortunately, though reluctant, and unsure of what medication to take, she was desperate and felt she had no choice due to the extreme severity of her pain. She was willing to accept any medication or treatment that would go some way to relieving the pain.

I was kind of winging it, I was literally taking pain relief from what I'd read online and like friends and family were giving me (Annie, BL. Line 49).

Requiring less pain relief was a goal in over half of the participants. Dependence on pharmaceutical medications was something participants were eager to avoid as much as possible, many preferred to tolerate a level of pain so as to avoid over medicating.

To be quite frank as far as pain relief is concerned, I mean, who wants to be taking pills all day erm...unless you really need them (Patrick, BL. Line 102).

I was taking way too many pain killers because I was in agony (Claire, 6W. Line 38).

Fran and Rob preferred to avoid pharmaceutical pain medication completely, choosing to use alternative methods in pain management.

I'm really not great with medicines...pharmaceuticals, erm, so yeah...I haven't really taken much of the pharmaceuticals... (BL, Line 31) ...I take lots of ginger, turmeric, erm...magnesium oil, yeah, I have like Epson salts (Fran, BL. Line 166).

I avoid painkillers, smoke weed and that (Rob, BL. Line 91).

Fran disliked intensely the negative effects she had previously experienced when using pharmaceutical analgesia. She explained that it had caused rashes and nausea and was extremely reluctant to retry them. At her baseline interview, Fran found these alternative treatments were effective, however, she was not expecting how much more severe her pain would become whilst waiting to be scheduled for surgery. In desperation she had resorted to pharmaceutical treatments in the time between baseline and surgery. She had not found them beneficial, feeling the side effects experienced with these drugs were not worth the small amount of pain relief they had.

Caution around dependence on pain medication was not the sole reason participants tried to limit their use. The side effects of pharmaceutical analgesia had a significant impact on participants' lives, expressed by some to be almost comparable with the pain they were taking the medication to address.

...just wanting to sleep for 3 days and been drugged up so you can't spell like "the" or "drugs (Claire, 6W. Line 228).

I'm supposed to take 2 codeine 4 times a day, now I can't do that because I'm spaced out of my head (Annie, BL. Line 68).

Side effects like inability to concentrate, extreme drowsiness, or irregular moods were all experienced.

I can't take morphine or anything because it sends me really...really trippy, like, even like days after I've had it, it makes me really...really trippy (Zoe, BL. Line 312).

This prevented participants from being present in their own lives and functioning in their daily activities. There was no balance between the two states, participants were either in extreme agony or absent from themselves, unable to concentrate or focus.

5.4 Giving up hope.

All ten participants reported a negative impact on their mental health as a consequence of their hip condition, however, the severity of this varied between participants. Some participants acknowledged the psychological impact briefly, whereas for others, the negative implications on their mental health were excessive and significant, resulting in deep depression and in some cases, thoughts of self-harm and suicidal ideation. The analysis of the data presented evocative and powerful descriptions from individual participants when reflecting on the psychological impact of living with their hip condition. In an attempt to organise the volume of data available and report the findings with clarity, data relating to psychological effects was categorised under two subthemes: Depression and Euphoria and Self-Imposed Isolation and Avoidance.

Though these themes interlink, each subheading contained sufficient unique information to separate each other.

5.4.1 Depression and Euphoria.

As discussed in Section 4.10.1.III, analysis and organisation of themes when using an IPA approach can encompass several techniques. When participants expressed the episodes of when they felt their darkest moods and deepest despair it struck me how stark the difference was to the discussions after surgery, where in some cases participants were euphoric with the outcomes of the operation. During the analytical process, it seemed appropriate in this instance to employ the technique of polarization (Smith et al., 2009). Only by comparing the two extremes could I hope to understand how dark those desperate depressive moods were and how significant the antithesis experienced post operation.

The stark contrast between participant's psychological state pre-surgery and post-surgery was demonstrated to an extreme with Claire. Claire experienced severe depression in her pre surgery interview. The despair and hopelessness were not only evident in her words and narrative, but also in her tone of voice and the clear emotion evident throughout the interview. Claire frequently sounded on the verge of tears throughout her dialogue, her voice would often crack and some sentences were shouted almost forcefully when narrating experiences, she described as being particularly negative and frustrating. Claire was often in tears when expressing how grave her depression had become. She revealed that acts of

self-harm and suicidal ideation had become commonplace with her and felt that should her THR not go ahead as planned, then she would not be able to continue living.

I can't keep doing this every day, I can't get through another week, because it's the same, every day's the same... (BL. Line 198) *I think I'm hanging on by a thread* (Claire, BL. Line 232).

Claire attributed her depression to the physical pain and restrictions imposed by her hip condition. She frequently reflected back to her profound depression and the suicidal ideations she experienced pre surgery at both the 6 weeks and 6 months timepoints.

I would self-harm (Claire, 6W. Line 247).

I was at the end of my tether; I didn't have any more give in me to try and keep going on. I needed the pain gone, telling people to...do whatever you have to do, just get rid of it or I'll get rid of myself (Claire, 6M. Line 79).

Claire's demeanour and visible mood in both her 6-week and 6-month interviews can aptly be described as euphoric. She spoke extremely fast in the interviews after surgery and struggled to believe how positive the outcome of the THR was, implying that it was almost too good to be true.

This is probably the best I've felt, which is probably why I can't get my head around it as well because...it's just mental (Claire, 6W. Line 299).

I laugh a lot more; I know I smile a lot more (Claire, 6M. Line 49).

A severe negative impact on mental health was also reported by Annie, Diane, and Fran. The severe pain and limitations to their life caused by their hip condition caused significant feelings of depression and hopelessness in Annie, Fran, and Diane. At her baseline interview, Diane associated her hip symptoms with her extremely low moods, low self-esteem, and relationship issues with her partner, she believed once the operation had resolved her hip condition then she could start living her life again. The symptoms of her hip were so all consuming in her life that it was understandable to me that should that be resolved, any aspect that the hip had an effect on would automatically improve.

...it just gets you down, it does emotionally affect me very badly and I just feel like I can't do anything anymore, it's horrible (Diane, BL. Line 39).

Fran's baseline interview was unusual in comparison to the other participants. She was upbeat throughout, emphasising a positive outlook and mindset.

I always believe that a positive mindset brings positivity (Fran, BL. Line 153)

Like Fran, Annie also attempted to maintain some positivity in her outlook. However, the overwhelming impact of her hip resulted in major distress and frustration.

I'm praying that this is going to do something, it's got to be better than what I am at the minute, it has to be (Annie, BL. Line 371).

This morning I got up, I was just very very tearful, erm, I'm really becoming pissed off (Annie, BL. Line 82).

These words were delivered in such a desperate way, panic was clearly evident in Annie's voice as she considered that her current situation was not sustainable but that the surgery may not be scheduled for over a year due to NHS waiting times.

I'm just like really can't see myself lasting (Annie, BL. Line 91).

Happily, Annie did achieve a very positive outcome post-surgery, though less extreme than Claire, Annie's 6-week and 6-month interviews were positive and happy, directly contrasting with the despair and negativity of her pre-operation experience.

I just smile every day when I get up (Annie, 6W. line 5).

I do feel stronger in myself mentally and physically, I could take on the world (Annie, 6M. Line 103).

Reflexive Account.

Dated 8th March 2023.

I experienced a significant emotional reaction when relistening to and analysing Claire's, Diane's, Fran's, and Annie's interview transcripts. The despair and feelings of hopelessness experienced by all four participants was obvious in not only what was said but in how it was expressed. They were all frequently moved to tears and emotional outbursts that evidenced their frustration and desperation with their situation before surgery. In turn, the extreme positivity exhibited by Claire and Annie in their 6-week interview also caused me slight trepidation. The contrast in mood appeared so extreme that I was concerned that once they had become accustomed to their post operative state, their mental health concerns and depression would return. Thankfully, at the 6-month interview, Claire and Annie's mood remained positive.

I recognised that my emotional response to the four participants description of their psychological state impacted upon my interpretation. I aimed to remain impartial but could not help but be compassionate to the dire misery Claire, Diane, Annie, and Fran were expressing. A reaction to this content and the way it was communicated is only natural and warranted in me as a human. I did, however, spend more time considering and reflecting on these narratives to ensure that my interpretation was balanced and reflective of the participants' lived experiences.

Diane and Fran did not experience a positive impact on their mental health at the 6-week and 6-month timepoints. In both Fran's and Diane's baseline interviews (pre operation), there was an expectation that once the surgery had occurred, then their lives would begin again, with improvement on all negative aspects of their lives they experienced prior to surgery. This was not the experienced result. Though, their hip condition had improved, this had not contributed to a desired improvement in other areas, for example, relationships and mental health, these topics will be explored further in other superordinate themes.

Unfortunately, at her interviews after surgery. Diane still struggled with function and pain, though she recognised that this was more due to other health concerns than the index hip. Her mood remained extremely low as did her self-esteem.

I think that's probably the reason why I'm probably low because it's just, you know...nothing changes. I expected like, you know, something like..." oh yeah, I'm feeling better, I've been aqua, I can do this, I can do that", and I can't even say I can do that (Diane, 6M. Line 37).

Importantly, Diane was able to recognise that her depression was influenced by other aspects of her life, rather than solely on her hip. She acknowledged that she could now focus on these other concerns and work towards resolving them whereas prior to surgery she was completely preoccupied on her hip condition.

Fran eventually opted to undergo surgery privately in order to speed up the process. The long wait for the operation Fran experienced had a detrimental effect on her psychological and mental health. She became desperate to have the operation, even considering self-harm in order to expediate the surgery.

I considered falling down the stairs so I could break my own hip to get a hip replacement, you know, that was the place that I was, so it's just like, I've stood at the top of the stairs many a day in the last year (Fran, 6W. Line 73).

Fran recognised that these thoughts of harming herself to expedite the operation were not an acceptable thought process, however, the fact that this was considered at all, even fleetingly, demonstrates the desperation and frightening despair Fran was experiencing. Fran's focus on attempting to maintain her positive mindset was still evident in her 6-week post-surgery interview. Though she acknowledged she was still struggling both physically and mentally because of her contralateral hip symptoms, she was very pleased with the result of her first THR and felt confident in having a good outcome with her second THR.

I've seen light at the end of the tunnel or had light at the end of the tunnel, and I'm just praying now that there is super light at the end of the tunnel (Fran, 6W. Line 82).

Unfortunately, at the 6-month interview, Fran was still waiting for her THR on her other hip. Despite her best efforts, she was no longer able to present the consistent positivity she had

portrayed at her baseline interview. The psychological effects of her hip condition and the mentally gruelling wait for surgery had taken a significant toll on her mood and mental health.

It's a nightmare. It feels like everything's on hold (Fran, 6M. Line 43).

As mentioned, all participants referred to the negative impact on their psychological health in their interviews. Whilst for some it was a major primary concern as with Claire, Annie, Diane, and Fran, for others it was briefly mentioned.

Importantly, for some participants, that it was acknowledged at all was important. Rob, Patrick, and Henry were all participants who placed a lot of importance on fulfilling a strong, controlled role in their lives, thus admitting any negative psychological effects could imply weakness they were reluctant to do:

...quality of life is not very good, I could quite...as a person it does make you quite depressed, you can't...you can't really do a lot (Henry, BL. Line 50).

...kind of, depression...when it's really bad, yeah, it's incredibly frustrating, and I have had times where it's...it's had me in tears to a degree, that I...you know...I just can't do the simplest of things (Patrick, BL. Line 265).

Although, only briefly acknowledged, this recognition of vulnerability and the negative effects on their mental health was an important admission in the interviews.

For Zoe, she attributed the negative effect on her psychological health as a direct consequence of her frustration with her limitations on her function caused by her hip condition. She had used physical exercise as a positive mood booster prior to her hip symptoms starting, therefore, the inability to exercise had a significant impact on her mood and mental health.

I feel like my mental health is probably suffering now with it... you do a bit of exercise and it's great you feel a lot better, but I can't do that (Zoe, BL. Line 210).

The experience of depression was briefly recognised by Scott; however, Scott did not attribute the depression to his hip symptoms. Scott was diagnosed with Rheumatoid Arthritis (RA) several years previously. It was this diagnosis of a lifestyle limiting disease that understandably negatively impacted his psychological health.

When I first got diagnosed, it affected it massively, I got severely depressed with the arthritis (Scott, 6M. Line 84).

Throughout the years since his diagnosis, Scott had adapted to his diagnosis and developed a very practical and sometimes positive outlook on his symptoms, treatment, and overall condition. Scott placed the severe depression experienced very firmly in his past

as a reaction specifically to his diagnosis. He gave no indication that this was an ongoing concern.

5.4.2 Self-Imposed Isolation and Avoidance.

Though heavily linked with the above subcategory, the data analysis identified many significant separate experiences from participants specifically describing isolating themselves and avoiding people and situations. Self-imposed isolation and avoidance of people or situations was a choice many participants opted for partly due to their depression or low mood, however, isolation and avoidance was also recognised in exacerbating the negative effects on mental health.

Diane spent a lot of time in her living room, she recognised that she was opting to isolate herself and avoid situations in which she would struggle.

I just want to sit, and just sit on my own and just shut myself away because there's like nothing, I just don't want... I can't do nothing. It's horrible, I hate it (Diane, BL. Line 134).

Claire also chose to seclude herself in a particular room in her house. Claire spent a great deal of time in her bedroom, choosing to isolate herself from her family.

I hardly go downstairs because I just can't get back up the stairs...I don't have a lot of meals downstairs with them because, quite honestly its more stress than its worth, it sounds really awful but...it's too much. I spend most of my time in my room sitting in bed (Claire, BL. Line 137).

Though both Claire and Diane opted to self-isolate, this was not a scenario which they enjoyed. Both participants wanted to leave their rooms and interact with family and friends, however, due to their hip condition and the associated psychological effects it initiated, neither felt like this was possible. They felt trapped. Chris and Henry both reflected on avoiding situations in which they felt they would be limited in their ability to participate, whether due to pain or mobility. Although, being prevented from participating in sporting activities was accepted as inevitable, other activities requiring less physical movement were also impacted.

Chris only recognised this after his THR. He admitted that he did not want to admit to himself how much effect psychologically his hip condition was having on him.

...limited me from doing quite a lot, erm it affected me mentally because it was...I suppose it was erm making me resent going to band practice, erm and I was like making out, like to my girlfriend, that I like don't want to do it anymore but I was making out that I was bored of doing it but it was actually because I was in a lot of pain, and I don't think I wanted to admit that to myself (Chris, 6W. Line 83).

Henry identified that he was a very social person. He tried to maintain an active social life with both his work and his friends. This lifestyle was severely restricted by his hip condition.

You do start to become a bit more reclusive, it's not ideal (Henry, BL. Line 128).

Henry recognised that the longer he had to wait for his THR, the more severe these restrictions would become. Therefore, like Fran, Henry chose to have his surgery completed in the private healthcare sector.

5.5 This is not who I'm meant to be.

The theme of self-image was a strong and prominent narrative throughout all 10 participants interviews. Whereas, some recollections of themes could differ amongst participants and vary between positive and negative experiences, all ten participants predominantly considered their hip concerns and condition to have a profoundly negative effect on their self-image, this was not solely identified pre surgery, but also impacted throughout the post operative interviews. During analysis, the following categories emerged: Body image is not great, People who are older than me are in a better condition, and How others see me.

5.5.1 Body image is not great.

Nine participants experienced negative feelings about the physical signs on their body caused by their hip condition. These aspects were attributed to stages both pre surgery and post-surgery. Muscle wastage and inability to exercise due to pain were both highlighted as impacting body shape and size before the operation. After surgery, scarring, leg length, and the unequal hip shape were cited as concerns, however, they were considered less impactful by participants.

Participants found that the experience of pain and inability to stay active often resulted in them putting on weight or struggling to lose weight effectively. For Diane, this affected her eligibility to have a THR, as the NHS has a criterion for patient body mass index (BMI) when providing funding for surgery. Diane found weight loss very challenging and had the surgery postponed twice due to her BMI. She resorted to attending NHS weight loss clinics to lose the weight required, and self-funding expensive weight loss injections. Diane was listed for the surgery when just below the specified BMI threshold. She continued to struggle with weight loss post-surgery. As previously discussed, the operation did not fully resolve Diane's pain symptoms and mobility struggles, therefore, a return to exercise did not occur as Diane expected it would. As far as Diane was concerned, her battle with her weight issues was never ending. A vicious circle where her weight caused her to feel unfit and underconfident, but unable to exercise or enjoy physical activity to lose said weight.

I sobbed my heart out in that room, just hearing, you know, go away, lose more weight (Diane, BL. Line 85).

Body confidence remained a significant obstacle for Diane post-surgery, Diane continued to feel severely underconfident about her appearance, this prevented her from feeling sexy and attractive and contributed to a continued negative impact on her relationship with her partner.

Weight loss featured highly in the female participants experiences, often heavily linked to self-esteem and confidence. The interpretation was that by losing weight and exercising a person could feel and look better, however, the inability to move and the pain it caused prevented exercising and restricted weight loss.

...when you feel fat and horrible, yeah, you do a bit of exercise and it's great you feel a lot better, but I can't do that. It's just too much pain you know (Zoe, BL. Line 219).

The frustration and despondency experienced by those participants who struggled with weight loss was evident in their voices throughout the interviews. It was a no-win situation; they displayed feelings of complete and utter inability to help themselves in this matter until the surgery had been completed.

Weight was not the only physical consideration when detailing body image. The shape of their bodies and the change experienced due to the hip condition and then the surgery was also described. Rob lamented the change in his physique, his physical condition was very important to him and working out and maintaining that level of fitness was a clear priority.

I see old pictures of myself and that, I mean I used to have muscles, I used to be buff, and now I can't do anything, my legs are like bloody twiglets (Rob, BL. Line 81).

Rob enjoyed working out and exercising at the gym and prioritised keeping himself in peak physical condition. This large part of his life had been completely taken away from him because of his hip condition. Rob had put a lot of hope into this aspect of his life being restored after the THR, there was no indication in his transcripts that he had ever allowed himself to consider any other potential outcome post-surgery.

Other participants described the loss of muscle definition in the affected leg and how it visually appeared unequal to the other, this was discussed mostly pre operation, however, participants did reflect back on their pre surgery body in the later interview timepoints.

I don't have lots of muscle and wastage in my right leg, or fairly wasted, because that was the worst (Scott, BL. Line 67).

It was really strange looking down at my legs, and my left was still quite chunky, but my right side was just sort of withering away (Patrick, 6M. line 161).

This perception of inequality between lower limb shape was not always resolved after the surgery with some participants expressing a remaining visual difference between hips and legs.

...it looks different to my left side (Annie, 6M. Line 89).

One would consider, in clothing this may not indicate a significant concern, however, the difference in size and shape affected clothing choice, leisure activities (swimming etc). Additionally, though other people likely did not notice this body difference, the participants were still significantly conscious of it, potentially affecting their confidence and how they responded to others and situations.

...body image is not great, I have really lumpy, I mean very lumpy legs erm (Zoe, BL. Line 272).

Leg length was also highlighted as a concern from the majority of participants. This again was discussed both before and after hip replacement.

I've got one leg longer than the other (Chris, BL. Line 33).

I still have got one leg is shorter than the other, so he wasn't able to sort that out (Henry, 6W. Line 52).

Post surgery, with the resolution of pain, participants who still had unequal leg length, made a conscious effort to adapt the way they walked to avoid limping.

I still have a slight difference in my leg height, and it won't allow me to walk properly yet (Scott, 6W. Line 28).

A noticeable limp was a primary indicator to the participants that they were different to others their age. For the participants, a limp indicated they were less able and less capable than they should be in comparison to their peers. It was a visual sign of disability, as will be discussed further in this theme, being viewed as disabled either by themselves or others was a significant concern.

The operation scar divided participants. Diane significantly struggled with the scar's appearance and its feel when touched. Diane had unfortunately experienced a wound infection whilst recovering from the surgery, the infection plus her family's negative response

to the appearance of the scar confirmed to Diane that the scar was something ugly and disgusting, better to be kept hidden.

The only thing that bothers me is the scar, you know like you can get out the shower, bath, or a shower, and I start drying myself down, when I touch that side of my leg it feels awful (Diane, 6M. Line 76).

Alternatively, Rob was very proud of the scar and attributed no negative feelings to it at all.

That's a beast, it's a good scar, not fussed about it, it's healed up, but if you saw it, you would be like, "bloody hell" (Rob, 6W. line 47).

Body image and confidence unavoidably impacts positive self-esteem and image. Some participants regained a level of confidence and esteem after the operation. Claire happily expressed that her wardrobe had brightened to reflect this new positive mood. She was wearing bright colours and patterns whereas pre surgery her clothing was limited to black.

All my wardrobe was black, and like when I got out of hospital... everything is colour and I'm like, who is she? Who is she? (Claire, 6W. Line 465).

Claire's outward representation of her improved mood and body image seemed to surprise herself more than anyone. She embraced this new lease of life as a new happier version of herself and her personality.

Rob was enthusiastically looking forward to the summer and regaining his muscle definition. When asked at the six-week timepoint what he would like to have achieved by the next time we spoke he answered:

How good I look in shorts ... if I've got my legs back...yeah, I want them looking like footballer's legs...get some calf definition (Rob, 6W. Line 86).

5.5.2 People who are older than me are in better condition.

Healthcare professionals frequently highlighted the participants' young age: these repeated references and reminders exacerbated feelings of inadequacy compared to others of their age. It was felt to be implied that there was a level of disability in the participants and sympathy was required for their situation.

...she said I feel so sorry for you because you're so young bless you (Claire, BL. Line 227).

Every time you see anyone, they're like, oh, you're very young to be having this, I mean I appreciate they mean well but it does kind of have a tendency of imprinting (Patrick, BL. Line 260).

Understandably, to repeatedly hear you are too young to undergo surgery can be wearing on oneself. It is undesirable for many people to feel as if they are the object of sympathy of others. Although, undoubtedly these comments from healthcare professionals were well intentioned and meant to be supportive, they often had the opposite effect, causing participants, like Claire and Patrick to reflect negatively and resentfully on their pre surgery situation.

Throughout the analysis, participants frequently compared themselves to what they perceived a peer or acquaintance of a similar age to be doing or capable of. This occurred at all three time points. Comparisons to other people their age were often an involuntary action and unanimously reflected negatively on the participant.

I'm relatively young, I look at some of the other parents at school and they're in their 40s and have got kids 7 and 10, I'm 35 and still can't do half the things they're doing. I mean I spent the best part of a year telling people I was 37, I'm not 37, I'm 35, erm...yeah really embarrassing (Zoe, BL. Line 147).

...the age I'm at, it does make it worse, because of the fact you are surrounded by other people who are...I mean I've got people who are older than me in better condition, which I know it's not just, it is a physical thing (Patrick, BL. Line 275).

Like with the well-meaning comments from healthcare staff, these self-comparisons caused participants to resent the situation and condition they were in before surgery. Other people were living life and doing things participants wanted and believed they should be able and capable of doing.

Reflexive Account

Dated 9th May 2023

Throughout analysis of the transcripts, I noted that participants continuously attempted to play down or dismiss any indication of resentment towards their situation. When referring to incidents or experiences where these feelings were initiated, the participants tended to use the word "frustrating" to describe their feelings or reactions. This felt to me as an inadequate word and underestimated how sobering the impact of these scenarios potentially was.

On reflection however, and on further consideration of this description, the word frustration became more fitting. The dictionary gives the meaning of the word frustration as "the feeling of being upset or annoyed as a result of being unable to change or achieve something" (Oxford English Dictionary, 1999, p.206). This explanation is particularly apt in these instances.

This highlighted to me that my perception of this word was not the same as what others thought it to be. The participants were conveying feelings that were significant by using an appropriate word for them. This realisation ensured I spent much more time considering the language used by participants in the interviews to ignore my understanding of what the vocabulary meant and to focus more on what it meant to participants and how they were utilising it.

5.5.3 How others see me.

Concern over being perceived as having a disability was a common. Having a disability or being perceived as limited than others was seen in an extremely negative light. It was clear that a priority in many cases was to regain the appearance of being as capable and functional as they perceived others their age to be.

Comments from others highlighting limited mobility, noticeable limp or limited function were frequently overheard in daily life. Chris worked with children and would commonly experience the children mimicking his walk or cheekily asking him if he had a “wooden leg”. Though he did attempt to dismiss these incidents in his interviews, he referred to them repeatedly, unconsciously revealing the negative impact they had had on him.

...had one situation where the kid... sort of doing an impression of my walk, but... and then maybe just innocent questions about, obviously... you know, have you got a wooden leg.... but yeah, that, yeah it does make me feel a bit shitty like, it is what it is I suppose (Chris, BL. Line 130).

The fear of being considered “disabled”, weak, less capable, or even less “attractive” than others their age who had no limitations was apparent throughout the transcripts. Though participants attempted to make a joke out of it, the effect it had on them was clear in their tone and reactions. Like Chris, many participants referred to similar incidents repeatedly and could often recall them in detail.

I can't walk I wobble, I'm fine...it's really attractive (Fran, BL. Line 57).

...you know, dragging your foot behind you or walking like Quasimodo, I'm like, thanks, cheers, thanks so much, but yeah everyone notices there's something (Zoe, BL. Line 117).

Being seen as a joke or something to be laughed at was also a concern. Rob recalled being laughed at by another man at his gym whilst attempting to complete his exercise. For Rob, this was an embarrassing incident as his physical appearance and fitness was such a key aspect of his life.

I can't train, you know what I mean, I try to do...tried to do a squat and the bloke I was doing it with started laughing at me. I looked a right tit (Rob, BL. Line 128).

Rob used the word “disabled” to describe how he would feel if the surgery did not give him the ability to perform at the same functional level as his peers.

I wouldn't be happy..... I'd feel disabled (Rob, BL. Line 135).

Diane utilised the word “crippled”, a word negatively associated with disability, when reflecting her current functional ability.

I'm crippled (Diane, BL. Line 130).

Henry and Claire were both reluctant to use a walking stick or any mobility aids to avoid being perceived as less capable than others. As will be discussed in the theme “My family are in bits”, participants chose to isolate themselves so as to avoid social situations where they could be seen as limited.

They said about getting a walking stick, I said...you know...I can't get a walking stick at 36 (Henry, BL. Line 68).

The potential of being singled out as needing support or assistance was distasteful to participants.

I didn't want to be like, the one friend who needed the crutches or the wheelchair (Claire, 6W. Line 449).

They wanted society to view them as strong, capable individuals. It was important that any outwardly visible signs of disability or restricted function be minimal.

5.6 My family didn't sign up for this.

All ten participants reflected in depth on the impact their hip condition had on their relationships. This was not only focused on relationships with a partner, but also relationships with family members, children, or friends. The priorities and experiences were multifaceted and consisted of varying concerns and considerations, the participants experienced feelings of guilt for the effect their condition was having on their loved ones, they highlighted the importance of support and assistance from their family, the effect their hip condition had on intimacy with their partner, and lastly the roles they perceived themselves to be failing at within the family unit. The topic of roles is a frequent point of discussion throughout the interviews and is explored in both this theme and “I can't do anything”.

The data in this theme is categorised into three subthemes: My family are in bits, Sex life? Forget it, and Failure to fulfil relationship roles.

5.6.1 My family are in bits.

The effect upon family members witnessed by participants was highlighted by all ten participants. During the baseline interviews this was unanimously reported as a negative effect. Annie and Chris' loved ones struggled to watch them suffer with the pain and limitations the hip imposed. Seeing someone important to you in agony or distress through pain and frustration in their ability causes significant distress and concern for family and loved ones. Knowing you are the cause of this distress to your relatives then creates feelings of guilt that you are the cause of this and exacerbates the misery the individual themselves is experiencing. There is no clear end to this cycle.

My family are in bits (Annie, BL. Line 87).

...gets a bit upset for me when she sees me struggle with certain things (Chris, BL. Line 102).

For Diane, this cycle of suffering caused a major breakdown in her relationship with her partner, initiating a temporary separation.

It's affected our relationship; we have had a breakdown about a couple of years ago and he went to stay with his mum for a little while (Diane, BL. Line 112).

Diane believed that her hip condition and the negative effect it had on her was a main catalyst for this relationship breakdown. She acknowledged that her low mood, negative body image and lack of intimacy also had an impact but attributed these factors also to her hip condition.

I tell him I'm in pain and he's just going to go, I've had enough, he's sick and tired of hearing about it basically (Diane, BL. Line 119).

The interviews taking place post operatively reflected a more positive effect on the participants' families for most but not all participants. Loved ones celebrated at seeing the change in participants. The cycle of guilt at affecting family and friends and this contributing to the low mood was broken and participants like Zoe and Annie could take an active and complete role in their family's lives.

...sons are chuffed to bits that I'm not hobbling around and always groaning (Annie, 6W. line 32).

As stated, this was not the case for all participants, like Diane, Fran discovered post-surgery that her other hip was also a significant concern. This continuation of symptoms from the

contra lateral hip meant her and her partner were unable to move on and there was minimal improvement in the effect the pain and her struggle had on her partner.

He's still very affected (Fran, 6M. Line 39).

Fran also struggled with the guilt she experienced when her partner felt the need to change his job to provide private healthcare so she could undergo the surgery as a private patient. The wait on the NHS has been extensive for Fran and the situation had reached the point where both she and her partner had made the decision to take a different job offering healthcare benefits. Fran explained that this job was paid less but on balance it had been the right decision for them at the time.

I have no idea where I would've been if husband, partner hadn't gone for employed work, I mean, don't get me wrong he's decreased his income by about 40 thousand pounds on the off chance I can get my hip operation (Fran, 6W. Line 68).

Support from partners and families or the absence of support was a central focus in participants experience. Feeling as though they had support from loved ones was integral to the participants mood and mental health throughout recovery. As will be explored, though support from family was imperative, participants did not enjoy being in the position where they needed support. They were eager to contribute to their partnership and provide that support as well as receiving it. The situation participants found themselves in was very one sided and unequal, because of the severity of their condition and its overwhelming effect on participants lives, emotional, physical and in some cases financial support was being solely provided by their partner.

He's really supportive about everything (Fran, BL. Line 51).

My wife's been brilliant...erm...to be quite frank with you, the first couple of weeks, I genuinely struggled (Patrick, 6W. Line 86).

In addition to psychological effects on family members, Zoe had a more physical concern for her young daughter. Zoe had an ongoing concern that her daughter was demonstrating similar hip symptoms to her, this concern had a huge impact on Zoe's anxiety and triggered significant feelings of guilt that this was something she as her mother had unknowingly subjected her child to.

She always complains about her hip, you know after running so then that just gets in your head, maybe it is hereditary, we're geared to have one leg longer than the other, it's a grave concern (Zoe, 6W. Line 127).

Despite approaching this subject several times to the consultant and other healthcare professionals, her concerns were not addressed nor discussed.

They are really reluctant to x ray her or do anything, it's a small thing, just a small thing, though it's highly unlikely that she will have the same issue, but we could...just...for my peace of mind, right okay...no (Zoe, 6M. Line 159).

This is clearly something that Zoe had no control over, however the guilt that this could be a condition she had imposed on her child was profound and not something she could easily reconcile herself to.

5.6.2 Sex life? Forget it.

Intimacy and sexual relationships were a major factor for eight of the ten participants. Notably, this aspect was a significant concern for all female participants. Three male participants described the effect their hip condition had on intimate relationships with their partner as a factor but not the primary reason for the loss of intimacy.

It definitely does have a part to play, erm, I mean, you know, if I'm in pain then forget about it, it's not even on the cards (Patrick, BL. Line 234).

Sometimes in certain ways it can be a problem (Chris, BL. Line 109).

Sexual activity can promote and encourage closeness and intimacy between partners, the inability to perform and fulfil that part of the relationship can have a significant knock-on effect. Intimacy and sexual activity are an expected part of a relationship with a spouse or partner. For some participants sex and intimacy was their way of expressing their love. Denying their partner these intimate acts had a negative impact on the relationship, excluding and limited the intimacy and closeness required for a successful and happy relationship.

This was not the case for every participant however, sexual activity and that method of displaying intimacy was not important for Scott who explained that to him and his girlfriend, sex was not a priority, and they showed their love and affection for each other in different ways that worked for them.

It's not a big thing for us, it never has been and even now it's not really (Scott, 6W. Line 120).

All five of the female participants cited a loss of intimacy in their relationship. This often corresponded with a reduction in sexual activity. The reasons for this loss of intimacy and impact on sexual activity were varied, and included pain, an inability to comfortably position themselves, concern from their partner that they are causing pain, and body confidence of the participant.

Sex life, forget it, that's gone out the window, there's not many positions I can get into that is comfortable (Annie, BL. Line 139).

There's, nothing intimate...nothing intimate..., I am really sad about that, it's obviously a big part of a relationship. He doesn't mention it (Fran, BL. Line 68).

The reasons for this loss of intimacy and impact on sexual activity were varied, and included pain, an inability to comfortably position themselves, concern from their partner that they are causing pain, and body confidence of the participant.

Been intimate rarely ever happens, I'm usually in too much pain, it's not comfortable (Zoe, BL. Line 69).

It gets to the point where the hip is dislocating out the socket and I'm like, Husband just like do something do something and he's like I don't know what to do and. You know that all goes out the window as well, that part of it (Claire, BL. Line 245).

For some, sexual relationships improved drastically after surgery, positively impacting participants' relationships with their partner. Claire and Annie were making up for lost time and were ecstatic to have regained the intimate part of their relationship which was so integral to them.

I've had no life and I've missed out on quite a lot so I'm very much like, I want to do this. We've spiced things up (Claire, 6W. line 133).

That's all good, that's all fine, we are like teenagers again (Annie, 6M. line 106).

Unfortunately, this was not the scenario for other participants. Though function had improved, other factors remained, primarily confidence in their own ability post-surgery and concern on the risk of dislocation.

The sex part of things, I mean, like in certain positions as I don't feel comfortable, I'm too nervous (Diane, 6W. line 130).

The aspect of sexual activity and impact of intimacy was not commonly discussed with the surgeon or other healthcare professionals before THR.

We haven't broached that topic (Annie, BL. Line 272).

When the subject was addressed, it focused on the aspect of functional ability in sexual activity, as opposed to the participant's feelings surrounding intimacy and their perception of sexual activity within this.

The consultant asked me a while ago, "was I physically able?" I was like "yes", he said "good", erm didn't really get into whether or not we were, but it was just kind of like could you still? (Patrick, BL. Line 243).

5.6.3 Failure to fulfil relationship roles.

The fulfilment of roles within social relationships and family units was identified as a significant priority for seven of the ten participants. Whether this be as a parent, partner, or source of support for their family, failure to fulfil these perceived roles caused major distress and guilt to participants and often was one of the primary reasons for the decision to undergo surgery.

As already touched upon, many participants felt unable to be a “partner” in relationships with their significant other. The dynamic of the relationship had changed from an equal partnership to one of dependence and perceived burden on their partner. It had become a carer and patient relationship and as such the balance of power in some ways had changed.

...he's not so much my partner now as my carer, that's a very.... very strong switch...swing in our relationship (Claire, BL. Line 178)

She is sort of my main carer (Scott, BL. Line 83).

These feelings of inequality in relationships caused guilt and sometimes resentment in the relationship. For example, Claire was desperate to fulfil a useful role in her household, she struggled to watch her partner complete any household tasks as he did not do them in the same way she did, she admitted this caused some resentment towards him for (in her perception) not completing housework as thoroughly as she wanted.

I know it sounds really awful, but I resent him in a way because I've had to get him to do so much (Claire, BL. Line 188).

The feelings of burdening their partner were evident throughout the analysis. Annie and Zoe lamented the situation of needing help with washing and dressing from their partner. This was not the kind of relationship they desired. Both yearned for an equal partnership with their spouse and had a profound sense of remorse, regret, and guilt that these activities and undignified tasks were being undertaken by their partner.

It's almost demoralising having to have someone look after you, with like intimate care and stuff, I was like, he shouldn't have to be doing this (Zoe, 6W. Line 90).

Failure to fulfil a parenting role to their children was a significant and emotional aspect of the interviews. As with relying on their partner, guilt on having to depend on their children for basic care and assistance with everyday tasks was keenly felt.

My kids have been classed as young carers since, my eldest is 19 this year, he's been a young carer since he was 7... the only one who really escaped is my youngest (Claire, BL. Line 119).

The word “escaped” used by Claire is very emotive. She perceives the role of caring for her as a trap or prison for her sons, a responsibility that prevented them being free or acting like the children they are. Her youngest son does not have to perform that role as Claire’s husband has given up work to fulfil that responsibility.

In addition to this, missing out on spending time with their children and being unable to fulfil an active role in their life was something many participants struggled with.

Being able to be.... I am “mum”, don’t get me wrong, my children are older, they don’t need me like toddlers do but still, there are so many things I can’t do with them, and I don’t like that. They’re not going to be at home forever, I’m missing out on valuable time (Annie, BL. Line 227).

The perception of abject failure in their responsibilities as parents was profound. Frustration and regret on missing out on spending time with their children at any age was repeatedly identified throughout the analysis of the transcripts.

It just doesn’t feel like you’re parenting well, kind of failing at your job (Zoe, BL. Line 144).

When these themes were expressed, I could clearly identify a sense of panic in their voices. This was time and experiences with their families they were never going to get back. There was a perception of running out of time with their children still being children and being unable to provide the parent figure the participant desperately wanted to be.

...just assumed I think that I would be kind of physically fit super Dad that would win all the Father’s Day races and typically the first Father’s Day race I had...I couldn’t compete (Patrick, BL. Line 399).

Participants referred to their goal in recovery as getting back to “normal”. The role participants perceived as “normal” to them was that of what they considered able bodied people of their age to fulfil; a strong, capable, independent person, who was actively looking after their children and participating in their child’s activities. Participants considered their hip condition and the limitations caused by this to significantly prevent them fulfilling these roles and responsibilities.

A little boy. And that’s the main thing if I’m honest with you, why...I mean, obviously I do, I work quite a bit because I need...we need to pay the bills and stuff, I mean I want to take him to the park and things like that, at the moment it’s very limited (Henry, BL. Line 41).

Other roles participants considered their responsibility will be explored further in the theme “I can’t do anything”, where the additional pressure to recover the participants place on themselves will also be discussed.

5.7 I can't do anything.

To regain function is recognised to be a primary reason for undergoing THR (Markatos et al., 2020). However, when participants reflected on function within the interviews it was more in reference to being functional and contributing to society as opposed to mobility and range of movement.

Within this superordinate theme the themes of employment, limitations and confidence in ability, pressure to recover, and sports and social life are all explored under the umbrella theme of function and purpose in society. The data is categorised into four subheadings: My hip controls everything, It's trying to find that balance, It was a big part of my life, and I can't not function.

5.7.1 My hip controls everything.

The hip condition had an all-consuming impact on life. Many participants expressed they felt they had lost themselves due to dealing with the limitations and pain prior to surgery. They identified it as all encompassing, replacing, and altering their personality, forcing them to compromise their lifestyle, and controlling every aspect of their life.

...it's like...taken over my world (Fran, BL. Line 32).

This resulted in profound feelings of resentment and bitterness over their lost lives as well as regret and mourning for the person they had been and the person the hip condition had created in its place.

Life is now and that's what I'm worried about, I'm missing so much of life because I can't do it, you know, and it sounds really bizarre, but it's become me, do you know, it's the only thing that I can concentrate on (Zoe, BL. Line 109).

For some participants, surgery had a positive effect, improving the impact the hip condition had on their life. The operation resulted in them become themselves again, the person they had lost.

I feel I have more purpose now, yeah...I feel like I'm more than just a bad hip, more than the pain, whereas before I didn't have that (Claire, 6M. Line 51).

As described in previous superordinate themes, the surgery did not provide the resolution hoped for with every participant. Both Diane and Fran had put a significant amount of hope

that the surgery would change their life for the better and they would be able to restart actively functioning in their life, however, this failed to occur.

It's making me slow down with everything (Fran, 6M. Line 30).

It's just silly things like that that are winding me up because I can't go back to doing everything normal (Diane, 6W. Line 68).

5.7.2 It's trying to find that balance.

Mobility and active functional movement in limbs and joints were discussed in the interviews, however, participants focussed more on how being limited in mobility and active functional movement affected their ability to contribute and play an active role in society.

I'm an active person, I want to do things, I like planting, you know, I like, I want to walk places... You know, you can't do it can you? I can't do it (Diane, BL. Line 126).

I can't do anything, you know what I mean (Rob, BL. Line 127).

The phrase, "I can't do anything" was consistently repeated, and was used to impress how complete and panoptic the effect on their life was.

It is getting on now, where you can't really do, certainly I can't really run, I can't run, I struggle to walk, I can't really do anything (Henry, BL. Line 24).

The hip condition did not just affect mobility or active function, confidence and social situations were also implicated. As a result of the pain and frustration they experienced they often were disinclined to socialise or go anywhere.

...being 28, I want to be active, I want to do things, I want to go out, you know I want to do things with my partner, it's just got to that point where we can't do that (Scott, BL. Line 104).

Post surgery, participants discovered that though physically the function and pain had improved, their confidence to actively participate in society took longer to recover.

I think it's trying to find that balance. You start to feel more and more normal as you're doing more and more, but you're also trying to rein that in because you're not necessarily as ready as you think you are (Patrick, 6W. Line 80).

Being accustomed to struggling contributed to feeling much more cautious and underconfident when considering taking on a more active role in society and participating in activities. The wariness of causing pain or discomfort by overdoing an activity, or causing

damage to the implant, resulted in participants being more hesitant and reluctant to participate and return to activities and lifestyles enjoyed prior to the hip symptoms. Finding the “balance” was a phrase used frequently throughout the data. Patrick, Annie, Claire, Chris, Henry, and Scott all referred to finding balance in their rehabilitation, it involved not recovering too fast to the point of damaging the implant or causing harm to themselves, but also recovering reasonably quickly so they felt there were progress.

5.7.3 It was a big part of my life.

Active hobbies, sport and exercise were highlighted as a priority in their recovery by over half of the participants.

Physical activity and sport were not only a priority due to the exercise. Rob described getting back to training in the gym as a method of regaining some routine in his life, resulting in what he called “normality”. Physical fitness and form were intensely important to Rob, his early life in the army had installed in him an enjoyment of physical exercise, this was an aspect of his life limited by his hip, that he profoundly missed.

...just want to go back to the gym and have some sort of normality, have some sort of routine (Rob, 6W. Line 51).

A common theme for Chris throughout all three of his interviews was his frustration that he could no longer play football, due to pain and physical limitations. Football was more to Chris than simply physical exercise but also the social aspect of participating in a team sport. It was clear that returning to football was not something Chris would be prepared to compromise on or adapt.

My main goal in general is just to get back to what my life was like before the pain, but it was...like just 5 a side or been on the seven-a-side team was...I loved it, it was a big part of my life and when I had to stop it was...it was erm...it was shit, err so it's one of the main goals because I love playing it, it wasn't at a high level but it was still important to me (Chris, 6W. Line 70).

Throughout the analysis, a fear of failing was evident in Chris' interviews. After his THR, Chris was much more cautious of returning to play than expected. The prospect that he would attempt to participate in a game and discover himself unable to play was a terrifying scenario he did not want to confront. At six-months post-surgery, Chris had still not returned to the game as he had hoped to. He indicated that he had initial plans to try a run and other lower intensity exercise independently to assess his own ability before returning to a team sport.

I think I will be a little bit hesitant the first couple of times (Chris, 6M. Line 57).

Happily, in other less physical activities, Chris had regained his ability to perform them as he did prior to his hip symptoms.

drumming is my main thing that I do in my spare time in erm, bands and stuff, so I'm glad that it's fixed that problem (Chris, 6W. Line 76).

The social aspect of sport participation and organised activities was also something Henry missed.

I'm very active, I played golf, erm, I socialise...you know, I loved walking...I am really social; I mean again it's that part of it that it really has affected (Henry, BL. Line 22).

Happily, at his six-month interview, Henry had been able to participate in golf again.

I played golf yesterday for the first time so that was really good, that was really, really enjoyable (Henry, 6M. Line 13).

Henry expressed limitations on being able to watch his favourite football team and his regret that he couldn't share this experience with his son as his father had shared with him.

I am a Chelsea supporter, I had a season ticket for 10 years, but again I wouldn't contemplate going down there now, I don't think I'd be able to walk there. But I would like to take my son and things like that, you know but obviously...I can't at the moment (Henry, BL. Line 174).

Physical activity and sport participation involves much more than purely playing the game or completing the exercises. It contributed to multiple aspects of the participants life, encompassing fitness, body image, social life, and mental well-being. The limitation in participating experienced when the condition of their hip deteriorated profoundly affected their lifestyle much more than expected.

5.7.4 I can't not function.

A consistent theme was the increased pressure participants put themselves under to recover quickly. The inability to fulfil the roles they perceived themselves as being responsible for caused a lot of distress and frustration, and impacted profoundly on many aspects of their life, for example, mental health, and their relationships with family and friends. This included the necessity of functioning at work and being in active employment. Due to this, the participants held an intense desire and expectation on themselves to recover quickly and completely. This pressure was as much from the participants themselves as their friends and family.

Claire regularly described the guilt she experienced for not functioning at a more active level for her children and family, during her six-week interview, she recognised that she was potentially her harshest critic and judge on her ability pre-surgery. This pressure on oneself to fulfil a role you believe is your responsibility is completely counterproductive, it intensifies

the sense of failure and acute frustration experienced when you are unable to perform how you believe the role should be performed.

I think my mental health problem is that I beat myself up a lot, like I push myself, like and have a lot of guilt about what I haven't done, what I can't do, so now that's another thing that I probably have to deal with (Claire, 6W. Line 54).

An aspect of this increased pressure to recover was centred on financial issues and the roles participants considered others of their age to be embodying in society (i.e., active, independent, useful). Employment was considered a necessity to provide for the participants families. Patrick was the sole wage earner in his family, due to ill health his wife was a stay-at-home mother. To their young daughter. Patrick was adamant in his responsibility to provide for his family and enable his wife to remain in her role in their household. Not working or providing that financial support was clearly not an option to Patrick, he was prepared to do anything to avoid that possibility.

I can't not function, I have to be able to go to work, erm as a family we don't have any other options really at the moment (Patrick, 6M. Line 126).

For Patrick, the inability to provide for his family was the primary reason for undergoing the THR. Not working and failing to provide financial support was something he had experienced in the past and was not something he was willing to consider in the future.

I need to work still for at least the next 10 to 15 years, erm, I'd quit tomorrow if I could, it's unfortunate it's my wages what enable my wife to stay home and look after my little one (Patrick, BL. Line 60).

Henry also detailed the pressure he felt to provide financially for his young family. At the time of the interviews, Henry's wife was pregnant with their second child. The decision to undergo surgery had been expediated due to the fact that in his pre surgery state, Henry was and felt incapable to contribute towards supporting his family, whether in a financial sense or in his role as a father and partner.

I work quite a bit because I need...we need to pay the bills and stuff (Henry, BL. Line 41).

Both Patrick and Henry had placed themselves in the patriarchal position of the family, taking on responsibility as sole financial provider and delivering practical support to their partner and children. Being unable to fulfil this role in their own eyes was viewed as an inexcusable failure.

All ten participants described the limitations and challenges their hip condition had introduced to their work. Some participants had had to give up work completely due to being able to fulfil the role their workplace required.

I got that thing in my hip, I wasn't really able to go to work, I was falling (Claire, BL. Line 162).

I had to stop work at the moment (Fran, 6M. Line 33).

Others had adapted their role significantly, causing frustration and feelings of failure and being a burden to their coworkers.

They are helping me out, they're putting me on lighter duties but really, I should be doing it...the guilt, I was, you know, letting my team down the residents as well, was letting them down (Annie, BL. Line 170).

Annie's use of the modal verb "should" creates pressure on her to achieve normality at work and perform as she sees her colleagues perform.

It's a nightmare at work, I've passed out at work before (BL. Line 22)...it could be more physical, I'm very lucky that it's a small family firm and they keep me on light duties, but you know, if I had a big contract...like a council contract or something like that, they would've binned me off by now (Rob, BL. Line 109).

For Annie, Patrick, and Rob the guilt they experienced due to being unable to completely fulfil their work responsibilities was significant. Their roles were primarily based in a team environment, where teamwork is essential in completing the given task. To be unable to contribute effectively and not feel as if they were "pulling their weight" exacerbated the feelings of failure already experienced. This is amplified by the fact that all three were younger than many of their colleagues, some of whom were living with other illnesses and co morbidities.

Reflexive Account

Dated 12th December 2021

Annie's guilt and struggle at "letting down" her colleagues by not being unable to fulfil her job role really resonated with me. As a nurse, working within a team is core in the ward and clinical environment. The workload stays the same regardless of how many colleagues are working. Therefore, if a staff member is unavailable or if they cannot perform to the required standard the other team members must take on additional work. I too have felt the same guilt and regret at being unwell and off work, I have also gone into work despite being unwell or unfit.

Because of this personal experience, I spent some time reflecting on these episodes in my working life and bracketing them to ensure that my own experiences did not impact Annie's voice in the analysis.

With their employers' support, Chris and Scott had adapted their role at work to ensure they could perform their position effectively. Chris now had less walking to do at work as his employer had tried to assign him working areas close to each other when able. Scott had completely changed his role to that of a more stationary position. Neither Chris nor Scott enjoyed this change, and both preferred their previous job role.

Work can be a struggle (Chris, BL. Line 114).

I had to stop doing that because I can't walk far or do anything basically (Scott, BL. Line 49).

Throughout all participant interviews, it was clear that fulfilling a working role and being in employment was incredibly important to all participants. Due to their age, this was an aspect of life they expected and strongly believed they had a responsibility to fulfil. Diane referred to working as "looking after herself". Employment provided her with an independence, a purpose in society.

I've always worked, so I've been always active, you know, I've always done cleaning jobs, worked in kitchens, erm, prisons, you name it, I've looked after myself, I've always worked (Diane, BL. Line 17).

In addition to the sense of purpose and independence, Annie greatly enjoyed her job, she loved the work and the people involved. The prospect of having to stop working was not financially concerning to her, it was no longer fulfilling the vocational and rewarding role she filled.

I don't want to stop doing that because I absolutely love my job, I'm really passionate about my job (Annie, BL. Line 106).

At the six-month time point most participants had returned to some form of employment. However, only three participants (Henry, Rob, Chris) had returned to the same level of activity in their job role as they had fulfilled prior to their hip symptoms starting. Three participants had returned to the same role but on limited or less physical duties (Annie, Scott, Patrick), three participants had taken on completely new roles in less physical employment (Diane, Zoe, Claire) and Fran had not yet returned to work.

I finished my old job, I stepped away from that, the thought of going back and lifting 12 to 13 kilos (Zoe, 6M. Line 48).

5.8 Conclusion of qualitative findings.

The superordinate themes discovered in the analysis of the data are broad and can vary in significance between participants. The vast amount of data generated in the Young Hip study was rich and complex and required a great deal of time and energy to organise,

analyse, and then interpret to ensure the voices of all participants were heard and noted. Some superordinate themes (for example, “I’m just constantly in pain”, “Giving up hope”, and some aspects of the theme “Living a process that does not reflect me”) can be considered universal to all age groups undergoing THR and the effect they have on the older patient can be found in current literature on this topic, however, other superordinate themes may be more unique to the younger patient, such as “this is not who I’m meant to be” and “my family didn’t sign up to this”.

These superordinate themes will be explored and examined within the current healthcare guidelines and available literature in the next chapter.

Though many of the findings expressed negative experiences and effects, a wide range of positive attitudes also emerged from the narratives. These included focusing on others who were worse off.

...people are in a much worse position than I am (Annie, BL, Line 96).

Many participants adopted the stoic approach of: ‘...*just got on with it...*’ (Rob, BL, Line 115) and “*that’s the hand you’re dealt, and you’ve just got to get on with it*” (Scott, BL, Line 127) attitude. Participants were often highly self-motivated.

...move onwards and upwards (Patrick, 6W, Line 187).

The source of this drive varied by individual but included avoiding dependence on others for physical needs, being able to do things they had enjoyed pre-symptoms and avoiding disability.

5.9 Patient Reported Outcome Measures (PROMs).

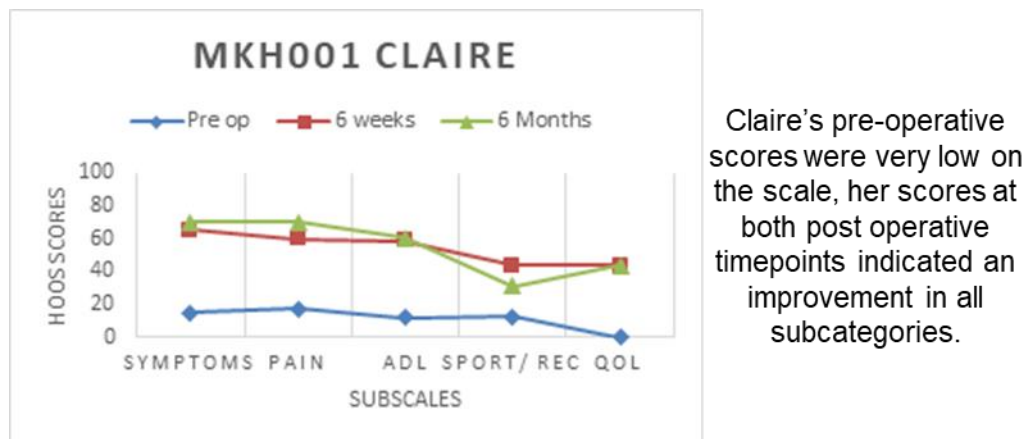
Since April 2009, PROMs are routinely collected by the healthcare team by every provider of NHS funded care throughout the patient’s recovery journey and are relied upon to measure health gain and to assess quality of health from the patient’s perspective. As described in the Section 2.4.4, PROMs consist of standardised questions and scoring scales, this raises concerns over whether PROMs are a true representation of the patient’s perspective and if these standardised topics are relevant to every patient group.

At each interview timepoint, the participant was asked to complete a HOOS questionnaire (Appendix 13). As presented in the study methods (Section 4.10.2), the purpose of this was to consider the outcome measures used in clinical practice (in this instance HOOS) to the participants own voice and personal consideration of their recovery. Feedback was also

received regarding the relevancy of the HOOS from participants, either within their interviews or in the form of written annotations on the HOOS questionnaires.

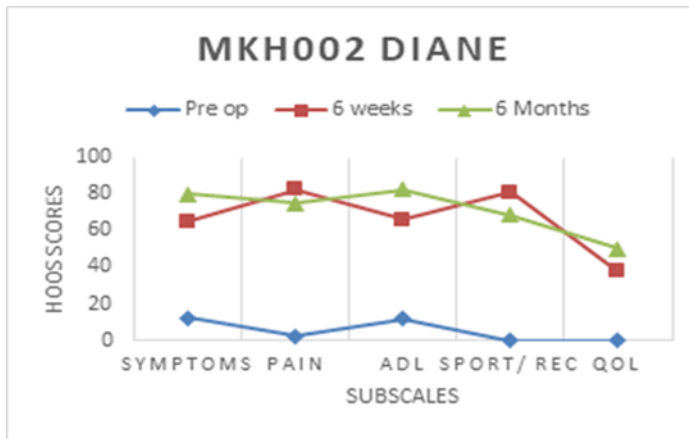
Participant scores are represented graphically as a HOOS profile for each participant (Figures 12 to 20). Missing data were treated as such; the average value for the dimension could be calculated if at least 50% of the subscale items were completed. If more than 50% of answers were omitted, the response for this dimension was considered invalid (Guenther et al., 2021).

The response rate was 83.3% from all participants. Out of 30 HOOS questionnaires administered, 25 were returned fully or partially completed. Five HOOS questionnaire were not returned. These included 6-week HOOS from Patrick and Henry. Zoe returned no HOOS at any interview timepoint; therefore, it was impossible to include her in this section of the analysis. Sections missing data have been noted under the respective participant's profile.



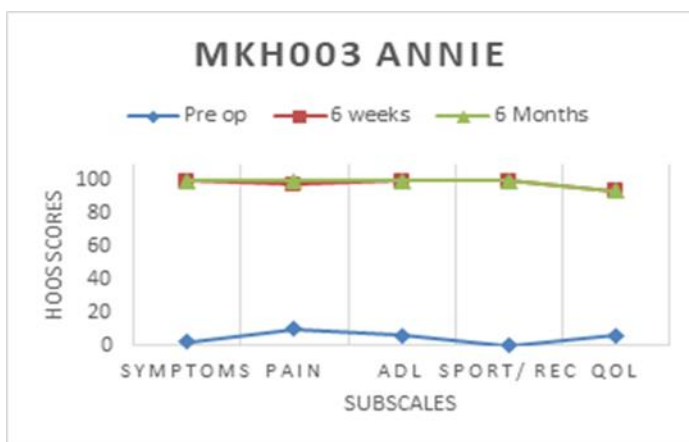
Claire's pre-operative scores were very low on the scale, her scores at both post operative timepoints indicated an improvement in all subcategories.

Figure 12. MKH001 Claire's HOOS profile prior to, six-weeks, and six-months after THR



Diane's post-operative scores demonstrated a drastic improvement in all subcategories. Her pre-operative scores were extremely low, marking 0 in the pain, sports/ recreation, and quality of life subcategories indicating extreme symptoms in these areas.

Figure 13. MKH002 Diane's HOOS profile prior to, six-weeks, and six-months after THR



Annie scored incredibly low in all subcategories at her pre-operative interview. Her scores post-operatively were in complete contrast, achieving 100 in some subcategories. These scores remained consistent at 6 weeks and 6 months post-surgery.

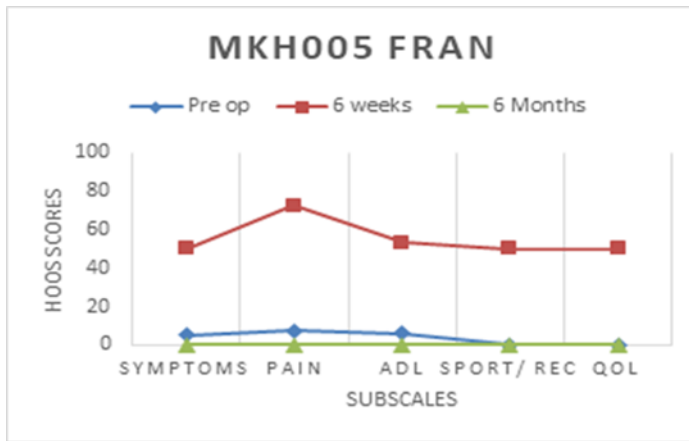
Figure 14. MKH003 Annie's HOOS profile prior to, six-weeks, and six-months after THR



With the data available, Patrick's scores indicate improvement between pre-surgery and 6 months post-operation. At 6 months post THR, Patrick's scores indicate minimal to no symptoms in the subcategories, pain, symptoms, and activities of daily living.

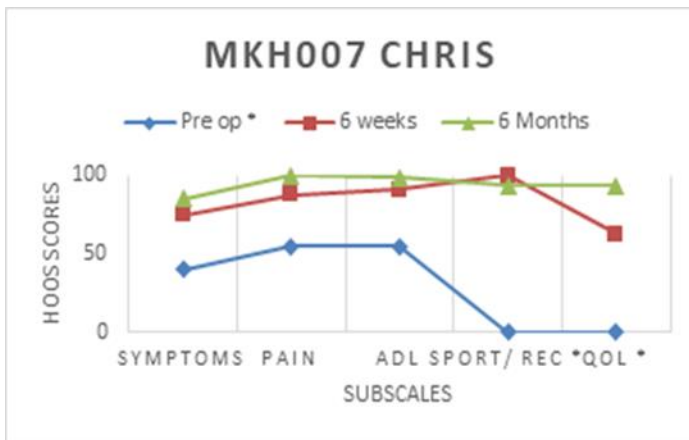
Figure 5. MKH004 Patrick's HOOS profile prior to and six months after THR

**six-month score for Sport/ Rec not completed.
six-week Data not available**



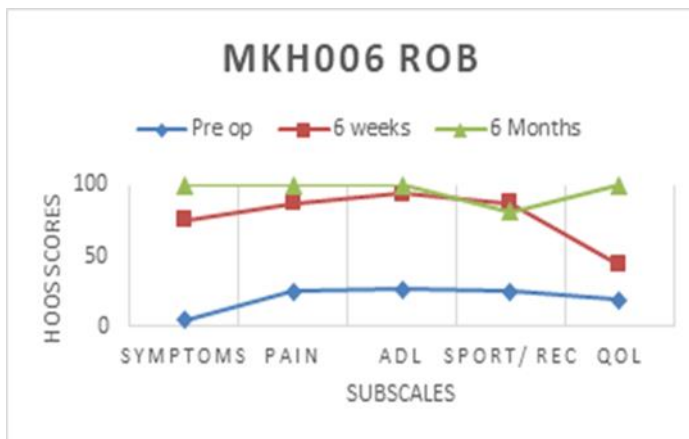
Though Fran's 6-week post THR score demonstrates improvement from her scores pre surgery, at the 6-month timepoint Fran's scores have deteriorated dramatically, scoring 0 (extreme symptoms) in all subcategories.

Figure 16. MKH005 Fran's HOOS profile prior to, six-weeks, and six-months after THR



Chris' scores demonstrated improvement between pre-and post-surgery in the subcategories of symptom, pain, and activities of daily living. However, due to the absence of baseline data for sport/ recreation and quality of life subcategories, it is unclear what improvement was indicated in these items post-THR.

Figure 17. MKH006 Rob's HOOS profile prior to, six-weeks, and six-months after THR



Rob's scores show great improvement between pre-surgery and post-THR, the score in the quality-of-life subcategory showed small improvement at 6 weeks post-surgery, but this score continued to improve at 6-months post THR.

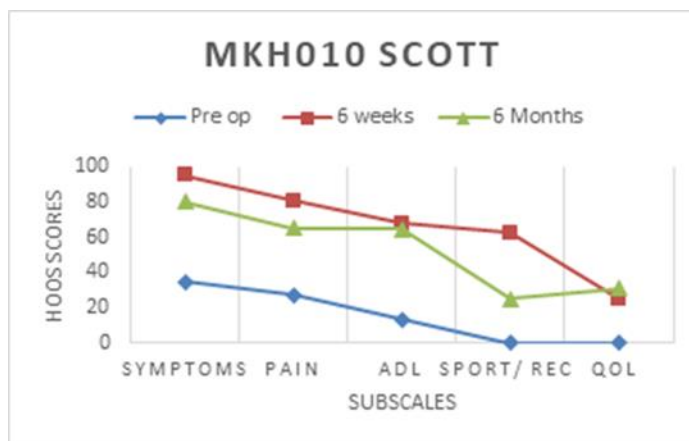
Figure 18. MKH007 Chris' HOOS profile prior to, six-weeks, and six-months after THR
Preoperative scores for sport/ rec and QOL missing.



Henry's pre-surgery scores for sports/recreation and quality of life both sit at 0 indicating extreme symptoms. His 6-month after THR scores are a significant improvement in all subcategories.

Figure 196. MKH009 Henry's HOOS profile prior to and six-months after THR

Six-week data not available.



Scott's scores reveal improvement in all subcategories, with his 6-week post-THR scores being higher than both baseline and 6-month post-surgery in all but one subcategory (quality of life).

Figure 20. MKH010 Scott's HOOS profile prior to, six-weeks, and six-months after THR

When all participant's collective mean standardised scores were compared in one graph, (see Figure 21) it showed a wide range of ability and self-perception at each timepoint. All participants' HOOS profile show improvement in all areas at six-weeks post-surgery. The greatest improvement in all participants was experienced within the initial six-weeks post-surgery. From six-weeks to six-months the improvement appeared to plateau for some participants, and in the cases of Fran and Scott the six-month scores are lower than the six-week scores. Fran's HOOS profile demonstrates a stark decline to zero in all subcategories. This is reflected in Fran's six-month interview, where she describes her situation at that timepoint as "the worst it's ever been".

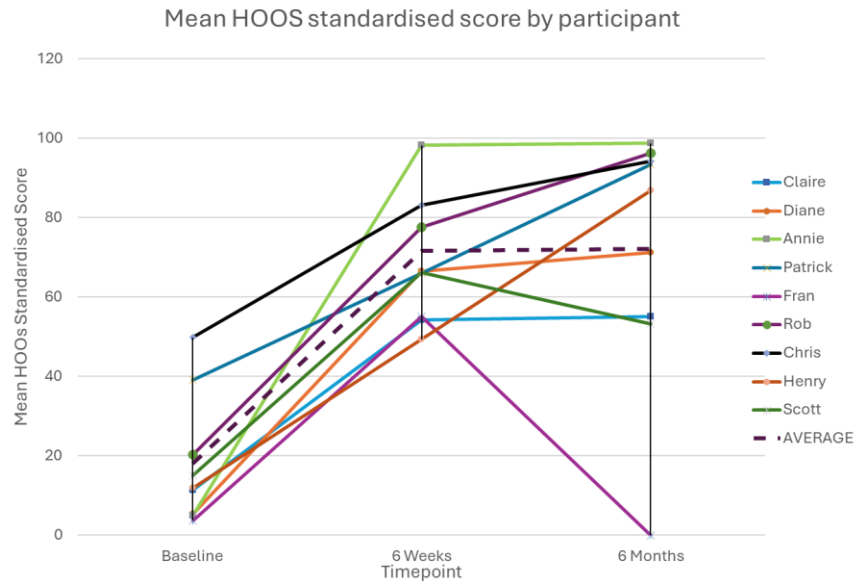


Figure 21. Participants mean standardised HOOS score at each timepoint

Diane’s scores post-surgery demonstrate a significant improvement in all subcategories, with scores consistently between 50 to 80 at post-operation interviews indicating almost a complete resolution of symptoms. This is in direct contrast to her drastically low scores at baseline. This improvement is not reflected in her interviews. Diane did not experience the outcomes she was hoping for post-THR and was still experiencing pain and limitations at the 6-month interview. In contrast, Claire’s scores showed improvement post-THR, although the difference was much lower in comparison to other participants. However, Claire’s interviews at both six-weeks and six-months reported significant improvement in her life and were euphoric in their content. This is not reflected in Claire’s HOOS profile. This disparity demonstrates the value of the patient voice in conjunction with the quantitative data presented by HOOS scores.

Notably, some participants’ HOOS profile did reflect the general improvement narrated in their interviews. The HOOS profiles of Chris, Rob, Annie, and Henry support the information expressed in both their six-week and six-month interviews.

The mean score in each category of the HOOS questionnaire was then calculated for all participants combined (see Figure 22).

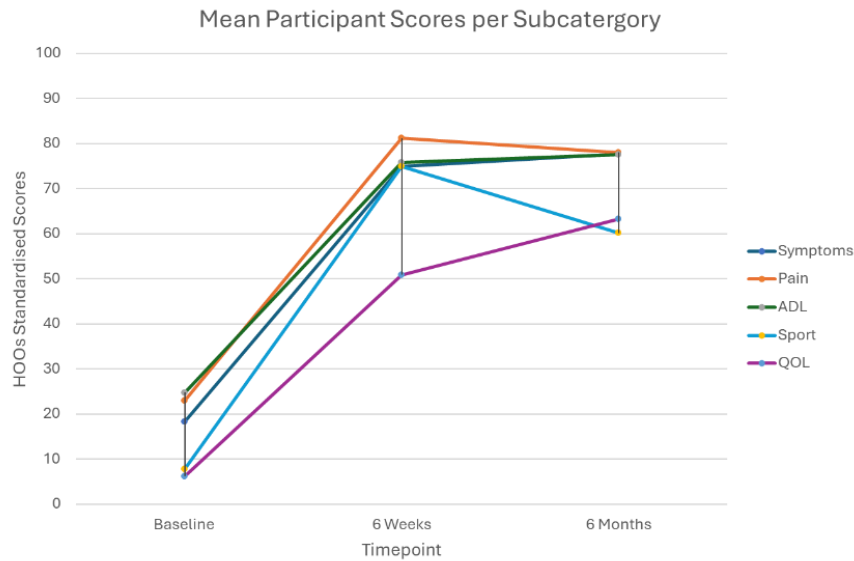


Figure 22. Participants combined mean score per subcategory

All subcategories demonstrated a significant increase in scores from baseline to 6-weeks post-surgery. The scores in the subcategories of quality of life, symptoms, and activities of delay living all continued to increase but at a smaller rate between 6-weeks to 6-months. However, the scores in the subcategories of pain and sport decreased. This drop in average scores could be influenced by participants such as Fran and Diane, who also experienced other conditions which continued to cause pain after THR. However, without this insight provided by the qualitative data, this potential reason would remain unknown.

When analysing the HOOS scores there was no statistical significance in patients age, gender, diagnosis, pre-surgery scores, or wait time to surgery. However, this is a small sample of participants, and it is difficult to identify statistical significance and patterns within small datasets.

Participants regularly annotated notes upon the HOOS questionnaires that were returned. These notations included comments such as “I’m wary of this task” in the “heavy domestic duties” item in the activities of daily living (ADL) section, and “I try not to do this” or “not allowed” in the “twisting/ pivoting” item in sports and recreation. The apprehension and caution felt by participants when attempting to recommence tasks that they predict may cause pain or damage to the implant is briefly mentioned but not explored in the HOOS, nor are sexual activity and psychological effects.

Whilst there is not the capacity to capture these nuances, the rigidity of the HOOS scoring system minimises their usefulness. This will be further explored in the discussion chapter.

5.10 Summary

The above chapter presents the final findings from the young hip study. These findings were taken from ten participants who took part in three interviews each, this resulted in thirty interviews overall. The findings are categorised into six superordinate themes, containing smaller subordinate themes grouped under each heading. Some themes emerged that feature in the current literature around patients undergoing THR and appear to be general regardless of patient age, these include pain, and in some respects the findings surrounding mental health and experiences of healthcare. However, other findings (for example, perception of function, self-image, and identity) appear to be much more focussed and imperative to the younger patient than to the older patient, and therefore, are not addressed by clinicians or within the current care pathways. Additionally, participants were starkly aware that they did not fit the usual criteria of a THR patient, they expressed feeling pressure to recovery quickly and rejoin society in a functional role considered normal for their age. The loss of independence and financial pressures resulting from lack of income were also common issues that challenged some participants' self-concept. Impact was not limited to the participant but also extended to family and friends.

The chapter also presents the participant scores for the HOOS that were completed at each interview timepoint, this was to assess if the usual way outcomes are measured in elective THR reflect similar results to the qualitative patient findings. Though, the HOOS scores did mirror some findings from some participants, they failed to represent the nuances in some aspects identified within the qualitative data. The next chapter will proceed to explore this in more depth.

Chapter 6. DISCUSSION.

6.1 Introduction

The Young Hip study set out to explore the young persons (<50 years) expectations following primary THR, and to identify what outcomes are important to them. This chapter commences by reiterating the reasons why the research was undertaken and recapping the study's aims and objectives.

This chapter discusses the study findings within the context of available literature. The original literature review (Section 3.3) was repeated and extended in December 2023. By re-running the original search any relevant literature published since 2021 could be identified and reviewed. Additional key word searches and combinations such as body image, care pathways, isolation, were included in the overall search strategy. These were topics that had arisen from the study findings, they were unexpected, therefore had not been considered in the original literature review. One additional paper was identified within this literature search (Ozturk and Ozturk, 2022), this paper included one participant aged 49 years and included several quotes from this participant. However, the paper did not present any additional themes to those already identified in the initial literature search, nor were any specific findings within the paper attributed primarily to that individual participant.

This chapter will explore the findings presented in chapter 5 in relation to the current care pathways and frameworks used with the NHS. This will enable the reader to judge the appropriateness of the recommendations presented at the end of this chapter for healthcare pathways and policies, and future research into young patients undergoing a THR. The limitations and strengths of the Young Hip study will also be presented and considered,

6.2 Research aims and objectives.

As noted in Section 1.2, an elective THR is a successful orthopaedic operation used to manage a wide variety of chronic hip conditions such as, Osteoarthritis (OA), Rheumatoid Arthritis (RA), Osteonecrosis (AVN) (Knight et al., 2011). Though it is an operation targeted primarily at the older patient population (Kurtz et al., 2009) the numbers of younger patients opting to undergo this surgery is increasing. Notably, the care pathways and successful outcome measures remain identical for both younger and older patients. It is unknown if younger patients' priorities and expectations of recovery are the same as their older counterparts, and if not, whether healthcare providers acknowledge and address younger patients' needs. To address this concern, it was important to explore younger patients'

expectations and priorities when undergoing a THR. Exploring this further within the literature review (see Section 3.3) revealed that though research presenting quantitative approaches and data for younger THR patients was abundant, qualitative literature exploring younger THR patients' voices and experiences was scarce and extremely limited. As such their voices were absent in the academic discourse and the evidence base used to influence their care and treatment.

The primary aim of this study was to explore the younger patients (≤ 50 years) expectations when undergoing a primary THR and address the priorities important to them. A secondary objective was to compare these narratives with a routine method of measuring a successful outcome in orthopaedic surgery (PROMs), then assess if the qualitative findings identified in this study correlated to the quantitative data evidenced in the PROMs used. The Young Hip study was successful in meeting its aims as it has explored and highlighted many aspects that have currently been overlooked when treating younger patients undergoing THR. Additionally, some aspects of patients' experience that are known to impact all age groups were found to have been unsuccessfully managed and fulfilled.

Each participant presented topics that could be categorised into each superordinate theme; however, participant's experiences were not reflected in every subordinate theme. This enforces the individuality of each participant; the superordinate themes reflected the commonality between the participants' experiences and identified areas important to this participant sample as a whole. The differences and nuances in how the participants experienced and presented the superordinate themes in their interviews are captured in the subordinate themes. This encompasses the dual focus of IPA methodology, it focuses on the unique experiences of individual participants, identifying ideographic themes that emerge from each transcript, The researcher proceeds to then look for overall patterns of meaning between participants, identifying "superordinate" themes that connect them (Smith et al., 2009).

As discussed in Section 3.2, different age parameters have been used in the literature to define a young person in terms of patients undergoing THR. However, the more common consensus in the literature appears to classify "young patients" undergoing THR as under 50 years (Malcolm et al., 2014; Ravi et al., 2012; Crowninshield et al., 2006) therefore, the Young Hip study enforced the upper age limit as 50 to be consistent with much of the literature. All ten patients recruited to Young Hip were aged 50 years or under.

The original literature review (Section 3.3) highlighted four common themes in the nine papers found. These were improving function and mobility, pain, patient expectations and education, and relationships. However, it was unclear if any of these themes could be solely

attributed to the younger patient THR population as the papers included did not differentiate between participant populations.

6.3 Pain and pain management.

The findings of the Young Hip study demonstrate many outcome priorities that can be attributed to both younger patients and their older counterparts when undergoing a THR. The resolution of pain and improvement of function are recognised as the key reasons for the creation and implementation of THR (Knight et al., 2011). The findings presented in the superordinate theme; “I’m just constantly in pain” support the wider literature on this topic which enforces pain as a significant concern for the wider patient population having THR (Barrack et al., 2000; Young and Buvanendran, 2014; Koyuncu et al., 2021). The findings also reinforce patients’ hesitation and anxiety around pain relief medication and their potential side effects (Demierre et al., 2011). As in the literature review, the findings in Young Hip, reported differing degrees of pain experienced and a variety of methods used to manage it (Berg et al., 2009; Demierre et al., 2011; Fujita et al., 2006; Goodman et al., 2020; Montin et al., 2002; Singh et al., 2019; Sjøveian and Leegaard, 2017; Strickland et al., 2017). In Young Hip, preoperative pain was described as having a much more significant impact overall to participants than post-surgery pain. However, not all participants experienced the complete resolution to their pain that they had hoped for, instead, other painful conditions other than the operated hip emerged that had previously been overlooked. Forcing some participants to come to terms that being pain free was not something that was attainable to them.

6.4 Person-centred care

As discussed in Section 2.5 “person-centred care” or “person-centred practice” remain central and integral in healthcare codes of practice, policies, and healthcare literature.

Person-centredness is described by McCormack and McCance (2010. p.13) 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.”

Shared decision making and therapeutic relationships between healthcare providers and patients are at the forefront of person-centredness and a key recommendation in the

National Institute for Health and Care Excellence (NICE) guidelines for primary joint replacement (NICE, 2020). Shared decision making has been shown to improve decision quality and the decision making process (Stacey et al., 2017), risk perception (Elwin et al., 2010), patient adherence (Joosten et al., 2008), and patient outcomes (Veroff et al., 2013). Additionally, it has also been proven to lower healthcare costs and resource utilisation (Veroff et al., 2013).

Aspects such as communication, information, and shared decision making, which are considered necessary in ensuring person-centred care and supporting therapeutic relationships were also identified as a high priority in the literature review. However, as will be detailed within this chapter, the Young Hip study found that the orthopaedic and trauma hospital care and engagement failed to meet the requirements for person-centred care with many of the participants.

6.4.1 Therapeutic partnerships.

Some participants in the Young Hip study described a positive therapeutic partnership between them and their consultant surgeon. Regrettably, this was not the case with some of the other participants. Both Henry and Diane were assessed and reviewed by junior doctors on the consultant's team (Section 5.2.1). These were not the same doctors at every appointment nor were they the doctor responsible for the final decision on surgery. This potentially limited the level of shared decision making that could be accomplished within that one appointment of 15 to 20 minutes and made it difficult to initiate and build upon a therapeutic and positive relationship. Participants in Young Hip described feeling dismissed or not being listened to by healthcare professionals. These feelings of being unheard and the subsequent absence of therapeutic partnerships was not limited to experiences pre-surgery. Though the study presented examples of positive therapeutic partnerships and evidence of shared decision making between healthcare staff and patients, these instances were not the norm amongst the participants. Shared decision making has been demonstrated to enhance patient autonomy in decisions relating to their health, presenting patients with more control and power over their own condition and treatment (Veroff et al., 2013; Blaiss et al., 2019). Though these studies are not exclusively focused on orthopaedic patients or surgical specialties, they advocate the importance of shared decision making in all areas of healthcare, particularly in the treatment of chronic health conditions (conditions of which are largely the cause of undergoing THR). Blaiss et al., (2019) report that the clinically related benefits of shared decision making include better outcomes, and improved adherence to treatment plans. For patients, shared decision-making improved patient knowledge (Allen et al., 2018), increased risk perception by the patient, less patient indecision, and allows the patient to make decisions consistent with their values (Stacey et

al., 2017). Veroff et al., (2013), Arterburn et al., (2012) and Legare et al., (2008) identified the benefits related to healthcare resources included less healthcare resource use, lower healthcare costs, lower rates of elective treatments, and lower rates of invasive procedures.

6.4.2 Imbalance of power.

Perception of control and power inequality were narrated by many participants in Young Hip, whether relating to the surgical procedure itself, or by the perceived reluctance and “battle” necessary to convince the surgeons to agree to surgery (Section 5.2.1). The imbalance of power between healthcare providers and consumers is widely recognised in healthcare literature and has been the focus of many quality improvement strategies over the years (Health Foundation, 2014; NICE, 2020; Department of Health, 2023). Within the literature review (Section 3.3), Dermierre et al., (2011) described the lack of control in the logistics of the operation, for example, risk of cancellation, waiting lists, and timings, as causing a negative impact on participants emotional and psychological well-being. Empowering patients to have control over their own care and treatment and implementing shared decision making are recognised methods in addressing this power imbalance, unfortunately these practices are still far from being routine (Joseph-Williams et al., 2014; Ocloo et al., 2020).

Clinicians and other healthcare professional often display an unquestioned confidence that they are acting in the patient’s best interest and assume that they have the ability to make the best decision on the patient’s behalf (Joseph-Williams et al., 2014). Clinicians have the medical knowledge and expertise, and have the qualifications to prescribe treatments, the healthcare organisations have the ability to deny the patient treatment based on policies and funding (Scholz et al., 2018). Aronson (2013) described patients feeling as if they represent a disease or condition and experience pressure to be compliant and agreeable, there is a concern that by disagreeing with clinicians or displaying dissent and becoming a “problem patient” could cause a negative impact on their treatment (Joseph-Williams et al., 2014). This was a perception clearly voiced by Claire in the Young Hip study. Trust and communication between her and the consultant had deteriorated to the point where Claire believed that should she complain or disagree with the consultant, the consultant would find a way to punish her, either by refusing to operate on her or in some other form.

The Young Hip Study included examples of patient perceptions of power imbalance and limited experiences of shared decision making. Participants reported feeling unheard by healthcare professionals when disclosing the significant impact their hip condition was having on their life, many felt themselves to be at a disadvantage due to their age in comparison to the expected demographic requiring THR. Participants reported feeling they had to “fight” to undergo surgery. Clinicians and healthcare professional frequently advised

that participants were “too young” and that it would be beneficial to wait until participants were older, that the implant would only last around 10 to 15 years and the younger they were the more revision surgeries they would require, therefore, better to delay as much as possible. Within Young Hip it appeared some surgeons focussed primarily on the biomedical health considerations and the expected length of time the implant would last prior to requiring revision when advising the participants. There appeared to be a disconnect and imbalance between what the surgeon believed to be in the patient’s best interest, to that of the patient’s own opinion. It is recognised across the wider literature that surgeons’ opinions and priorities can differ greatly to that of patients when considering what consists of a successful outcome (Jourdan et al., 2012; Ghomrawi et al., 2011; Moran et al., 2003; Janse et al., 2004). Evidence shows that clinicians often have higher expectations of successful outcomes in younger THR patients than that of older patients (Jourdan et al., 2012; Kinkel et al., 2009). This scenario was clearly demonstrated in Zoe’s experience. The surgeon and other healthcare staff informed Zoe that she was progressing very well immediately post-surgery and did not require any follow up or physiotherapy because she was young and would “bounce back”. As presented in Section 5.2.2, Zoe struggled enormously in her rehabilitation and her reality did not reflect the healthcare professional’s expectations. Malcolm et al., (2014), Ghomrawi et al., (2011) and Roos et al., (1999) demonstrated that surgeons’ expectations are significantly associated with joint related clinical data and radiological assessments, for example, positioning and survival of the implant, alleviation of pain and function of the joint. Alternatively, patients focus on aspects that are mainly psychological and non-joint related, such as ability to participate in recreational activities and effect on mental wellbeing (Jourdan et al., 2012). As was identified in Young Hip, not all these priorities of the patients are addressed in the usual way of reporting post operative outcomes, this will be considered in more detail later in this chapter. This differing of priorities and the miscommunication associated with this was demonstrated with consistency throughout the findings in Young Hip. Findings from the patient and public involvement (PPI) study (Section 3.4) also reflect these experiences, participants also reported feeling unheard by clinicians and being informed they were too young for treatment, though the PPI study was not solely focused on THR patients, the similarities in findings mean these experiences are not unique to participants in the Young Hip study.

The findings of both the PPI study and Young Hip strongly suggest that young patients in elective orthopaedics and musculoskeletal specialities are being unintentionally grossly under served. Clinicians and healthcare professionals are utilising the research available to provide the best evidence-based practice possible to all patients, unfortunately the research currently available does not address the younger patient nor does it recognise

that this demographic potentially has very different priorities and needs than their older counterpart.

6.4.3 Inconsistent information and varied expectations.

One of the four themes identified in the literature review centred around patients' expectations and education, it was stated that the information provided by the healthcare professionals directly impacted patient expectations. The literature review highlighted that managing patient expectations was a high priority for the younger patients included in the studies explored (Goodman et al., 2020). Insufficient information presented by the healthcare team led to searching for further clarification from other sources, sources that were not always accurate or helpful (Berg et al., 2019; Demierre et al., 2011; Lafosse et al., 2008; Sjøveian and Leegaard, 2017). This finding was also enforced by the participants in the Young Hip study.

When describing the THR surgery and subsequent rehabilitation and recovery, participants in Young Hip expressed a broad range of expectations. Some participants, for example, Patrick, Fran, and Diane had extremely high hopes of positive outcomes after THR. Though Claire and Chris expressed a more guarded optimism for after surgery, this was contradicted at times when they discussed particular hopes and goals, indicating that privately they hoped for much higher levels of rehabilitation than directly stated. These expectations were built on a wide variety of influences and experiences.

Participants in the Young Hip study cited past experiences with healthcare as having a significant impact on their expectations. Many participants knew or had met someone who had undergone joint replacement in the past. These acquaintances had always had positive outcomes and had successfully returned to activities they had performed prior to their hip symptoms. Participants were optimistic that this would be the case for them too, particularly as they were younger than other patients. They believed their younger age would have a positive effect on the speed of recovery and rehabilitation. As discovered in Young Hip, this was seldom the reality. Quantitative research over the wider general THR patient population enforces these high expectations in younger patients. There are many studies available that use PROMs to assess expectations and satisfaction between patients pre and post THR. As with surgeons, the results showed younger patients had significantly higher expectations pre-surgery than older patients (Scott et al., 2012; Vogl et al., 2014). These higher expectations were also linked to poorer outcomes in younger patients, Aalund et al., (2017) and Malcolm et al., (2014) demonstrated poorer hip related quality of life scores, greater hip symptoms, and poor mental health scores post-surgery in younger THR patients. The methods used in these studies were quantitative, meaning it was not possible to identify the patients' reasons behind these scores. Both Fran and Diane had very high

expectations of the improvement undergoing THR would have on their lives, these expectations were not fulfilled, though both participants identified that it was other concerns and conditions that prevented this.

It is important to highlight that the study took place during the COVID19 pandemic. Usual care pathways implemented to improve patient communication and manage their expectations, joint school and many face-to-face appointments were suspended due to social distancing and lock down requirements. Pre-operative patient education has been found to successfully decrease patients' preoperative anxiety (Alanazi, 2014; Bergin et al., 2014; Louw et al., 2013; McDonald et al., 2014) and contribute to successfully managing patient expectations for recovery and rehabilitation (Malcolm et al., 2014; Jourdan et al., 2012). Though it may not have an independent impact on clinical postoperative outcomes measured in quantitative methods, such as inpatient length of stay (Wainwright et al., 2020), Specht et al., (2016) identified the importance of preoperative information and education in providing reassurance and support for patients. The insufficient or inconsistent information provided by the healthcare system had a direct impact on participant expectations in Young Hip. This included failing to manage realistic expectations, (for example, Fran and Diane, and the waiting time for surgery) or forcing participants to seek answers and advice from other potentially inaccurate or misleading sources. In Young Hip, one participant had experienced attending joint school pre pandemic, Chris reported the experience had been "helpful", though the other attendees had been significantly older, causing him to be acutely aware of their differences. This experience echoed the reports found in the PPI study (Section 3.4). Participants in the PPI study described attending joint school and being acutely aware their needs and priorities were starkly different to that of other attending patients. The care pathways and support processes that were available during and after the pandemic were viewed by some participants as very much focused on the older patient undergoing THR. Rob and Zoe both expressed that they felt their individual needs as a younger patient were not being addressed by the routine healthcare pathways and assessments currently in practice. There is no existing evidence exploring whether preoperative patient education should be tailored between specific groups of patients, for example, younger active patients ranging to older sedentary patients (Wainwright et al., 2020). The Young Hip study indicates that the younger THR patient is not benefiting as fully from these pathways as their older counterparts. Therefore, further research is vital in clarifying whether preoperative education should be tailored to specific patient groups and demographics, and how specific information should be provided to certain patient demographics.

None of the participants in Young Hip discussed the potential of implant failure within their transcripts. Each individual would have had the risks of surgery outlined and explained to

them by their clinician when the decision to undergo the operation had been made. Many participants had explored other sources of information about THR in addition to this. It would have been difficult to ignore the potential negative outcomes associated with the procedure. Despite this, no participant indicated that they had considered it as an outcome that could happen to them, it was not something they had considered, or if they had, was not something they wanted to dwell on.

Participants consideration of the implant itself was multi-faceted and complex. Some participants embraced and accepted it as a part of them, whilst others struggled with the concept of a metal implant becoming part of their body. Participants were often dismissive of the likely need for revision surgery in the future, labelling it as “tomorrow’s problem”. However, the participants awareness of this future requirement could be identified by the caution and care participants displayed when considering activities that may damage or put too much pressure on the implant. There was a constant strive for balance with participants, the need to live their life with as few restrictions as possible compared with the urgency of protecting their new hip, making it last as long as possible and preventing the need for multiple operations in the future.

6.5 What is meant by function.

The improvement of function is also a primary goal for patients undergoing THR. In older patients, the term function is primarily used to describe mobility and range of movement within the joint (Aalund et al., 2017; Scott et al., 2012). The findings of Young Hip represented a different meaning to the term “function”. This perception centred around their responsibilities and roles in society, for example, actively functioning at work or fulfilling their role in their family unit or in their social life. This understanding of function identified in the Young Hip supports the findings presented in the literature review, where two featured studies reported the limitations of function and mobility directly influenced participants’ ability to fulfil their role, either professionally or socially (Singh et al., 2020; Goodman et al., 2020). This inability caused significant feelings of guilt and caused negative implications to participants’ mental health. Notably however, these studies along with the other limited evidence base still link the term function heavily with mobility and do not separate the two meanings. This limits the depth in which this alternative meaning of function can be explored.

6.5.1 Current outcome measures.

As presented in the findings, participants frequently expressed that the assessment questionnaires and care pathways were focussed heavily on the older patient undergoing THR. Many participants did not feel their individual concerns and requirements that were

more relevant to them as a younger patient, had been identified and addressed by healthcare professionals. This included the HOOS questionnaires participants routinely completed for the clinicians and physiotherapists. When comparing the Young Hip participants' HOOS scores with their own voices and opinions on their experiences, there was disparity between the outcomes indicated by the HOOS scores and the information narrated by the participants. Some participants who healthcare would consider having had extremely successful outcomes based on their HOOS scores expressed very different outcomes when narrating their experiences. There is no available section within any type of validated PROMs questionnaires where patients can express any psychological effects, impact on sexual activity and relationships, concerns of body image, and fulfilment of roles and responsibilities in working and family life. The Young Hip study identified these aspects as important priorities to the younger THR patient, yet they are not routinely addressed in the way successful outcomes of THR are measured in the NHS.

Current outcome measures used in the healthcare setting use the word function to solely focus on mobility and the physical aspect of activities of daily living (ADL). This is evident in the questions featured in any of the PROMs questionnaires currently routinely utilised for orthopaedic patients. The HOOS is recommended specifically for young adults (Ackerman et al., 2021; Kuijpers et al., 2020), it has more detail than other routinely utilised PROMs in orthopaedics. HOOS divides its questions into sections, thus making it easier to identify any particular aspect of concern or improvement. However, it completely associates the term "function" with the ability to perform physical tasks. Though the Young Hip findings highlighted mobility and range of movement as a concern to participants, the impact was much more keenly felt in what the lack of mobility and movement meant for their active participation and roles in their lives and society. The HOOS defines the subcategory of ADL with range of movement and limited mobility. It explores difficulty in performing sports by rating levels of pain. The HOOS does not have the capacity to explore other reasons why patients may not choose to participate, such as confidence, mental health, or concern around damaging the implant. All these reasons were identified as significant concerns by participants in Young Hip and continued to impact quality of life for many months after the surgery. Lack of confidence in the hip is identified with one item in the quality-of-life subcategory, though this is not further explored in any other items in the HOOS. Additionally, the lowest-scoring option that is available to give when exploring pain and mobility in the HOOS is "extreme". This implies that the function described is possible but causes extreme pain. There is not an option available for those functions which the patient finds themselves incapable of. Instead, participants commented "N/A" or "cannot do" in answer to the "running" or "twisting" items in the sports / recreation subcategory. Patient perspectives of function and the implications it involves are not being identified and addressed within the

HOOS or any current outcome measures. There were also instances of participants scoring low scores in HOOS completed 6-months post-surgery. The qualitative data provided insights into this decrease and provided potential explanations, without the additional qualitative information the resulting score could provide misleading or inaccurate information relating to the operated hip. The misplaced reliance on other PROMs to accurately assess outcomes was also highlighted by participants in the PPI study. PPI participants were clear in that they wanted more in terms of their recovery than what the PROMs they had completed were assessing.

Importantly, there was no correlation or patterns in the HOOS data relating to participant gender, age, hip condition, baseline scores, or time waiting for surgery. However, to identify aspects of statistical significance often requires larger sample sizes, therefore, potential patterns across the data could emerge with a larger study sample and its potential cannot be discounted.

The HOOS scores presented within Young Hip demonstrate successful outcomes in most participants. However, with some notable exceptions, the implications from the qualitative findings were primarily that of negative experiences, this is despite participants often making a conscious effort to adopt a positive attitude when able. Within the qualitative findings not one participant in the study expressed they regretted the decision to undergo surgery (though some were reluctant to have further surgery in the future). This is not unique to the study, Ozturk and Ozturk (2022) also identified the prevalence of negative experiences over positive in their qualitative paper exploring life after THR focusing on older patients. The focus of the human memory on negative experiences is widely recognised in psychology and associated specialities. Adults tend to apply more significance and be impacted much more by negative experiences than positive ones (Vaish et al., 2008). Individuals also tend to record negative stimuli more easily, but also reflect longer and more deeply on negative effects (Cui, 2021). This appears to be affected by age, with multiple studies suggesting that as individuals age, they experience these negative effects much less frequently than younger adults and are able to focus more on positive experiences in their lives (Charles et al., 2003; Carstensen et al., 2000; Charles et al., 2001; Mroczek and Kolarz, 1998). This phenomena may go some way in providing an understanding of why the HOOS scores potentially present some differences to the qualitative findings, specifically in the instances where HOOS demonstrated positive outcomes, but participants primarily reflected on their negative experiences. It is important not to use this reasoning as a cause to discount the negative experiences and reflections within the qualitative findings. However, by possessing an awareness of this negative inclination of humans, it enables us to understand and interpret the findings and results of Young Hip more thoroughly.

6.6 Roles and responsibilities.

As discussed in chapter 2 and chapter 3, elective total hip replacement is conceptualised as an operation of old age, usually as a result of chronic conditions often considered unavoidable in older people, such as osteoarthritis. Society assumes that THR and the conditions it addresses are rare in younger people and therefore less accepted, it expects certain abilities and responsibilities from the younger adult age groups to perform active roles and be functional in society, this expectation is reflected heavily in the Young Hip participants themselves. What these roles were, and the pressure applied to participants to fulfil them (by themselves and others) was influenced by their “difference” in terms of what they, their associates, and the wider society expected of them. The notion of participants not fitting this expected norm for THR had significant and wide-ranging influence on their own and other’s responses to the condition and their recovery experiences. Participants often experienced unconscious bias from healthcare staff and clinicians in addition to the general public and those around them. Young Hip demonstrated that the experience of young adults undergoing THR (from onset of symptoms to diagnosis to surgery to recovery and rehabilitation) has physical, psychological, and sociological sequelae affecting both the person and those around them.

6.6.1 Employee and provider.

Though, qualitative research exploring employment in younger patients undergoing THR is unavailable, as stated in the literature review, there is extensive quantitative literature available on the themes clinicians and researchers assume to be important to the younger THR patient population. These topics are generally considered relevant to the overall age group in question (Borg et al., 2017; Kurtz et al., 2009; Malcolm et al., 2014; Tilbury et al., 2014) and include employment, sports and leisure, sexual activity, and caring responsibilities for young families.

Kuijpers et al., (2020) and Tilbury et al., (2014) estimate that 15% to 45% of patients who undergo THR are of working age. Working age in the UK is currently up to 66 years of age (Department for Work and Pensions, 2023). Responsibilities and expectations can be significantly different for a 60-year-old working adult to that of a 35-year-old working adult. All ten participants in Young Hip were of working age and subject to other responsibilities or social expectations. Over half of the participants had dependents. All except two were working in some capacity. The two participants not working was due directly to their hip condition. The hip symptoms, and then subsequent operation and recovery period had a big impact on work and finances as well as participants ability to maintain their own physical and financial independence. The potential inability to provide financial support for their

dependants was a major concern. This is enforced by Li et al., (2006), who identified that hip conditions treated with THR are associated with increased missed workdays, possible loss of employment, and subsequently reduced income for the household. Loss of employment and earnings results in a significant burden on both the patients and their families (Tilbury et al., 2014).

In addition to financial benefits, Cook et al., (1982) and Ross and Mirowsky (1995) demonstrated that employment is beneficial for both physiological and psychological well-being, important for mental, emotional, and physical health (Waddell and Burton, 2006; Gignac et al., 2004). This is evident in some participants narratives in Young Hip. Several participants had a personal motivation to return to work quickly. They gained psychological benefit from being in employment, as it encouraged a work identity and feelings of self-worth. This was an aspect of working that Diane and Claire clearly missed as both displayed a sense of pride in having had an active working life prior to their hip symptoms.

6.6.2 Partner and parent.

Relationships and support from family and friends were highlighted as a key theme in the literature (Sjøveian and Leegaard, 2017; Berg et al., 2019). The importance of both physical and emotional support was identified as crucial in patients' recovery (Strickland et al., 2017; Demierre et al., 2011; Montin et al., 2002). In the Young Hip study, participants named their spouse or partner as providing the majority of support and bearing a significant impact. This often-included practical support and their partner having to take on roles and responsibilities normally undertaken by participants. This change was sometimes difficult for participants to accept and could result in feelings of resentment towards their partner. Though not focussed on chronic orthopaedic conditions or THR, wider literature exploring chronic disease and relationships enforce this inexplicable resentment as a normal reaction (Bruhn, 1977; Dalteg et al., 2011), especially in responsibilities more commonly perceived as linked to a specific gender role (Bianchi and Milkie, 2010; Gabriel and Schmitz, 2007; Lopez et al., 2012). In Young Hip this experience was more commonly narrated by the females with children, who believed they were "missing out" on their children's childhood and failing in the task of being a "good" mother. The expectations of partners and family members also had an impact on relationships in other ways. Participants described a slower than expected recovery contributed to interpersonal friction and frustration from their partners who were required to continue taking on increased responsibilities.

The dynamics of relationships with partners were unavoidably altered. Many participants felt their relationship with their spouse or girlfriend/ boyfriend was no longer a partnership. They had become dependent on their partner for emotional, practical, and in some cases, financial support. They were unable to fulfil their role in the partnership and could not

reciprocate or balance this support in any form. Children or dependents had also taken on more responsibility in the family dynamics. This perception of themselves as a burden and being unable to function in the parent or partner role they believed to be their responsibility, caused tremendous feelings of guilt and frustration for the situation.

For Zoe, the feelings of guilt were further exacerbated by concerns that her hip condition could be hereditary and affect her daughter. Parental guilt in cases of hereditary conditions is extensively explored in studies research rare genetic disorders (Chapple et al., 1995; Severijns et al., 2021) and is accepted as being unfounded, that view does not lessen the feelings of the parent. In conditions known to have a genetic link, parents and families are often seen by a genetic councillor, whose main goal is to educate and inform, but additionally works towards relieving these feelings of guilt and shame (Chapple et al., 1995; Persky et al., 2020). Unfortunately, in Zoe's case, the notion her daughter may be displaying the same hip symptoms was not addressed, nor was information provided about her own diagnosis that may have put her mind at rest. Therefore, in addition to Zoe's own struggles and frustrations, she carried the underlying concern that her daughter may be sentenced to the same experience.

Sexual function and activity are considered an important aspect of quality of life for adults of all ages (Rohde et al., 2014), however, impaired health associated with aging or other chronic health conditions is considered to affect sexual activity (Nicolosi et al., 2004). Abdel-Nasser and Ali, (2006), El Miedany et al., (2012), Besiroglu and Dursun, (2019) and Schairer et al., (2014) reported high prevalence of impaired sexual health among persons living with chronic diseases. Nilsing Strid and Ekelius-Hamping, (2020) conducted a qualitative paper in persons over 52 years with OA found participants all reported various degrees of limitations in SA. Harmsen et al., (2018) and Lavernia and Villa, (2016) found that 64–82% of those who undergo THR for osteoarthritis report impaired sexual health. Much of the literature exploring THR and sexual activity (SA) primarily assesses SA before and after THR and demonstrates that THR has a beneficial effect on SA (Baldursson and Brattström, 1979; Lafosse et al., 2008; Meyer et al., 2003; Stern et al., 1991; Todd et al., 1973), however, the expectations of SA post-surgery are not always fulfilled (Harmsen et al., 2018). Concerns surrounding SA and subsequent improvement after THR is more frequently reported in women (Lafosse et al., 2008; Meyer et al., 2003). This is reflected in the Young Hip findings, every female participant in Young Hip reported issues and concerns about SA and intimacy with their partner before surgery, two women experienced improvement in this area after THR. However, though physical function had improved in their hip, the other three female participants continued to struggle with confidence in both their ability and the implant. Three male participants also reported their hip condition having a negative effect on SA. Importantly, the male participants did not cite their hip as the primary impact, but

rather other logistics in their lives, such as work and young children. On reflection, the female participants appeared more comfortable in discussing SA with the researcher, this may be due to the researcher being a female. Participants may have perceived some common ground between themselves and the researcher making it easier to share more personal and private details. Denying their partner these intimate acts had a negative impact on the relationship, excluding and limited the intimacy and closeness required for a successful and happy relationship.

Despite the high occurrence of impaired SA in patients with chronic health conditions, such as OA or RA, the impact of THR on sexual activity and intimacy is a topic recognised to often being unaddressed or considered by clinicians and healthcare staff (Harmsen et al., 2017; Coradazzi et al., 2013; Dahm et al., 2004, Manninen et al., 2022). The participants in the Young Hip study support this statement. The hospitals and clinical areas the participants visited had no leaflets or information packs presenting advice on sexual activity and intimacy. This was also not a common discussion point with clinicians or healthcare professional. Only Patrick reported having this topic briefly and inadequately addressed by his surgeon, where the surgeon asked if Patrick “was still able to”. No other participants recalled the topic being approached at all. This failure to address the important topic of SA is considered by wider literature to be the result of many perceived barriers, for example, worry about causing offense, personal discomfort, lack of time, resources, or knowledge (Dyer and das Nair, 2013). In the context on THR, the Young Hip study suggests an additional reason. THR is considered an older patient operation, therefore, healthcare professionals are unaccustomed to discussing SA in the context of THR due to the perceived asexuality of their usual older patient population. There is an inaccurate generalised perception that sexual activity (SA) and old age are mutually exclusive (Billings, 2006; Taylor and Gosney, 2011). Therefore, previous research has shown that the majority of healthcare professional do not discuss SA with older patients incorrectly assuming it to be a topic of irrelevance (Gott et al., 2004; Taylor and Gosney, 2011). However, as the evidence strongly demonstrates this assumption is completely inaccurate, and the Young Hip study along with the wider literature overwhelmingly supports clinicians discussing sexuality with THR patients.

As considered in Section 6.4.3 which explores the value of pre-operative education, the literature exploring the topic of SA and THR states that education and information to be invaluable in promoting confidence and positive sexual health, there is also suggestions that education could also help decrease pain and facilitate self-confidence and self-awareness, promoting an improved body image (Meiri et al., 2014). As in other aspects of recovery and rehabilitation, clinical assessment of improvement in SA appears to be focused solely on the physical function rather than the underlying psychological concerns

of the patient. Though there was a singular attempt to approach the subject of SA in a clinical appointment, it was insufficient and inadequate in obtaining the relevant information important to the patient and focused completely on the physical aspect of SA rather than the nuances of intimacy required in a happy relationship.

6.6.3 Strong and sociable.

The improvement of quality of life, particularly in respect to social participation and interaction, was noted as an integral theme in younger patients in the literature. Social interaction and participation in leisure activities was also identified in Young Hip as a priority to participants. Chris and Henry both expressed desire to return to their chosen sporting activity, this was not solely for exercise but also the social benefit of engaging in a group sport. For Rob, being able to work out at the gym again, was a key priority in his recovery. Many of the other participants described missing long walks and other light exercise activities due to their hip condition and looked forward to regaining the ability to complete these post-surgery. In studies exploring return to sport activities and exercise after THR results indicated a reduction in participation post-surgery, however, this was less of a concern to participants than the problems they experienced with pain or ADL (Kinkel et al., 2009). Importantly, these studies often exclusively focused on the older patient, of which usually the majority had retired. This was not the case in the study reported here as the young hip study participants were all of working age and subject to other responsibilities or social expectations.

Studies using quantitative data to explore outcomes state that many younger patients engage in high impact sports and recreational activities post THR (Clohisy et al., 2008; Kinkel et al., 2009; Malcolm et al., 2014) and that this is one of the highest rated priorities in this patient demographic (Jourdan et al., 2012; Mancuso et al., 2009). However, studies on the broader THR patient population described participation in sports and exercise to be one of the least fulfilled outcomes after THR and one of the primary reasons for dissatisfaction in the prosthesis (Jourdan et al., 2012; Malcolm et al., 2014; Nilsson et al., 2003; Mannion et al., 2020).

As stated in Section 6.5.1, the current evidence vastly relies upon the various PROMs available to explore outcomes in research and inform recommendations and improvements in patient care. When considering why patients are reporting being dissatisfied with their ability in returning to sports and exercise, the PROMs are focused completely on functional scores and physical symptoms, with little to no consideration of psychological or social impact.

Despite returning to exercise and sports being a priority to the participants in Young Hip, this goal took significantly more time to reach than expected. A fear of being perceived as incapable, weak, or disabled was apparent. Participants were acutely aware of how others perceived them, many tried to disguise or play down the negative effect it had on them when other people commented upon the way they walked or their inability to accomplish routine tasks. However, the frequent references to these situations and the detail in which they could recall them belied their cavalier attitude to them. Participants described 'hiding' a recurring limp and actively managing activity levels or adapting activities to cover up physical limitations. Patients' awareness of other's perceptions, and the negative connotations this could have on the patient's confidence or mental health is not addressed or considered in either current healthcare outcome measures or the current available literature. Only one article featured in the literature review presented the finding that younger participants often felt family and friends failed to understand their experience of chronic pain and disability (Goodman et al., 2020).

6.7 Personal Identity.

Self-image and how patients perceive themselves is also not broached within current literature on young patients undergoing THR. Changes to the participant's body shape, due to muscle wastage, leg length, and weight gain because of limited ability to exercise, all impacted to participant's self-confidence and self-image. These priorities were also addressed in the PPI study and were highlighted as significant concerns by the PPI participants. Again, these outcomes are not addressed in HOOS, other PROMs, or any outcome measures used routinely in the clinical setting. This means that these concerns and priorities are not recognised or explored unless the participant addresses it themselves to healthcare staff. The findings of Young Hip present the multi-faceted theme of self-image (both physical and psychological) having a significant impact on a range of other aspects within the participants experience, including relationships and fulfilment of roles, and mental health. The perception of beauty and the ideal body is inescapable in society, meaning the pressure to conform to the ideal is immense.

Pre-surgery, the participants expressed the experience of the hip controlling everything, it became all consuming. Many participants described a feeling of losing oneself and being "just a bad hip". The struggle to maintain self-identity whilst suffering from a chronic illness is recognised in literature (Fonte et al., 2018; Trindade et al., 2018), many studies identify patients often suffer an identity crisis when confronted with loss of independence and increased reliance on others (Lin et al., 2021). Patients suffering from chronic illnesses perceive themselves as increasingly disabled and ineffective (Bacconnier et al., 2015), often subconsciously transferring that belief onto other people and assuming others see them the

same way (Tice and Wallace, 2003). This difficulty in maintaining self-identity is heavily represented in the Young Hip study and is further compounded by the fact that the participants in Young Hip did not fit the commonly accepted profile for patients requiring THR, therefore, did not fit in with the “norm” that was expected by others.

6.8 Mental Health

The ten participants in Young Hip all experienced a negative psychological impact from their hip condition, participants’ mental health was impacted by a combination of experiences ranging from healthcare and treatment, function, and inability to fulfil roles and responsibilities, relationships, and the effect their hip condition had on loved ones, to self-image and self-confidence.

Avoidance and isolating oneself was a way of coping with their depression and negative feelings for many participants in the study. Unfortunately, it is recognised that this way of managing low moods and depression is often counterproductive and can exacerbate the issue, sending patients further into a depressive state (Wang et al., 2022; Siviero et al., 2020). Literature exploring depression stemming from social isolation and the avoidance of social interaction due to chronic hip conditions demonstrate this is an important concern in the older THR population (Cattan et al., 2005; Iredell et al., 2004; Siviero et al., 2020). It has been proposed that, on average, depression and anxiety can be much more severe and debilitating in younger patients undergoing THR than older patients (Malcolm et al., 2014). Despite this suggestion, no further research into this topic has been identified. Importantly, the participants did not just experience social isolation, they were also isolated in their experiences. This was identified through both the verbalisations that friends and family did not understand and expected more from their recovery, and also the care pathways offered from the healthcare providers did not address what was required to them.

The researcher found that the female participants in Young Hip were much more open and expressive about their mental health and depression than the male participants (Section 5.4.1). The male participants acknowledged the impact experienced but often chose to move on to different topics and avoided discussing it in any more depth. Evidence states that it is common for experiences in chronic conditions to be influenced by gender norms (Clarke and Bennett, 2013). Chronic conditions often present symptoms of fatigue, pain, and loss of strength and function, these symptoms directly undermine a man's ability to achieve and adhere to hegemonic masculinity, which is typically associated with autonomy, control, invulnerability, physical strength, and social power and prowess (Bernardes and Lima, 2010; Gibbs, 2005). As discussed in the findings chapter, this perception of masculine identity and responsibilities, and the ability to fulfil the associated roles was essential to

Patrick, Henry, and Rob. Thus, by revealing any vulnerability by admitting to the impact on their mental health, indicated that it was a significant priority despite the lack of detail.

6.9 The younger THR patient.

Notably, many findings presented in the Young Hip study could be generalised across all age groups, however, some nuances in importance and priorities are evident. The theme of function and its differing meaning to younger participants results in many areas of concern being overlooked in the care pathways for THR and the outcome measures. Greater awareness of healthcare staff and the wider public regarding the increasing incidence of THR in young people could have avoided some of the negative experiences participants in this study recounted. These appear to have been based on clinician and healthcare staff's own assumptions and unconscious biases, underpinned by experience and evidence-based-practice utilising the current quantitative outcome measures, for example, radiographic outcomes, revision rates, and PROMs. The potential inadequacy of PROMs for the young THR population has also been highlighted by this study. Further work to determine suitable person-centred measures for this specific client group might help start to address some of these issues by taking account specific needs of young individuals post THR. The participants reported experiencing an increased pressure to recover from surgery quickly (Section 5.7.4), this pressure could be self-imposed or displayed by others, such as family, friends, and in Zoe's case by healthcare professions and the surgeon. There was also a pressure to fulfil the roles considered to be their responsibility by society. These roles varied, and the responsibilities required to undertake them were often created in the mind of the participant. They included that of parent, partner, provider, supporter, and that of fulfilling the norm of what their peers were physically capable of. This is remarkably different to that of the older patient undergoing THR, who society assumes should require extra practical help, may be retired with no dependants relying on them financially, and potentially has other co-morbidities contributing to the commonly held view of a slower, less capable individual. The findings of Young Hip enforced the themes presented in the literature review, however, themes such as "this is not who I'm meant to be" and "my family didn't sign up for this" and subthemes included under these superordinate titles, are not identified with the available literature on young patients undergoing THR. Interestingly, a semblance of these themes are present in the findings in the PPI study, though this study was unable to expand on these topics.

Participants identified that because they did not fit the commonly accepted older patient profile for THR, the current care pathway does not always suit their needs. A care pathway offers a standardised approach to the implementation of best practice care, however, the benefit of this may be limited unless there is enough flexibility to accommodate the needs

of individuals who do not fit expected social or professional norms. As a result, developing more a flexible THR care pathway that recognises the increasingly non-homogeneous nature of THR patients could help to address some of the issues raised by this study and more effectively support the recovery of younger patients.

6.10 Study Limitations

This thesis includes three published articles in addition to the Young Hip study. Section 3.3 presents the literature review undertaken to identify the current literature available exploring the priorities and expectations of the younger THR patient in their own voice. The absence of quality qualitative data relating to the priorities and expectations of young adults when undergoing THR limited the potential relevance of the themes presented in the review findings. This was exacerbated by the uncertainty within the included studies as to whether these themes could be attributed directly to younger THR adults, due to the participant samples containing a range of ages and in some, incorporating both TKR and THR.

The initial methods considered in the Public and Patient Study presented in Section 3.4, was to approach potential patients via the hospital's outpatient department and request completion of paper questionnaires and then ideally inviting suitable patients to take part in in-person focus groups. However, the safety measures implemented during the COVID-19 pandemic curtailed these proposals to mere suggestions. Though there are positive outcomes in using an on-line survey method (as detailed in Section 3.4). Completing the survey on-line limited the depth and detail into which topics could be explored. Despite the survey's overall high response rate, numbers of respondents from black and ethnic minorities were low. Efforts to include a more diverse population were ineffective. This could potentially lead to an omission of an important topic specifically important to some cultures or ethnic groups within the findings.

The purpose of the bibliometric review in Section 4.4 was to highlight the absence of qualitative research within the orthopaedic specialty. The multitude of medical and surgical journals available meant it was impossible to search every archive of every journal, therefore, the examples of qualitative orthopaedic research that undoubtedly feature in high impact non-orthopaedic journals were not included within this search.

The qualitative study, "Young Hip" has limitations. Although congruent with an IPA approach, the participant sample size was small in this study. As such further research and exploration is recommended within the themes identified.

The youngest participant was 28 years of age, thus adult patients within the age bracket of 16-27 were not represented in the Young Hip study, this potentially means that priorities and

expectations of that of younger adults in this age bracket are absent in the findings. As in the PPI study (Section 3.4), all ten participants in Young Hip identified as Caucasian. This was unavoidable in this scenario as the sampling process was purposeful and not selective based on race or culture. However, it is important to acknowledge that this lack of ethnic or cultural diversity may limit the broadness of the data and result in potential omissions of important findings unique to different patient cultural backgrounds.

Involving participants from only one NHS hospital is also a notable constraint in the Young Hip study. The scope of the research was selected for pragmatic reasons as the researcher worked within the trust and was familiar with its policies and patient pathways. Focusing recruitment to a single NHS trust and geographical area made it simpler to identify and approach potential participants, and importantly made the study achievable for a part-time, student researcher with limited resources. This consideration is a practical contingency faced by many researchers (Silverman, 2013).

Transparency with the study has been strived for by identifying my positionality within the research, outlining the procedures, and providing transcript examples (see Appendices 3, 14, 15, 16) to allow the reader to reflect on the interpretations and consider potential alternatives. Additionally, though extracts have been included, they appear out of context and could possibly lack depth (Potter and Hepburn, 2005).

As is the case with qualitative research, it is acknowledged that findings result from both the subjective interpretation of both the participant and the researcher. A different researcher would have different interview transcripts (as the dynamics of the interviews would be completely different) and may have interpreted the data differently resulting in different findings.

6.11 Study Strengths.

A major strength of the Young Hip study is the inclusion of young THR patients as participants. To my knowledge, this is the first study to qualitatively explore the experiences, expectations, and priorities of patients undergoing THR that are 50 years of age and under. Thus, voices that have previously not been heard have now had their experiences captured.

The interviews were undertaken by a single researcher which ensured a consistent approach was maintained throughout each of the interviews. Additionally, the longitudinal aspect of the three interviews at three different timepoints in the patient journey enabled a positive and trusting relationship to build between the participants and the researcher. The rich and detailed resulting interview data, including the disclosure of some very personal and sensitive experiences, demonstrate that this relationship was successfully achieved.

The experiences shared at each interview was the participant's present or directly recent experiences, this avoided the reliance on memory to recollect the thoughts and feelings directly attached to the experiences and enabled the participant to narrate a more true and clearer account of what their lived experience meant to them.

The primary aim of the Young Hip study was to explore the priorities and expectations of the participants using IPA methodology. Limited method triangulation was introduced in the collection of the quantitative data presented in the participants' completed HOOS. The quantitative data was intended to be used to explore the correlation between the two data sets and not as standalone data to be analysed as an outcome. As stated in chapter 5.9, the two methods were not always coherent to each other and in some cases indicated and presented very different findings. To mitigate this incongruity between the two methods and to maintain trustworthiness throughout the Young Hip study, a range of other strategies were employed as recommended by Lincoln and Guba (1985). These strategies are presented in full in the methods chapter and include transparent interviewing, transcribing and data analysis procedures; a structured and consistent approach to data analysis (based on Smith et al., 2009); staying as close as possible to the language and terminology used by participants in analysing and reporting the study findings; providing an audit trail and ensuring study data is available; demonstrating researcher reflexivity throughout all research processes.

Chapter 7. REFLECTION ON THE RESEARCH PROCESS.

7.1 Researcher reflexivity.

My experience as a trauma and orthopaedic nurse had both positive and negative impacts when conducting the Young Hip study. As a healthcare professional with extensive experience in caring for patients undergoing THR I began the research journey with many pre-conceived ideas and views I was unaware of, such as it was inadvisable to offer a THR to a younger person, due to the needs for continual revisions in the future, and that many young patients requiring a THR had experienced health and hip problems since birth. These assumptions stemmed from the literature that currently informs evidence-based practice in THR studies exploring outcomes and results using PROMs and focusing on the older patient population (Aalund et al., 2017; Bayliss et al., 2017; Adelani et al., 2014). As healthcare professionals we are trained to implement evidence-based practice within our clinical lives (Kim et al., 2020), however, if that evidence is limited or insufficient then how do we ensure we are meeting our patients' needs and providing appropriate care. These pre-conceived assumptions were clearly evidenced in the aspect of function discussed in Young Hip. My initial idea of what function is, was that of mobility and range of movement directly associated with the hip joint and implant. When emerged in the analysis, this idea changed dramatically to represent the findings detailed in chapter 5. It caused me to consider that my first thought of the meaning of function was taken from my role as a Trauma and Orthopaedic (T&O) nurse and the PROMs questionnaires used in my clinical setting that use the word function to focus on the physical aspect of activities of daily living. The participants in Young Hip represented an alternative meaning of the word "function" to include the fulfilment of their perceived roles and responsibilities in society.

As explored in Section 4.3, orthopaedic research overwhelmingly favours quantitative methods, these necessitate an objective approach by the researcher. However, any research project is influenced heavily by the subjective position of the researcher. Individual experiences, knowledge, histories, and values guide selection of subject areas to research, influence choices on research design and methodology, and affect data analysis and interpretation. By using reflexive practice, we can close the gap between researcher and the researched, encouraging a sense of empowerment, and building a collaborative work between the researcher and participant (Etherington, 2004). Reflexive practice requires us to situate ourselves within our research and demonstrate a level of self-awareness. It reminds us to be mindful of our thoughts and feelings throughout the research process. Interpretative phenomenological analysis requires the researcher to demonstrate constant reflexivity. As a double hermeneutic methodology, it accepts that both researcher and

participant make use of personal experience to make sense of the wider world. In research, this assumes that we draw upon our own knowledge and experiences to gain insight into participant's lived experiences and make sense of the data.

The set-up of the study was relatively straight forward. Working within the NHS hospital in which the study was centred presented a significant support network from both the research department and the trauma and orthopaedic department in the set up and conduct of the study. I began the Young Hip study as a MRes student. The MRes was converted to a PhD after the first year, this transfer was completed with not an insignificant amount of anxiety and nervousness from myself. It had never been my intention to undertake a PhD, however, the volume of work I had set myself in ensuring the Young Hip study was as successful as possible was, on reflection, unrealistic and impractical. Lack of confidence in my own ability and intelligence resulted in great reluctance and hesitation in transferring to a PhD, and the eventual decision to do so, required a great deal of faith in myself and my work ethic, and support from those around me and my supervisors.

Initially I was working towards a two-year study period as is usual for a part time MRes, this meant that it was necessary to open the Young Hip study for recruitment as soon as possible, to allow sufficient time for recruitment. However, it was not recruitment that presented a challenge, due to the ongoing impact of the pandemic on healthcare services the waiting lists for elective surgery were enormous with much uncertainty around operating times, bed space, and surgeon/ staff availability from day to day. As the study progress, there were concerns that surgeries may not be completed by the study end date and therefore, valuable follow up data may be excluded. Operation waiting time was dependent on the consultant's availability and assessment of clinical need, meaning some patients waited somewhat longer than others. Consequently, participants recruited later than others had the operation sooner. Due to this the original recruitment target of six - seven participants was increased to enable six - seven participants to undergo surgery prior to study completion date, recruitment therefore continued until six - seven participants had received their THR reaching the final recruitment number of ten. However, as it happened, all ten participants three stages of data collection were completed in the time allotted.

My own experience of clinical research is overwhelmingly that of quantitative methods. The studies I have worked on and led in my clinical environment are seeking concise objective data, success or failure of an intervention is assessed using mortality rates, adverse events, or clinical data. PROMs are implemented to assess participants' own views on the outcomes. Participants are assigned a study number on enrolment which is used to identify them throughout the study. Although, the study number is a practical way of identifying individual participants whilst maintaining anonymity, it can feel impersonal and dehumanising. I particularly wanted to avoid this in my own research.

IPA is not the only method to provide insight into the lived experience of participants. It was essential to me that the Young Hip study focussed on the participant's experience itself, rather than the socio-cultural factors that impact the experience. I chose an IPA approach in my research as I wanted to highlight the importance of treating participants in research as individuals with expert knowledge and experience in the research field rather than subjects. IPA places the participant at the centre of the research as the expert and prioritises their individual experience in a way that is not possible with other qualitative approaches. An IPA approach enabled me to address the imbalance that automatically weighs in favour of the researcher as the instigator of the research. The study methods aimed to empower the participants and reinforce that their thoughts and feelings about their experiences were valid and important, encouraging them to speak as openly and candidly as possible. As data collection progressed this approach became imperative as all the participants described situations where they had felt unheard by or unimportant to professionals.

Data-collection proceeded smoothly. Due to apprehension, participants' anxiety of surgery on the day of operation may restrict an open and frank dialogue, I was initially reluctant to conduct baseline interviews in the hospital on the day of surgery. However, time constraints and participant preference made this unavoidable for two participants (Patrick and Rob). In Patrick's case, the interview proceeded extremely well, with no interruptions and ample time for Patrick to discuss all the information he wanted to. Unfortunately, this experience was not repeated with Rob. Rob's interview pre-surgery was interrupted by other clinical staff needing to prepare him for surgery, the dialogue appeared hesitant and more stilted than I had previously experienced, potentially due to nerves around the imminent surgery. Finally, the digital recording device stopped prior to the end, causing Rob's final minutes of narrative to be recorded through copious detailed notes by myself, this was difficult to do whilst still attempting to maintain active listening and eye-contact. These notes were then added to the end of Rob's transcript. This was an important learning experience for me and concluded in me subsequently always ensuring enough time for interviews and never conducting them on the same day as surgery again. Adopting semi-structured interviews as the method of data collection promoted participant control of the dialogue and the topics addressed within the interview. I attempted to separate my roles of researcher and nurse in the participant's perception. I took pains to ensure I never directly cared for a participant in any clinical area or was present on the ward whilst the participant was an inpatient. I wore civilian clothes and avoided using jargon or medical terms in study materials or in communication with the participant. These strategies were implemented to further address inherent power influences within the study. On reflection, I feel that transcribing the interviews myself enabled me to feel closer to the participant and the data. As a novice researcher, I felt that

this process allowed me to immerse myself more completely within the data and allowed me to create a better understanding and interpretation of the participants lived experience.

I did not successfully predict the emotional labour required in conducting the interviews. Having never conducted a qualitative interview prior to this study I was blind to what to expect, despite reading a wide range of theory, methodology, and examples of successfully qualitative and IPA interview techniques, they did not prepare me for the true experience of a “live” interview. Challenges presented a number of factors, primarily actively maintaining a reflexive and conscious stance throughout the interview’s changing situation. For example, continuously and simultaneously maintaining and managing an awareness of building rapport and a relationship with the participant, managing the environment (for example: external noise and interruptions, privacy, time keeping, and technology involved such as recording devices), and ensuring I maintained reflexivity throughout. I had considered that the participants narratives may contain memories and experiences that may be distressing and traumatic for them to discuss. I had put strategies in place to manage these occurrences. However, I was not prepared for the wide range of emotional and traumatic experiences shared by participants, nor the emotional impact felt by myself as a researcher. These experiences ranged from, deep depression, suicidal ideation and self-harm, and fears surrounding hereditary issues, amongst others.

In hindsight, these topics should not have been surprising as many were identified within the findings of the PPI study (Section 3.4). However, these topics had not been explored in detail within the PPI study. Biggerstaff and Thompson (2008) also advise, raising of distressing and personal themes are phenomena closely associated with interpretative phenomenological approaches, due to the less structured nature of the interviews and the autonomy this provides the participant. Importantly, it does highlight the holistic perception participants have on their condition and the wider influences surrounding the surgery and recovery participants believe to be important.

Despite the emotional and distressing themes included in some interviews, I found all the participants to be open, honest, and forth coming. Many participants expressed that they experienced some benefit to participating in the Young Hip study in terms of their mental health. They described a sense of relief after talking to me about a particularly distressing experience. Participants expressed that talking through their experiences, especially negative topics, had made them feel better and had acted as a sort of therapy. It is worth highlighting, that the opportunity to discuss experiences and priorities is not a routine service that is offered to all THR patients. Many participants informed me that they hoped by participating in the study, they would contribute towards changing things within healthcare so future patients would not have similar experiences.

7.2 Insider/ outsider issues.

Positionality is an important issue in research which identifies the status of the researcher within their own research. It forces the researcher to account for their characteristics and/or standpoint to enable others to judge the impact these may have on the research findings (Alasuutari et al., 2008). My aim in the Young Hip study was to enable an emic or “insider” ‘...interpretive rendering from the inside...’ (Charmaz, 2004, p980) of young THR patients’ experiences. An emic or ‘insider’ perspective implies a subjective, informed position or a study in which the researcher is strongly invested (Kahuna, 2000). Understanding my role as a researcher was not without challenges. Arber (2006) states that the role of the researcher must be as critically appraised as the research itself. My experience working in healthcare had demonstrated to me that research results and findings can be easily discounted if not transparent and its methods robust. Interpretative research using qualitative methods requires a positivist, empirical approach (Kahuna, 2000), therefore the role of the researcher and their positioning in the research requires particular scrutiny to ensure the study’s findings are reliable. Being both an insider with knowledge and experience of the conditions, operations, and care pathways experienced by the study participants and an outsider as the researcher with no personal lived experience presented difficulties (Kahuna, 2000).

Some experiences narrated by the participants resonated heavily with situations I had experienced within my own life. For example, when Annie discussed her feelings of guilt when calling in sick to work and knowing this would place added burden to her colleagues, this was an experience I could recognise. Additionally, I am also a mother of two young boys and have had experience of a severe musculoskeletal injury which prevented me physically playing an active role in their lives and activities for a significant period of time. Though these personal experiences in my life are not identical or completely reflective of the participants experiences, they do possess some core similarities. I recognised that my emic positionality within these episodes involuntarily impacted upon my interpretation of the participants experiences. Therefore, because of this personal experience, I spent some time considering and reflecting on these narratives to ensure that my interpretation was balanced and reflective of the participants’ lived experiences. I also recorded these emotions and reflections in a research journal to help provide a useful audit trail (Arber, 2006) and maintain effective reflexivity (Asselin, 2003).

Additionally, the positionality on how others position the researcher also presented a challenge. For example, colleagues within the trauma and orthopaedic department treated me as an insider, recognising my emic experience as a healthcare professional and working colleague. Throughout the research process I was acutely aware of my position as a trauma

and orthopaedic nurse and the potential conflict between this and my role as a researcher. I constantly strived to keep the researcher role, any involvement with the participants, and the study activities completely separate to my clinical role. I ensured I was never involved in participants' direct care and actively avoided meetings and clinical discussions involving them. So as to limit the potential impact this role and experience could have on the research and its findings, I took great effort to compartmentalise my professional role separately to that of the researcher. Before any contact with the participants, I took five - ten minutes of quiet to organise my thoughts and identify any assumptions and pre-conceived ideas I may have. I noted these in my research journal (Appendix 4) to ensure I could revisit them at the end and identify any potential biases that may have occurred prior to analysis, I regularly revisited my thoughts and interpretations in relation to this to confirm I was staying as accurate as possible to the participants data rather than my own pre assumptions.

Being perceived by the participants as a member of the clinical team was also of concern. If participants considered me as included in the healthcare body responsible for their treatment, they could potentially censor their narrative or take the opportunity to clarify some clinical concerns they had. As considered in the method chapter (Chapter 4), this situation is often identified as a challenge in the nurse-researcher experience. I was very aware of consciously remaining in the researcher role to avoid adopting my nurse role when these situations occurred. Fine (1994) described these episodes as "walking the margins" that separate self as researcher from study participants. I found these situations difficult as I was aware that by declining to answer questions it could have a negative ongoing effect of the relationship between myself and the participant. Therefore, I opted to defer the answering of these clinical questions to the end of the interview and sought to maintain constant conscious awareness and reflexivity to recognise these issues if they arose.

Despite recognising that an emic perspective may benefit and encourage rapport between myself and participants, I attempted to adopt an etic or outsider position when conducting the interviews and throughout the analysis. However, this dichotomy of insider-outsider positions is less distinct than I initially considered. Throughout the research process, I came to understand my positionality and reflexivity as the researcher as an ever evolving and dynamic process, requiring conscious and continual effort to strike a balance between involvement and detachment (Arber, 2006; Kahuna, 2000). Despite constantly striving to actively listen closely to participants' experiences and maintaining an interested but unbiased position, I found myself involuntarily considering how I would feel in their situation, and how some of my own experiences had triggered similar responses and emotions to what they were describing. Consciously recording these thoughts and the potential impact they may have, is a technique I found useful in maintaining reflexivity. Though these perspectives could potentially be valuable in enriching data interpretation, my sole aim was

to remain as true and accurate as possible to the participants' experiences. Despite using my "insider" status as a trauma and orthopaedic nurse and as an individual fulfilling the roles of mother, partner, employee, and peer of similar age to the participant, I was highly aware as a researcher of unintentionally and unduly influencing the data collection and analysis process. My aim was to get "inside" the experiences of the participants during the interviews, and then subsequent analysis and reporting stages, therefore remaining faithful to participants' priorities and enhancing validity (Green and Thorogood, 2018). Dwyer and Buckle (2009) suggest that occupying the space between insider-outsider is practical for the qualitative researcher and embraces the blurred and complex boundaries between the two positions. The researcher is an individual with multiple identities that are fluid, situated within context, and inform the positions from which they engage and make meaning of the world (Acevedo et al., 2015). Therefore, I chose to embrace my changing positionality throughout the research process and adopt the insider-outsider perspective, utilising all aspects of my identity to enhance the understanding and interpretation of the phenomena (Kezar, 2002).

Undertaking this study has been an adventure. It has challenged assumptions and pre-conceived ideas I was initially unaware of. My knowledge as a nurse has been enhanced and I believe I have become a better nurse due to the exploring the findings within this study. Before starting this research study, I believed I was a "good listener", however, the communication and listening skills I gained from conducting the interviews forced me to reconsider this self-assessment, additionally the rich information emerging from the analysis and interpretation has highlighted the importance of reflecting on what was said to better understand other's meanings rather than take the words at face value. I have developed knowledge, skills, and confidence and capability as a qualitative researcher. More importantly, I believe I have gained a deeper understanding of the participant's experience, which is impossible to gain from the limited appointment times allocated in the clinical care setting.

7.3 Summary of chapter

This chapter has considered my feelings and thoughts throughout this research journey. It shares my continual efforts to be aware of my prior opinions, judgements, and assumptions to ensure they have no effect on the study findings. I began this process as an individual who had only ever contributed to the research of others, who had never considered any further academic education after their nursing degree and had no real idea of the processes and milestones involved in an academic pathway. Throughout the duration of this research, I cannot fail to recognise my growth as a researcher and a nurse, personally and professionally.

Chapter 8. CONCLUSION and RECOMMENDATIONS

8.1 Conclusion to the Young Hip study

THR are considered a safe and effective operations used to treat a variety of musculoskeletal conditions (presented in Section 2.2). The operation was initially introduced and developed to treat the older patient population; however, its use in younger patient groups is increasing. Current care pathways and guidance with healthcare does not differentiate between patient age groups, and in a vast majority of cases, younger patients undergo the same pre-surgery planning and education, and post-surgery rehabilitation pathways as their older counterparts. This is despite the potential that younger patients may have extremely different priorities and expectations when having THR than older patients.

The aim of the young hip study was to explore the experiences and expectations of the younger patient undergoing THR. The specific objectives associated with this aim were to explore:

Primary Objective

- To identify the priorities and expectations of the younger patient (<50) when undergoing a THR and explore if these priorities are being addressed in current healthcare pathways?

Secondary Objectives

- To assess if current methods of measuring outcomes from the patient's perspective in clinical practice address the priorities and expectations highlighted within the qualitative findings.
- To consider and assess the use of qualitative methods in trauma and orthopaedic research and its potential value to healthcare practitioners working in trauma and orthopaedics.

The study achieved this aim and in doing so has identified the gap in the body of knowledge regarding the priorities and expectations of younger THR patients in their own words, as opposed to the assumptions of healthcare providers and researchers. The initial stages of this study identified and highlighted the lack of qualitative research in trauma and orthopaedic literature and promoted its use in future trauma and orthopaedic research to enhance the focus upon person-centred care within the specialty. The PPI study presented in chapter 3 established that younger patients with lower limb musculoskeletal injuries or conditions (in some cases treated by THR) felt sidelined and ignored by healthcare professionals. It presented some aspects of the patients' priorities that are not routinely

identified or addressed in healthcare pathways. These findings enabled me to ensure these themes were included within the interview schedule of the main study to establish if they were as important to participants in Young Hip as the PPI participants had stressed them to be.

The Young Hip study then used an interpretative phenomenological analysis (IPA) method to explore young THR patients' experiences, expectations, and priorities when undergoing a THR. It conducted in depth semi-structured interviews at three points of the patient's treatment journey (baseline/ pre-surgery, 6-weeks post-operatively, 6-months post-surgery). The IPA approach was then utilised to analyse, interpret, and present the findings from the interviews of ten individuals experiences of this procedure. In doing so the young hip study presents the first qualitative exploration solely focussed on younger THR patients.

The study highlighted many areas of the participants' lived experience that has not been acknowledged within current literature and subsequently not addressed or recognised in current healthcare practice. The participants were starkly aware they did not fit the assumed demographic of a usual THR patient, identifying that at times care pathways and information provided by healthcare staff did not always address their needs. Pressure to recover quickly, whether from themselves or from others was keenly felt throughout many narratives, the pressure was sometimes also perceived as coming from clinicians and their preconceived professional assumptions on what was considered "normal" for this patient age group. The participants in Young Hip did not consider the term function to have the same meaning (mobility and range of movement) as within healthcare environments and assessments. The participants perceived the term to apply to what they considered to be their roles and responsibilities in society, being unable to fulfil these roles and be the capable, attractive, useful individual they wished to encompass, caused substantial frustration and often had a significant negative impact upon their mental health.

Based on the study findings, the appropriateness of current care pathways for the target population has been appraised and recommendations made for future research, healthcare practice, and policy to enhance future care for this patient group.

8.2 Recommendations

The Young Hip study presents an in-depth exploration of the young THR participant's experiences and their thoughts on their own recovery and priorities. Their insights into trauma and orthopaedic hospital care and patient pathways reveal many improvements that could potentially influence and improve the delivery of person-centred care in orthopaedic and trauma practice for young THR patients.

8.2.1 Recommendations for future practice.

- Review of the THR care pathway approach to the care of young patients. Consider its appropriateness and relevance for patient groups who do not fit the accepted norms in terms of age, recovery, and rehabilitation needs. It is important that this review includes young persons who have the lived experience of undergoing a THR in addition to clinicians, healthcare professionals, and healthcare managers. Including these experts by experience will counteract potential assumptions and cognitive biases present within healthcare professionals and enable the review to consider the wider social and psychological impacts experienced by young patients that have been highlighted in Young Hip.
- When planning the operation, identify topics important to the patient and ensure they are addressed by a healthcare professional, especially difficult and sensitive topics, for example, sexual activity, and psychological impact of surgery. Ensure the patients understand the information provided. These topics could be included in preoperative assessment appointments by nursing staff or other allied healthcare professionals and not restricted to surgeon outpatient appointments.
- Encourage and build therapeutic relationships through open communication and active listening between healthcare professionals and patients to enable positive partnerships and person-centred care.

8.2.2 Recommendations for future research.

The findings of this study indicate several areas for further research.

- Further research is needed with a larger sample of participants across different sites, ethnicity, and diagnosis explore further and in more depth the themes presented in this study. This will demonstrate a degree of transferability.
- Explore the forms of communication and the quality of information given to young THR patients throughout the patient journey. Consider the most effective format of information and the best way it could be provided, for example, paper information leaflets during outpatient appointments, online webchats with healthcare staff, or even regulated online group calls with other consenting patients. Also, further exploration is needed into when this information should be provided, pre-surgery or during rehabilitation?
- Further research including qualitative methods needs to be more visible within trauma and orthopaedic literature, this applies to both clinical journals targeted primarily at surgeons in addition to journals focussed upon allied health

professionals. The Young Hip study demonstrated that some patient reported outcome measures used in orthopaedic practice fail to capture many nuances of the patient concerns identified using qualitative methods. Therefore, to ensure practice is effectively fulfilling patient needs, further examples of qualitative research giving voice to that patient needs to be evident and disseminated in orthopaedic research.

- Explore the impact of THR in young patients on their families and members of their social network. By understanding their perception and experiences it could help develop their ability to support the patient's recovery and additionally provide support for all parties in the changing relationship dynamics.
- Explore the different pre-surgery educational needs in different demographics of orthopaedic patients. Assess if categorising patient groups as per age or activity levels for pre-operative education delivery improves patient experiences and outcomes and enables patients to meet and create a support network of those undergoing similar experiences.
- Using qualitative methods explore orthopaedic surgeons, healthcare professionals', patients, and families/carers assumptions on young patients undergoing THR. Current evidence in this area grossly uses PROMs data to inform results. By employing a qualitative methodology in exploring the subject, further clarification and detail may be highlighted on reasons for higher expectations of young patients' recoveries.

8.2.3 Recommendations for policy.

- Review provisions for pre-operative education and post-operative discharge rehabilitation and physiotherapy for young THR patients (Accessibility, funding, and access).
- Health policy frameworks need to outline and support the development and implementation of person-centred care for young THR patients.
- Current NICE guidelines on pre- and post-operative rehabilitation in THR do refer to sub-groups of patients who may experience difficulties with activities of daily living, have specific clinical needs, or are not responding to self-directed rehabilitation, and advise further support provided for these patient groups (NICE, 2020). However, this guideline is broad and relies upon the clinical decisions and assessments of healthcare staff as to which types of patients fall under these categories. As demonstrated in Young Hip, healthcare staff tended to consider young patients as not requiring any further support with recovery or rehabilitation. By highlighting the

experiences of younger patients, Young Hip identified that the more complex expectations and priorities of younger THR patients may have benefitted from more support and guidance through their treatment and rehabilitation journey. Further provision of education and training for healthcare professionals to enable them to acknowledge the potential differing needs between younger and older THR patients is essential, and by extension THR patients from other different groups and backgrounds. Healthcare guidelines, such as NICE, would benefit younger patients by acknowledging their differing and more complex needs and in doing so prompt healthcare staff to consider how best to support them.

8.3 Closing summary

Person-centred care is an essential aspect of delivering quality care by any healthcare professional. It is not more relevant to one discipline or healthcare role than another and is a necessary priority for all staff working within a caring environment. This thesis has demonstrated the importance qualitative research methods has on person-centred care and why these methods are as essential as their quantitative counterparts. The patient's own voice is key in promoting and improving care. Unfortunately, when a patient presents in a way that does not fit the usual patient profile for a treatment or condition, their voice can often be marginalised or lost in the standard patient population. The Young Hip study has spotlighted some aspects of the young THR patient's experience that have not been considered in previous literature, these aspects are relevant and need to be considered by all healthcare professionals. By considering and implementing strategies to address these issues in the future is a vital step in ensuring quality and person-centred care for younger THR patients.

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Appendix 1. GIRFT Care Pathway for primary elective THR

Image available from National Health Service England, NHS., 2023. Getting It Right First Time (GIRFT) [online]. //gettingitrightfirsttime.co.uk

Appendix 2. Fundamental requirements for person-centred-care.

(adapted from the Health and Social Act 2008)

The care and treatment of service users must:	<ul style="list-style-type: none">a. Be appropriate.b. Meet their needs.c. Reflect their preferences.
Activities that must be carried out:	<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 service users or relevant persons to understand the care or treatment choices available and to discuss, with a competent health care professional or other competent person, the balance of risks and benefits involved in any particular in any particular course of treatment.d. Enabling and supporting the service user or 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 service users or relevant persons to manage the service user's care or treatment.f. Involving the service user or 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 service users or 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.

Appendix 3. Example of transcript from interview.

Baseline Interview with Rob (MKH006). 20th May 2021.

Face-to-Face Interview. Location- private room in hospital.

LM – if you wouldn't mind just telling me how it all started?

Rob – Erm, injury in the army and then I got referred to a physio, because of my knee...was hurting, but then the physio asked me to lay at the end of the bed and put my legs down and rest and obviously one leg stayed up and he was like, "well it's not your knee mate, it's your hip". I just got used to the pain. I only had physiotherapy, the army wouldn't send me for x rays and things like that so it was never dealt with and then I left the army.

LM – Nothing was diagnosed?

Rob – No

LM – How long ago was this?

Rob – *looks up at ceiling.* oof...I'd say...after 2012, sometime after that. That's when I went in for the knee...about the problems with my knee, I must've done the injury before that, probably basic training.

LM – So, you've been living with it for quite a while?

Rob – Yeah, yeah, yeah, just greased it out. *grins*

LM – How is the pain recently?

Rob – Erm...I'm just always in pain, I don't know any different, do you know what I mean.

LM – Does it affect your mobility?

Rob – Yeah, yeah, I walk with a limp.

LM – How has it affected things like work?

Rob – Err...oh...it's a nightmare at work, I've passed out at work before.

LM – Because of the pain?

Rob – Yeah, holding a radiator, luckily, like I was on my hands and knees.

LM – What do you do?

Rob – Heating Engineer

LM – How long have you done that for?

Rob – Err. 5 years...5 and a bit years.

LM – So the pain affects you at work, how about function?

Rob – Yeah, yeah, yeah, it's mainly sleep, I can't sleep on it, that's the worst thing, so I never ever get enough sleep, so I'm just tired all the time.

Appendix 4. Extract of reflexive recordings made before and after study interviews.

Claire Baseline Interview 13/03/2021

Telephone

<p>Pre-Interview</p> <p>What do I know?</p> <p>40F Other MSK conditions in addition to hip Considered “complicated” by surgeon.</p> <p>Thoughts</p> <p>?has children ?home life First interview= nervous, not sure how it will go/ what to expect. Interview schedule not yet tested on patients.</p> <p>How do I feel?</p> <p>Nervous, I have never undertaken an interview before. Interview was taking place via telephone due to time constraints, would have preferred the first interview to be face-to-face so could attempt to implement the guidance and advice I had read on interview techniques in IPA and qualitative research methods. No idea what to expect, or how long it will take. Reminder to listen to participant, NOT a conversation. Don't let nerves get better of you and start talking nonsense.</p>
<p>Post- Interview</p> <p>What do I know now?</p> <p>Married with 3 sons (similar age/ slightly older than mine) Long journey to treatment, lots of inconsistencies with treatment plan Feels let down by health service.</p> <p>Thoughts</p> <p>Very difficult interview Participant very distressed at times – I had to take on reassuring role. Unable to be a mother the way I perceive the role to be (active caring) Time running out to be a mother in this way (kids growing up, will need her less/ differently) Significant lack of control in her own treatment Long interview – emotional I am aware clinically that COVID has had significant impact on elective surgeries and wait times. Seeing it from patient's perspective. I can understand the frustration she felt by the constant postponements and changes in treatment plans. Feel like I went in at the deep end in terms of interview experience. Very long interview, Claire was very emotional and the experiences she described were very emotive.</p>

Her experience with healthcare staff was extremely negative based on her narrative, I did not recognise the staff members from her descriptions as my relationship with them is very different. Did feel awkward hearing her speak about them in a negative light – need to ensure that I separate myself more from them in future study activities. REMEMBER: I am NOT a nurse and their colleague in this situation, I am a researcher, and my priority needs to be to LISTEN to the patient and encourage a positive relationship.

Make significant effort to organise next interview time point as face-to-face, would be beneficial to observe non-verbal communications and body language within the interviews.

How do I feel now?

Relieved, first interview completed.

I am excited as have gathered a large amount of rich data.

I hope that allowing Claire to talk about her experience has had a positive effect on her and has helped her feel better.

Maybe a talked too much in the interview, note to listen back and try to identify times I should have shut up a bit more.

Appendix 5. REC Letters of confirmation



Health Research Authority

London - Chelsea Research Ethics Committee

Research Ethics Committee (REC) London Centre
Skipton House
80 London Road
London
SE1 6LH

Telephone: 0207 104 8029

13 January 2021

Mrs Louise Mew
Milton Keynes University Hospital NHS Foundation Trust
Research and Development
Academic Centre
Milton Keynes University Hospital
MK6 5LD

Dear Mrs Mew

Study title: An Exploration of the Young Patient's (50 years and under) own expectations of outcomes following a Total Hip Replacement.

REC reference: 20/PR/0858

Protocol number: 2021/IRAS/LM

IRAS project ID: 273277

Thank you for your letter received on 22 December 2020, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study. The revised documentation has been reviewed and approved on behalf of the PR sub-committee.

Confirmation of ethical opinion

On behalf of the Research Ethics Committee (REC), I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Good practice principles and responsibilities

The [UK Policy Framework for Health and Social Care Research](#) sets out principles of good practice in the management and conduct of health and social care research. It also outlines

the responsibilities of individuals and organisations, including those related to the four elements of [research transparency](#):

1. [registering research studies](#)
2. [reporting results](#)
3. [informing participants](#)
4. [sharing study data and tissue](#)

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database within six weeks of recruiting the first research participant. For this purpose, 'clinical trials' are defined as the first four project categories in IRAS project filter question 2. Failure to register is a breach of these approval conditions, unless a deferral has been agreed by or on behalf of the Research Ethics Committee (see here for more information on requesting a deferral: <https://www.hra.nhs.uk/planning-and-improving-research/research-planning/research-registration-research-project-identifiers/>)

If you have not already included registration details in your IRAS application form, you should notify the REC of the registration details as soon as possible.

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit: <https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/>

N.B. If your study is related to COVID-19 we will aim to publish your research summary within 3 days rather than three months.

During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you haven't already done so, please register your study on a public registry as soon as possible and provide the REC with the registration detail, which will be posted alongside other information relating to your project. We are also asking sponsors not to request deferral of publication of research summary for any projects relating to COVID-19. In addition, to facilitate finding and extracting studies related to COVID-19 from public databases, please enter the WHO official acronym for the coronavirus disease (COVID-19) in the full title of your study.

Approved COVID-19 studies can be found at:

<https://www.hra.nhs.uk/covid-19-research/approved-covid-19-research/>

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report
- Reporting results

The latest guidance on these topics can be found at <https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/>.

Ethical review of research sites

The favourable opinion applies to all NHS/HSC sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" above).

Approved documents

The documents reviewed and approved by the Committee are:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of materials calling attention of potential participants to the research [YOUNG HIP Poster]	1	18 November 2020

Evidence of Sponsor insurance or indemnity (non-NHS Sponsors only) [Sponsor Insurance Document]		01 August 2020
GP/consultant information sheets or letters [GP Letter v2]	2	17 December 2020
Interview schedules or topic guides for participants [YOUNG HIP Interview Framework]	1	18 November 2020
IRAS Application Form [IRAS_Form_25112020]		25 November 2020
Letter from funder [Letter from Funder MKUH]		16 November 2020
Letter from sponsor [BU letter from sponsor]		17 November 2020
Other [REC Completed Queries]	*Received 22/12/2020	
Participant consent form [YOUNG HIP Consent Form]	1	18 November 2020
Participant information sheet (PIS) [Participant Information Sheet]	2	17 December 2020
Referee's report or other scientific critique report [Evidence of peer review]		12 November 2020
Research protocol or project proposal [YOUNG HIP Protocol]	1	18 November 2020
Summary CV for Chief Investigator (CI) [L Mew CV]		17 November 2020
Summary of any applicable exclusions to sponsor insurance (non-NHS sponsors only) [EL PL and Products]	1.0	01 August 2020
Validated questionnaire [HOOS Patient Reported Outcome Measures]		

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: <https://www.hra.nhs.uk/planning-and-improving-research/learning/>

IRAS project ID: 273277	Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project.

Yours sincerely

PP

Mr Roger A'Hern Chair

Email: chelsea.rec@hra.nhs.uk

Enclosures: "After ethical review – guidance for researchers" [SL-AR2]

Copy to: Mrs Julie Northam



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales



Mrs Louise Mew
Milton Keynes University Hospital NHS Foundation
Trust
Research and Development
Academic Centre
Milton Keynes University Hospital
MK6 5LD

Email: approvals@hra.nhs.uk

13 January 2021

Dear Mrs Mew

HRA and Health and Care

Study title: An Exploration of the Young Patient's (50 years and under) own expectations of outcomes following a Total Hip Replacement.

IRAS project ID: 273277

Protocol number: 2021/IRAS/LM

REC reference: 20/PR/0858

Sponsor Bournemouth University

I am pleased to confirm that [HRA and Health and Care Research Wales \(HCRW\) Approval](#) has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see [IRAS Help](#) for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to [obtain local agreement](#) in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document “[After Ethical Review – guidance for sponsors and investigators](#)”, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The [HRA website](#) also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **273277**. Please quote this on all correspondence.

Yours sincerely,
Gemma Oakes

Approvals Specialist

Email: approvals@hra.nhs.uk

Copy to: *Redacted* **List of Documents**

The final document set assessed and approved by HRA and HCRW Approval is listed below.

<i>Document</i>	<i>Version</i>	<i>Date</i>
Contract/Study Agreement template [YOUNG HIP Contract Template]	1	01 July 2018
Copies of materials calling attention of potential participants to the research [YOUNG HIP Poster]	1	18 November 2020
Evidence of Sponsor insurance or indemnity (non-NHS Sponsors only) [Sponsor Insurance Document]		01 August 2020
GP/consultant information sheets or letters [GP Letter v2]	2	17 December 2020
Interview schedules or topic guides for participants [YOUNG HIP Interview Framework]	1	18 November 2020

IRAS Application Form [IRAS_Form_25112020]		25 November 2020
IRAS Application Form XML file [IRAS_Form_25112020]		25 November 2020
Letter from funder [Letter from Funder MKUH]		16 November 2020
Letter from sponsor [BU letter from sponsor]		17 November 2020
Organisation Information Document [OID]	1.6	17 December 2020
Other [REC Completed Queries]	*Received 22/12/2020	
Participant consent form [YOUNG HIP Consent Form]	1	18 November 2020
Participant information sheet (PIS) [Participant Information Sheet]	2	17 December 2020
Referee's report or other scientific critique report [Evidence of peer review]		12 November 2020
Research protocol or project proposal [YOUNG HIP Protocol]	1	18 November 2020
Schedule of Events or SoECAT [YOUNG HIP Statement of events]	1	23 November 2020
Summary CV for Chief Investigator (CI) [L Mew CV]		17 November 2020
Summary of any applicable exclusions to sponsor insurance (nonNHS sponsors only) [EL PL and Products]	1.0	01 August 2020
Validated questionnaire [HOOS Patient Reported Outcome Measures]		

Information to support study set up.

The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

Types of participating NHS organisation	Expectations related to confirmation of capacity and capability	Agreement to be used	Funding arrangements	Oversight expectations	HR Good Practice Resource Pack expectations
There is only one participating NHS organisation therefore there is only one site type.	Research activities should not commence at participating NHS organisations in England or Wales prior to their formal confirmation of capacity and capability to deliver the study.	An Organisation Information Document has been submitted and the sponsor is intending to use a separate site agreement.	No external study funding has been sought.	A Principal Investigator should be appointed at study sites	The sponsor has confirmed that local staff in participating organisations in England who have a contractual relationship with the organisation will undertake the expected activities. Therefore, no honorary research contracts or letters of access are expected for this study.

Other information to aid study set-up and delivery.

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.

- The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

Appendix 6. YOUNG HIP Patient Information Sheet



YOUNG HIP



An Exploration into the Young Patients' (≤ 50 years) expectations following primary Total hip arthroplasty: what outcomes are important to them? A Qualitative Study.

Participant Information Sheet

Research Ethics Committee Reference: 20/PR/0858

We would like to invite you to take part in a research study.

- Before you decide on whether you wish to take part, it is important for you to understand why this research is being done and what it would involve for you.
- Please take time to read the following information carefully and discuss it with others if you wish before you decide.
- Ask us if there is anything that is not clear or if you would like more information.
- Thank you for reading this information about the research study.

You are eligible to take part in this study if you are aged between 18-50 years of age and you are about to have a Primary Total Hip Replacement (THR). We are aiming to recruit between 6 to 7 patients to participate.

Participation in this study is entirely voluntary, so it is up to you to decide whether or not to take part.

If you wish to participate, you will be asked to sign a consent form and you will be given a signed and dated copy to keep.

You are free to withdraw from the study at any time without giving any reasons for the decision. A decision to withdraw or decision not to take part will not affect the standard of care you receive.

If you or any family member have an on-going relationship with BU or the research team, e.g. as a member of staff, as student or other service user, your decision on whether to take part (or continue to take part) will not affect this relationship in any way.

What is the purpose of this study?

Total Hip Replacements (THR) are amongst the most common operations performed in Orthopaedic Surgery. Although the majority of these operations are performed on older patients, there is a dramatically increasing demand for THR amongst younger patients' suffering with hip disorders. To be confident Healthcare Professionals are providing effective care for these younger patients, we need to be sure we address the patient's own individual needs and priorities throughout their treatment and recovery.

Currently, patients having a THR follow the same Patient Pathway regardless of their age. Because more of these patients are older, this pathway can focus on the needs of older people. This may make it less suitable for younger people. There is a real need to identify whether this pathway is meeting the needs of the younger patients undergoing THR. This study seeks to explore the priorities and goals of this group of patients and examine if the healthcare provided is meeting these.

What will happen if I take part?

You will receive the normal care that you would expect under the NHS. In addition you will be asked to attend three interviews with the researcher. The first one will be around the time you and your surgeon decide on surgery, the second will be six weeks after surgery and the final one six months after surgery. These interviews can take place either by face-to-face, remotely via video call, or via telephone. The interviews will always be arranged at a time convenient for you. These interviews will last around 30-40 minutes (though this is entirely your decision) and will explore your individual goals throughout your recovery. You will also be asked to complete a short activity score at each interview, it is important for the purposes of the study that this questionnaire be completed in respect of the hip with the replacement only. The interviews will be recorded and transcribed by the researcher. All the information you provide will be treated confidentially. The audio recordings of your activities made during this research will be used only for analysis and the transcription of the recordings for illustration in conference presentations and lectures. No other use will be made of them without your written permission, and no one outside the project will be allowed access to the original recordings.

What are the possible risks of taking part?

There are no risks in taking part in this study. Your THR procedure is not part of the research study, and the risks and benefits of this procedure should be discussed with your usual doctor, as part of your usual clinical care. Your participation in this study should not affect your decision whether or not to proceed with a THR or other suggested treatments.

What are the potential benefits of participating?

Although you may not benefit directly from participating in this research, we hope that the information learned from this study can be used in the future to benefit other younger patients having THR.

If I change my mind, what happens to my information?

After you decide to withdraw from the study, we will not collect any further information from or about you. As regards information we have already collected before this point, your rights to access, change or move that information are limited. This is because we need to manage your information in specific ways in order for the research to be reliable and accurate. Further explanation about this is in the Personal Information section below.

Who should I contact if I change my mind or have any questions about the study?

Please contact the research team using the contact details at the end of this form. Your participation in the research study is entirely voluntary. You are entitled to withdraw from this study at any time and continue to receive the same standard of care from your doctors.

Keeping your information if you withdraw from the study

If you withdraw from active participation in the study we will keep information which we have already collected from or about you, if this has on-going relevance or value to the study. As explained above, your legal rights to access, change, delete or move this information are limited as we need to manage your information in specific ways in order for the research to be reliable and accurate. However, if you have concerns about how this will affect you personally, you can raise these with the research team when you withdraw from the study.

You can find out more about your rights in relation to your data and how to raise queries or complaints in our Privacy Notice.

If you have any complaints or concerns with the running or management of this study, please contact

Professor Vanora Hundley, Deputy Dean for Research and Professional Practice, email researchgovernance@bournemouth.ac.uk.

The Patient Advice and Liaison Service (PALS) provide support and information for NHS patients, their families and carers. This service helps resolve any concerns or problems you may have when you are using the NHS and can provide information on how to get independent help if you wish to make a complaint. You can contact the service at Milton Keynes University Hospital directly on 01908 995 954 Email: PALS@mkuh.nhs.uk.

Will my taking part in this study be kept confidential?

All information collected for this study will be labelled with your unique study number and not your name. Only this number will be used on any research-related information collected during the study so that your identity as a participant in this study will be kept confidential.

Your personal details will be kept securely and confidentially by the researcher at Milton Keynes University Hospital on password protected secure NHS computers. No identifiable data will be shared with any other parties or researchers.

With your consent, we will inform your GP that you are taking part in this study. You do not have to agree to this, however, and if you would rather we did not notify your GP then we will not.

Bournemouth University (BU) is the organisation with overall responsibility for this study and the Data Controller of your personal information, which means that we are responsible for looking after your information and using it appropriately. Research is a task that we perform in the public interest, as part of our core function as a university.

Undertaking this research study involves collecting and/or generating information about you. We manage research data strictly in accordance with:

- Ethical requirements; and
- Current data protection laws. These control use of information about identifiable individuals, but do not apply to anonymous research data: “anonymous” means that we have either removed or not collected any pieces of data or links to other data which identify a specific person as the subject or source of a research result.

BU’s [Research Participant Privacy Notice](#) (appendix 1) sets out more information about how we fulfil our responsibilities as a data controller and about your rights as an individual under the data protection legislation. We ask you to read this Notice so that you can fully understand the basis on which we will process your personal information.

Research data will be used only for the purposes of the study or related uses identified in the Privacy Notice or this Information Sheet. To safeguard your rights in relation to your personal information, we will use the minimum personally-identifiable information possible and control access to that data as described below.

If you wish to receive the published results from this study then your contact details will be kept on NHS password protected computers in order to send these out to you. Any identifiable data will be deleted after the results have been sent.

Project governance documentation, including copies of signed participant agreements: we keep this documentation for a long period after completion of the research, so that we have records of how we conducted the research and who took part. This data will be kept for 5 years after the end of the study. The only personal information in this documentation will be your name and signature, and we will not be able to link this to any anonymised research results.

What type of information will be sought from me and why is the collection of this information relevant for achieving the research project's objectives?

The study seeks to discover and explore the personal goals and priorities of the younger patient throughout their journey from pre THR to rehabilitation and hopefully recovery. The interviews will be informal and mainly led by the participant in order to discuss the topics which are important to them.

Who has reviewed this study?

Before any research goes ahead it has to be checked by a Research Ethics Committee. This study has been reviewed and given favourable opinion by the **London – Chelsea Research Ethics Committee**.

Who is organising and funding this research?

The Chief investigator for this study is Louise Mew, Louise Mew is a Surgical Research Nurse at Milton Keynes University Hospital, she is also currently studying at Bournemouth University. The study is funded by Milton Keynes University Hospital. The Sponsor is Bournemouth University.

What will happen to the results of the research study?

The results from this study may be published in journals, presented at healthcare meetings and via social media so other healthcare professionals caring for similar patients can learn from the results. However, you will not be identified in any reports, publications or presentations. During your involvement, you will be asked whether you would like to be informed of the results of the study.

The information collected about you may be used in an anonymous form to support other research projects in the future and access to it in this form will not be restricted. It will not be possible for you to be identified from this data. To enable this use, anonymised data will be added to BU's online Research Data Repository: this is a central location where data is stored, which is accessible to the public.

As described above, during the course of the study we will anonymise the information we have collected about you as an individual. This means that we will not hold your personal information in identifiable form after we have completed the research activities. The only exception to this would be if you have opted to receive the results of the study as detailed in the sections above.

You can find more specific information about retention periods for personal information in our Privacy Notice.

We keep anonymised research data indefinitely, so that it can be used for other research as described above.

Finally

If you decide to take part, you will be given a copy of the information sheet and a signed participant agreement form to keep.

Thank you for considering taking part in this research project.

Appendix 1



Research Participant privacy notice

This Notice is for people who are participating in, or have been invited to participate in, an academic research project being undertaken by BU students and/or staff (“BU researchers”). You should read this Notice alongside the participant information sheet provided to you by BU researchers.

Questions

If you have any questions or concerns about participation in a research project and how your data will be collected and managed for the project, please contact the BU researchers using the details in the participant information sheet.

If you have any other questions or concerns about BU’s processing of information for research purposes and the content of this privacy notice, please contact the **BU Data Protection Officer (DPO)**:

Email: dpo@bournemouth.ac.uk

Telephone: 01202 962472

Address: Poole House, Bournemouth University, Fern Barrow, Poole BH12 5BB

Your rights as a data subject and how to exercise them

Under the data protection laws you have a number of rights in relation to our processing of your data. In summary these are:

- Right to request access to your data as processed by BU and information about that processing [“subject access request”]
- Right to rectify any inaccuracies in your data
- Right to request erasure of your data from our systems and files
- Right to place restrictions on our processing of your data
- Right to object to our processing of your data

- Right to data portability: where we are processing data that you have provided to us, on the basis of consent or as necessary for the performance of a contract between us, you have the right to ask us to provide your data in an appropriate format to you or to another controller.

Most of these rights are subject to some exceptions or exemptions. In particular there are limits on your right to restrict our processing or erase your data where this would impact adversely on the integrity and value of academic research, although as explained above we will usually agree to withdraw your data from studies where this is possible.

If you would like to exercise any of your rights as outlined above, you can contact the DPO as above or visit the Data Protection page on our website

<https://www1.bournemouth.ac.uk/about/governance/access-information/data-protection-privacy> to access the relevant forms.

We will always aim to respond clearly and fully to any concerns you have about our processing and requests to exercise the rights set out above. However, as a data subject if you have concerns about our data processing or consider that we have failed to comply with the data protection legislation then you have the right to lodge a complaint with the data protection regulator, the Information Commissioner:

Online reporting: <https://ico.org.uk/concerns/>

Email: casework@ico.org.uk

Tel: 0303 123 1113

Post:

Information Commissioner's Office

Wycliffe House

Water Lane

Wilmslow

Cheshire SK9 5AF

About this notice

In this Notice, "BU", "we", "our" and "us" refers to Bournemouth University Higher Education Corporation.

As a result of your participation in our research, BU will hold your "personal data", i.e. information in a form that identifies you as individual [often referred to as "data" in this Notice].

BU is the data controller of the information it collects and processes as described in this Notice. This means that it has the core legal responsibility to safeguard the information and ensure it is processed lawfully. The law is set out in the EU General Data Protection Regulation (called "GDPR") and a new UK law, the Data Protection Act 2018. In particular BU must:

- Take steps to ensure that the data it processes is accurate and up to date;
- Give you clear information about its processing of your data, in one or more privacy notices like this one and the participant information sheet (referred to together in this section as a "Privacy Notice");
- Only process your data for specific purposes described to you in a Privacy Notice, and only share your data with third parties as provided for in a Privacy Notice; and
- Keep your data secure.

Information about your data protection rights as a data subject is set out in the second section of this Notice.

How and why we will collect your personal data

We would like you to participate or continue your participation in academic research being carried out by BU researchers.

“Research” is a form of disciplined enquiry which aims to contribute to a body of knowledge or theory. The BU researchers carrying out the research may be undergraduate or postgraduate students (working under appropriate staff supervision), BU staff or a combination of staff and students. The research may be carried out only by BU researchers, or it may involve BU researchers working in collaboration with researchers in other organisations. BU processes provide that BU researchers will only carry out research where the results of the research will have value for society, and where the research will meet relevant ethical standards or requirements. BU researchers will provide you with a participant information sheet setting out details of the particular research study. This will explain the purpose of the research, the criteria for participating (i.e. why we think you are a suitable person to be involved), what is involved in participation (i.e. what we will ask you to do) and which data we will be collecting or generating and retaining in the course of the research project. It will also explain how we will use your data in our research outputs, and let you know if your data will be shared in an identifiable form with any third parties, such as collaborators from other organisations.

In addition to data we collect from you or generate through interactions with you as part of the research activity, we will also hold your personal data within project governance documentation (in particular participant agreements or consent forms) and records of any communications with you through email or letter. These will usually need to be retained for audit purposes even if you decide not to take part or withdraw from participation at a later date.

How we look after your data

BU will hold the data we collect about you in hard copy in a secure location and on a BU password protected secure network where held electronically.

Except where it has been anonymised, your personal information will be accessed and used only by appropriate, authorised individuals and when this is necessary for the purposes of the research or another purpose identified below. This may include giving access to BU staff or others responsible for monitoring and/or audit of the study, who need to ensure that the research is complying with applicable regulations.

The participant information sheet will provide further information about any measures specific to the research project which will be used to control access to your data or minimise the use of your data in an identifiable form.

Further uses of your data

We will usually only use your identifiable data for the purposes of the specific research project, and for associated monitoring and audit activities carried out by authorised individuals with responsibility for those activities. If we intend to use your identifiable data in any other related research project or for research over a longer period, this will be explained in the participant information sheet.

Where the research results in your data being anonymised and forming part of a statistical research dataset, we may store it in our research archive and use it (in that anonymised form) for future research.

Sharing your data

BU researchers will have access to your personal information in identifiable form as described in the participant information sheet. If it is necessary for the purposes of the research project for other people to have access to your personal information in identifiable form, this will also be explained in the participant information sheet. This may be the case if we are conducting the research in collaboration with other organisations (e.g. another university or an NHS body), if we need to use an external service (e.g. transcription) or if our work is monitored or audited by another organisation, such as a separate organisation providing funding for the research or a collaborator organisation with its own audit requirements.

If we do share your data in this way, there will be arrangements in place to ensure that the other organisation keeps your data secure and only processes it as necessary for the specific purpose relating to the research project.

Retention of your data

The participant information sheet will explain the length of time for which we expect to keep your data in identifiable form, and why we retain it for this period. This will include information about the duration of the project and whether it is necessary to keep data in identifiable form for the whole of that period. It will also inform you of any intention to keep identifiable data for a longer period, for example where there is an intention to link this research to outputs from another project, or to study changes to factors or outcomes over time.

In setting retention periods BU researchers will take account of any need to retain data in identifiable format to enable them to verify their research outputs, for example if their results are queried before or after publication, through peer review or where their research is subject to assessment or examination. They also need to take into account any requirements on BU to make data available for audit. However BU researchers should also set retention periods so that data will not be kept in identifiable form when this is no longer necessary either for the purposes of research in itself or for associated purposes such as audit. Where longer retention periods are identified as appropriate, this will be kept under review to ensure that we only keep identifiable data where this is necessary for continuing research purposes.

Appropriate security measures and access controls will be applied to identifiable data where a research project is complete and we are storing research data only for audit or verification purposes.

Legal basis for processing your data

The law states that we can only process your personal data if the processing meets one of the conditions of processing in Article 6 GDPR. If we are processing special category data (i.e. personal data which relates to your ethnicity, sex life or sexual orientation, health or disability, biometric or genetic data, religious or philosophical beliefs, political opinions or trade union membership), our activities also have to meet one of the conditions in Article 9 GDPR. Under the data protection legislation we need to explain the legal basis for holding your data, i.e. which of these conditions apply.

In general, where we are collecting and processing your personal data for the purposes of an academic research project the following conditions apply:

- Article 6.1(e) of the GDPR, i.e. our processing is necessary for the performance of a task carried out in the public interest. Research is a task that BU performs in the public interest, as part of our core function as a university;
- Article 9.2(j) of the GDPR, i.e. our processing is necessary for research purposes or statistical purposes (this condition applies as long as we are applying appropriate protections to keep your data secure and safeguard your interests: these are described above).

Consent is not generally the legal basis under the data protection legislation for use of your personal information for research. This is because we can only rely on your consent as the basis for processing data if we would always be able to act on a withdrawal of consent, by removing your data from our research project and outputs. Often we would not be able to do this in the context of a research project, as this could affect the validity and integrity of the research process and/or the outputs from the research.

We do ask for your consent to your active participation in the research, and you can withdraw this consent at any time. For example, if we have asked you to take part in interviews, complete a questionnaire or undergo observation you can pull out of these activities at any point. This consent to participation in the study does not mean that we are relying on your consent as the legal basis to the on-going use of your information through the course of the project and in the research outputs. If possible, where you withdraw from participation in this way we will also withdraw your data from the research project, but this will depend on the stage we have reached in the project and how your data has been used. We will not be able to withdraw all of your data from the study if this will have an adverse impact on the integrity and validity of the research. Even if we withdraw from the study your data that has been collected or generated within the research project, we will usually need to retain copies of your data within the project governance documentation (e.g. records of consent forms and possibly some communications with you).

However you may be asked for consent for specific uses of your information as follows:

- If we need to access information in your medical records for the purposes of the research, the law of confidentiality states that we can only do this with your consent. Once you have given consent, our on-going use of this information is covered by the conditions in the data protection legislation as described above;
- If we intend to use your personal data in our research outputs in an identifiable way, we will only do this if you specifically consent. For example, we will ask for your consent to include your photo or your name in any research reports or other outputs, and for inclusion of any film footage of you in any film to be produced as an output of the research. You can withdraw this consent at any time prior to publication or broadcast. Any refusal or withdrawal of this consent will not affect the on-going legal basis for the use of your information for the research itself, which is covered by the other conditions in the data protection legislation as described above.

The BU researchers will ask you to sign a participant agreement. This will set out any consents that are being requested for specific uses of your information, and it will also ask you to confirm that you have been given access to this Notice.

Appendix 7. YOUNG HIP Patient Consent Form

IRAS ID: 273277

YOUNG HIP version 1.0, dated

18/11/2020 Centre Number: Milton Keynes University Hospital (MKUH)

Study Number:

Participant Identification Number for this trial:

CONSENT FORM

Title of Project: YOUNG HIP

Name of Researcher: Mrs Louise Mew



Please initial box

- 1. I confirm that I have read the information sheet dated..... (version.....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
- 2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
- 3. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
- 4. I understand that the information collected about me will be used to support other research in the future and may be shared anonymously with other researchers.
- 5. I agree to my General Practitioner being informed of my participation in the study. (optional).
- 6. I understand that the interviews I participate in, whether face to face, telephone or video call, will be audio recorded and transcribed by the Researcher. I give permission for these recordings.
- 7. I agree to take part in the above study.
- 8. I would like to be informed of the results of this study and agree that my personal contact details be kept in order to send me the results, I understand my details will be deleted after the information has been sent. (optional).

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

When completed: 1 for participant; 1 for researcher site file; 1 to be kept in medical notes.

Appendix 8. YOUNG HIP GP Letter



01908 995 116
Louise.Mew@mkuh.nhs.uk

Dear Dr.

Subject: Patient taking part in the Young Hip study at Milton Keynes university Hospital.

I am contacting you today to inform you that [name of the participant] is taking part in a research study sponsored by Bournemouth University. The Young Hip Study is a qualitative study exploring the younger patient's (≤ 50 years old) priorities and goals when undergoing a Total hip Replacement.

Participation in the Young Hip Study will not affect the normal care the above patient will receive at Milton Keynes University hospital. In addition to the routine appointments, the patient will participate in three semi-formal interviews throughout their treatment journey, the first prior to their operation, the second six weeks after surgery and the final interview scheduled for six months post procedure. These interviews can take place either by face-to-face, remotely via video call, or via telephone, dependant on patient preference. These interviews will last around 30-40 minutes and will explore the participant's individual goals throughout their recovery. The interviews will be audio recorded and transcribed by the researcher.

Please find enclosed a copy of the Participant Information Sheet your patient has received. If you have any questions about the study, please contact me at the address given above.

Best wishes,

Louise Mew

Chief Investigator
Surgical Research Nurse

As a teaching hospital, we conduct education and research to improve healthcare for our patients. During your visit students may be involved in your care, or you may be asked to participate in a clinical trial. Please speak to your doctor or nurse if you have any concerns.

Chief Executive: Joe Harrison
Chairman: Simon Lloyd

Appendix 9. YOUNG HIP Screening Log (Redacted)

YOUNG HIP Screening Log

Screening Date	Participant Initials	D.O.B	MRN	Pt Eligible? Y/N	Date of Consent	Reason Patient Not Recruited	Participant Study Number
11/03/2021	[REDACTED]	[REDACTED]	[REDACTED]	Y	13/03/21		[REDACTED]
11/03/2021	[REDACTED]	[REDACTED]	[REDACTED]	Y	08/04/21		[REDACTED]
11/03/2021	[REDACTED]	[REDACTED]	[REDACTED]	Y		unable to re contact	
11/03/2021	[REDACTED]	[REDACTED]	[REDACTED]	Y	15/03/21		[REDACTED]
12/03/2021	[REDACTED]	[REDACTED]	[REDACTED]	Y	13/03/21		[REDACTED]

Page 1 of 3

YOUNG HIP Participant Log

YOUNG HIP Screening Log

Screening Date	Participant Initials	D.O.B	MRN	Pt Eligible? Y/N	Date of Consent	Reason Patient Not Recruited	Participant Study Number
31/03/2021	[REDACTED]	[REDACTED]	[REDACTED]	Y	13/05/21		[REDACTED]
31/03/2021	[REDACTED]	[REDACTED]	[REDACTED]	Y	04/04/21		[REDACTED]
07/05/2021	[REDACTED]	[REDACTED]	[REDACTED]	Y	31/05/21		[REDACTED]
21/05/2021	[REDACTED]	[REDACTED]	[REDACTED]	Y	01/07/2021		[REDACTED]
16/08/2021	[REDACTED]	[REDACTED]	[REDACTED]	Y	27/08/2021		[REDACTED]

Page 2 of 3

YOUNG HIP Participant Log

YOUNG HIP Screening Log

Screening Date	Participant Initials	D.O.B	MRN	Pt Eligible? Y/N	Date of Consent	Reason Patient Not Recruited	Participant Study Number
15/11/2021	[REDACTED]	[REDACTED]	[REDACTED]	Y	17/11/2021		[REDACTED]

Page 3 of 3

YOUNG HIP Participant Log

Version: 1.0
Date: 18.11.2020
IRAS number: 273277



YOUNG HIP

**Are you a patient who is scheduled to
have a Total Hip Replacement?**

Are you between 18-50 Years Old?

**Are you interested in the opportunity to
improve care by participating in
research?**

**You may be eligible to participate in a study
exploring the goals and priorities of younger
patients undergoing a THR.**

**If you are interested in finding out more with no
obligation to participate, please ask your Doctor
or contact:**

**Louise Mew (Research Nurse) on
louise.mew@MKUH.nhs.uk**

Tel 01908 995116

Appendix 11. Interview Guide
Appendix 12. Details of the interviews

	Claire	Diane	Annie	Patrick	Fran	Rob	Chris	Zoe	Henry	Scott
Baseline date	13/03/2021	24/03/2021	26/03/2021	08/04/2021	11/04/2021	20/05/2021	31/05/2021	01/07/2021	27/08/2021	18/11/2021
Location	Telephone	Video Call	Telephone	Face-to-face	Telephone	Face-to-face	Telephone	Telephone	Telephone	Telephone
Duration	49 mins 5 secs	36 mins 12 secs	59 mins 16 secs	49 mins 19 secs	27 mins 27 secs	12 mins 24 secs	24 mins 25 secs	38 mins 2 secs	28 mins 10 secs	21 mins 11 secs
6 week date	29/04/2021	28/10/2021	04/08/2021	10/05/2021	03/03/2022	14/07/2021	29/07/2021	12/01/2022	13/01/2022	31/01/2023
Location	Face-to-face	Telephone	Face-to-face	Telephone	Telephone	Face-to-face	Face-to-face	Telephone	Telephone	Face-to-face
Duration	43 mins 0 secs	26 mins 41 secs	11 mins 31 secs	27 mins 40 secs	26 mins 41 secs	9 mins 44 secs	23 mins 25 secs	31 mins 12 secs	17 mins 1 sec	30 mins 24 secs
6 week date	20/09/2021	14/03/2022	07/12/2021	04/10/2021	29/08/2022	18/11/2021	15/12/2021	09/04/2022	07/04/2022	27/04/2024
Location	Telephone	Telephone	Telephone	Telephone	Telephone	Telephone	Telephone	Telephone	Telephone	Face-to-face
Duration	22 mins 48 secs	26 mins 28 secs	21 mins 28 secs	33 mins 5 secs	17 mins 25 secs	6 mins 42 secs	9 mins 55 secs	26 mins 51 secs	7 mins 55 secs	11 mins 47 secs

Appendix 13. Hip disability and osteoarthritis outcome score (HOOS)



Hip disability and Osteoarthritis Outcome Score (HOOS) Survey

Patient Name: _____ Patient MRN: _____
Date: _____ Affected Hip: R L (Circle One)

Instructions:

This survey asks for your opinion about your hip and helps us understand how well you are able to complete your usual activities. Answer each question by ticking the appropriate box (only one box for each question). If you are uncertain about how to answer a question, please give the best answer you can.

I. Symptoms

Answer these questions thinking of your hip symptoms and difficulties in the last week.

S1. Do you feel grinding, hear clicking, or any other type of noise from your hip?

Never (+0) Rarely (+1) Sometimes (+2) Often (+3) Always (+4)

S2. Difficulties spreading legs wide apart

None (+0) Mild (+1) Moderate (+2) Severe (+3) Extreme (+4)

S3. Difficulties to stride out when walking

None (+0) Mild (+1) Moderate (+2) Severe (+3) Extreme (+4)

Stiffness is a sensation of restriction or slowness in the ease with which you move your hip joint.

S4. How severe is your hip joint stiffness after first wakening in the morning?

None (+0) Mild (+1) Moderate (+2) Severe (+3) Extreme (+4)

S5. How severe is your hip stiffness after sitting, lying, or resting later in the day?

None (+0) Mild (+1) Moderate (+2) Severe (+3) Extreme (+4)

Symptoms Subscale Score: $100 - \left[\frac{(\text{symptoms subscale sum} * 100)}{20} \right] = \underline{\hspace{2cm}}$

II. Pain

P1. How often is your hip painful?

Never (+0) Monthly (+1) Weekly (+2) Daily (+3) Always (+4)

What amount of hip pain have you experienced the last week during the following activities?

P2. Straightening your hip fully

None (+0) Mild (+1) Moderate (+2) Severe (+3) Extreme (+4)

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P3. Bending your hip fully

None (+0) Mild (+1) Moderate (+2) Severe (+3) Extreme (+4)

P4. Walking on a flat surface

None (+0) Mild (+1) Moderate (+2) Severe (+3) Extreme (+4)

P5. Going up or down stairs

None (+0) Mild (+1) Moderate (+2) Severe (+3) Extreme (+4)

P6. At night while in bed

None (+0) Mild (+1) Moderate (+2) Severe (+3) Extreme (+4)

P7. Sitting or lying

None (+0) Mild (+1) Moderate (+2) Severe (+3) Extreme (+4)

P8. Standing upright

None (+0) Mild (+1) Moderate (+2) Severe (+3) Extreme (+4)

P9. Walking on a hard surface (asphalt, concrete, etc.)

None (+0) Mild (+1) Moderate (+2) Severe (+3) Extreme (+4)

P10. Walking on an uneven surface

None (+0) Mild (+1) Moderate (+2) Severe (+3) Extreme (+4)

Pain Subscale Score: $100 - \left[\frac{(\text{pain subscale sum} * 100)}{40} \right] = \underline{\hspace{2cm}}$

III. Function, daily living

This section describes your ability to move around and to look after yourself. For each of the following activities, please indicate the degree of difficulty you have experienced in the last week due to your hip.

A1. Descending stairs

None (+0) Mild (+1) Moderate (+2) Severe (+3) Extreme (+4)

A2. Ascending stairs

None (+0) Mild (+1) Moderate (+2) Severe (+3) Extreme (+4)

A3. Rising from sitting

None (+0) Mild (+1) Moderate (+2) Severe (+3) Extreme (+4)

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A4. Standing

- None (+0) Mild (+1) Moderate (+2) Severe (+3) Extreme (+4)

A5. Bending to the floor/pick up an object

- None (+0) Mild (+1) Moderate (+2) Severe (+3) Extreme (+4)

A6. Walking on a flat surface

- None (+0) Mild (+1) Moderate (+2) Severe (+3) Extreme (+4)

A7. Getting in/out of car

- None (+0) Mild (+1) Moderate (+2) Severe (+3) Extreme (+4)

A8. Going shopping

- None (+0) Mild (+1) Moderate (+2) Severe (+3) Extreme (+4)

A9. Putting on socks/stockings

- None (+0) Mild (+1) Moderate (+2) Severe (+3) Extreme (+4)

A10. Rising from bed

- None (+0) Mild (+1) Moderate (+2) Severe (+3) Extreme (+4)

A11. Taking off socks/stockings

- None (+0) Mild (+1) Moderate (+2) Severe (+3) Extreme (+4)

A12. Lying in bed (turning over, maintaining hip position)

- None (+0) Mild (+1) Moderate (+2) Severe (+3) Extreme (+4)

A13. Getting in/out of bath

- None (+0) Mild (+1) Moderate (+2) Severe (+3) Extreme (+4)

A14. Sitting

- None (+0) Mild (+1) Moderate (+2) Severe (+3) Extreme (+4)

A15. Getting on/off toilet

- None (+0) Mild (+1) Moderate (+2) Severe (+3) Extreme (+4)

A16. Heavy domestic duties (moving heavy boxes, scrubbing floors, etc)

- None (+0) Mild (+1) Moderate (+2) Severe (+3) Extreme (+4)

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A17. Light domestic duties (cooking, dusting, etc)

- None (+0) Mild (+1) Moderate (+2) Severe (+3) Extreme (+4)

$$\text{Daily Living Subscale Score: } 100 - \left[\frac{(\text{daily living subscale sum} * 100)}{68} \right] = \underline{\hspace{2cm}}$$

IV. Function, sports and recreational activities

This section describes your ability to be active on a higher level. For each of the following activities, please indicate the degree of difficulty you have experienced in the last week due to your hip.

SP1. Squatting

- None (+0) Mild (+1) Moderate (+2) Severe (+3) Extreme (+4)

SP2. Running

- None (+0) Mild (+1) Moderate (+2) Severe (+3) Extreme (+4)

SP3. Twisting/pivoting on loaded leg

- None (+0) Mild (+1) Moderate (+2) Severe (+3) Extreme (+4)

SP4. Walking on uneven surface

- None (+0) Mild (+1) Moderate (+2) Severe (+3) Extreme (+4)

$$\text{Sports and Recreation Subscale Score: } 100 - \left[\frac{(\text{sports and recreation subscale sum} * 100)}{16} \right] = \underline{\hspace{2cm}}$$

V. Quality of Life

Q1. How often are you aware of your hip problem?

- Never (+0) Monthly (+1) Weekly (+2) Daily (+3) Constantly (+4)

Q2. Have you modified your life style to avoid activities potentially damaging to your hip?

- Not at all (+0) Mildly (+1) Moderately (+2) Severely (+3) Totally (+4)

Q3. How much are you troubled with lack of confidence in your hip?

- Not at all (+0) Mildly (+1) Moderately (+2) Severely (+3) Extremely (+4)

Q4. In general, how much difficulty do you have with your hip?

- None (+0) Mild (+1) Moderate (+2) Severe (+3) Extreme (+4)

$$\text{Quality of Life Subscale Score: } 100 - \left[\frac{(\text{quality of life subscale sum} * 100)}{16} \right] = \underline{\hspace{2cm}}$$

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Appendix 14. Example of stage two of Smith et al., (2009) six steps of analysis - Make initial notes to systematically capture observations.

Zoe (MKH008) Baseline Interview. Telephone. 01 July 2021.

<p>Zoe – Yeah, you know they do, they do, like they'll come to hug me and say, "is that your bad side?" and then they will adapt on how the come towards you to be cuddled or, you know, when you snuggle up on the sofa, you know, I cant really do that, or they'd have to sit kind of next to me but not on my lay, you know, my little girl is still quite little like she wants to cuddle up. She really is very cuddly, and even my middle boy, he is a cuddler, he's quite... I think there's a term for it, but he can tell when you're in pain, he can tell when you're upset, and he wants to be with you and make you feel better and he has to adapt how he comes and sits next to me and how he cuddles me and everything.</p> <p>LM – How does that make you feel?</p> <p>Zoe – It just doesn't feel like you're parenting well, kind of failing at your job, you know. It is hard, very hard to... think about, am I doing enough for them? You know, not being able to get down on your hands and knees and play, or play a game of football, or run around a park with her, it's... it's not nice, I'm relatively young, I look at some of the other parents at school and they're in their 40s and have got kids 7 and 10, I'm 35 and still can't do half the things they're doing. I mean I spent the best part of a year telling people I was 37, I'm not 37, I'm 35, erm... yeah really embarrassing.</p>	<p><i>then they will adapt on how the come towards you to be cuddled or, you know, when you snuggle up on the sofa,</i></p> <p>Kids adjust how they communicate with her to avoid causing her discomfort</p> <p>Children want to make her feel better, not their role. <i>Her role as a mother is to make them feel better</i></p> <p><i>It just doesn't feel like you're parenting well, kind of failing at your job</i></p> <p>Failing in her role as a mother</p> <p><i>I'm relatively young, I look at some of the other parents at school and they're in their 40s and have got kids 7 and 10, I'm 35 and still can't do half the things they're doing</i></p> <p>Comparing herself unfavourably to other parents</p> <p><i>Bad Mother-failing in her role</i></p>	<p>Relationships Inability to fulfil role</p> <p>Feelings of guilt, failure</p> <p>Comparing to others</p> <p>Failing as a parent</p>
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Appendix 15. Example of stage four of transcript analysis - Search for connections across emergent themes for each case.

Henry (MKH009)

BASELINE	My family didn't sign up for this.	
P5, L1	A little boy. And that's the main thing if I'm honest with you, why... I mean, obviously I do, I work quite a bit because I need... we need to pay the bills and stuff, I mean I want to take him to the park and things like that, at the moment it's very limited	partner due to give birth soon, pressure to work to provide for his family Pressure to work Fulfil perceived role Wants to be active with his young son, fulfil an active father role
P5, L2	my son knows I've got a bad leg yeah, oh yeah one hundred percent, he knows I can't ... I can't go for certain walks, or I have... I can't do as much as other people, so yeah, one hundred percent he's picked up on it	Young son is aware of his fathers condition, aware son knows that he cannot always actively do things with him Relationships Fulfilling role as father
P7, L1	She's obviously getting quite stressed now as well, she actually has to do a lot, she does a lot with our son anyway, she does a lot... I mean obviously we try and share duties; I mean if I do dinner, but I come back and my leg is hurting I literally can't do a lot. It's obviously very bad for her that I've got... I mean having my three-year-old to look after then if I come back... I mean not having to look after me but if I cant be as active as I should be, and then obviously she's nearly... what she's 32 weeks pregnant. It is quite draining but to be fair, she does... I mean she does	partner feeling pressure, having to pick up more tasks at home due to his pain and limited function Relationships Pressure to support partner Inability to fulfil role feelings of guilt at not being able to provide the support his partner needs

	do as much as she can but people have their limits, and my boy obviously when he's charging around and that, obviously it can be a bit hard.	
P8, L5	I just want to be able to walk without it hurting, you know, like you say I want to do this...I don't want to do anything big, I just want to get my normal life back, been able to walk, been able to do things, and take my son to the park, been able to do the shopping, been able to help out more, been able to work, you know, and just not be in so much pain really, is the main thing, just being able to get to more normal	priorities are to regain basic function

Appendix 16. Example of stage six of transcript analysis – looking for patterns between data

Subordinate theme of Sex Life? Forget it.

Fran BASELINE		
P6, L1	there's, nothing intimate...nothing intimate	No intimacy with partner
P6, L6	I'm sad about that, yeah, I am really sad about that, it's obviously a big part of a relationship. He doesn't mention it. LM – Is that due to function, pain or something else? NC – Pain...pain, yeah	Lack of intimacy affects both of them – failure to fulfil this part of relationship – recognises intimacy is important
Chris BASELINE		
P7, L8	not really, no... sometimes in certain ways it can be a problem, erm but it's not really got to the point where I'm like a 98-year-old trying to get into certain positions.	– not major negative effect on intimacy.
Zoe BASELINE		
P4, L16	you know never mind relationship it's everything encompassed isn't it. Every part of life it affects. Been intimate rarely ever happens, I'm usually in too much pain, it's not comfortable	Pain prevents SA and intimacy
P5, L6	not having that intimacy has a knock-on effect on to him as well.	Lack of intimacy affects partner too
Zoe 6 MONTHS		
P6, L10	That's not a thing as yet, because of a lot of things, Not just to do with my hip but the kids and time together, bit of both, it's not really a thing, he makes the odd comment but there's no engagement from him let alone from me, it's kind of...yeah it's at stalemate almost	Still no intimacy with partner, but not necessarily due to hip problems. Partner hasn't tried to initiate anything but has commented on the situation