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Psycho-social impact of developmental dysplasia of the hip and of differential access to early diagnosis and treatment: A narrative study of young adults

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Abstract

Objectives: Symptomatic developmental dysplasia of the hip can present in the young, active adult patient and can lead to severe pain and disability at a young age. The overall aim of the study was to deepen the understanding of the impact of developmental dysplasia of the hip on young adults' quality of life and psycho-social well-being, focusing on how differential access to early diagnosis impacted the trajectory of the disease and treatment options.

Methods: We conducted semi-structured interviews and gathered online stories from 97 participants. A narrative and thematic analysis was used to integrate the dataset producing a multi-dimensional view.

Results: A narrative plot showing how events unfolded over time was identified for each participant. Two common plots were identified: Plot 1 focused around those participants who received a prompt diagnosis and were treated within 12 months of diagnosis (n = 22) and Plot 2 focused around those who experienced a late/delayed diagnosis (mean = 8 years; range = 12–364 months) (n = 75) and thus delayed treatment. Participants in Plot 2 became more debilitated over time and experienced chronic hip pain for a prolonged period before an accurate diagnosis and/or intervention was made. It was clear from the narratives when pain persists over time, participants' quality of life and psycho-social well-being were affected.

Conclusions: Developmental dysplasia of the hip is an under-recognised condition; more research is needed to develop a clear clinical picture that can be used to alert frontline health professionals to the potential for developmental dysplasia of the hip so that they can promptly diagnose patients and refer them to specialist centres. Patients can also experience a profound impact on their quality of life and psycho-social well-being. Patients actively seek information from support groups about all aspects of their condition. Further research is required to determine the long-term impact of developmental dysplasia of the hip to develop evidence-based information for clinicians and patients.

Keywords

Hip dysplasia, developmental dysplasia of the hip, adult hip pain, qualitative, psychological, psycho-social, arthritis, impact, quality of life, surgery, periacetabular osteotomy, diagnosis, outcomes

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Introduction

Hip dysplasia

Developmental dysplasia of the hip (DDH) is a condition that is associated with pain, functional limitations and secondary arthritis.[1] Insufficient femoral head coverage is usually the dominant feature of DDH pain. DDH refers to a range of developmental hip disorders, from a hip that is mildly dysplastic, concentrically located and stable, to one that is severely dysplastic and dislocated.[2] Mild dysplasia might never manifest clinically or not become clinically apparent until adult life, whereas severe dysplasia is most likely to present clinically in later infancy or early childhood, with severe limping as a likely symptom.[3] In a dislocated or subluxated hip, the femoral head is completely or partly displaced from the acetabulum. This disorder can be

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associated with secondary acetabular dysplasia, whether or not the dislocation or subluxation persists. In a stable dysplastic hip, the acetabulum is dysplastic but the femoral head is stable and not displaced. While the two disorders might share the same antecedents, it is not known whether stable acetabular dysplasia in late adolescence is preceded by dysplasia and instability in infancy or is modifiable by early treatment.[4] Other grey areas include questions over whether stable, but mildly dysplastic, hips in childhood and adolescence have implications for hip function and also the risk of osteoarthritis in adult life.[4]

This article concerns adult DDH, where the acetabular deformity results in structural instability and mechanical overloading of the acetabular rim that, when left untreated, can lead to progressive hip degeneration.[5] DDH represents a significant worldwide disease burden and is thought to be the aetiology of 25%–43% of end stage osteoarthritis of the hip[6,7] Indeed, some instability has been identified in as many as 15% of new-born infants.

The exact causes of DDH are not known. Contributing factors are first born babies (not as much room in the womb), girls (more ligament laxity), positive family history and breech position that stretches the hips.[8] In spite of the frequency of DDH in babies and the potential for lifelong disability caused by DDH, awareness of this condition is poor, even within the medical profession and professions allied to health, both in primary and secondary care.[9] While in some countries (in particular, Austria, Netherlands, Germany and Norway[9]) babies are screened as infants for this condition, such screening programmes have not been taken up in inter alia the United Kingdom and the United States, where evidence of effectiveness is judged as tentative.[9] In consequence, neonatal screening is uncommon in the United Kingdom or the United States.[9] In adults, dislocation and subluxation can be diagnosed through clinical examination, but some form of imaging, usually plain X-ray, is necessary for the diagnosis of stable acetabular dysplasia.[10]

Many patients with symptomatic and functionally limiting hip dysplasia experience symptoms prior to the development of advanced secondary osteoarthritis. Patients frequently present in adolescence or young adulthood with pre-arthritic hip symptoms.[11] When left untreated, this structural abnormality can be associated with progressive hip degeneration and eventual end-stage disease.[12] Currently, there is very little research exploring pre-arthritic symptoms and their impact on the person's quality of life (QoL) and psycho-social well-being.

Given the known correlation with secondary osteoarthritis, various corrective hip osteotomy techniques have been proposed for the treatment of symptomatic dysplasia, all aiming to preserve the hip for a number of years.[13,14] For example, acetabular reorientation can optimise femoral head coverage, decrease articular cartilage loading, delay or prevent the development of secondary osteoarthritis and enhance patient function and activity.[11–17] To optimise the clinical results of hip joint preservation procedures, the hip should be treated in the pre-arthritic or early arthritic phase of the disease;[14] thus, early diagnosis is important. For young adults, access to early diagnosis is crucial as it enables a greater number of treatment options, including joint preservation surgery, which in turn could lead to better physical and psychosocial outcomes.

For health care providers to make a timely diagnosis of symptomatic acetabular dysplasia, they must have a familiarity with the clinical presentation, common findings on physical examination and radiographic abnormalities. However, there is a paucity of detailed information regarding the specific signs and symptoms of early symptomatic hip dysplasia and even less research which considers the overall impact on the patient's QoL and psycho-social well-being. Furthermore, dysplasia is a chronic illness, which has no well-defined recovery point and is a profoundly disruptive experience. It affects patients' everyday life, and the assumptions underlying their lives are altered and may need to be re-examined. Recent qualitative research has shown that its symptoms can be acute, enduring, chronic and long-term and have a devastating impact on QoL, especially on younger women.[18–20]

Hip pain can result in considerable impairment and disability. Many DDH patients experience chronic hip pain for a prolonged period before an accurate diagnosis and/or intervention.[8,13,15] This complexity of pain is especially evident when it persists over time as psychologic, economic and social factors can interact with physical factors to change a patient's report of pain and subsequent disability.[21] Pain as it relates to insomnia and anxiety has been the focus of lower back pain research.[22]

However, there has been little research into the burden of chronic pain in young and middle-aged adults with hip dysplasia. Data on pain for DDH have been limited to clinical notes and reports on patient pain and associated physical examination findings.[8,13,15,20] These same descriptive studies report the insidious onset of pain, with the average time of symptom onset to diagnosis being 3.1–5.1 years, respectively.[8,13] In addition, patients often have to have several major surgeries over their lifetime. However, few authors have documented the impact of major hip surgery at a young age. Our previous research[18,19] highlighted the traumatic emotional and QoL effect of total hip replacement (THR) surgery in young women. Many would rather have reconstructive surgery that may not last many years, rather than lose their native hip joint.

A feature of many studies considering a chronic illness is that the temporal dimension of the disease experience is largely ignored. This applies at both methodological and conceptual levels. Research on the impact of diagnosis and treatment on sense of self commonly use a cross-sectional approach, examining these issues with participants who are all at different stages in the illness trajectory. In contrast, the study we present here set out to explore the trajectory of

DDH, from first perceptions of its onset to the participants' current location on the life-course trajectory. In essence, our study and this article set out to uncover the physical, psychosocial and QoL impact of hip dysplasia in young adults over the trajectory of the disease.

Aim

The overall aim of the study was to deepen the understanding of the impact of DDH on young adults' QoL and psychosocial well-being, focusing on how differential access to early diagnosis impacted the trajectory of the disease and treatment options. This involved the following:

1. Mapping the trajectory of DDH over a person's adult life, allowing insight into how the condition affected their QoL and psycho-social well-being;
2. Identify significant time points in the participants' stories using narrative analysis, combined with in-depth thematic data analysis;
3. Explore participants' narratives telling the story of their life with DDH over time and draw out a common or set of plots unfolding within their stories.

Design

As befits an exploratory study, a research method was needed to enable easy capture of the experience of participants early on in their DDH journey and to follow them over time as they made choices about what to do following diagnosis. Capturing a broad range of experiences was essential to begin to map out the trajectory of DDH over the lifespan. A narrative approach combined with in-depth thematic data analysis was used to draw and map out significant events/critical turning points in their life with DDH and its impact on their everyday lives.

Procedure

Recruitment

Two different sources were used to recruit participants. First, interviews were conducted by the lead author at an adult hip clinic within a specialist hospital centre. We anticipated that these patients would be getting the best treatment. There are two reasons for this: (a) care would be delivered by a nationally recognised expert and (b) optimum treatment should result, with patients receiving the most suitable surgical treatment, for example, reviewing them to see if they were suitable for osteotomy treatment. Patients for recruitment to the study were contacted prior to their appointment at the clinic. These appointments could relate to a patient with an initial diagnosis, pre-op or post-op checks, from 6 weeks post-op up to 1 year. The patients were then consented to take part in the study. They were interviewed after their appointments in a quiet room next to the clinic.

Second, participants were recruited from an online web forum. To capture a potentially wider perspective, we wanted to include participants from different countries, socio-economic status and experience of different funded (state/private) services and participants who may have or were waiting for hip replacement surgery.

Three criteria that guided the selection were accessibility by an outsider, dedicated focus on DDH and its activeness.[18] Sampling was purposeful: first, an Internet search was undertaken to identify a suitable message board aimed at young women diagnosed with DDH. The term 'hip dysplasia, congenital hip dysplasia (CHD) DDH' was entered into the *Google* search engine. The first 10 websites with message boards that did not require a username or password were selected for further examination. Second, the boards were assessed for their focus on DDH. Seven of the message boards focused on general hip problems, with DDH coming up only as an occasional thread. The other three focused solely on DDH. Third, these three message boards were monitored to establish which sites were the most active and popular, with the intent of targeting the most active posters at the time of data collection. The most active message board was chosen and the most active posters at the time of data collection were targeted for the final data collection.

The site moderator was contacted, and permission was given to access the site for the research. An advert was placed on the site asking for volunteers to complete a screening questionnaire. This asked specific questions about their age, age of diagnosis, time taken to confirm their diagnosis, number and type of surgeries and whether they were bilateral or unilateral. To gain insight into a potential diverse range of experiences, the participants were purposively sampled to ensure variability in terms of type of diagnosis (bilateral or unilateral), time of first diagnosis (previous diagnosis or history of surgery as a child, vs. no previous history or sudden diagnosis) and participant age. If chosen to participate, each potential participant was asked to write a narrative/story detailing their experiences of living with DDH. To assist this, they were provided with a topic guide.

National Health Service (NHS) ethical approval was obtained for the clinical interviews and university ethical approval was obtained for the online data collection. To protect the anonymity of its members, the message board is not identified.

Analysis

A narrative and thematic analysis was used, aimed at integrating the dataset to produce a multi-dimensional view; both authors analysed the data and discussed and agreed outcomes at key points in the analysis process. Narrative analysis added temporality and plot; thematic analysis allowed patterns in the data to be identified. The thematic qualitative data analysis approach centred on identifying patterns in the data.[23] We used both a deductive perspective,

directed content analysis (using themes drawn from our previous qualitative research[18,19]) and inductive, drawing out additional themes from participants' stories.[24] Further analysis was undertaken to explore how patterns related and inter-connected. The trajectory of DDH over a lifespan was mapped identifying significant time or turning points allowing insight into how the condition affected the typical younger adults at these pivotal points. A narrative plot showing how events unfolded over time was then identified for each participant and similarities and differences in the plots, and associated stories, were explored with a view to see if there was one common plot or a set of plots, for example, in relation to differentiation to an early, young adult or late adult time of diagnosis.

Narrative analysis

The stories were read in two ways. Initially, the text was read to gain a 'naive understanding' and to become familiar with its overall meaning. The second reading allowed 'comprehension', giving a more detailed understanding, supported by explanations.[25] During this phase, the data were coded and an outline for each story was mapped. Mattingly[26] suggests that stories are 'event-centred' and actions can be placed within a plot which has a beginning, middle and end. They are also 'experience-centred'; they do not merely describe what someone does in the world but what the world does to that someone. The third reading brought together explanation and understanding to allow an in-depth level of interpretation. Because stories are essentially meaning-making structures, care was taken to preserve the way the participants constructed their stories and the meanings attached.[27] As Frank[28,29] argued, the narratives themselves were recognised as the participants' accounts/stories at the time they were written and have truth-value for them at that time. Each story, organised in a timeline (e.g. first awareness of pain, finding out what was wrong, treatment decisions, etc.), was then closely re-read to identify the events that made up the story, that is, the plot. The 'events' in our context are significant events (such as the onset of severe pain) and/or turning points (such as cannot cope with pain, must seek help), with the events relating to each other in a pattern or time sequence. The plots were constructed drawing on the ideas of the Russian folklorist Propp[30] who analysed the basic plot components of Russian folk tales to identify their simplest irreducible narrative elements.

Organising the data

The initial narrative analysis of each participant, and comparisons, showed definitive evidence of two different plots, and associated stories, according to an early (treated within 12 months of diagnosis) (n = 22) or a late/delayed (mean = 8 years; range = 12–364 months) (n = 75) diagnosis. Each of these two plots was also associated with a different aim that participants in the plot were pursuing.

Thematic analysis

Thematic analysis was also used to help identify patterns in the dataset. The emerging themes were then reassessed to explore how the varied patterns were related and inter-connected. We also categorised the data by participant diagnosis and treatment stage, enabling us to focus the analysis around the different phases of the illness trajectory and compare differences in experiences of hip dysplasia across the dataset. Three phases were explored:

1. Beginning – experiences before and up to diagnosis. Each story started at a different time point (dependent on the case and their narrative account), but usually with their first memories of experiencing DDH until the time of diagnosis.
2. Middle – surgery and up to 1 year post surgery. Significant events around treatment were identified for each participant.
3. End – after 1 year post surgery and resulting lifelong care.

A narrative plot was then developed for each participant. The plots were mapped to see if one common/typical plot could be created, and thus provide an in-depth understanding of the concerns and impact of living with DDH.

Results

The participants

Twenty-nine interviews conducted within the clinic and 68 stories generated from the online forum were analysed (total n = 97). Participants' ages ranged from 18 to 42 years (mean = 32) and most (n = 92; 94%) were female. All the participants had a confirmed diagnosis of DDH. For 53 participants, the left hip was affected, for 21 participants the right hip and 23 participants were affected bilaterally. The patients were all at different stages in their illness trajectory. Their body mass index ranged from 18.5 to 65 (mean = 32), and time since diagnosis ranged from 6 to 364 months (mean = 8 years).The treatment stage of each patient varied (Table 1).

Analysis and interpretation of the narrative plots and associated stories

Insight into the three phases of the narrative plots (differentiating between the beginning, middle and end) is presented below. The intention is to provide an overall picture of the journey of someone diagnosed with DDH, from first awareness to the concluding part in their treatment

Table 1. Patients' treatment stages.

Treatment stage	Number (n = 97)	Percentage
Beginning – experiences before and up to diagnosis	32	33
Middle – surgery and up to 1 year post surgery, significant events around treatment were identified for each participant	36	37
End – after 1 year post surgery and lifelong care	29	30

journey, commonly post-treatment. Within each significant stage of the plot, event themes are illustrated. Two plots emerged from the narratives: (a) Plot 1: those participants who received a timely diagnosis and were treated very quickly (within 12 months) at a specialist centre (N = 22), and (b) Plot 2, those participants who experienced delays in ascertaining a diagnosis (N = 75) and described more severe symptoms and impact on QoL. By presenting these two plots, distinct differences between the participants' experiences of hip dysplasia are articulated.

The two different plots reflected participants' differential access to early diagnosis and onset of symptoms. Plot 1 (n = 22) comprised participants who received a prompt diagnosis. These participants had experienced minimal delay from initial symptom presentation to first surgery, and the mean average age at time of diagnosis was 22 years (median = 26; range = 15–32). In contrast, Plot 2 participants (n = 75) had experienced significant delays in ascertaining a diagnosis and their age at the time of diagnosis was substantially higher (mean = 29; median = 32; range = 21–48 years).

Plot 1: a timely diagnosis

The aim of those who received a timely diagnosis centred on identifying how to manage their DDH and their treatments. The plot gradually unfolds over time moving through five main phases/critical turning points: (a) seeking a diagnosis; (b) seeking to preserve the hip joint, for example, by developing ways to cope with the condition through lifestyle changes and/or postponing treatment; (c) deciding on treatment options; (d) coping with treatments and post-surgery recovery; and (e) coming to terms with the need for long-term treatment/care.

Beginning: experiences before and up to diagnosis

'First awareness'. Commonly, memories were described that illustrated when the participants first became aware of their hip dysplasia.

> I think things got worse when I was pregnant carrying extra weight, my hips started to hurt, I couldn't stand by the end of the day; my hips ached I would come home and collapse.

One common incident recounted was their first feeling of acute hip pain and its nature. 'I remember walking on one particular holiday in flip-flops, the pain at night was awful'. Participants described significant events when they first began to be aware of pain and discomfort with their hip. This varied between a one-off sharp stabbing pain triggered by an activity or fall and gradual onset of pain after prolonged activity, the latter being more common. Notwithstanding, many did not do anything about these symptoms, for example, by seeking medical or other help, until the symptoms started to impact more on their normal activities.

'Making changes/adaptation'. The narratives pointed to a second sub-theme where participants began to change their lifestyle to manage their hip pain. A gradual process was described, first to minimise activities that caused pain. Often this would be by reducing the mileage in runs or changing to lower impact activities such as swimming and cycling.

> I was always able to run through it; the pain was never that severe. But the fact that it kept coming back started to concern me. So, I reduced my running and started to swim more, and the pain seemed to ease even though it was still there.

> I was managing pain, reducing impact activities that made it worse, or taking days off exercise sitting down more. Then I kind of realised what was going on, my hip was hurting more and more often, and the pain gradually got worse.

Another common description was changing footwear:

> I started to take trainers with me wherever I went so I could slip them on … They kind of helped to reduce the shock and sharp pain pushing through my hip.

'Seeking support, following advice and pacing'. Participants all described how they did not seek help/advice initially and tended to self-manage until they needed pain relief. Later, they all sought help and advice from a clinician, usually a general physician (GP) or physiotherapist, some also consulting personal trainers and fitness experts. For these participants, as their symptoms were having such an effect on their overall QoL, they kept going back for further advice.

However, DDH was commonly not recognised by the clinician immediately. Most of the participants were diagnosed with soft tissue injuries and advised to avoid high impact activities. Often they were either put on a strengthening

programme or told to take rest and minimise certain activities to manage the symptoms.

> My physio prescribed some exercises to increase strength once I gave up running … I did start to feel better, but the pain didn't completely go away and also I kept trying to run again but the pain would return.

This cycle of pacing was described frequently. Eventually, even with the adaptions and pacing, the participants still experienced pain. It was at this point that they persisted in seeking advice and help. The pain became enough to interrupt their lives and impact of their QoL, leading them to cease doing certain activities or decline social invitations. This was a period of being in 'limbo', living with a level of pain which would be reduced by adapting their lifestyle. However, it was difficult for them to understand why and when the pain would become a problem. Participants also described interrupted sleep patterns, feeling uncomfortable sitting and standing for prolonged periods. For others, the pain was less invasive, but it still interrupted their daily life.

'Getting a diagnosis'. The participants' accounts revealed their own substantial lack of awareness of hip dysplasia and also, most significantly, the lack of awareness of health care professionals. A small number of participants described being very forthright and asking their GP for a referral to a hip specialist, while others referred themselves privately. A common approach was joining hip groups on the Internet and, through social media, gaining advice from other people with hip dysplasia. This provided support to participants and helped them to find appropriate advice. These participants were often advised on a range of things, from seeking specialist care onto how to manage the pain.

> The support I received was invaluable; the group advised me on the best hospitals … who to see, what to ask. I saw a hip specialist; he confirmed it was hip dysplasia and went through the options for surgery with me.

Participants described how positive and helpful this was in not only gaining the care required and receiving useful advice in managing the condition and providing overall reassurance.

The Plot 1 participants were all referred to a specialist centre where they received the diagnosis or referred soon after they received a diagnosis. Only one participant had been diagnosed by the GP and one participant was referred by a physiotherapist who suspected that the symptoms could be due to a structural problem, such as dysplasia.

> My physio tried lots of things, then she referred me on as nothing was really helping the pain, and after 6 months I still wasn't able to return to running and impact activities. I am only 21 and this isn't normal.

Within this 'Beginning' phase, participants described the impact of receiving a diagnosis of hip dysplasia. The women had to deal with the discord between the medical uncertainty and the lived certainty of hip pain. Participants found it hard to deal with their having a condition that was a 'structural problem' and not something that could be resolved by physiotherapy or changing their lifestyle, especially when the pain was not always there.

> I was stunned I would need surgery … My surgeon very bluntly told me this was major surgery and without it I (would) just gradually get more debilitated. What made this worse was that sometimes I had no pain at all.

As this group received a prompt diagnosis within a specialist centre, treatment options were clearer. Most participants had a fairly undamaged joint and would thus be candidates for osteotomy surgery (re-orientation of the hip joint), itself a highly invasive surgery and needing up to a year to recover. They understood that this was the only option to preserve their natural joint and to prevent early hip replacement.

> It came as a real blow finding out I would need surgery 100 miles away from home, I needed to be off work for a long time, no one could say (for) how long, and I would need a lot of help at first when I went home … With 3 toddlers this was going to be tough.

Participants outlined the impact of receiving a definitive diagnosis and presentation of treatment options. A mix of emotions were described, as up to this point in their life, a large number of the participants were fit and healthy. They felt very 'disorientated' in that the condition was affecting their everyday lives and lifestyle. Moreover, they did not anticipate needing such invasive surgery to treat their hips. Many different reactions were depicted. For half, it was a case of 'let's just get this done and move on'. For the others, another cycle of seeking support and managing through pacing began, thus, to try to see if they could manage without surgery, or at least postpone it. This group found it difficult to understand why their symptoms were affecting their lives; they were not life threatening, sometimes being minimal, and yet they needed major surgery:

> I struggled to get my head around the fact my symptoms were not extreme but I needed this massive surgery.

For the bilateral patients, three were asymptomatic in the other hip and four had symptoms in both hips. For these patients, much of their narratives at this point focused on which hip to treat first, whether to leave the asymptomatic hip and monitor it for symptoms or, if both were symptomatic, how long to leave in between operations:

> I was left feeling devastated finding out both hips were affected although I only have symptoms in one at the moment.

> I had severe dysplasia in both hips. When I had the first surgery the Right was not giving me any bother … 6 months into my recovery it started giving me pain … That was tough, not only feeling the pain but knowing I would need surgery in the near

> future in that hip too. I felt like I was just trapped with this condition … like my life would never get back to normal.

All participants experienced an underlining feeling of shock and distress. Many described being very unsure of the surgery and what would happen after the surgery. Descriptions of what they would be able to do later were described as 'vague' and differed among participants. A key concern was for how long their hip would 'last' before a THR or revisions.

Middle treatment

All Plot 1 participants had reconstruction surgery (peri-acetabular osteotomy or triple osteotomy). All described the gravity of the surgery and the long recovery.

> I was really poorly. The first 6 weeks were hard, I couldn't do very much. I felt vulnerable like I had lost my independence … Asking people to do things was hard … The recovery was difficult my leg felt so weak, but I persevered with the exercises and found I gradually got stronger. I still walk with a slight limp 2 years on. I'm not sure if that will ever go.

Participants also described the isolation they felt.

> As I started to feel better. I felt really isolated being at home, especially in the daytime when all my friends were working, I did join a PAO Facebook group which was great for getting tips and general advice and reassuring me. But I missed my normal life.

Those who were further on after their surgery described how hard the recovery was:

> The surgeon said it would probably be a year before I felt the real benefit from the surgery, the recovery is hard my muscles feel weak and I am still battling not to limp … Initially I was afraid of doing too much … I had to take every day as it came, small steps. I moved back in with my parents so that I didn't need to worry about feeding myself, doing laundry, etc, so I could focus on getting better.

They also described the lack of certainty that went with rehabilitation.

> There was no clarity about what should be happening and when … I didn't know if I was doing well or making a slow recovery.

Normal life was also affected: 'I had to defer my university course'.

> I had to take a lot of time off work to have the operation and then recover. My job as a police woman involves standing walking around, so I had months off, then I had to go back a few days a week but take a more sedentary role. It was really soul destroying.

End: lifelong care

The participants were generally hopeful about the future. Many talked about their aspirations post-surgery:

> I hope at some point in my life to be pain-free. I hope to be able to do the things physically that I want to do and not pay the price later. I hope to do things after double PAOs that I never did before PAOs … I want to finish a triathlon … I want to complete a century (100 mile) bike ride … I want to take up downhill skiing.

Participants also talked about how hard it was returning to their normal self-post-surgery. Many had been fit and healthy and very active.

> The experience has given me a lot of perspective. I am forever grateful for being able to walk again and I will never take it for granted.

All participants struggled to deal with the fact that it would take a long time to recover and be active again.

> Before DDH, I felt pretty good about myself. I was in good shape. I was healthy. Since having my PAO, I have gained some weight and I'm having a really hard time losing it. I want to be at my pre-surgery weight before I go into my next surgery or I'll just end up even more overweight. It gets me down a lot lately. I just can't seem to lose the weight. Intense exercise aggravates my operated hip, so I try to stick to regular but moderate exercise. It's just not having an effect on the scales.

Each recovery journey differed. The very active participants wanted to get back to normal; others were happy to be able to walk, wear normal clothes, be able to work and have a social life. All participants also worried about the future of their hips,

> I wanted to know the long-term effects of the condition, whether it was going to be okay to run or whether I shouldn't make huge demands on my hips.

The 'endings' in this group highlighted many positive narratives. For example, many of the participants further down the journey were able to return to sport and activities. However, 'Endings' was clouded by an uncertainty of what the future might hold. Many participants were aware of future hip replacement surgeries or further surgeries on the other hip. They felt something of great significance had changed in and impacted on their everyday life and lifestyle:

> I have been through a huge life changing operation, but this might not be the end. I most likely will need to go through this again in the future … That's the part I struggle with.

Plot 2: delayed diagnosis

A contrasting plot was found for those participants who had a delayed diagnosis (longer than 1 year, mean = 8 years). The aim of those who had a delayed diagnosis centred around trying to establish what was wrong with their hip and, post-diagnosis, with how to cope with their newfound diagnosis of DDH and treatment options. The plot gradually unfolds over time moving through five main elements: (a) coping with hip pain, making changes and adapting their everyday lives and lifestyle; (b) seeking advice and pacing their

activities; (c) obtaining a definitive diagnosis; (d) coping with treatments and post-surgery recovery; and (e) coming to terms with the need for long-term treatment/care.

Beginning: experiences before and up to diagnosis

The first experiences of hip dysplasia were similar. Plot 2 participants referred to the onset of pain and symptoms in a similar manner to those in Plot 1. However, some Plot 2 participants did not pinpoint any dramatic turning points and described the gradual onset of pain. All participants described being able to monitor and draw out a relationship between their activities and the pain. Life went on as usual until their hip pain reached the point where it became so persistent that it could not be normalised and controlled anymore. The pain interrupted and made social functioning in everyday life impossible. The participants thus reached in their everyday lives dramatic turning point, where pain interrupted normal walking, sitting, sleeping, and other vital functions of everyday life.

Making changes and adapting. At this time, a greater difference between the two plots became evident. For participants in Plot 2, 'making changes and adapting' was very prolonged, up to 5 years for some, and many participants became very debilitated over a period of years. Participants described 'pacing and changing their routines' to cope with the pain initially. They all described managing using pain killers, rest and adapting their lifestyle. For example, one participant described,

> My usual Saturday morning would be going to the gym in the morning, then a relaxed walk around town in the afternoon. This changed to doing one or the other as the pain would be too bad at night if I tried to do both. I would then start to limit how far I went in town by picking shops close to each other with a sit-down coffee break. When I look back it was awful. I could barely walk before my op.

Participants also described changes in engagement with family and peer groups, for example, actively avoiding trips or events that required prolonged walking or standing around. The workplace could offer challenges to those participants who were required to stand or sit for a long time: 'I struggled at work and I had to spend more and more time sitting down'.

Often this realisation of a need to do something more, such as seek help, took quite a while. Commonly it was only many years later, that they sought help and/or began to focus or realise they need to find ways to cope with this ongoing or recurring pain and discomfort. The subthemes 'Seeking Support', 'Following Advice' 'Pacing' lasted much longer for this group.

Plot 2 participants sought support from a range of professionals, GPs physiotherapists, personal trainers, chiropractors, osteopaths, psychiatrists, psychologists and, sometimes, complementary and alternative medicine practitioners. Despite seeking support and seeing many practitioners, a diagnosis was not made until this group became very debilitated and their problems were significantly impacting on their QoL.

> It was confusing at first because I'd seek help, slow down, adapt my lifestyle and then feel better … The pain would go and then I would be back to square one. When I went to the physio she would tell me to lay off running and high impact sports etc. This went on for years as I was confused about what was wrong … then suddenly I had a rapid decline. My symptoms dramatically got (such that) I could barely walk, I was in pain all the time. I couldn't work, go out. My life was disappearing.

There were many stories of being sent home with pain killers and exercises and told to manage the pain themselves. 'I even underwent physiotherapy treatment because they thought it was just a soft tissue injury. This went on for years'.

A further difference between participants in Plot 1 and Plot 2 was that, for those in Plot 2, their cases were never, at this stage, escalated to specialist care for a diagnosis. So the cycle of 'making changes > seeking support > following advice' continued, with participants moving between the three depending on their pain and symptoms at the time. They described many of years of living with pain and feeling debilitated. Over time, the symptoms got worse and their function declined dramatically.

> I just struggled, it was hard not being able to play with my kids like other moms … the pain killers helped but I never even thought I'd ever be pain-free … I reached a point where I could barely go out. Every journey or trip had to be carefully planned as I couldn't walk very far … Sitting for a long time also caused me problems … Sleep was difficult; I was constantly sleep deprived.

> I changed the way I shopped to buying groceries in petrol stations as I could no longer get round a large supermarket.

The majority of participants also described the impact of the growing disability on their psycho-social welfare.

> I became very isolated as I couldn't go out much. This affected my confidence and I got that I didn't want to go out at all … I stopped volunteering to go places, even simple things like the coffee run (which was a walk up the high street) just so I didn't have to move.

Participants also reported the effect on education and work and its significance.

> I didn't go to university as I knew I would not cope being away from my parents. I can go later but I felt like I was behind all my friends … I felt different when we met up; they were all having a great time and I had to stay at home.

> I developed an eating disorder. I would say it had a lot to do with how I was feeling at the time, in pain isolated, no-one understood me it was the one way I could control my life.

> I got moved around the department to do jobs that didn't require moving around as much but even sitting was hell all day … basically you are in constant pain and that sucks.

A small number of participants described just getting on and living with these severe symptoms, believing that there was nothing that could be done about it. This often went on for years and had an impact on all areas of life.

Middle

Diagnosis. Diagnosis happened a long time after symptoms had started and through varied routes.

> I was back and forth to the GP for years. It was only when I moved (that my) new GP referred me to a hip specialist and I got a diagnosis.

> I kept googling my symptoms and eventually found an on-line, self-help group who told me good surgeons to see … I paid privately, got the diagnosis and then had to wait a long time for my operations, more delays. But at least I knew what was wrong.

Online support featured quite heavily in their stories. Most of the participants used this to seek support for their diagnosis and to help them work through and understand treatment options. As their symptoms and cartilage damage by now were more severe, the treatment options were more limited. Difficult decisions often needed to be made as to whether a PAO was an option or whether a THR was more appropriate.

> After being told the only option was a hip replacement … which I couldn't get my head around. I found a patient advocate on the internet, I sent my CT scans and X-rays to them, they sent them to a surgeon in India and 2 in America. There was a consensus that a resurfacing might be possible. So I persevered and found a surgeon in the UK who was prepared to try a resurfacing. This cost me a lot of time, energy and stress.

Participants expressed anger that their hip dysplasia had not been picked up earlier. For those in Plot 2, the delays were up to 8 years (n = 76, range = 2–8 years, average = 5.2 years). Many participants described how they had been told their joints were too damaged to do an osteotomy but that they now needed a hip replacement. Delayed diagnosis was limiting their treatment choices.

Treatment. Those post-surgery described their recovery, which was generally long and intensive. Many years of disability meant they would take longer to recover physically and emotionally.

> The physio told me that having a misshapen joint for all those years meant that my muscles now no longer knew how to work properly and would have to be retrained. I know when the pain started to go away I felt so weak my left leg was so much thinner than my right. I found physio hard as I was so out of shape. I'd put on weight and generally I felt really pathetic.

> I struggled with the whole thing the physical recovery. But it was so hard re-engaging in life, going out meeting people was hard. I still felt like the old me, really self-conscious about the way I looked and walked.

End lifelong care

The participants reflected on their experiences. This group differed from those in Plot 1, as many were very angry that it had taken so long to get a diagnosis and be treated. They depicted a very detrimental effect on their QoL. They all highlighted future fears of further surgery and disability. Some, in contrast, were able to adapt and move on with their lives.

> Having a hip replacement age(d) 38 is not ideal but it has enabled me to live my life again pain-free. I worry about using it too much or putting too much pressure onto it … How long will it last? I am quite fearful. But you must move on with your life. I have lost so much of it going through all of this.

Discussion

The overall aim of the study was to deepen understanding of the impact of DDH on young adults' QoL and psycho-social well-being, focusing on how differential access to early diagnosis impacted the trajectory of the disease and treatment options. Two common plots were identified: one focused around those participants who received a prompt diagnosis and the other focused around those that experienced a late/delayed diagnosis, and thus delayed treatment. Differential access to early diagnosis and its impact on participants' everyday lives, its quality and their lifestyle, and treatment options was evident through their stories. This is reflected in the two plots, whose main differences lie in the elements unfolding through the stories, particularly prior to receipt of a definitive diagnosis and deciding on treatment options.

The plots allowed us to map the trajectory of DDH over an adult's life, giving insight into how the condition affects persons with DDH. We were able to identify significant turning points in the patients' stories and explore in detail these significant events. Events ranged from experiences before and up to diagnosis (the Beginning phase), onto treatments up to 1 year post surgery (the Middle phase) and, finally, to the period after 1 year post surgery and lifelong care (the End phase).

The findings highlighted the differing illness trajectories emerging from both plots. The first signs and symptoms experienced were similar in both plots. Making changes, adapting and seeking support were much more prolonged for participants in Plot 2, and diagnosis was delayed (mean = 8 years; range = 6–364 months). This delayed diagnosis time is great but consistent with that found in Nunley's[8] case series, where the average time to diagnosis was 61.5 months in 57 skeletally mature patients. Moreover, as in our study, most of their patients were female (72%) and presented with an insidious onset of activity related

pain (88%). This suggests a definitive clinical, and patient, need to accelerate time to diagnosis. Indeed, Coombs et al.[11] highlighted that only recently has the clinical presentation of symptomatic acetabular dysplasia been characterised. The presenting symptoms in patients can be variable and radiographic analysis is challenging, particularly in those patients presenting with mild acetabular dysplasia.[5]

When seeking support, our participants described going to see a range of clinicians and usually on several occasions. Participants, in both plots, were often advised to reduce activities such as sport and exercise. More often than not, this led to a reduction in the severity of symptoms, with the pain returning if and as soon as they returned to higher impact activities. Differences then emerged in how the participants in each plot responded and took on this advice. Those in Plot 1 were either more persistent in going back to clinicians to report the return of symptoms or the clinicians were more aware of hip dysplasia and referred them on to specialist centres. In contrast, participants in Plot 2 took much longer to obtain a diagnosis, and they became more debilitated over time. In some cases, our participants were advised to do exercises or limit sports without a proper diagnosis, with the clinician, commonly the GP or physiotherapist, perceiving their pain and symptoms coming from a soft tissue injury. The pain experience of participants in Plot 2 was thus similar to that found in Nunley's study where moderate-to-severe pain was experienced by 77% on a daily basis.[8] Nunley's physical examination findings also showed limp (48%), positive Trendelenburg sign (38%) and a positive impingement test (97%). Indeed, many participants in Plot 2 experienced chronic hip pain for a prolonged period before an accurate diagnosis and/or intervention was made. In wider literature, chronic pain is considered as comprising a complex interaction between physiological, psychological and social factors, and as often resulting in or maintaining disability.[21] For example, Prather et al.[31] found patients who are considered candidates for hip preservation surgery often present with pain for prolonged periods of time.

Our study extends existing evidence in presenting the broader QoL and psycho-social impact of hip pain and the considerable impairment and disability caused by DDH, differential access to early diagnosis and choice of treatment options. It also highlights the problems of coping with such a progressive and variable condition. In addition, for our participants, their hip dysplasia impacted on work, education potential and wider social connections, sometimes resulting in impacts on key developmental milestones, such as missing university, participation in normal, young-person social activities and developing bonds with peers.

It was clear from the narratives that both groups were struggling to cope with the symptoms and the diagnosis. Several psychological issues were described. This complexity of pain, and its psychological impact, is especially likely when it persists over time, as psychological, economic and social factors can interact with physical factors. It was evident from the narratives that treatment is focused primarily around adjusting the hip structure. Because this hip pain may be chronic, these patients develop other co-existing, modifiable disorders related to pain that may also go undiagnosed in this young and active population. This finding coheres with Prather et al.[31] who found that hip patients with radiographs demonstrating minimal to no hip arthritis experienced significant cofounding with other modifiable disorders, such as sleep, insomnia and anxiety. This highlights a need for more research. Prather et al.[31] also suggested that if recognised early in presentation, treatment of insomnia and anxiety ultimately will improve outcomes for hip patients, whether they are treated either conservatively or surgically for their hip disorder.

The experiences of participants in Plot 2, and their associated stories, show the difficulties in gaining an early diagnosis and highlight the need to raise awareness of hip dysplasia to frontline clinicians such as physiotherapists and primary care physicians. The data show many incidents where patients were not referred on for specialist care. Indeed, other research has emphasised that accurate radiographic analysis of young adult patients with acetabular dysplasia is a critical component of the clinical evaluation.[5] It is therefore crucial that frontline clinicians recognise the clinical signs of DDH, so they can refer patients for X-ray and early access to specialist hip surgeons in secondary care and thus potentially ensure an early accurate diagnosis and prompt treatment.

Again, more research is needed to identify early signs and symptoms that primary care physicians and physiotherapists could recognise as indicative of hip dysplasia. Moreover, there is also a need to raise awareness among clinicians, both in primary and secondary care, and at-risk patients and their families. Indeed, many of our participants were unaware that their symptoms could indicate hip dysplasia. They, thus, spent many years trying to get a diagnosis and treatment, while their condition was dramatically declining. In addition, persons with DDH with early diagnosis have more available treatment options, particularly centred on preserving the hip joint, replicating a finding of our early qualitative research.[19] For example, reorientation periacetabular osteotomy, despite being very invasive and having a long rehabilitation and recovery period, is only indicated in active patients with preserved articular cartilage.

The plots and associated stories also varied in relation to how mentally prepared for surgery participants were. Plot 1 participants struggled as the symptoms were very variable. However, once they stopped certain high impact exercises, they ceased to have any symptoms, so it was difficult to comprehend why such invasive surgery was necessary. In contrast, Plot 2 participants welcomed any treatment that would relieve the symptoms they had had for so long, but they were still fearful that surgery would make things much worse. However, in general, across participants in both

plots, surgery was difficult, as they all had to take a long period of time out of their usual lives and routines to recover, with many then feeling very isolated. Participants' access and use of online web forums was reported to provide a great support mechanism. Many of the participants used the forums to seek advice from others with DDH on recovery exercises. This study and our previous research showed the depth of discussions that happened on these forums and highlight a need for more post-operative information and support from health care providers.

The endings and lifelong care phase differed between participants in the two plots. Those that had a quicker pathway to diagnosis and treatment tend to recover and adapt better than those who have experienced a lengthy time to diagnosis and treatment. Thus, participants in Plot 1 tended to recover and return to normal activities within the recommended parameters of time, compared to those in Plot 2 where treatment decisions were more limited. Many of these participants also struggled knowing they had to have a hip replacement. Moreover, recovery from surgery was also very difficult. It is important to note that little research has been conducted looking at optimum physiotherapy and rehabilitation for persons with DDH.

Our participants also described the lasting impact of DDH, both physical and emotional. Participants in both plots considered the long-term health of their hips. Participants in Plot 1 wanted to know if they should be doing anything to help the survival of their native hip, for example, sticking to low impact sports. Those in Plot 2 wanted to know how long their hip replacement would last and feared further operations. Both groups talked about the need to re-define their sense of self, for example, through developing other coping strategies and developing other interests conducive with living with a hip condition. Those in Plot 2 described how hard it was to pick up their lives when they had lost so much through the hip disability they had experienced. These findings point to a potential need for psychological support to be offered to those suffering with hip dysplasia, and especially those who experienced a late diagnosis.

There are several key messages that can be delineated from this research. First, DDH is an under-recognised condition by both the general public and among clinicians. More research is needed to develop a clear clinical picture that can be used to alert frontline health care professionals to the potential for DDH so that they can promptly refer patients to specialist centres. In addition, there is a need for greater awareness among the general public and policy makers about DDH and to highlight its impact on persons with DDH and their families. Second, our study demonstrated that patients struggle to cope, both physically and psychologically. More research is needed to identify confounding conditions, such as stress, anxiety and insomnia, in persons with DDH and also to explore coping strategies, and the development of support mechanisms to address these psychological issues, Third, DDH has been seen very much as a physical condition corrected by surgery. However, patients express a need for much more detailed information about their condition. In its absence, they seek information from online web support groups. While exchanging insights and experiences with others with DDH is highly valued, notwithstanding there remains a risk that information provided may not, at least in clinical terms, be authoritative or based on up-to-date evidence. Fourth, our study demonstrated that participants are very concerned about the long-term health risks and the longevity of their operations. As there is limited knowledge about the psycho-social impact of DDH, and other paediatric hip conditions, such as Perthes,[32,33] outcome measures do not currently exist to provide a longitudinal profile of these patients, an issue that some of our other research is targeted.

Limitations

The study recruited participants from two sources: a specialist hip clinic in a single clinic site, and a single, but dedicated, DDH online web forum. In both instances, participants were effectively volunteers who felt able, and were prepared to take time, to tell their story. Our participants' stories may thus not fully represent patient stories. Indeed, forum participants are likely to be those who are more concerned about their diagnosis and treatment options and want to be proactive in finding out as much as they can. By implication, those who are more vulnerable and less proactive may not have taken the first step of looking for and joining, and/or active posting, in such a forum.

A further limitation of such data is that it is not possible to ask the members to expand on points of interest or ambiguity (as would be done in the course of an interview). This suggests a potential need for further research with patients from additional specialist hip clinics, along perhaps with random sampling at different times in their health care journey and, if possible, pursuit of additional avenues to recruit web-bases participants, from example, by using the websites of two charities (DDH UK and STEPS Charity Worldwide) for those with hip disorders. Notwithstanding, a sizable number of persons were recruited to our study from our two sites, enabling us to build on our earlier small-scale exploratory study.[18,19] In addition, selection of participants in both instances was theoretically informed to provide insight across the participants' illness journey with DDH.

Using patient narratives which are generated over a short time period does not facilitate sequential data analysis. Thus, data saturation may or may not have been the case in our study. However, the fact that significant numbers (22 and 75) were located in one of each of two plots that unfolded from their stories suggests that this may be the case.

At the same time, our data have provided fuller insight into participant experiences. This was built on the participants' own stories. To assist the participants, we provided a set of topic areas that they might structure their story around. However, patient stories may be seen as a limitation, as the

stories may be either more positive or negative reconstructions of the past, depending on the current impact of their hip condition on their everyday life and functioning. However, we concur with Frank[29] that patient stories have a truth-value at the time they were recounted. Moreover, the participants themselves are the only ones who can appropriately and effectively tell their story.

Further work in a more extended study is warranted, both drawing on this and other DDH-specific websites. It could valuably include interviews carried out over time with the same participants, from first symptoms to conclusion of treatment. Interviews would also enable exploration of these specific points of interest or ambiguity lying in the postings and to supplement insight into their perspective. More generally, the findings of our research to date are suggestive of possible areas for inclusion in a condition-specific measurement tool to assist DDH surgeons and other health care practitioners to monitor the treatment they provide and to help evaluate treatment effectiveness longitudinally; this forms a focus of other research we are conducting. In conclusion, our findings build on the extant literature and provide another lens by which to understand the process of how a disability and/or a visible difference can, over time, affect confidence, self-esteem and body image in young women.

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