SPLASH Study

Exploring caregiver perspectives of adults with **S**evere and **P**rofound and multiple **L**earning Disabilities **A**ccessing **S**edentary **H**ydrotherapy (**SPLASH** Study)

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Copyright statement

Abstract

Background:

The term Learning Disability (LD) defines a significant impairment in cognition and social functioning, present from birth/early-childhood with a lifelong enduring impact. Severe LD (SLD) and Profound and Multiple LD (PMLD) diagnoses are made when intelligence quotient falls below 35 and 20 respectively. Physical disability in LD is largely neurological as brain development is interrupted/affected.

While the effectiveness of hydrotherapy (use of water for therapy/rehabilitation) is proven in many neurological conditions (e.g. Cerebral Palsy, Alzheimer's/Parkinson's disease), evidence regarding adults with SLD/PMLD is lacking. Previous research in other neurological populations (e.g. Cerebral Palsy/stroke), has centred on the biomedical-model of disability, highlighting a need for exploratory and biopsychosocial research (combining biomedical with psychosocial factors: e.g. wellbeing, support/care needs).

Aim:

Exploring caregiver perspectives of adults with Severe and Profound and Multiple Learning Disabilities accessing sedentary hydrotherapy.

Design/methodology:

In this qualitative study, caregivers of adults with SLD/PMLD were recruited through public advertising and participated in virtual semi-structured interviews and an online-questionnaire. The biopsychosocial International Classification of Functioning, Disability and Health framework underpinned the study methodology, informing the main interview topics and questionnaire. Topics included: health, function, welfare, connections and support. Thematic analysis was used to analyse interview data, while the questionnaire provided demographic and contextual data.

Findings:

Twenty-three caregivers participated in the study: five family, nine health-professional, eight paid, one volunteer. Alongside barriers/facilitators and the impact of Covid-19, six unique themes of importance were identified: body systems, choice, motivation and inspiration, emotions, quality interaction, family bonding and social inclusion.

Conclusions:

Through exploring caregiver perceptions of hydrotherapy and adults with SLD/PMLD, SPLASH Study has gained unique biopsychosocial insights into the experiences of a population underrepresented in research literature. Caregivers reported wide ranging impacts including physical improvement, and psychological as well as social benefits: these should be considered in future research and practice development.

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Abbreviations

ACPPLD	**A**ssociation of **C**hartered **P**hysiotherapists for **P**eople with **L**earning **D**isabilities
BSRM	**B**ritish **S**ociety of **R**ehabilitation **M**edicine
CHC	**C**ontinuing **H**ealth **C**are
CP	**C**erebral **P**alsy
CSP	**C**hartered **S**ociety of **P**hysiotherapy
GMFCS	**G**ross **M**otor **F**unctioning **C**lassification **S**ystem
ICF	**I**nternational **C**lassification of **F**unctioning, Disability and Health
IQ	**I**ntelligence **Q**uotient
LD	**L**earning **D**isability
LeDeR	**Le**arning Disability **De**ath **R**eview (known as the Learning Disability mortality review)
MCA	**M**ental **C**apacity **A**ct
MRes	**M**aster's by **Res**earch
MSK	**M**usculo-**Sk**eletal
NIHR	**N**ational **I**nstitute for **H**ealth **R**esearch
NHS	**N**ational **H**ealth **S**ervice
PEG	**P**ercutaneous **E**ndoscopic **G**astrostomy
PMLD	**P**rofound and **M**ultiple **L**earning **D**isability
PPE	**P**ersonal **P**rotective **E**quipment
SLD	**S**evere **L**earning **D**isability
SPLASH Study	Exploring caregiver perspectives of adults with **S**evere and **P**rofound and multiple **L**earning Disabilities **A**ccessing **S**edentary **H**ydrotherapy
SRR	**S**ociety of **R**esearch in **R**ehabilitation
TaSSeLs	**Ta**ctile **S**igning for **Se**nsory **L**earner**s**
UK	**U**nited **K**ingdom
VQ	**V**olitional **Q**uestionnaire
WHO	**W**orld **H**ealth **O**rganization

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CHAPTER ONE: INTRODUCTION AND RESEARCH RATIONALE

1.1 Introduction to learning disabilities

The term 'Learning Disability' (LD) defines a significant impairment in cognition and social functioning, with onset from birth/early childhood and has a lifelong enduring impact (Department of Health 2001). Adults with LD present with a wide range of cognitive and physical abilities, although Intelligence Quotient (IQ; a solely cognitive measure) is often accepted as an appropriate severity indicator (Hardie and Tilly 2012). 'Severe LD' (SLD) diagnosis is made when IQ is below 35, and 'Profound and Multiple LD' (PMLD) when IQ falls below 20 (Hardie and Tilly 2012).

Physical disability in LD is largely neurological in nature, as usual development of the central nervous system is interrupted/affected during gestation or early childhood (due to genetics, traumatic injury, or illness; Bruce and Standley 2019). This leads to the cognitive and social impairments which are later used to identify the presence of LD (Department of Health 2001).

High tone (hypertonia) causes muscles to contract too much, making limbs very tight and stiff, whereas low tone (hypotonia) results in muscles being unable to contract enough, sometimes affecting the individual's ability to sit/stand without support (Mosby 2013): either state of altered muscle tone can result in physical disability. Altered tone is a common neurological feature among people with LD yet it has no relationship with the severity of the individual's cognitive or social impairments (Bruce and Standley 2019). In many other neurological conditions (e.g. Multiple Sclerosis, Cerebral Palsy (CP) and stroke), the severity of diagnosis directly correlates with severity of physical disability (Palisano et al. 1997). However, severity of LD and physical disability are not synonymous (Bruce and Standley 2019); for example, assumptions cannot be made that everyone with PMLD requires a wheelchair. The disparity between cognitive and physical abilities in LD invalidates the classification systems used to define disability in other neurological conditions; such as the 'Gross Motor Function Classification System' (GMFCS) developed for children with CP (Palisano et al. 1997). Thorough biopsychosocial description including cognitive, physical/medical, and independence/care needs of the sample is therefore vital in strengthening the potential generalisability/transferability and relevance of LD study findings.

1.2 Introduction to hydrotherapy

Hydrotherapy is the use of water for therapy and rehabilitation (Mosby 2013); it can be active (the service user moves their own body), passive (the service user remains relaxed and allows the water/third party to move their body) or sedentary (largely passive, but the service user does not need to remain completely still/relaxed). Both passive and sedentary hydrotherapy are delivered by a third-party, e.g. Physiotherapist or carer (Figure 1).

Image redacted: taken from https://www.harrys-hydro.org/

Figure 1: Photograph illustrating passive/sedentary-hydrotherapy (Harry’s Hydro 2020)

In active hydrotherapy, the service user follows instruction/demonstration in order to carry out specific exercises or activities in the pool; this form of hydrotherapy is also commonly referred to as aquatic exercise (Myers et al. 2013). In passive hydrotherapy, the service user follows instruction to remain completely relaxed, and to allow themselves to be moved – either by third party (e.g. therapist/carer), or by resistance of the water itself as a result of the support given to them either by floatation aids, or third party (Myers et al. 2013). For the purposes of this study, the term ‘sedentary hydrotherapy’ is used to describe an approach which is largely passive in nature (i.e. movements are applied to the body by third party/water), but does not rely on the service user having the cognitive ability to follow the instruction to remain completely relaxed and non-participatory in their therapy.

While active hydrotherapy is often high-intensity with the aims of improving strength and exercise tolerance, both sedentary and passive hydrotherapy have the aims of managing muscle tone and using the properties of the water to move the body in ways which are not possible on land (Myers et al. 2013). These aims align themselves well to the treatment of many neurological conditions, e.g. CP, Alzheimer’s and Parkinson’s disease (Myers et al. 2013; Kim et al. 2015). As previously mentioned, physical disability in LD is largely neurological in nature, it is for this reason that many therapists choose sedentary and passive hydrotherapy interventions when determining the most appropriate therapy programmes for individuals with LD (this ‘evidence informed practice’ is discussed further in the following section).

1.3 Practice context relating to hydrotherapy and adults with LD

A Public Health England report from 2016 (Public Health England 2016) estimated that 1.5 million people in the United Kingdom (UK) had a learning disability: approximately 1,130,000 of which were adults, and 350,000 had a diagnosis of SLD/PMLD. The report concluded that these figures amounted to approximately 2.16% of the adult UK population. Here in Dorset there are 4,851 adults with LD diagnosis on their medical records (Our Dorset 2021); it isn't known how many of these adults have SLD/PMLD. The accuracy of these statistics is difficult to determine given that the terms “learning difficulty” and “learning disability” are often incorrectly used interchangeably, leading to the inclusion of adults with difficulties such as dyslexia or attention deficit hyperactivity disorder within these statistics (Bruce and Standley 2019). While adults with learning difficulties experience very real challenges which may impact on their social functioning, there is no associated cognitive/intellectual impairment relating to these diagnoses (Bruce and Standley 2019). It is also of note that these are the most recent national statistics available as this information is not regularly updated, but rather sourced only to be presented alongside significant policy or legislative change (e.g. Valuing People (Department of Health 2001) and the Care Act (Department of Health 2014)). This lack of current and up to date epidemiological information illustrates how under-served the adult LD population is; perhaps surprising given that an NHS report from 2021 estimated 151,565 adults to be in receipt of long term, social care funded services, solely in relation to their learning disability (NHS Digital 2021).

Section 1.2 discusses the definition of hydrotherapy and the clinical rationale for its use with neurological patient populations. According to Bruce and Standley (2009) many LD Physiotherapists consider hydrotherapy as a suitable alternative treatment when land based therapy fails to achieve outcomes, and they use this to underpin their clinical reasoning when identifying or prioritising which patients should access hydrotherapy. However Heath and Pataky (2014) argue the unique properties of water (particularly buoyancy, thermodynamics and hydrostatic pressure) mean hydrotherapy is more than just a therapeutic tool of last resort. Heath and Pataky (2014) suggest these properties create a unique environment which enables patients to benefit in ways which are impossible on land. Therefore urging therapists to consider hydrotherapy as a first line of treatment to enable specific patients to attain land based goals, rather than a backup plan when land-based therapy has failed. There are no specific recommendations relating to the indication of hydrotherapy specifically for adults with SLD/PMLD, and no statistics available regarding the number of adults with LD to whom these recommendations would apply. Due to the paucity of adult LD physiotherapy research (later discussed in sections 1.4 and 2.2), a “standards of practice” document was published following consultation with experienced specialist LD Physiotherapists through four rounds of online questionnaires using a Modified Delphi technique (Bruce and Standley 2019). The “standards of practice for Physiotherapists working with adults with an LD” suggest hydrotherapy may be indicated when service-users are unable or unwilling to tolerate land-based therapy programmes, or when additional therapeutic input is required to supplement existing land-based therapy programmes (Bruce and Standley 2019). While these practice standards therefore document the clinical reasoning and rationale underpinning current LD physiotherapy practice in relation to hydrotherapy, they also demonstrate the lack of specific adult LD hydrotherapy evidence on which Physiotherapists could base their clinical practice.

Physiotherapists are able to implement many of the practice recommendations within this "standards of practice" document (Bruce and Standley 2019) without requiring external approvals or resources (e.g. manual therapies require no increased costs or use of specialist facilities). However, hydrotherapy presents a specific challenge as Physiotherapists are rarely in a position to agree funding for sessions, or to cover the increased costs of carer time or travel arrangements. Historically hydrotherapy was widely available for adults with LD (including SLD/PMLD) through attending NHS run hydrotherapy pools; many of which were located within NHS long stay LD institutions and so were widely available, free of charge, to adults with LD living in such institutions or the community (Auty 2007). Here in Dorset, the NHS trust responsible for LD services ceased to own a hydrotherapy pool in 2013 when the NHS long stay LD unit, where it was located, closed under the campus reprovision project (Department of Health 2001). This NHS trust have not run a hydrotherapy pool since this time and have no plans to replace this facility. Sadly the number of hydrotherapy facilities nationally is similarly diminishing; with ever increasing funding pressures in the NHS, pool managers have struggled to justify the funding required to maintain hydrotherapy facilities (Chartered Society of Physiotherapy [CSP] 2022). In response to many pools closing due to Covid-19 pressures, the CSP have now launched a campaign encouraging Physiotherapists, patients and the public to advocate for their local services to reopen (CSP 2022). Without access to an NHS run hydrotherapy pool, populations, such as the adult LD population here in Dorset, require funding to access privately run hydrotherapy pools.

Disability and care related funding in England is presently available via three streams: self-funding (the individual pays privately for their care), social care funding (means tested, including any assets; Department of Health 2014) or NHS Continuing Health Care (CHC) funding (not means tested, but eligibility requires individuals to meet very strict and specific criteria; Department of Health and Social Care 2018). As CHC eligibility is determined by specific health needs, not diagnoses, it is not possible to determine how many adults with LD are in receipt of CHC funding let alone how many of these adults access hydrotherapy (Department of Health and Social Care 2018). However an NHS Digital report from 2021, estimates that the majority of adults with both LD diagnosis and funding needs relating to long term care, are in receipt of social care funding for their usual package of care. Social care funding commissioners largely view hydrotherapy as a health related intervention (perhaps reinforced by the strong biomedical focus of existing hydrotherapy research which is later discussed in Chapter Two), subsequently leading to refusal of funding for hydrotherapy sessions and any associated costs. The lack of specific biopsychosocial adult LD hydrotherapy evidence therefore means current hydrotherapy access for adults with

SLD/PMLD is sporadic and inequitable; dependent upon whether each individual is able to meet the stringent criteria for CHC eligibility, or how loudly they have someone to advocate for them. This therefore highlights the necessity for biopsychosocial hydrotherapy research relating to the adult SLD/PMLD population.

1.4 Autobiographical rationale

After 12 years of working as an LD Physiotherapist, I knew it was time to challenge myself further. My passion as an LD Physiotherapist is always in wanting to deliver the best possible care to my clients. The phrase 'best possible care' conjures up imagery of robust evidence bases and gold standard frameworks, but from my own clinical practice I am fully aware of the paucity in physiotherapy research regarding adults with LD.

Over the years I have become skilled at 'evidence informed practice', as opposed to 'evidence based practice'. 'Evidence informed practice' involves taking the best available evidence (often relating to other non-LD neurological populations) and applying it to specific individuals on my caseload. This is often a challenge due to the heterogeneity of the adult LD population, particularly in those at the SLD/PMLD end of the LD scale. Many of these adults have very specific genetic diagnoses or syndromes which don't easily correlate to existing research in people with other neurological conditions; therefore, I feel it is important to use thorough biopsychosocial descriptions such as those described in the previous section.

Through personal experience I have witnessed how this paucity of adult-LD physiotherapy evidence can create discrepancies between professionals about best practice for individual clients, resulting in inequity in the allocation of funding and access to services; hydrotherapy being one such service. So, I was incredibly excited when Diverse Abilities advertised the opportunity to undertake adult SLD/PMLD hydrotherapy research and offered a scholarship to complete a Master's by Research (MRes).

I am a passionate advocate for the needs of adults with LD, and through conducting this MRes study I am not only pushing the boundaries of my comfort zone through developing new research skills, but I'm also taking the first steps to addressing the paucity of adult-LD physiotherapy research and hoping to open the door for future research in the field of hydrotherapy and adults with SLD/PMLD.

CHAPTER TWO: HYDROTHERAPY AND LEARNING DISABILITIES: THE LITERATURE

2.1 Introduction

The following narrative literature reviews explore existing knowledge regarding hydrotherapy and adults with SLD/PMLD, before further exploring existing knowledge regarding sedentary hydrotherapy and other similar complex-neurological populations. The specific literature review questions were: "what previous research exists in exploring the effects of, and perspectives regarding, hydrotherapy on adults with SLD or PMLD?" and "what previous research exists in exploring the effects of, and perspectives regarding, sedentary-hydrotherapy on people with SLD, PMLD, quadriplegia or other, similar, complex-neurological presentation?".

Both of these literature review questions lend themselves well to scoping review methods (Aveyard 2019). However, to maximise candour and replicability, the researcher also adopted a systematic approach to the literature searches - full details of the search terms and processes undertaken can be found in Appendices I and II. The researcher applied PICOT principles (Population, Intervention, Context, Outcome, Type) to facilitate the identification of articles meeting the inclusion criteria and data extraction, prior to synthesis, for the production of the subsequent narrative reviews (Aveyard 2019). The inclusion/exclusion criteria (Appendices I and II) for these reviews determined the context and interventions of accepted studies. Summaries of the populations and types of included studies are set out in Table 1; summaries of the outcomes are set out in Table 2.

2.2 Hydrotherapy literature in the field of LD

In order to fully explore existing hydrotherapy literature in the field of adult SLD/PMLD, a systematic literature search of six databases (MEDLINE, CINAHL, SPORTDiscus, Cochrane, ScienceDirect and SocINDEX) was performed (see Appendix I). Search terms included "hydrotherapy" (including different terms and variations), and "learning disability" and its variations, namely: "learning dis*", "intellectual disabilit*", "mental retardation" or "development* dis*". The following key publications were also searched using the same terms: Journal of Aquatic Physical Therapy, British Journal of Learning Disabilities, Physiotherapy Journal and Aqualines: The Journal of the Hydrotherapy Association of Chartered Physiotherapists. Reference lists from identified studies were also manually searched for additional studies. After the initial search identified 75 studies, manual screening removed duplicates and studies relating to different populations (e.g. children or adults with mild to moderate LD), and non-hydrotherapy treatment modalities. Only one article (L'Huillier et al. 2016) related to both hydrotherapy and the adult SLD/PMLD population, highlighting the lack of research in this area. While it may seem inaccurate that only one study could be found, Oliver et al. (2003) discuss why the paucity of research in adults with LD spreads across many clinical fields; suggesting concerns regarding capacity and consent can often create barriers relating to ethics, and the heterogeneity of the population's biopsychosocial needs can limit sample sizes - both creating impossible limitations for large and randomised trials, and inhibiting the interest of less experienced researchers conducting smaller studies.

L'Huillier et al. (2016) presented a single-centre study conducted in the USA, using case series methodology to determine the effectiveness of aquatic physical therapy in 13 adults with severe-profound learning disabilities. Participants attended two hydrotherapy sessions per week for eight weeks. These sessions were carried out in warm water with assistance from one or two caregivers, were 30 minutes long, and comprised of passive limb stretches, water-based function, and elements of the Bad Ragaz ring method. Bad Ragaz is a form of neurological-hydrotherapy focussing on improving co-ordination and tone through relaxation (passive) and movement in functional planes (active; L'Huillier et al. 2016). Baseline measurements were taken of participants' passive range of movement, tone, function, pain, volition and ease of care. Follow up measurements were then taken weekly for the eight week duration, and three times during the subsequent five weeks after the hydrotherapy intervention ceased.

Using quantitative data analysis, the researchers concluded that hydrotherapy had positive effects on the outcomes of passive range of movement, tone, function, volition and ease of care in adults with SLD/PMLD and that these effects were maintained throughout the five weeks after hydrotherapy intervention had ceased. Although the researchers also observed a trend towards improvement in pain scores, this was not found to be statistically significant.

Before discussing the limitations of L'Huillier et al.'s study (2016), the different models of disability must first be understood. While there are many and varied models which attempt to define disability, there are three key models: biomedical, psychological and social (World Health Organization [WHO] 2001). The biomedical model of disability is built on the belief that if I know your diagnoses and demographics, I can define your level of disability (WHO 2001). The psychological model of disability is built on the belief that disability is a perception built on one's own (often distressing) experience (Johnston 1996); this model is often combined with the social model of disability to be described as the psychosocial model of disability. The social model of disability is built on the belief that disability is a social construct, and is not caused by individuals' physical abilities/impairment but external factors instead (WHO 2001).

These models all converge to form the singular framework of the biopsychosocial model of disability, which recognises the complex interplay between these models, and highlights the limitations of viewing disability through any one of these singular frameworks alone (WHO 2001). For example, where the biomedical model of disability would identify someone's lower limb weakness and mobility limitations as the reason for being unable to enter a shop, the social model would identify the presence of stairs and lack of other access options as the reason. Both models have identified specific reasons for the inaccessibility, but fail to consider the role the other perspectives may have had; adopting the biopsychosocial model would have enabled both perspectives to be considered, along with an understanding of how the person's psychological state might also have affected access.

Chapter One introduced the disparity between cognitive (psychosocial) and physical abilities (biomedical) within learning disabilities, explaining that severity of LD diagnosis does not directly correlate with the severity of physical disability or social functioning. This complex interplay between cognitive, physical and social factors highlights the importance of LD research adopting a biopsychosocial underpinning, including thorough biopsychosocial sample description.

L'Huillier et al. (2016) provided thorough biomedical description of participants in terms of gender, age, LD diagnosis, neurological diagnoses, mobility status, medication history and other co-morbidities (e.g. epilepsy or gastrostomy tube feed). Exclusion criteria included not living in Marklund (a residential and training centre in Illinois), not having previously attended the Marklund hydrotherapy programme, or having a history of challenging behaviours or incontinence in the pool. The detailed description of participants' medical histories strengthens this study's generalisability and has clear relevance to its aims of measuring largely physiological impact. However, the researchers did not describe the psychosocial needs of the sample (e.g. level of care); therefore limiting thorough understanding of the sample population and subsequent application of these results. For example, without contextual psychosocial description (e.g. support required in the water or cognitive ability to follow instruction) clinicians are unable to apply these findings to specific clients with LD on their caseloads.

Through their predominant focus on quantitative physiological outcome measures (e.g. range of movement, tone, function and pain), L'Huillier et al. (2016) demonstrate an underpinning of the biomedical model of disability. However, through the measurement of two psychosocial outcomes (ease of care and volition), they showed some consideration beyond biomedical factors.

Ease of care was measured by asking caregivers to provide a rating (on a six point scale), before and after each hydrotherapy session, regarding participants' ease of transfers, washing and dressing. As stated previously, L'Huillier et al. (2016) found statistically significant improvement in the ease of care relating to these tasks. However, their quantitative approach to measurement of ease of care prevented exploration of the full context or reasons behind the scores; for example, it is not possible to determine whether the measured improvement in ease of care scores was due to increased participant independence with these tasks, or physical fatigue resulting in caregivers experiencing improved ease of passive care. This illustrates the paradigmatic limitations that quantitative research places on understanding, and highlights the need for further interpretivist exploration in this field.

Volition was measured using a volitional questionnaire (VQ) to determine whether each participant's level of engagement was passive, hesitant, involved or spontaneous while completing a task which was new to them. L'Huillier et al. (2016) combined the water-based VQ scores with the VQ scores of a new land-based task in order to present the findings as a quantitative outcome measure, which showed statistically significant improvement. However, the water-based VQ scores could also have been used to fully describe participants' level of participation within the hydrotherapy program. Although L'Huillier et al. (2016) described the components of the hydrotherapy program used, the level of participation remains unclear as some elements of the intervention imply a passive approach (e.g. passive limb movements), while others indicate a conversely active approach (e.g. Bad Ragaz). Through presenting the combined VQ scores as a qualitative outcome measure, L'Huillier et al. (2016) therefore limit the descriptive quality of the data required to provide full context for the hydrotherapy intervention delivered. This reiterates the need for thorough biopsychosocial sample description (particularly regarding cognition, physical abilities and social functioning) in order to strengthen the potential generalisability/transferability and relevance of LD study findings.

The findings of L'Huillier et al. (2016) are significant to the adult SLD/PMLD community, not least because it is the only hydrotherapy study on adults with SLD/PMLD, but because these quantitative results clearly evidence the positive physiological impact hydrotherapy can have on this population (e.g. range of movement, tone and function). The remaining gap in knowledge regarding hydrotherapy and adults with SLD/PMLD therefore relates to the interpretivist understanding of any potential hydrotherapy impact beyond these specific physiological factors. Further exploratory research into the potential biopsychosocial impact of hydrotherapy and adults with SLD/PMLD is therefore needed.

2.3 Hydrotherapy literature in the wider field of complex-neurology

Due to the paucity of adult SLD/PMLD hydrotherapy research, a further scoping literature search was conducted (using a systematic approach) exploring sedentary hydrotherapy (that is, non-active) and other complex neurological populations (e.g. CP, brain-injury and quadriplegia; Appendix II). Six databases were examined (MEDLINE, CINAHL, SPORTDiscus, Cochrane, ScienceDirect and SocINDEX); search terms included "hydrotherapy" (including different terms and variations), and the following: "learning dis*", "intellectual disabilit*", "mental retardation", "cognitive* impair*", "cognitive dysfunction", "quadriplegi*", "tetraplegi*", "brain injury", "spinal cord injury", "physical disability", "Rett* syndrome", "Down* syndrome", "parkinson* disease", "multiple sclerosis", "MS", "prader-willi syndrome", "cerebral palsy", or "development* dis*". The following key publications were also searched using the same terms: Journal of Aquatic Physical Therapy, British Journal of Learning Disabilities, Physiotherapy Journal and Aqualines: The Journal of the Hydrotherapy Association of Chartered Physiotherapists. Reference lists from identified studies were also manually searched for additional studies. After the initial search identified 314 studies, manual screening removed duplicates and studies relating to different populations (e.g. musculoskeletal conditions or early stages of degenerative disease), non-hydrotherapy treatment modalities or studies in relation to solely active hydrotherapy interventions. Fifteen papers were identified which investigated complex neurological populations and sedentary hydrotherapy.

Table 1 shows the populations represented within these studies, and the methodologies used to investigate the impact of sedentary hydrotherapy.

Condition	Sample age	No. of studies	References	Methodology
Cerebral Palsy	Paediatric	5	Gorter and Currie 2011	Literature review of quantitative case series studies
			Jorgić et al. 2014	Quantitative case series
			Lai et al. 2015	Quantitative quasi-experimental prospective study
			Güeita-Rodríguez et al. 2017	Qualitative content analysis
			Ballington and Naidoo 2018	Quantitative pretest-post-test crossover design
Autism	Paediatric	4	Vonder Hulls et al. 2006	Quantitative survey
			Vaščáková et al. 2015	Quantitative case series
			Caputo et al. 2018	Quantitative controlled trial (not randomised)
			Zanobini and Solari 2019	Quantitative controlled trial (not randomised)
Rett Syndrome	Paediatric	1	Lotan and Barmatz 2009	Narrative literature review and qualitative case study
Learning Disabilities	Adult	1	L'Huillier et al. 2016	Quantitative case series
Alzheimer's disease and Parkinson's disease	Adult	2	Myers et al. 2013	Mixed-methods (qualitative and quantitative) case report
			Volpe et al. 2017	Quantitative randomised controlled pilot study
Stroke	Adult	2	Chon et al. 2009	Quantitative case study
			Kim et al. 2015	Quantitative randomised controlled trial

Table 1:The populations and methodologies in sedentary neurological-hydrotherapy research

These 15 studies mainly centred on the biomedical model of disability and all reported positive physiological outcomes in range of movement, balance and function (all references in Table 2). The full list of positive outcome measures reported by these studies are set out in Table 2 alongside their underpinning model of disability. Although researchers also observed a trend towards improvement in the outcomes of non-verbal communication, pain, gait velocity, quality of life and self-perception, these were not found to be statistically significant (Gorter and Currie 2011; Lai et al. 2015; L'Huillier et al. 2016; Caputo et al. 2018). Only one study observed a negative impact of hydrotherapy, Myers et al. (2013) reported hydrotherapy caused a short-term increase in the risk of falls of a gentleman with Alzheimer's disease, and attributed this to the observation that he was more motivated to stand and mobilise on land for two to three hours after his hydrotherapy session. However, Myers et al. (2013) were also keen to report that aside from this initial period, the gentleman's falls risk was actually progressively lowered as a result of hydrotherapy intervention.

Underpinning model of disability	Positive outcomes reported in study findings/results	Other outcomes considered	No. of studies	References
Biomedical	balance, gross motor function, mobility, posture, range of movement, tone.	None	6	Chon et al. 2009 Jorgić et al. 2014 Kim et al. 2015 Vaščáková et al. 2015 Volpe et al. 2017 Ballington and Naidoo 2018
Biomedical with some secondary psychosocial consideration	**Biomedical:** balance, behaviour, cognition, gross motor function, mobility, range of movement, strength, tone, verbal communication. **Psychosocial**: ease of care, emotional functioning, enjoyment, relationships, volition.	<u>No significance found:</u> **Biomedical:** non-verbal communication, pain. **Psychosocial:** quality of life.	4	Vonder Hulls et al. 2006 Lai et al. 2015 L'Huillier et al. 2016 Caputo et al. 2018

Biopsychosocial	**Biomedical:** balance, breathing, circulation, cognition, communication, co-ordination, energy expenditure, function, mobility, pain, posture, range of movement, strength, tone. **Psychosocial:** behaviour, control, emotional functioning, enjoyment, orientation, relationships, relaxation, social skills, volition.	<u>No significance found:</u> **Biomedical:** gait velocity. **Psychosocial:** barriers, self-perception. <u>Negative impact observed:</u> **Biomedical:** falls	5	Lotan and Barmatz 2009 Gorter and Currie 2011 Myers et al. 2013 Güeita-Rodríguez et al. 2017 Zanobini and Solari 2019

Table 2: The disability models underpinning sedentary neurological-hydrotherapy research

Table 1 shows 12 of these studies used quantitative methodology, one mixed-methods and two qualitative. Table 2 shows that six of these quantitative studies took a purely biomedical approach to measuring the impact of hydrotherapy on the physiological outcomes of balance, gross motor function, mobility, posture, range of movement and tone (Chon et al. 2009; Jorgić et al. 2014; Kim et al. 2015; Vaščáková et al. 2015; Volpe et al. 2017; Ballington and Naidoo 2018). These findings support the physiological findings of L'Huillier et al. (2016) who reported positive impact on passive range of movement, tone and function.

While four studies also explored some psychosocial aspects (ease of care, emotional functioning, enjoyment, relationships and volition), they lacked the necessary qualitative component to fully explore and understand the subsequent psychosocial impact of hydrotherapy on their sample of individuals with complex-neurological conditions (Vonder Hulls et al. 2006; Lai et al. 2015; L'Huillier et al. 2016; Caputo et al. 2018).

Five studies were identified as having biopsychosocial underpinning (Lotan and Barmatz 2009; Gorter and Currie 2011; Myers et al. 2013; Güeita-Rodríguez et al. 2017; Zanobini and Solari 2019). Two of these studies implemented qualitative methodology in the form of narrative case report: one regarding a young girl with Rett syndrome and the other regarding a gentleman with Alzheimer's disease (Lotan and Barmatz 2009; Myers et al. 2013). Despite their biopsychosocial underpinning and consideration of some psychosocial factors (e.g. cognition, mood, and communication) both studies maintained narrative emphasis on physical health factors such as balance, co-ordination and mobility. Thus, further evidencing the strong focus the biomedical model of disability has within existing sedentary neuro-hydrotherapy research, and the need for further interpretivist and exploratory qualitative research.

One study (Zanobini and Solari 2019), took a social stance and investigated the impact of hydrotherapy on the social impairments of children with autism spectrum disorder. However, through specifically focussing on (and quantitatively measuring) the child's communication skills and behaviours associated with autism, this study is unable to contribute to knowledge regarding any potential wider social impacts of hydrotherapy (e.g. caregiver attention, support needs or societal perceptions). Although Zanobini and Solari (2019) highlight that hydrotherapy can have a positive impact on the specific social outcomes of behaviour and communication, further interpretivist research is required in order to explore any wider social impacts. These behaviour and communication outcomes were also demonstrated in a population with little or no associated physical disability, so has limited generalisability to an LD population with both cognitive and physical impairment.

To their strength, two studies employed a biopsychosocial framework and found hydrotherapy to have positive impact on mobility, function, strength, posture, energy, concentration, emotional functioning, engagement and relationships (Gorter and Currie 2011; Güeita-Rodríguez et al. 2017). However, the diversity of populations and interventions included within Gorter and Currie's (2011) unsystematic-literature review limits generalisability, specifically when considering the application of sedentary hydrotherapy to adults with SLD/PMLD.

Güeita-Rodríguez et al. (2017) were the only researchers to use qualitative methodology to employ a biopsychosocial framework. They conducted semi-structured interviews and focus groups with the aim of exploring parental experiences relating to hydrotherapy and their children with CP. Thirty-four parents participated: 18 in focus groups, 16 in interviews. Using categories of functions from the World Health Organization's International Classification of Functioning, Disability and Health, version for Children & Youth, the researchers then used content analysis to deductively analyse transcripts in order to produce a list of domains on which parents perceived hydrotherapy to have impact. While Güeita-Rodríguez et al. (2017) identified a diverse range of functional categories impacted, their use of deductive content analysis prevented interpretivist exploration and understanding of participants' experiences. Their analysis reduced in-depth exploratory qualitative data (transcripts) into a restrictive list of categories of functions; subsequently preventing the reporting of participants' personal experiences or perceived reasons behind the reported areas of impact. This emphasizes the need for further interpretivist and exploratory qualitative research, and the importance of utilising an inductive analysis approach.

The findings of these studies are of importance because there is such paucity in adult-LD physiotherapy research, resulting in clinicians using the best available evidence (often relating to other similar populations) and applying it to specific individuals on their caseloads (Oliver et al. 2003). As explained in Chapter One, physical disability in LD is largely neurological in nature. Clinicians may therefore choose to use the findings of these complex-neurological hydrotherapy studies as the best available evidence to inform clinical practice within the field of adult SLD/PMLD. However, application of these findings to adults with SLD/PMLD is limited due to the heterogeneity of needs within this population, particularly in relation to the complex interplay between cognitive, physical and social factors (Oliver et al. 2003): which would therefore demand further biopsychosocial description of the samples and the interventions delivered than are available within each of these 15 studies.

In summary, this narrative scoping review highlights there is sedentary hydrotherapy research with evidence of some biopsychosocial impact in relevant non-LD populations. While the findings of these studies do not directly apply to the adult SLD/PMLD population, they are sufficient to indicate the need for further exploratory research into the potential biopsychosocial impacts of hydrotherapy on adults with SLD/PMLD.

2.4 Conclusion

This narrative scoping review highlights a lack of interpretivist biopsychosocial hydrotherapy research within the adult SLD/PMLD population. Taking a solely medical approach to exploratory SLD/PMLD research omits the significant social impairments these adults experience (e.g. independence/care needs). Conversely, a solely psychosocial model of disability would omit the impact of this population's complex health needs (e.g. mobility/posture; Department of Health 2001). Therefore, in order to deeply understand and explore any impacts of hydrotherapy in this field, a comprehensive biopsychosocial approach is needed.

Looking wider to similar complex-neurological populations (such as those included in the search terms; Appendix II), this narrative scoping review highlights the remaining paucity of interpretivist research using qualitative methodology in the field of sedentary neuro-hydrotherapy. Therefore, in order to deeply understand and explore experience and any perceived impacts of sedentary neuro-hydrotherapy, an interpretivist approach is required.

2.5 The current study: a statement of purpose

As discussed previously in this chapter, one of the most significant barriers to adult LD research is the topic of capacity and consent (Oliver et al. 2003). While a primary principle of the Mental Capacity Act ([MCA]; 2005) is the assumption of capacity until proven otherwise, the presence of cognitive impairment (e.g. SLD/PMLD) is sufficient to require a formal assessment of someone's capacity to consent to take part in research. In order for a study involving participation of adults with SLD/PMLD to gain ethical approval for these necessary processes (e.g. assessment of capacity and consultee nomination) approval would have been necessary from an appropriately qualified National Health Service (NHS) research ethics committee. As later explained in Chapter Five, this was not possible for SPLASH Study as, due to the impact of Covid-19, the National Institute for Health Research (NIHR) closed NHS ethics submission to Master's level studies. This study instead focussed on exploring the impact of hydrotherapy through the perceptions of those who know the adult SLD/PMLD population best – their caregivers.

Through exploring caregiver perceptions of hydrotherapy and adults with SLD/PMLD, this study offers unique biopsychosocial insight into the experiences of a population currently underrepresented in research literature. This knowledge will contribute to clinicians and researchers better understanding the full impact of hydrotherapy on individuals with SLD/PMLD. The themes explored in this study may also help to form a foundation knowledge which can be used as a basis for future research; with the aim of generating evidence which could be used to affect change in policy and wide-scale practice.

This study's paradigmatic underpinning of interpretivism may also result in the contribution of new knowledge to the wider field of sedentary neuro-hydrotherapy. The themes explored through this study may therefore inspire further investigation in future studies on other complex-neurological populations, similarly with aims of generating evidence which could be used to inform practice.

2.6 Aims and objectives

2.6.1 Research question

How do caregivers experience and perceive hydrotherapy to impact on adults with SLD/PMLD?

2.6.2 Scope

To explore caregiver experiences and perceptions of hydrotherapy on adults with SLD/PMLD, with particular focus on whether there is any perceived biopsychosocial impact. Caregivers will comprise of paid carers, family members and health/social care professionals who hence forth will be referred to as caregiver(s).

2.6.3 Aim

Exploring caregiver perspectives of adults with Severe and Profound and multiple Learning Disabilities Accessing Sedentary Hydrotherapy (SPLASH Study).

2.6.4 Objectives

To explore:

- caregiver experience of hydrotherapy in relation to adults with SLD/PMLD.
- if hydrotherapy has any biopsychosocial impact on adults with SLD/PMLD, through caregiver experiences/perceptions.
- if adults with SLD/PMLD experience any barriers/facilitators in accessing hydrotherapy, through caregiver perceptions.

2.6.5 Anticipated outcomes

- Contribution to the hydrotherapy knowledge base in the currently underrepresented field of adult SLD/PMLD.
- Publication of findings in a peer-reviewed journal (e.g. Journal of Aquatic Physical Therapy, British Journal of Learning Disabilities, or Physiotherapy Journal).
- Presentation at relevant national conferences (e.g. Virtual Physiotherapy UK 2021 or Rehab 2021).
- Any findings of this study may help form a foundation for future researchers to investigate further.
- Any findings of this study may be considered by funding authorities and caregivers when developing services or making a case for hydrotherapy in this client group.

CHAPTER THREE: RESEARCH DESIGN

3.1 Introduction

This chapter presents the methodology and methods used within SPLASH Study and discusses the researcher's rationale behind each research design decision.

3.2 Research philosophy

On considering this study's research question, an underpinning of interpretivism may appear obvious due to the exploratory nature of the question. Interpretivism doesn't seek to prove or persuade but concerns itself with understanding the specific experiences of individuals and their differences; being built on the assumption that reality is not something which can be objectively measured, but requires researcher involvement in order to understand individual's perceptions and beliefs, often relating to their lived experiences (Saunders et al. 2016).

However, due to the heterogeneity of the adult LD population and the previously explained importance of thorough biopsychosocial description of sample populations in order to strengthen generalisability of LD study findings, the researcher initially considered the paradigm of pragmatism in attempting to answer this research question. This was based on the understanding that a pragmatic approach would allow for in-depth exploration of the topic, whilst also allowing for analysis and presentation of findings in a way which has real world impact (Pihlstrom 2015).

Pragmatism and interpretivism both share the exploration of experience as a common factor; however, where pragmatism concerns itself with real world impact, interpretivism is concerned only by the experiences of individuals, and the differences between them (Saunders et al. 2016). Where taking a pragmatic approach would have allowed for real world interpretation and subsequent application of findings (Pihlstrom 2015), it became clear this wouldn't align with the study's aims of unrestricted exploration of caregiver experience and perceptions. This study's interpretivist paradigm therefore provides unique understanding of caregiver experiences and perceptions in relation to hydrotherapy and adults with SLD/PMLD: providing new knowledge and understanding to supplement current quantitative biomedical research.

3.3 Study design

3.3.1 Methodology

Whilst still considering the paradigm of pragmatism for this study, the researcher considered implementing a mixed-methods component design (Caracelli and Greene 1997). Using this methodology within SPLASH Study would have allowed quantitative physiological assessment data (e.g. outcome measures of posture, contractures and tone) and caregiver questionnaire data to be used to provide understanding of the impact of hydrotherapy which could then be discussed in line with individual caregivers' experiences (interview data): under the singular paradigm of pragmatism. Figure 2 illustrates the mixed-methods component design methodology considered at this point.

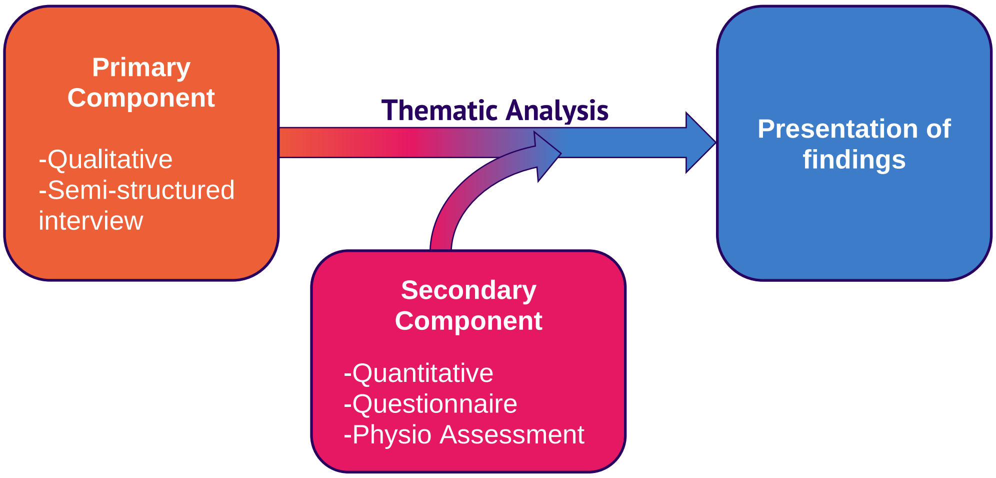


Figure 2: The disregarded mixed-methods component design for this study

On returning to the specific research question and aims for this study, it was apparent that not only did the quantitative physiological assessment data fail to contribute towards the study's aims, but the paradigm of pragmatism (specifically the application of findings) was indeed discordant with the purely exploratory nature of the study's research question.

As discussed in the previous section, SPLASH Study is underpinned by the paradigm of interpretivism. Using this paradigmatic underpinning enabled the researcher to identify a purely qualitative methodology, using semi-structured interviews to explore caregiver perceptions: demonstrating congruency to the study's interpretivist stance and aims. The subsequent addition of qualitative descriptive/contextual questionnaire data, was used to strengthen both credibility (adding depth to understanding of the lived experience of each individual and the knowledge generated) and greater contextual understanding (enabling biopsychosocial description of the SLD/PMLD care-receiver sample) of study findings, without distracting from the study's interpretivist underpinning.

3.3.2 Sampling

A convenience sample (Saunders et al. 2016) of self-selected volunteer caregivers was recruited through public advertising (posters/leaflets/social media) and via a Diverse Abilities gatekeeper. Diverse Abilities is a charity seeking to provide a broad range of personalised services for children and adults with disabilities in Dorset: running both a day opportunities centre and a support living service for adults with LD. They are also a dedicated sponsor of SPLASH Study and funder of this MRes. Figures 3 and 4 outline this study's processes and exclusion criteria. Participant interviews were booked on a first come first served basis; no preference was given to any particular caregiver type.

Saunders et al. (2016) suggest that while self-selected volunteer convenience samples can weaken the internal validity of quantitative research, this sampling method has higher credibility in qualitative studies (particularly in comparison to haphazard sampling) as participants who are motivated to take part in this research are usually those who have specific experiences/perceptions they are keen to impart. The researcher therefore identified self-selected convenience sampling as the most appropriate sampling method for SPLASH Study.

There was no pre-determined sample size for this exploratory study, as recruitment continued until data saturation was reached. It was agreed that the researcher would determine data saturation when no new major themes developed from two consecutive interviews (O'Reilly and Parker 2012), in each of the three caregiver types (paid carers, informal caregivers and health/social care professionals). Interviews were analysed sequentially to enable saturation to be identified.

3.3.3 Methods

As described in the methodology section above, semi-structured interviews and a contextual caregiver questionnaire were identified as the most appropriate data collection tools. As this study was initially designed prior to the Covid-19 pandemic it was anticipated that interviews would be held face to face, and participants would be required to bring completed paper copies of the questionnaire with them to interview. Figure 3 illustrates SPLASH Study's proposed pre-Covid-19 processes and methods.

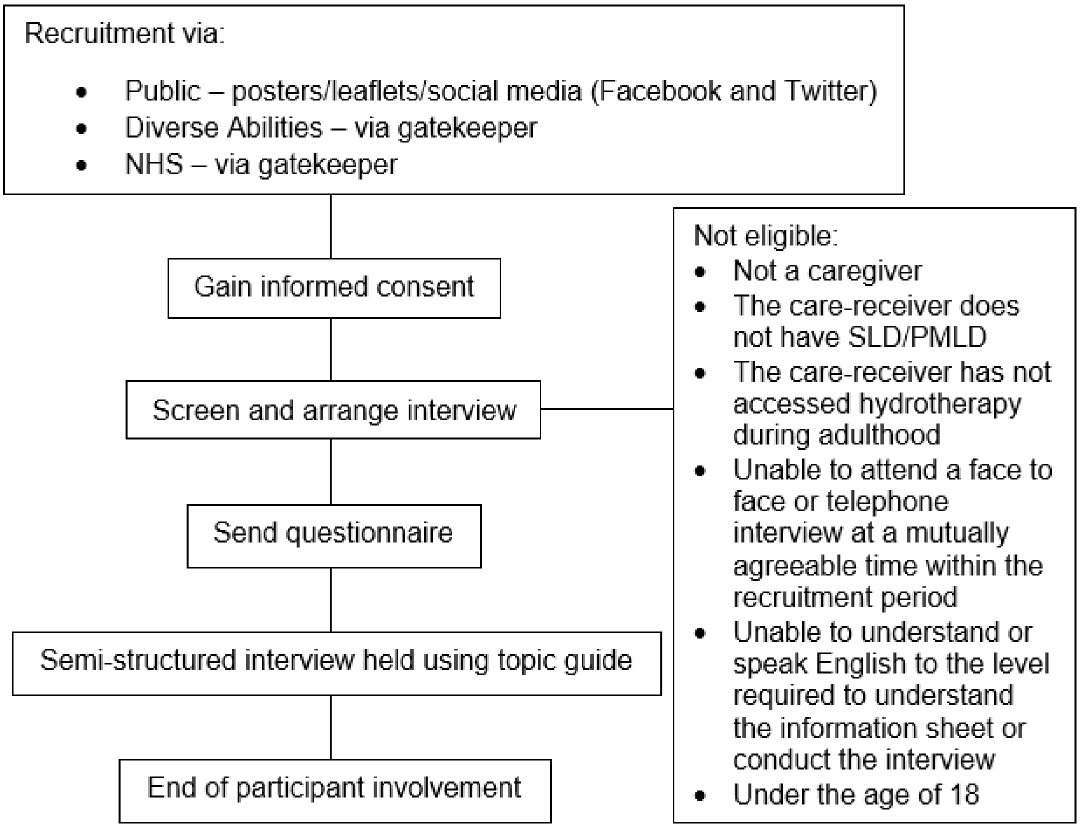


Figure 3: SPLASH Study's proposed processes and methods pre-Covid-19

In response to the Covid-19 pandemic, the methods were adapted to enable online/virtual data collection in the form of an electronic questionnaire (incorporating all three elements of gaining informed consent, participant screening and the contextual caregiver questionnaire; Appendix IV) and virtual semi-structured interviews using videoconferencing. The electronic questionnaire took participants no longer than 10mins to complete, and they were given the choice as to which videoconferencing platform they preferred to use. Most interviews lasted around 40 minutes. Figure 4 illustrates the final processes and methods used for SPLASH Study.

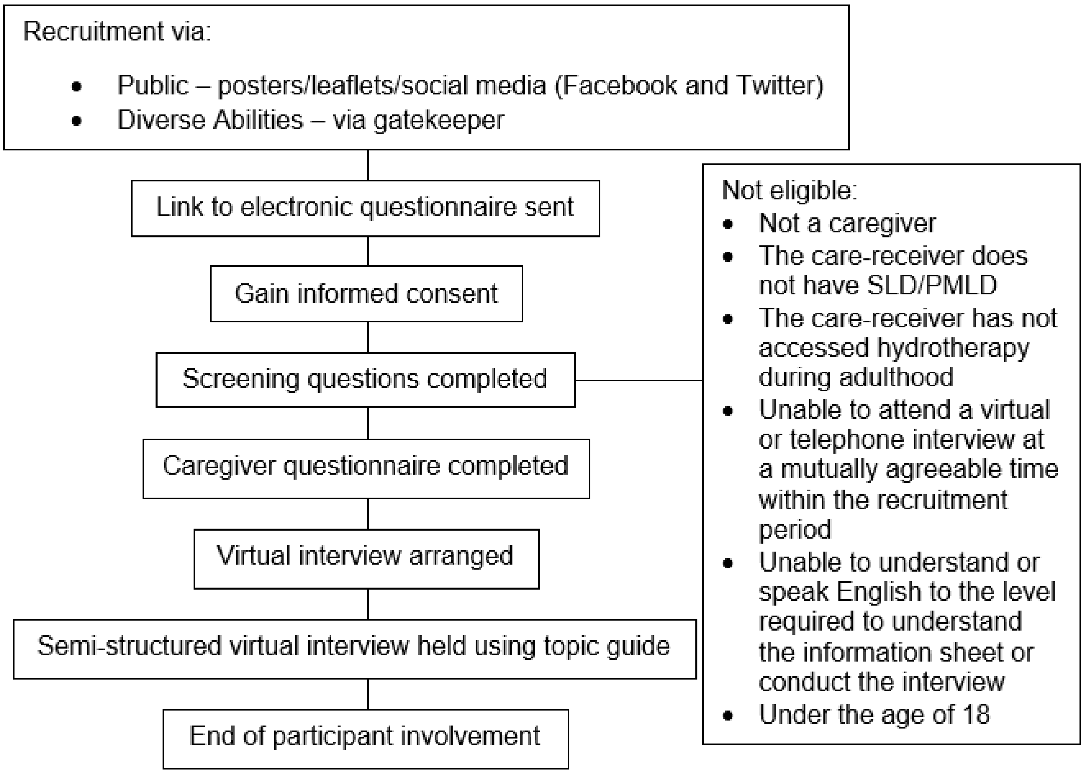


Figure 4: SPLASH Study's actual processes and methods

<u>3.3.4 Developing the tools</u>

While developing the data collection tools for use within SPLASH Study, it was important to heed the study's research question and aims of exploring caregiver experience and perceptions relating to hydrotherapy and adults with SLD/PMLD, with particular focus on whether there is any perceived biopsychosocial impact. Having previously identified interviews and a contextual questionnaire as the ideal data collection tools, it was important to select a suitable biopsychosocial framework, compatible with interpretivism, which could be used to inform a semi-structured interview topic guide and contextual questionnaire.

The International Classification of Functioning, Disability and Health (ICF; WHO 2001) is a globally-recognised biopsychosocial framework, which comprises seven main factors: health condition, body functions/structure, activities, participation, environmental, personal and contextual factors (Figure 5).

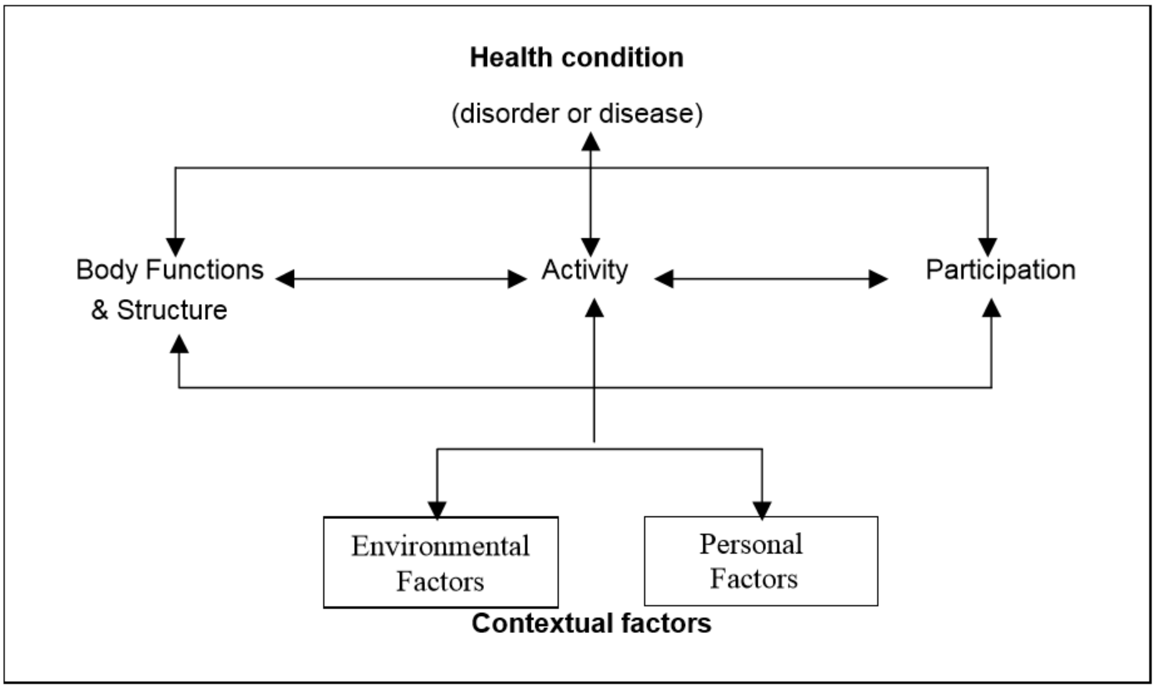


Figure 5: The biopsychosocial ICF framework (WHO 2001, p. 18)

This study's interview topics and subsequent guide (Appendix III) were developed from the ICF (WHO 2001), following an iterative process of public engagement and response to their feedback. Initially the researcher compiled a long list of all the ICF categories; this list was 25 topics long (containing topics from each of the sections relating to body functions, body structures, activities and participation). Following discussion with LD physiotherapy colleagues, the researcher determined this list was too long and participants would become bored and frustrated by the amount of time taken to answer questions relating to each category. The researcher then grouped similar categories together in order to identify the main overarching themes. This resulted in a new list of six topics: health, function, welfare, communication, support and night-time. Following further discussion with two parent caregivers, the theme relating to "communication" was changed to "connections", and the example question relating to this category was changed to focus on asking whether each caregiver perceived hydrotherapy to have any impact on the way their care-receiver connects with them or others. This allowed the focus to shift toward the caregiver/receiver relationship and away from the biomedical aspect of communication; resulting in the final version of the topic guide (Appendix III). It is important to understand that although specific question examples are given within the topic guide, the iterative nature of the semi-structured interviews allowed for the flow of the interview to be led by each participant, whilst also allowing for development of new questions as participants raised specific topics which had not been pre-empted by the researcher; these questions were then included in subsequent interviews. Examples of these unexpected topics include social inclusion/exclusion, emotions, and nutrition.

The contextual questionnaire, also underpinned by the ICF (WHO 2001), asked participants about their caring role, the level of involvement they have in the care-receiver's life, their biopsychosocial needs (e.g. diagnoses, communication support needs and level of care), and the type of hydrotherapy they receive (Appendix IV).

3.3.5 Interviews

Each virtual semi-structured interview was booked for a time and date of the participant's choosing within the recruitment window. The questionnaire allowed participants to express their preference of video conferencing platform (e.g. Skype, Teams or Zoom) prior to the interview being arranged. Once the time and date had been confirmed, the link to the interview was sent by email to each participant, along with a separate electronic-calendar invitation also containing the interview link.

In preparation for each interview, the researcher was equipped with a printed topic guide (Appendix III), a glass of water, back up audio recorder, paper and a pen. In line with this study's reflexivity strategies (Table 5) the researcher wore non-clinical, neutral clothing and considered what participants could see in the background during the virtual interview (e.g. allowed participants to see there was no one else in the room, but ensured the background was not distracting, cluttered or untidy).

On the day of the interview, if the participant didn't arrive within five minutes of the arranged time a follow up telephone call was attempted to offer technology support, to determine if the interview could still go ahead, or to offer for it to be rearranged.

At start of each interview, before recording, the researcher put the participant at ease and reiterated the purpose of the interview in relation to SPLASH Study's aims: particularly highlighting there are no "right or wrong" answers, only the participant's unique thoughts, experiences and perceptions were important in relation to hydrotherapy and the person they support. Participants were reminded they could stop or pause the interview at any time without needing to give a reason and were given opportunity to ask any questions prior to the recording starting.

Throughout the interviews, the researcher asked open questions in line with the study's topic guide (Appendix III). Participants were encouraged to speak freely and the researcher used active listening principles such as verbal and non-verbal encouragement, paraphrasing and probing to keep the interview flowing and deepen understanding (Louw et al. 2011). The researcher also used note taking and drinking water to create a comfortable space for participants to continue to talk or to allow them to think. Participants were always given opportunity to add more to each topic before the researcher moved on to another, and at the end of the interview participants were specifically asked if there was anything else they would like to talk about. Interviews ended with a question about whether participants had experienced anything surprising in relation to hydrotherapy; this was largely viewed by participants as a positive question.

At the end of each interview, participants were thanked for their time and contribution to adult LD hydrotherapy research, and were encouraged to follow the study’s social media accounts to enable them to find out more about future dissemination of findings.

After each interview, field notes were completed and labelled with the participant’s anonymised number, and were saved along with the audio and video recordings in the study’s electronic site file on the university’s secure server, in line with the study’s data protection plan. The interview recordings were then transcribed verbatim and these transcripts were also stored electronically in the study’s electronic site file, on the university’s secure server. The researcher both conducted the interviews and transcribed recordings personally, enabling familiarisation with the data: subsequently facilitating the inductive thematic analysis process of coding/identifying themes (Braun and Clarke 2006). Transcripts were coded manually by the researcher and reviewed by the supervisory team for verification and consistency. Descriptive questionnaire data was then applied to the codes/themes using NVivo software: after thematic analysis, prior to write-up.

3.4 Data analysis

As discussed in Chapter Two, one existing sedentary neuro-hydrotherapy study with ICF (WHO 2001) underpinning was identified (Güeita-Rodríguez et al. 2017). While Güeita-Rodríguez et al. (2017) sought to explore the experiences of caregivers relating to hydrotherapy and children with CP, their use of content analysis limited depth of understanding and experience by stripping the context from their data. Within the context of SPLASH Study, it was therefore important to use a data analysis method which would freely enable and facilitate depth of understanding of the caregiver experience and perceptions gathered through the semi-structured interviews.

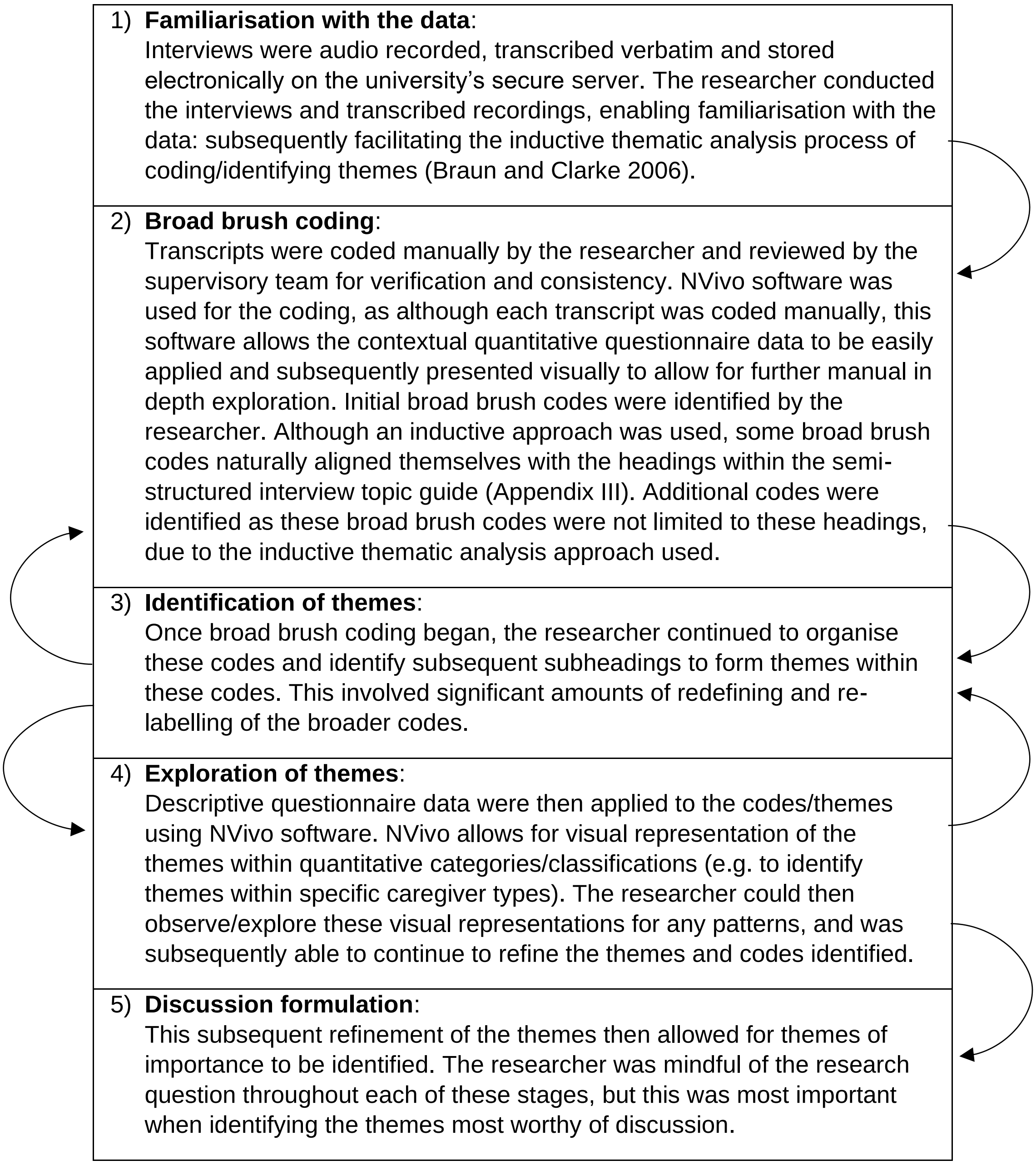
Thematic analysis allows for individual exploration of themes without reliance on development of an all-encompassing theory (Braun and Clarke 2006). Due to this alignment with the study’s aims and paradigmatic underpinning, the researcher therefore identified thematic analysis as the most suitable analysis method for this study.

When using thematic analysis to interpret semi-structured interview data, there is temptation to consider a deductive approach by using the interview topic guide to identify initial themes of importance and then analyse within them (Braun and Clarke 2006). However, taking a truly interpretivist approach to this exploratory hydrotherapy study required any/all themes to be considered for importance, not simply the topics identified by the interview topic guide (Appendix III). The researcher therefore recognised the limiting effect deductive thematic analysis would have on the study's findings. Through employing an entirely inductive method of thematic analysis to analyse the study interview data, unconstrained exploration of caregiver perceptions was permitted; subsequently resulting in the identification and presentation of themes with higher congruence to each caregiver's experience (Braun and Clarke 2006).

The descriptive/contextual caregiver questionnaire data was not analysed but used to provide biopsychosocial description of the participants, and applied to identified themes to add depth to understanding of caregiver experiences: therefore strengthening the study's credibility by adding depth to understanding of the knowledge generated. The following section discusses the full analytical strategy for this study in greater depth as illustrated in Figure 6.

3.5 Coding and developing themes

As established in the previous section, an inductive thematic analysis approach was used to analyse this study's interview data. The specific analytical strategy for this study was formulated prior to analysis of any study data, and largely aligns with the structure set out by Braun and Clarke (2006). It is important to consider the iterative nature of inductive thematic analysis so as to understand that these stages were not followed entirely sequentially as their numbering may suggest. Figure 6 sets out this study's full analytical strategy and illustrates the process undertaken to identify and develop the codes and themes, before identifying the concluding themes of importance (as set out in Chapter Four).



1) **Familiarisation with the data**: Interviews were audio recorded, transcribed verbatim and stored electronically on the university's secure server. The researcher conducted the interviews and transcribed recordings, enabling familiarisation with the data: subsequently facilitating the inductive thematic analysis process of coding/identifying themes (Braun and Clarke 2006).
2) **Broad brush coding**: Transcripts were coded manually by the researcher and reviewed by the supervisory team for verification and consistency. NVivo software was used for the coding, as although each transcript was coded manually, this software allows the contextual quantitative questionnaire data to be easily applied and subsequently presented visually to allow for further manual in depth exploration. Initial broad brush codes were identified by the researcher. Although an inductive approach was used, some broad brush codes naturally aligned themselves with the headings within the semi-structured interview topic guide (Appendix III). Additional codes were identified as these broad brush codes were not limited to these headings, due to the inductive thematic analysis approach used.
3) **Identification of themes**: Once broad brush coding began, the researcher continued to organise these codes and identify subsequent subheadings to form themes within these codes. This involved significant amounts of redefining and re-labelling of the broader codes.
4) **Exploration of themes**: Descriptive questionnaire data were then applied to the codes/themes using NVivo software. NVivo allows for visual representation of the themes within quantitative categories/classifications (e.g. to identify themes within specific caregiver types). The researcher could then observe/explore these visual representations for any patterns, and was subsequently able to continue to refine the themes and codes identified.
5) **Discussion formulation**: This subsequent refinement of the themes then allowed for themes of importance to be identified. The researcher was mindful of the research question throughout each of these stages, but this was most important when identifying the themes most worthy of discussion.

Figure 6: This study's analytical strategy

3.6 Ethical considerations

This non-interventional study was granted favourable opinion from Bournemouth University ethics in January 2021 (see ethical approval letter; Appendix V). Potential participants were given time to read the study's participant information sheet (Appendix VI) prior to deciding whether they wished to take part; the study's recruitment window was the only time limitation. Participation has not affected services caregivers have received or will receive in future. There were no intended participant payments. Interview burden was minimised by offering virtual appointments at participants' convenience using their preferred videoconferencing platform. Where no suitable videoconferencing platform could be identified, interviews were conducted via telephone. Participants were informed that they could stop the study at any time without giving a reason.

A group of caregiver volunteers (health professionals, family members and paid carers) known to the researcher reviewed and approved the interview topic guide and provided feedback on the study title. This feedback resulted in a change of wording from “exploring caregiver perspectives of Severe and Profound and multiple Learning disabled Adults accessing Sedentary Hydrotherapy (SPLASH Study)” to “exploring caregiver perspectives of adults with Severe and Profound and multiple Learning disabilities Accessing Sedentary Hydrotherapy (SPLASH Study)”. These changes were adopted in order to ensure the study maintained focus on caregivers’ perceptions of hydrotherapy-impact on the care-receiver as a person, and not the labels of disability.

Distress was not anticipated as this study did not aim to explore sensitive/personal topics; however, it was impossible to predict what individuals may have found upsetting/sensitive. Participants were able to stop the interview at any time and take a break or end the interview if they experienced distress. Table 3 details the identified possible risks and appropriate mitigating action plans implemented.

Hazard	Severity	Likelihood	Action
Participant concern regarding the study	1 Negligible	1 Rare	Researcher will attempt to address any study concerns. If concerns remain, researcher will provide supervisor contact details and offer to pause, end or reschedule the interview without participant needing to give a reason. If participant would like to make a complaint, researcher will provide both supervisor contact details and faculty DDR name and complaints email address.
Participant experiences distress or fatigue	1 Negligible	2 Unlikely	Researcher will offer to pause, end or reschedule the interview without participant needing to give a reason.
Participant distress continues	2 Minor	1 Rare	Researcher will offer to pause, end or reschedule the interview without participant needing to give a reason. Researcher will encourage participant to contact their GP or local ‘Improving Access to Psychological Therapies’ service.
Participant highlights bad practice	1 Negligible	2 Unlikely	Researcher will encourage participant to raise this with the service-provider directly.
Participant discloses safeguarding concern.	3 Moderate	2 Unlikely	Researcher will follow safeguarding procedures, including contacting the local safeguarding adults board.

Participant experiences harm (e.g. accident or ill-health).	3 Moderate	1 Rare	Researcher will follow health and safety procedures, including calling 999 if appropriate.

Table 3: This study's risk assessment

Throughout the recruitment and data collection periods none of these issues arose, with the exception of a small number of participants asking for further information about the rationale behind the study (e.g. asking if the researcher intended to develop a local hydrotherapy service for adults with SLD/PMLD) and some participants wishing to pause the interview temporarily due to a disruption in the privacy of the interview at their end (e.g. the telephone ringing, someone entering the room to ask a question). In all cases the participant was keen to continue with the interview after the disruption had been resolved. No participants were identified to have experienced distress, fatigue or harm. No participants disclosed bad practice or safeguarding concerns.

3.7 Maximising trustworthiness

In qualitative research, quality is determined by the trustworthiness of the study (Korstjens and Moser 2018). Lincoln and Guba (1985) suggest that qualitative trustworthiness can be broken down into the four main components of credibility, transferability, dependability and confirmability. Table 4 evidences how SPLASH Study has considered each of these components, and the strategies implemented to maximise the trustworthiness of the study.

Trustworthiness component	Considerations	Strategies
Credibility	During data collection: • Understanding of meaning • Clarity of conflicting perceptions • Ensuring the breadth and depth of theme exploration	• Active listening techniques were employed during interviews, including paraphrasing of previous content to ensure the correct inference was understood. • When themes came up multiple times during one interview, clarity was sought if views conflicted previously made statements by that participant. • Themes from previous interviews were questioned during subsequent caregiver interviews. • Data saturation was determined through no new themes presented in two corresponding interviews of the same caregiver type.
	During data analysis: Ensuring the accuracy of interpretation	• Iterative data analysis process carried out in line with the study's pre-determined analytical strategy (Figure 6). • Review and verification of interview data coding by the supervisory team.
Transferability	Heterogeneity within the adult SLD/PMLD population	Detailed caregiver questionnaire (Appendix IV), resulting in readers being able to gauge the transferability of these findings to specific individuals known to them.

	Variety in hydrotherapy environments and interventions	Detailed caregiver questionnaire (Appendix IV), resulting in readers being able to gauge the transferability of these findings to specific contexts and interventions relevant to them.
Dependability	During data collection: • Minimising researcher bias • Ensuring consistency of data collection	• Implementation of reflexivity strategies (Table 5). • Use of interview topic guide to ensure consistency of breadth in questions and prompts (Appendix III).
	During data analysis: Ensuring consistency of data analysis	• Iterative data analysis process carried out in line with the study's pre-determined analytical strategy (Figure 6). • Review and verification of interview data coding by the supervisory team.
Confirmability	During data collection: Clarity and candour regarding the data collection processes followed	• Use of interview topic guide to ensure consistency of breadth in questions and prompts (Appendix III). • Use of audio recording to enable accurate transcription and field notes to capture appropriate contextual data. • Review and verification of recordings and transcripts by the supervisory team. • SPLASH Study's data set will be made available through the university's online data repository.
	During data analysis: Clarity and candour regarding the data analysis processes followed	• Iterative data analysis process carried out in line with the study's pre-determined analytical strategy (Figure 6). • Review and verification of interview data coding by the supervisory team.

Table 4: This study's trustworthiness strategies

These issues are all further discussed reflectively in Chapter Five under the study's strengths and limitations section.

3.8 Reflexivity

Through its ontology, interpretivism demands inclusion of the researcher's beliefs/assumptions (Saunders et al. 2016). While it is therefore important for the reader to understand the researcher's own beliefs and assumptions in order to understand the lens through which the data has been interpreted; perhaps more significantly, failure of the researcher to recognise/identify their own assumptions can result in bias in the data collected long before analysis (Korstjens and Moser 2018).

The beliefs and assumptions of this researcher are explained in the autobiographical rationale and reflection in Chapters One and Four respectively. While the researcher's significant experience of working with adults with LD and knowledge and skills relating to hydrotherapy could be viewed as a positive to enabling understanding of caregivers' perceptions and experiences, care needed to be taken to ensure bias was minimised during data collection so as not to place pre-conceived limitations on participants' realities (Saunders et al. 2016). Table 5 evidences the reflexivity strategies implemented throughout SPLASH Study in order to minimise researcher bias.

Stage of study	Reflexivity considered	Mitigating actions	Rationale
Throughout MRes	Researcher thoughts, beliefs and motivations	Ongoing researcher reflective journal and discussion of thoughts/feelings in relation to the study during supervision.	Minimise bias by ensuring breadth of exploration.
Literature review	Prior assumptions and experience	Literature review verification and input from the supervisory team.	Minimise bias by verifying suitability and saturation of literature.
Prior to study design	Prior assumptions and experience	Researcher reflection on prior assumptions and expectations.	Minimise bias by identifying limitations of own assumptions.
Study design	Prior assumptions and perceptions	Use of ICF (WHO 2001) to inform data collection tools/guides.	Minimise bias by ensuring breadth of exploration and saturation of data.
Data collection	Awareness of the social setting (participant and researcher) and how other social roles (e.g. caregiver and Physiotherapist) may potentially influence participant contributions	Use of interview topic guide to ensure consistency in questions and prompts. Recruitment will be from a much larger geographical area than the researcher currently covers in her clinical role. Appearance: researcher will wear non-clinical, neutral clothing during interviews. Researcher is using her married name to carry out this research, whereas professionally she is still known by her maiden name.	Minimise influence by ensuring consistency and depth of exploration, saturation of data, and reinforcing participant-researcher role.
Data analysis	Researcher assumptions and perceptions	Thorough review and verification of interview data coding by the supervisory team.	Minimise bias by verifying and increasing accuracy and consistency of data analysis.

Table 5: This study's reflexivity strategies

These reflexivity strategies were successfully implemented as planned throughout the duration of the study: from study design through to completion of data analysis. Despite using her married name and ensuring neutral non-clinical clothing was worn, the researcher was aware the influence her Physiotherapist identity was having on participants during data collection. Some participants (of all caregiver types) already knew the researcher through her clinical role, and most participants previously unknown to the researcher requested to know more about the researcher at the start of the interview: often assuming her to have an LD physiotherapy background. The researcher noted that in some circumstances (mostly family members) this prior rapport lead to the participant feeling more relaxed and subsequently dialogue would flow freely from the start of the interview. Whereas, in other circumstances (particularly Physiotherapists or paid carers) dialogue would initially be inhibited by the participant’s fear of researcher expectation. At the start of these interviews, the researcher took time to explain her role as researcher, and the personal and qualitative nature of the questions which would be asked; particularly stressing that there are no right or wrong answers, no expectations, and reminding them that the aim of the interview was to record their unique and personal perceptions and experiences. The researcher then perceived every participant to appear more comfortable and dialogue continued unhindered. This reflexivity strategy hadn’t been considered prior to data collection but was subsequently implemented consistently throughout.

CHAPTER FOUR: FINDINGS

4.1 Introduction

The scope of this study was to explore caregiver experiences/perceptions of hydrotherapy and adults with SLD/PMLD, with particular focus on whether there is any perceived biopsychosocial impact and any experienced barriers/facilitators. This chapter will therefore present the study findings in terms of the perceived impact upon care-receivers as experienced by their participant caregiver.

4.2 Participants

As discussed in Chapters One and Two, the heterogeneity of the adult SLD/PMLD population can limit the generalisability of LD studies. Therefore in order to strengthen this study's transferability, biopsychosocial demographic data were collected from caregiver participants both about themselves and in relation to the person they care for. Where caregivers have multiple care-receiver responsibilities, they were asked to recall their most recent/prominent care-receiver for which to provide the biopsychosocial description. Both the caregiver and represented care-receiver descriptive data will be presented throughout this section in order to provide full understanding of the sample population represented within this study.

4.2.1 Caregiver sample

Twenty-three caregivers of adults with SLD/PMLD were interviewed: 11 via Zoom, 10 via Teams, one via Skype and one via telephone. The majority of participants (13) lived in south-central England where the researcher was based; two lived in south-east England, one east-midlands England, one west-midlands England, one north-east England, two south-east Wales, two south-central Wales and one south-west Wales. The proportion of caregiver types are illustrated in the pie chart below (Figure 7).

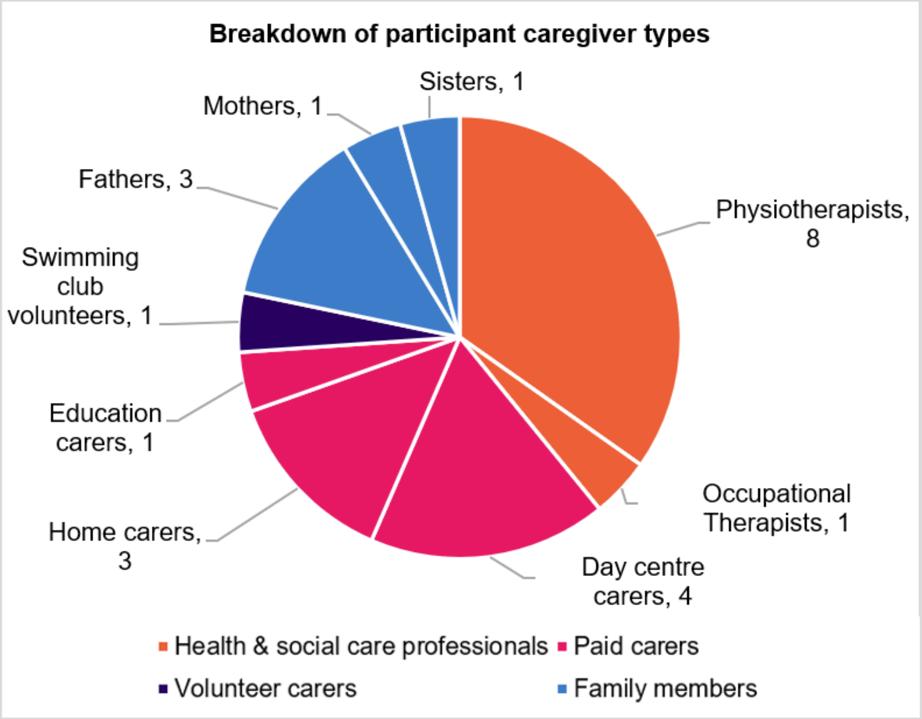


Figure 7: The caregiver roles within SPLASH Study's sample

Twenty-one caregivers reported at least weekly involvement with the person they care for. The full breakdown of caregiver involvement is presented in Figure 8 below.

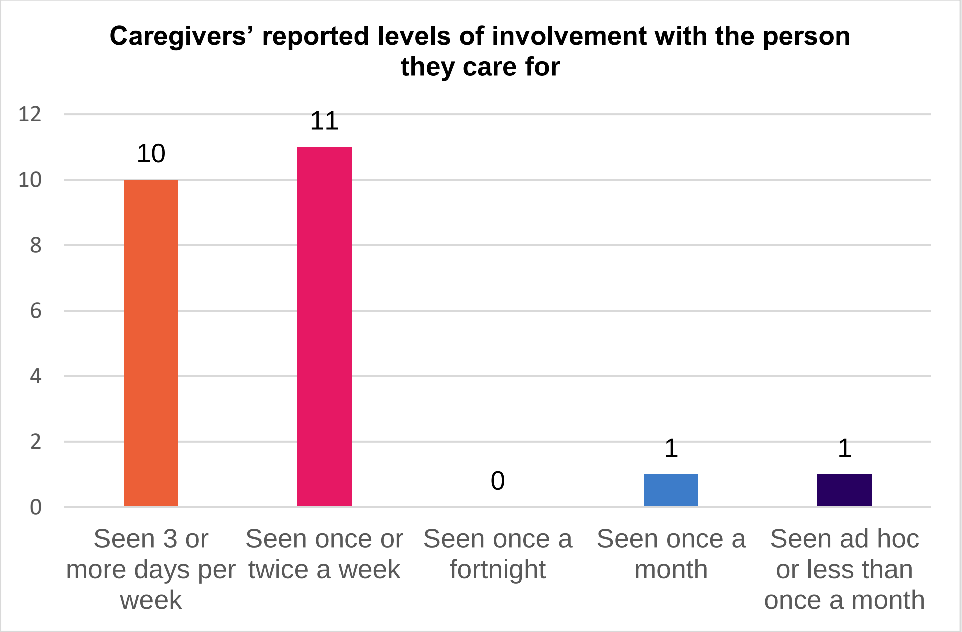


Figure 8: SPLASH Study caregivers' reported levels of care-receiver involvement

4.2.2 Represented care-receivers

When asked about the person they care for, 14 participants reported their care-receiver to be male and nine female. Seventeen participants reported their care-receiver to have a diagnosis of PMLD and six SLD. Every represented care-receiver had a diagnosis of SLD/PMLD, but caregivers listed the following as additional co-morbidities alongside their LD diagnosis: Angelman syndrome, asthma, autism/autistic traits, Behcet's syndrome, significant visual impairment/blindness, CP (reported by 12 caregivers), chromosome 8 disorder, constipation, epilepsy (reported by nine caregivers), global developmental delay, hip dysplasia/dislocation, holoprosencephaly, hydrocephaly, microcephaly, Sandifer's syndrome and Walker Warburg syndrome. Figure 9 shows the distribution of care-receiver ages represented within the study.

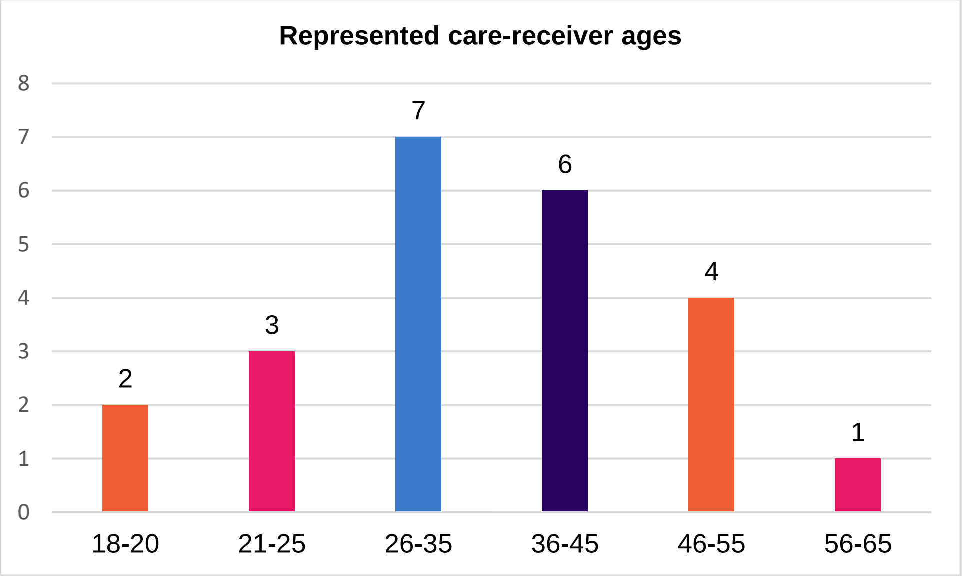


Figure 9: The distribution of care-receiver ages represented within SPLASH Study

As discussed in Chapter One, the cognitive interplay with physical factors means the GMFCS (Palisano et al. 1997) is not validated for use within adult LD populations. However, Bruce and Standley (2019) are not alone in using the descriptors from this classification tool in the wider context of complex physical disability to illustrate the level/severity of physical disability specific individuals are experiencing. For this reason caregivers were asked to select which descriptor (relating to the GMFCS) would be most appropriate for the person they care for. Figure 10 illustrates that most of the care-receivers represented in this study fell in the category of highest physical disability. This is particularly noteworthy as participants with GMFCS levels IV and V are particularly under-represented in existing sedentary CP-hydrotherapy research, with only seven GMFCS level IV participants included in two studies and no participants with GMFCS level V (Gorter and Curry 2011; Lai et al. 2015).

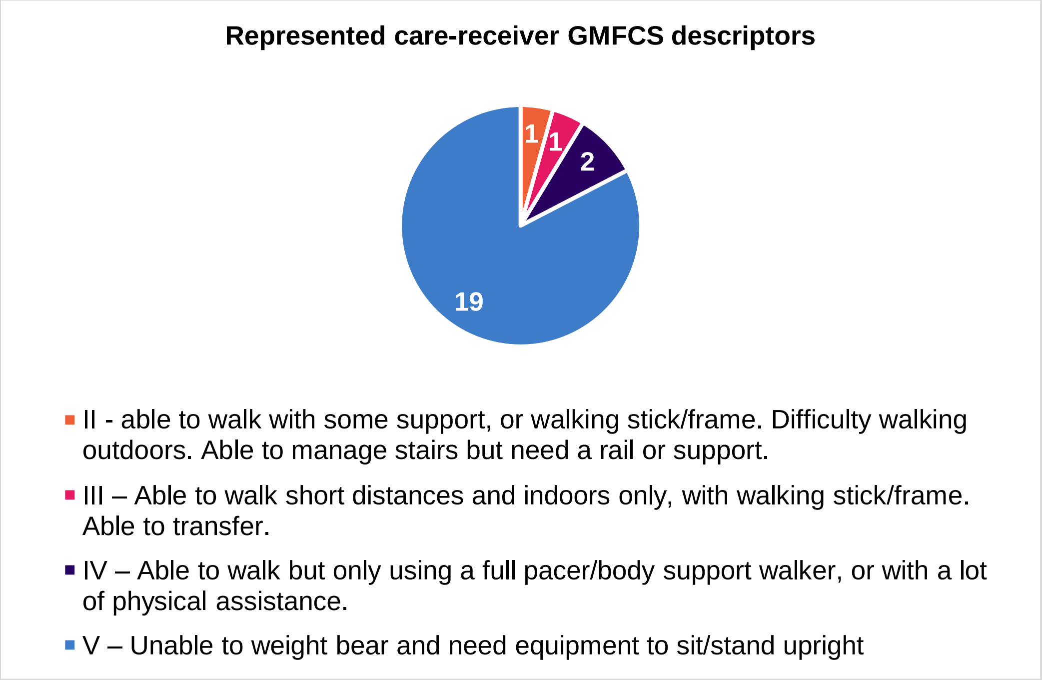


Figure 10: The distribution of care-receiver physical disability descriptors represented within SPLASH Study

In order to provide more specific description about their care-receiver's postural needs, caregivers were asked to provide information on their care-receiver's muscle tone, trunk symmetry, affected limbs, and any contractures or postural management equipment used. The prevalence of each of these is shown in Figures 11, 12, 13, 14 and 15 respectively. Hypertonia refers to increased tone which is not velocity dependent, spasticity is increased tone which is velocity dependent, while hypotonia refers to reduced or low tone (Mosby 2013).

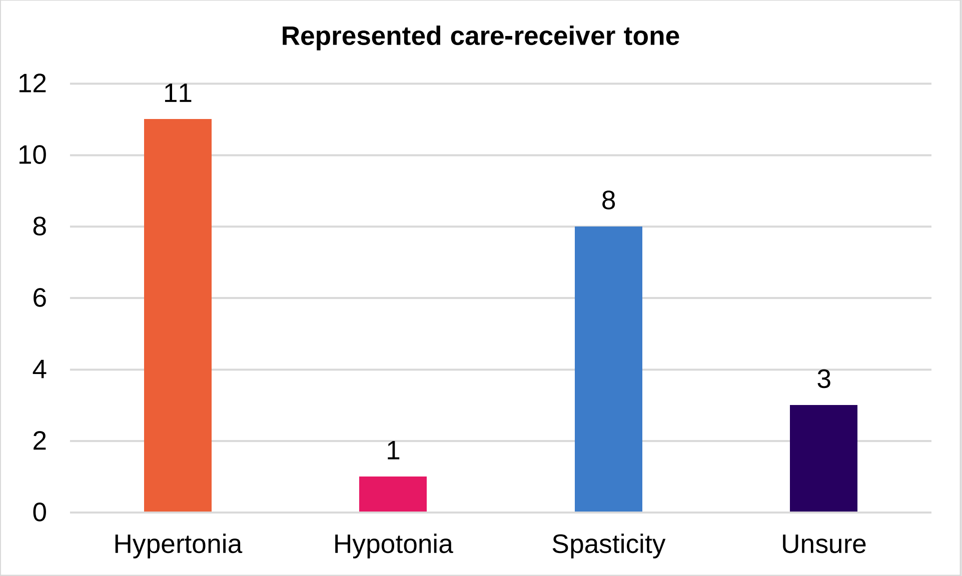


Figure 11: The muscle tone of care-receivers represented within SPLASH Study

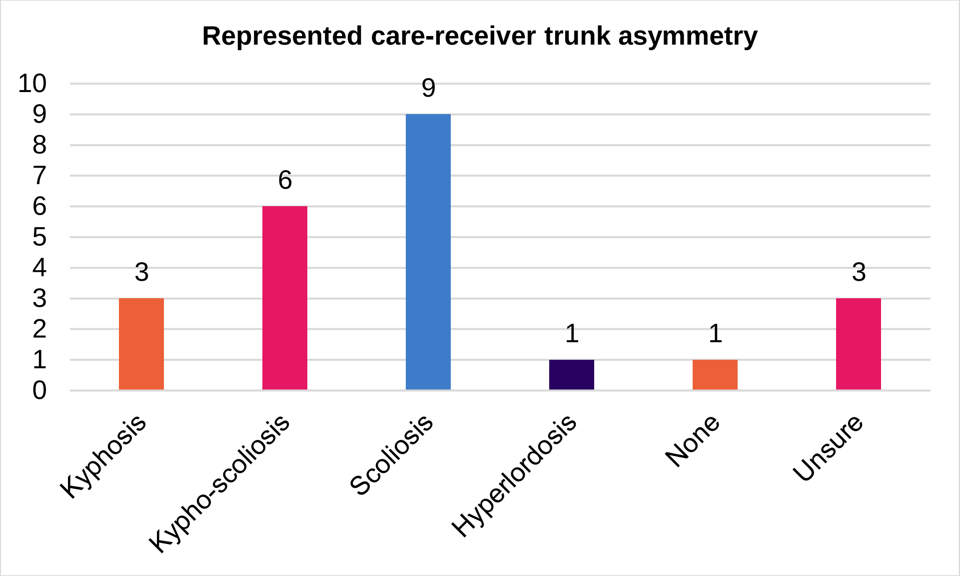


Figure 12: The trunk symmetry of care-receivers represented within SPLASH Study

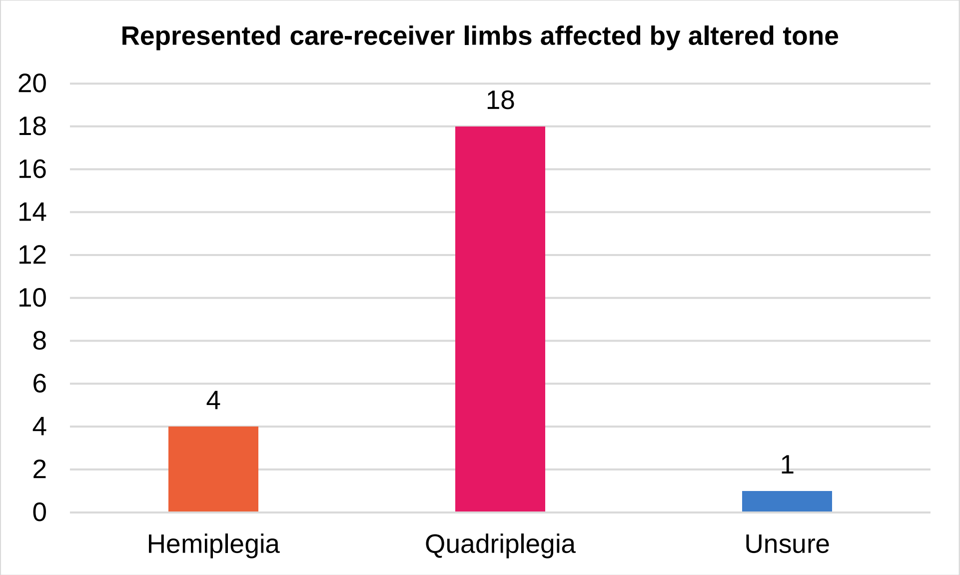


Figure 13: The affected limbs of care-receivers represented within SPLASH Study

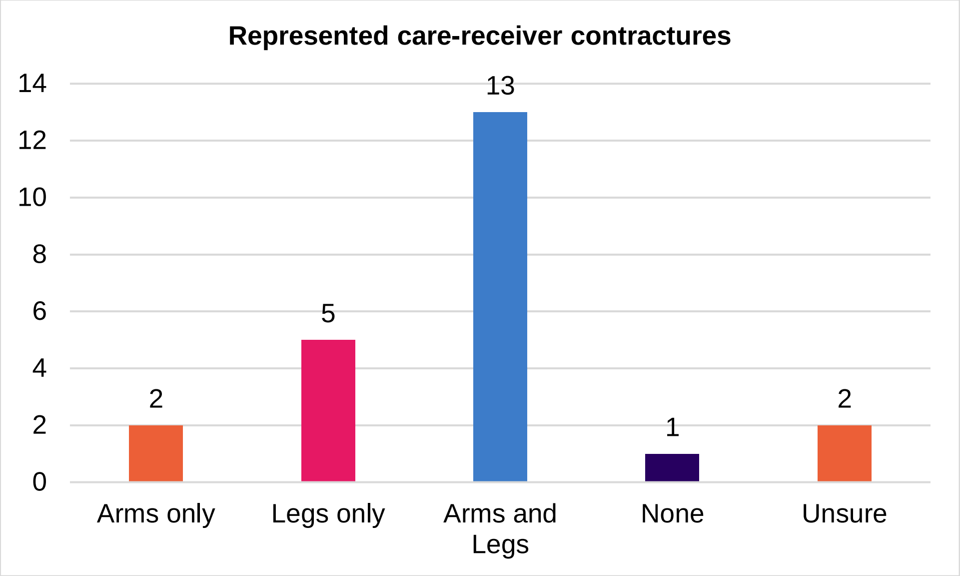


Figure 14: The reported contractures of care-receivers represented within SPLASH Study

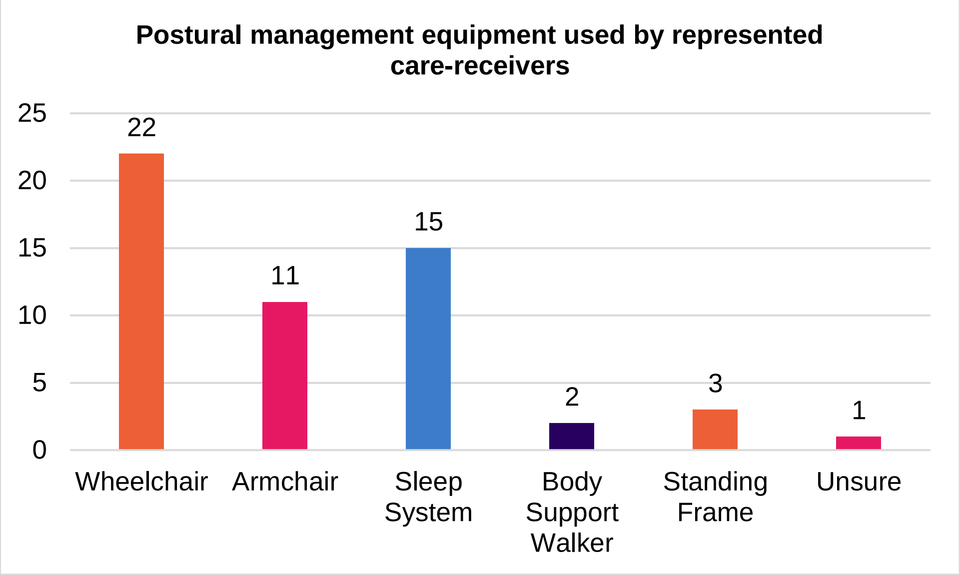


Figure 15: The postural management equipment used by care-receivers represented within SPLASH Study

Communication featured within the study's semi-structured interview topic guide (Appendix III), yet adults with SLD/PMLD can present with a wide range of communication needs and abilities (Bruce and Standley 2019). In order to fully understand the range of communication needs of care-receivers represented within the study, caregivers were asked to advise on the communication support needs of the person they care for. Figure 16 illustrates the range of communication support needs of care-receivers represented in this study.

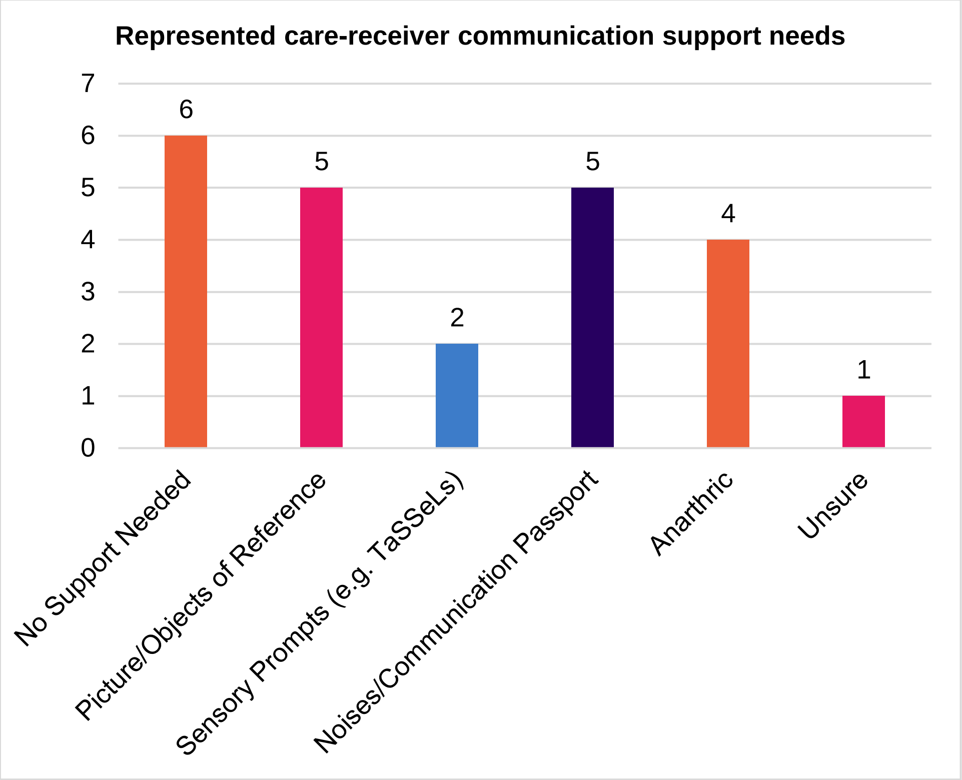


Figure 16: The communication support needs of care-receivers represented within SPLASH Study

4.2.3 Social context

As defined in Chapter One, significant impairment in social functioning is a fundamental aspect in the diagnosis of LD (Hardie and Tilly 2012). In order to better understand the social support needs of care-receivers represented within the study, caregivers were asked to comment on the type of accommodation their care-receiver lives in, the care packages in place, and the funding authorities of both care packages and hydrotherapy. Figures 17, 18 and 19 illustrate the social context of care-receivers represented in this study.

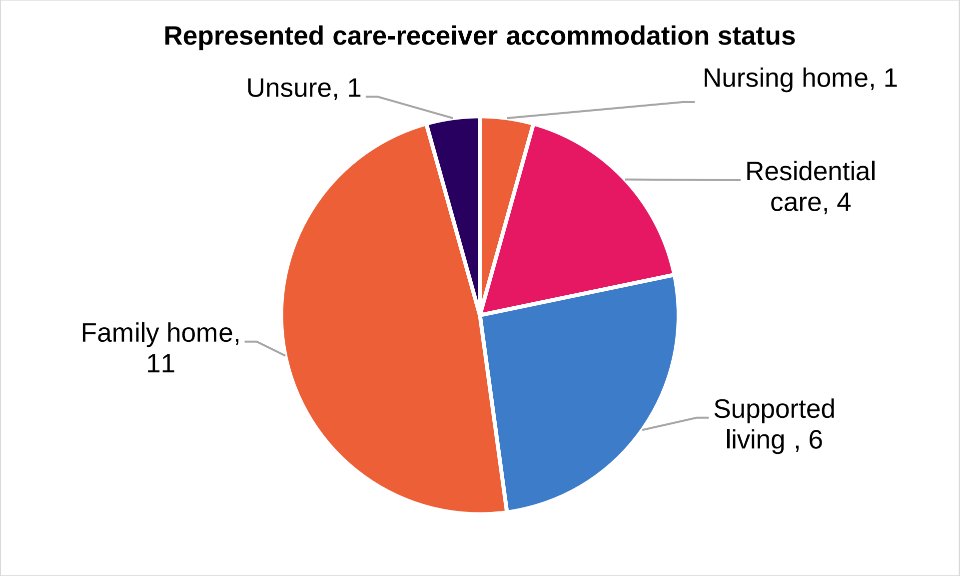


Figure 17: The accommodation status of care-receivers represented within SPLASH Study

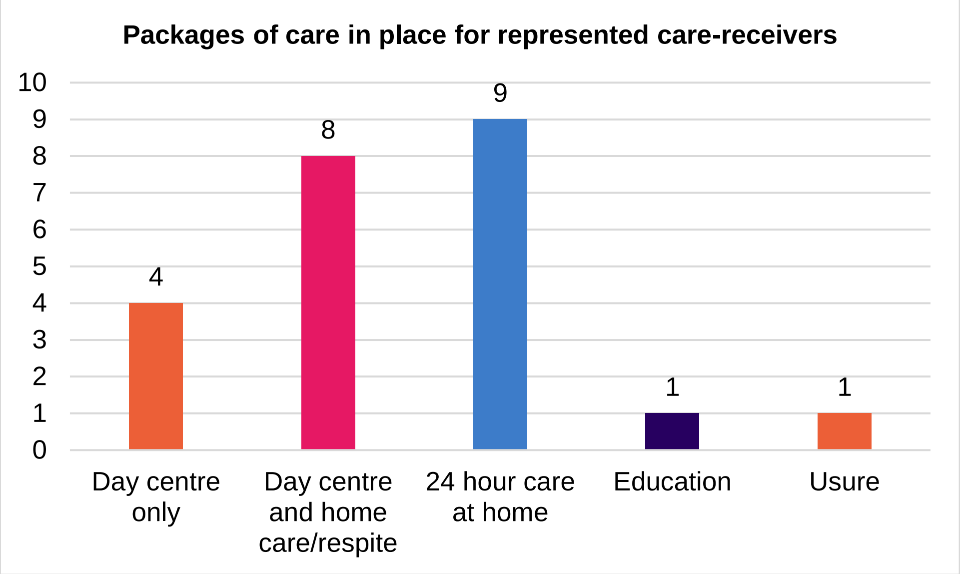


Figure 18: The care packages in place for care-receivers represented within SPLASH Study

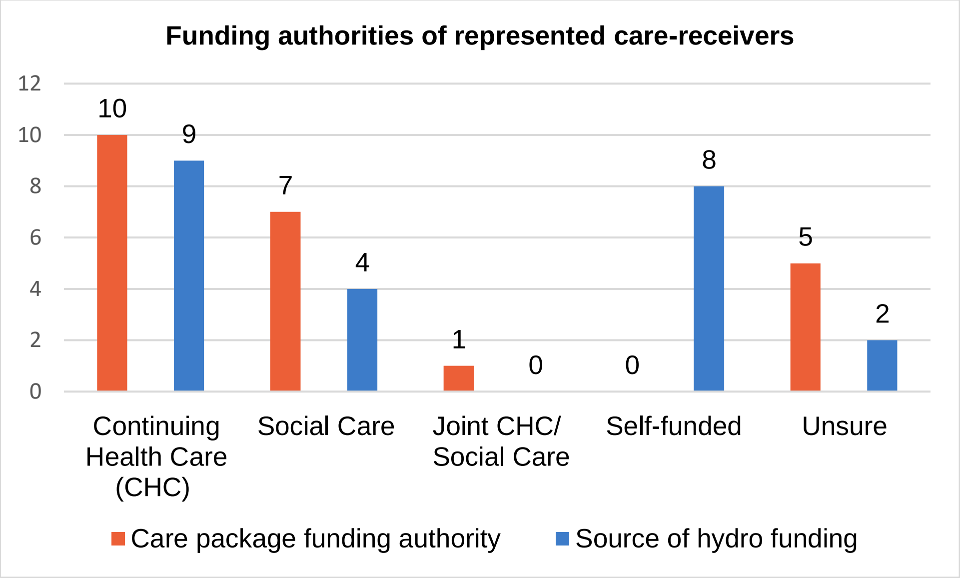


Figure 19: The funding authorities of care-receivers represented within SPLASH Study in relation to care and hydrotherapy

4.2.4 Hydrotherapy intervention

As discussed in Chapter Two, the heterogeneity of hydrotherapy interventions can limit the generalisability of hydrotherapy studies. In fact Gorter and Currie (2011) identified this variance as a limitation of their literature review, due to the difficulties it created in synthesising findings. In order to strengthen the transferability of this study, caregivers were asked to report on care-receivers' usual hydrotherapy frequency (before the Covid-19 pandemic), water temperature and activities undertaken during a typical session. Figures 20, 21 and 22 illustrate the hydrotherapy interventions represented in this study.

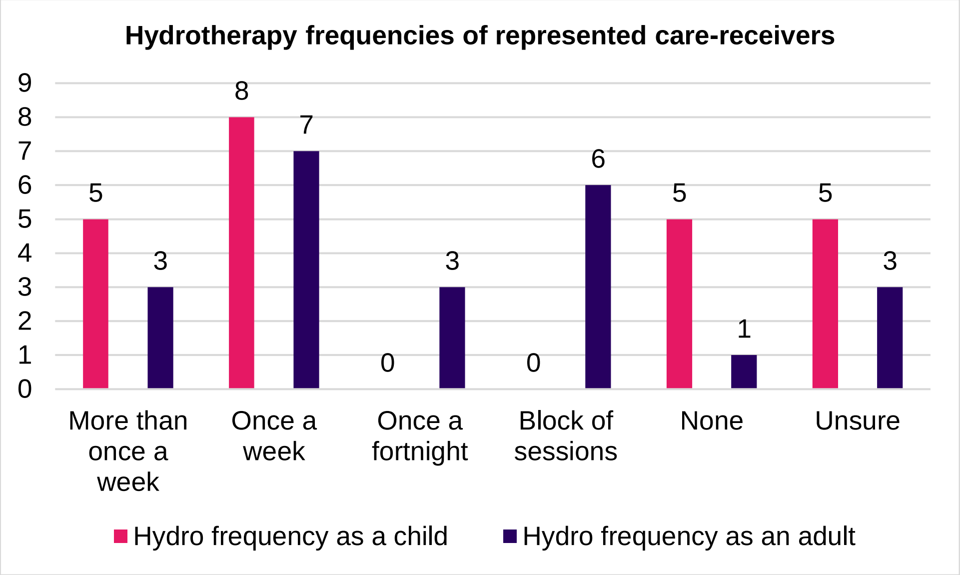


Figure 20: The usual frequency of hydrotherapy interventions represented within SPLASH Study and how these compare to when the represented care-receivers were children

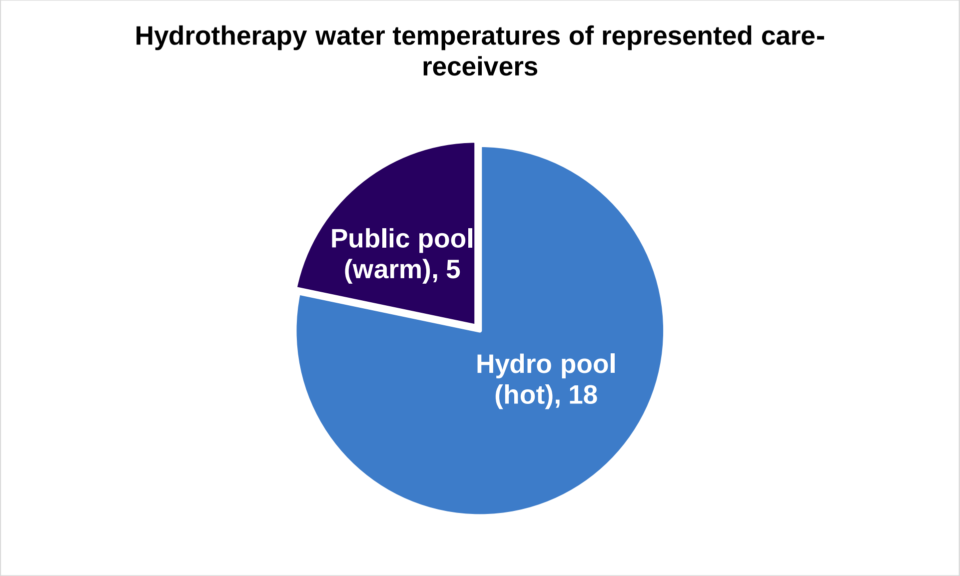


Figure 21: The temperature of hydrotherapy interventions represented within SPLASH Study

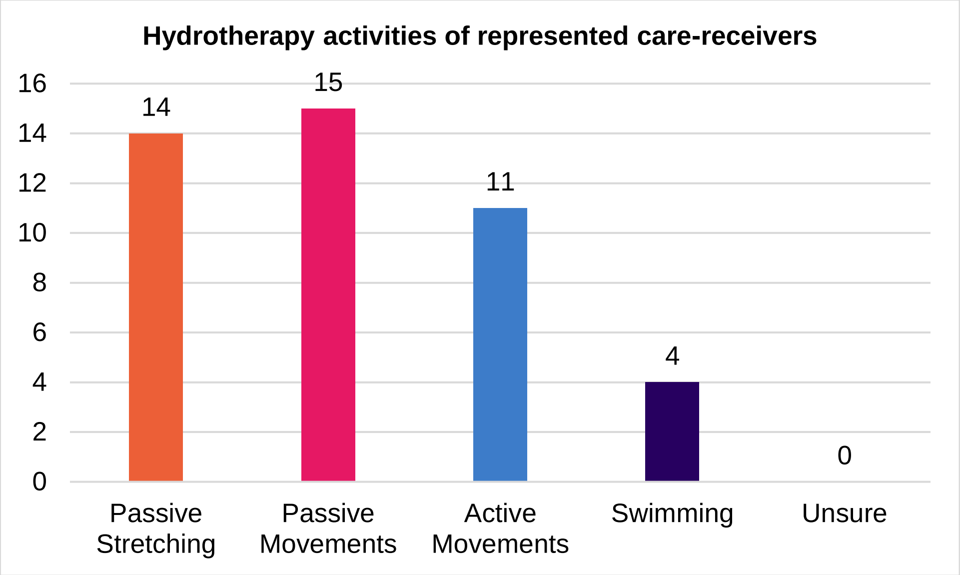


Figure 22: The types of hydrotherapy interventions represented within SPLASH Study

Supporting transferability, these biopsychosocial demographics may be of particular interest to professionals when considering whether the findings of this study could be transferable to specific individuals on their caseloads.

4.3 Autobiographical reflection: identifying themes of importance

In order to explain my personal rationale for identifying particular codes as themes of importance I want to describe the reflective process I have gone through to find them. Below is an extract from my reflective journal.

> "*Qualitative writing is hard, at least I think so. Despite being a very reflective clinician, I'm a quantitative researcher at heart. I've been hitting brick wall after brick*

> *wall while trying to write up my findings and discussion and have finally come to the realisation that this is because I've been trying to take a pragmatic approach when writing up interpretive research.*
>
> *My pragmatic heart wants to take a logical, structured approach and to report on every single finding I've found, but my timescales and word count simply won't allow for this. Neither will the reader's attention! "Find your story", the textbooks tell me (Saldana 2011). I know I'm supposed to use the narrative to flow through from study design, through data collection and analysis to the findings and discussion. So here I am pulling my hair out trying to work out what my story is… but forgetting to include myself in it.*
>
> *I already know that interpretive research has to include the researcher, and that the very nature of qualitative research means it simply isn't possible to remove myself from my research (Saunders et al. 2016), no matter how hard I might try [see this study's reflexivity strategies in Table 5]. Somehow that message became lost when I began to dive into my data and try to make sense of it all. I've created a huge list of themes and subthemes [Appendix VII]…but no one's going to listen while I talk through them all…let alone read my thesis if I try to write them all down.*
>
> *Frustrated, I went back to my research question, and looked again at my table of themes [Appendix VII]. Apart from the first subtheme of physiological health impacts, all were unique to this study. I thought about which themes had been particularly important to participants – which did they mention with little prompting? Which did they keep coming back to? Which were they the most animated about? This reduced the list of themes to only eight, but that was still too many.*
>
> *Finally I thought of myself - why did I want to do this research? Why hydrotherapy? And why adults with LD? That's when I finished writing my autobiographical rationale (Chapter One). This inspired me, so I switched off my laptop and got the post-it notes out - which themes were important to me and the research question? I wrote them all out, and this time counted only six themes. I pondered on why those themes had been particularly significant to me: they were all unique to my study, they were all topics participants had been passionate about, they were all afforded through opportunities potentially unique to hydrotherapy, and between them they had potential to impact not only on individuals with LD and their care networks but even on wider society. I finally found my story.*"
>
> (Extract from Carrie Tbaily's personal reflective journal 2021)

So this is my rationale for identifying these particular codes as themes of importance; they contribute to the knowledge-gap in existing research, they are important to the study's participants and to myself, they illustrate the potentially unique opportunities hydrotherapy presents, and they have potential to impact on adults with SLD/PMLD, their care networks and even wider society.

4.4 Presentation of themes

When reading these findings, it needs to be borne in mind that the researcher was female, in her early thirties, with 12 years' experience of working as an NHS community LD Physiotherapist: 10 years of which have been working within an integrated health and social care community LD service. The researcher also has over 10 years of experience in educating university physiotherapy undergraduates while on clinical placement, as well as six years of experience of providing annual lectures on topics such as LD awareness, postural management and reasonable adjustments. The researcher has completed formal hydrotherapy training in both Halliwick (2021) and Aquaepps (Epps 2009) approaches, and has experience of delivering active, passive and sedentary neuro-hydrotherapy for adults with LD in hydrotherapy pools (including hospital, private and educational settings), as well as private and public swimming pools within the community.

The full catalogue of this study's findings are presented as broad brush themes, themes and subthemes in Appendix VII. As explained in the previous section, the identified themes of importance for this study are body systems, choice, motivation and inspiration, emotions, quality interaction, social inclusion and family bonding. These themes have been identified by the researcher as themes of importance because they contribute to the knowledge-gap in existing research, they are important to both study participants and researcher, they illustrate the potentially unique opportunities hydrotherapy presents, and they have potential to impact on adults with SLD/PMLD, their care networks and wider society.

With over 200 subthemes identified by this study (Appendix VII) it wouldn't be appropriate to attempt to present them all in detail within this thesis. As Chapter Two highlights, existing studies focus strongly on the physiological impacts of sedentary neuro-hydrotherapy, this chapter will therefore begin by presenting SPLASH Study's findings in this domain. The chapter's subsequent presentation of findings will then focus on this study's identified themes of importance; before concluding with findings regarding caregiver experience of barriers/facilitators in accessing hydrotherapy, in order to fulfil all of the study's objectives.

4.5 Caregiver perceptions regarding hydrotherapy and health

The full themes and subthemes identified by caregivers in relation to the impact of hydrotherapy and health needs are set out in Row 1 of Appendix VII. In order to remain focussed on this study's themes of importance only the themes of physiological health impacts and body system impacts will be presented in this section; Table 6 sets out the subthemes incorporated within these topics.

Themes	Subthemes
1. Physiological outcomes	• Balance & co-ordination • Core stability • Function & independence • Maintenance • Mobility & movement • Pain • Posture & positioning • Strength • Tone
2. Body system impacts	• Appetite • Bone density • Bowel motility & management • Circulation & swelling • Immune system • Infection (chest and urinary tract) • Seizure activity

Table 6: Themes and subthemes relating to health needs

4.5.1 Caregiver perceptions regarding hydrotherapy and physiological outcomes

When asked during interviews about any perceptions regarding hydrotherapy and the health of adults with SLD/PMLD, all 23 participants reported experiences of positive impact on their care-receiver's physiological outcomes. Paid carers and family members often reported their perceptions using practical care-receiver examples, only occasionally using descriptive phrases to define these impacts, such as building strength, encouraging movement, increasing flexibility, relaxing tightness, reducing stiffness and working muscles.

> *"The first sort of three of four days [after hydrotherapy] his his movement is much greater, it's easier to actually do the exercises, it's not so hard (gesticulates passive stretching) to get him to relax and stretch. Um, and he feels more comfortable as well in that first part of the week."* (Father of a son with SLD)
>
> *"If you can imagine all your joints are rigid for the majority of the day. And then with the pool it just relaxes the muscles."* (Adult LD day centre carer)

Whereas health professional caregivers tended to report their perceptions in terms of specific physiological outcomes and terminology such as improvements in balance, coordination, core stability, gait, motor function, muscle strength, pain, posture, range of movement and tone. It is also of note that these health professionals often assumed such physiological outcomes are well represented within LD-hydrotherapy research: using phrasing such as obviously, as you know, and I'm sure you're aware to prefix their perceptions of positive physiological impact.

> *"But if we, um, position them [an adult with SLD/PMLD], and use the positioning in the water, um then, then we can utilise the resistance… […] for the strengthening aspect. As well as the stretching."* (Adult LD Physiotherapist)

> *"If we've got profound and multiple [an adult with PMLD] with walking, I mean the gait. We do a lot of work [in hydrotherapy] with strength and balance and gait."* (Adult LD Physiotherapist)

Caregivers attributed the cause of these physiological impacts to factors such as improved care-receiver confidence and motivation, alongside unique environmental properties (such as the warmth of the water, buoyancy and turbulence). While these views were shared by all caregiver types, health professional participants offered additional causational hypotheses, suggesting ease of positioning (e.g. ability to transition from supine to prone or standing), accessibility of the care-receiver (e.g. passive hip flexion to end of range extension), and regulatory sensory input (e.g. proprioception and vestibular) could also be contributing towards these positive physiological impacts.

> *"Just to put the patients in a different position. […] From prone to supine, or or either on their side, is is much easier than changing position [on land]."* (Adult LD Physiotherapist)

> *"It's a really nice way to get vestibular input as well. Um, so (tilts head to the left) the movement of their head in space and um... But whilst, like I said earlier, whilst them not having to think about that postural control, whilst them not having to maintain that upright position, especially if they've got kind of floaties, it's all kind of movement stuff, it's all very stimulatory, but it […] can be all sorts of different ways of moving that you cannot get on land."* (Adult LD Occupational Therapist)

While all 23 caregivers perceptions were concordant with positive physiological impacts in the water, some continued to describe an additional impact they perceived on land. Indeed, Physiotherapist participants even reported land-based physiological impairment/difficulty as their clinical reasoning for prioritising someone for access to hydrotherapy.

> *"We have service users that come through, um, that require hydro, as part of um like a Botox regime or um rehab needs, um if they've been unwell or had um a hospital stay and we need to get back some some movement or if they've lost a range in some of their joints. And we'll use hydrotherapy […], as like a rehab program for them."* (Adult LD Physiotherapist)

All participants had positive perspectives to share in relation to physiological hydrotherapy impact; so although every caregiver provided unique perceptions and experiences, there were few conflicting views within this theme. The only notable conflicts were reports from two paid carers and one family member who highlighted how the physiological outcomes of pain and tone can be negatively impacted after the hydrotherapy session if the poolside air is too cold or they are rushed with washing and dressing (e.g. when there are limited accessible changing facilities).

> *"Showering and drying afterwards, getting him dressed, you know, because even though you come out of a nice warm pool, the hydro pool, obviously suddenly then the cold hits him. […] Um, and obviously then he sort of gets tight again."*
> (Father of a son with SLD)

Due to the resultant negative physiological impacts of these issues, despite passionately reporting many other perceived positive hydrotherapy impacts on their care-receivers, two of these caregivers continued to question whether it was in the best interests of their care-receiver to continue to attend hydrotherapy unless these issues could be mitigated through caregiver preparation and organisation.

> *"So the staff have to like, hoist them in… it it it's a conveyor belt. It's very hard work, and it has to be orchestrated."* (Manager of a PMLD residential home)

4.5.2 Caregiver perceptions regarding hydrotherapy and body system impacts

When prompted during interviews to consider any impacts hydrotherapy might have on the health of adults with SLD/PMLD, caregivers were keen to attribute hydrotherapy input to positive impacts on multiple body systems, including musculoskeletal and neurological systems (as presented in the previous section), cardiovascular and lymphatic systems, digestive system, immune system, respiratory system and urinary system. Caregivers reported these perceptions through specific care-receiver examples of reduced chest infections, urinary tract infections and seizure activity, improved digestion and bowel motility, bone health and management of lower limb swelling, and increased appetite and immune system function.

> *"Those that were tube fed, they they sort of… internal (clasps hands together with fingers interlocking), like it was hard for the feed to go down [the Percutaneous Endoscopic Gastrostomy (PEG) tube] because they were you know.. everything, their muscles were tight and everything, and when they came out of hydro the feed just went down a lot easier, it didn't keep getting blocked, and things like that."*
> (Physiotherapy assistant in an education setting)

Many caregivers (particularly family members and paid carers) reported a deterioration in their care-receiver's body system outcomes during the Covid-19 pandemic, and similarly attributed this to the fact that pools were closed and so most care-receivers were unable to access hydrotherapy.

> *"It really helps with their muscles, like during covid our guys are so stiff. Um. They're on more medication because of this. Where before we dealt with it more naturally."*
> (Paid carer of adults with PMLD)

> *"In this last year she's obviously, she's not had any hydro at all, so she struggled with the bowel side of things. Um, and that's one of the the main focuses of LeDeR [the Learning Disabilities Mortality Review Programme] isn't as well? Is management of constipation."* (Adult LD Physiotherapist)

During SPLASH Study interviews, five caregivers talked about the positive impact they perceived hydrotherapy to have on care-receivers' respiratory health; reporting reduced incidence of chest infections and subsequent hospital admissions when receiving regular hydrotherapy, and how they feel the environment helps with secretion management.

> *"He used to have quite a lot of chest infections. […] And hospitals [meaning hospital admissions] and is look like, […] um is look like his hospitals admission they are quite low since he started hydrotherapy."* (Adult LD Physiotherapist)

Two professionals and one family member talked about the positive effect they experienced hydrotherapy to have on their care-receiver's lower limb swelling; reporting observing immediate improvement following each hydrotherapy session, although admitting they perceive no preventative effect.

> *"She has got, when she's sitting, a lot a lot of oedema. […] Her legs and her feet swell a lot […] so we can always tell when she's been in the pool […] you can physically see the swelling go down."* (Mother of a daughter with SLD)

Caregivers attributed this positive reduction in swelling to the exercise element of hydrotherapy increasing cardiovascular circulation, the lower limb movement improving peripheral vascular circulation, and the warmth and pressure of the water improving lymphatic drainage.

> *"A lot of our [adults with] s-, severe/profound and multiple learning disabilities have minimal movement themselves. So the the the water, um, warmth and the water pressure as well, will help with that lymphatic drainage, swelling in the legs."*
> (Adult LD Physiotherapist)

Three carers of multiple care-receivers reported perceiving hydrotherapy to have a positive impact on reducing seizure activity during sessions, attributing the cause of this to the relaxing and sensory environment achievable within hydrotherapy sessions.

> *"I noticed that we didn't get a lot of seizure activity in the water […] we also have people with epilepsy that we've never had an incident [of] a seizure in the pool or anything like that. […] I don't know whether it's the, it's the motion or the stimulation of different things? Or the fact that it's a completely different environment that's...?"*
> (Paid carer for an epilepsy charity)

Ten caregivers reported an improvement in bowel management, even to the point of requiring less medication for the treatment of constipation following regular hydrotherapy input. Sadly caregivers reported experiencing the inverse of this through care-receivers requiring a notable increase in bowel medication when hydrotherapy sessions ceased during the Covid-19 pandemic.

> *"Their bowels are better [after hydrotherapy]: our guys don't move, and we've got a lot of risk of bowel obstructions. […] And we've really, where we've been in covid, we're really, we've had to increase everybody's bowel medications, because they're not moving as much."* (Manager of a PMLD residential home)

Nineteen participants had positive perspectives to share in relation to hydrotherapy impact on body systems; the four participants who didn't report positive experiences relating to hydrotherapy and body systems similarly didn't report any negative perceptions or experiences in this area. The only notable conflicts were reported by caregivers who had otherwise reported very positive body system experiences. Two health professionals reported experience of skin integrity being negatively affected when the skin on the soles of the feet of two care-receivers broke down (one reported redness, the other superficial grazing). These participants attributed the skin breakdown to the fact that these care-receivers were usually non-weight bearing on land, and so the skin on the soles of their feet was particularly sensitive and had been aggravated by the rough anti-slip pool flooring as they were both able to stand and mobilise in the pool. Both professionals reported this was mitigated by supporting their care-receivers to wear orthotics or wet suit shoes during all future hydrotherapy sessions. Two paid carers reported concern that hydrotherapy attendance could trigger seizure activity if the care-receiver was not properly mentally prepared for the transition into the water, or if not changed quickly enough after the session and so would get cold.

> *"He has epilepsy as well, so that could trigger that [seizure activity] as well. So you have to be mindful of that. The shocking factor."* (Adult LD day centre carer)

One family member and one paid carer described the impact attending hydrotherapy can have on the nutritional intake and digestion of adults with SLD/PMLD, as the specific timings of hydrotherapy sessions require caregivers to adapt the timings of care-receivers' food and medication. They explain how this is particularly challenging for those care-receivers who require percutaneous endoscopic gastrostomy feeding as often their feeds need to be sped up in order to finish in enough time around the session.

> *"We have to take lunch with us, and then some people have to be fed in the car after, because we're at three o'clock by this stage. But we can't feed before 'cause they'll probably vomit in the pool."* (Manager of a PMLD residential home)

Although these are all potentially negative impacts on care-receiver's body systems, all five caregivers agreed there were ways these impacts could be completely mitigated by prior risk assessment and effective care-planning.

4.6 Caregiver perceptions regarding hydrotherapy and mental health/wellbeing

This study's themes of importance of "choice, motivation and inspiration" and "emotions" sit within the broad brush theme of mental health and wellbeing (Row 3 of Appendix VII). In order to remain focussed on this study's themes of importance only the themes and subthemes set out in Table 7 will be presented in this section.

Themes	Subthemes
1. Choice, motivation and inspiration	• Choice & control • Motivation • Inspiration of exploration

2. Emotions	• Inclusion & satisfaction • Confidence & understanding • Freedom & weightlessness • Happiness & excitement • Relaxation, calm & comfort • Safety & caring proximity

Table 7: Themes and subthemes relating to mental health and wellbeing

4.6.1 Caregiver perceptions regarding hydrotherapy and choice, motivation and inspiration

This study's "choice, motivation and inspiration" theme of importance sits within the theme of enabling autonomy (Row 3.2, Appendix VII) and was raised by thirteen caregivers, spanning all caregiver types. When asked about any perceptions regarding hydrotherapy and the mental health/wellbeing of adults with SLD/PMLD, participants became energised and were keen to describe their experiences of how their care-receivers had more choice and control in the water during hydrotherapy sessions: providing examples of care-receivers being able to choose where they wanted to go in the water, and to control their bodies and movements in order to complete activities which they wouldn't be able to do on land. Seven participants attributed this to the reduction in physical limitations care-receivers' experience when in the water: further explaining their perceptions that this is partly due to increased physical ability in the water, but also due to reduction in requirement for postural equipment.

> *"It's the only place that they can be… able to move by themselves. Because they are not able to support themselves in sitting or standing, and so to be able to float freely, and move their legs to move themselves from one place to another, is a real boost for them."* (Adult LD Physiotherapist)

Fifteen caregivers reported perceiving increased motivation in their care-receivers during hydrotherapy sessions. When asked to provide examples, these caregivers cited hydrotherapy as affording the following opportunities which in turn improved their care-receiver's motivation: meaningful decisions (e.g. choosing which carers to support them), responsive actions (e.g. cause and effect: such as pushing an object down in the water, and feeling it splash as it floated to the surface again), achievable goals (due to increased physical ability and reduced restriction), improved alertness and engagement (due to the sensory environment and quality interaction, as presented below) and fun.

> *"It kind of encourages that movement, but in a fun way? it's not... they're not moving because someone's telling them to swim, they're moving because they're in the pool and you naturally want to move and splash."* (Disability swimming club volunteer)

One paid carer described hydrotherapy as providing the opportunity for adults with SLD/PMLD to:

> *"take ownership over their own body really without having to talk to someone or or have someone holding them the whole time."*
> (Physiotherapy assistant in an education setting)

The perception that hydrotherapy provides a rare opportunity for adults with SLD/PMLD to have space and distance from caregivers was shared by a total of eight participants: using words such as freedom, independence and autonomy. One health professional advised that carers should be actively promoting independence (such as the distance perceived during hydrotherapy), as 'reduction of restrictions' is a main principle of the MCA (2005). This professional summarised her perceptions as to how this subsequently impacts on adults with SLD/PMLD:

> *"They've always got someone with them. And actually, um…if you've got the right floating devices, if you've got the right um support, or even if they can do it themselves, it means that that carer can step back a bit more. They don't have to be so close, and in their face, and touching. And and and that's got to give you a sense of freedom, and and control of your life as well, which is gonna then obviously improve wellbeing."* (Adult LD Occupational Therapist)

The subtheme of inspiration of exploration comprises all the factors of choice, control, motivation, and independence. Inspiration of exploration and was expressed by caregivers through practical care-receiver examples. For example, non-verbal care-receivers exploring and expressing their sense of humour physically by splashing a carer who didn't want to get their hair wet, deliberately moving to the far end of the pool when they hear the hoist (indicating time to get out), as well as the following much less obvious example:

> *"You get him into the water and you suddenly realise that he's got this inflatable ball, and he's kind of pushing it, and he's exploring, pushing it underneath his, underneath his back and grabbing it with the other hand."*
> (Physiotherapy assistant in an education setting)

Fifteen participants had positive perspectives to share in relation to hydrotherapy impact on choice, motivation and inspiration; while eight participants didn't report positive experiences relating to this theme, participants expressed no negative perceptions under this theme either.

4.6.2 Caregiver perceptions regarding hydrotherapy and emotions

This study's findings relating to emotions are presented as facilitation of feelings in Row 3.1 of Appendix VII. When asked during interviews about any perceptions regarding hydrotherapy and the mental health/wellbeing of adults with SLD/PMLD, all 23 participants reported experiences of hydrotherapy positively impacting on their caregivers emotions, more specifically regarding the facilitation of feelings. During interviews, participants of all types regularly reported (often repeatedly throughout interviews) their experiences of care-receivers' happiness, joyfulness and excitement during hydrotherapy sessions. Several caregivers of multiple care-receivers (i.e. each caregiver had responsibility for more than one care-receiver) reported consistently witnessing hydrotherapy change a care-receiver's bad mood into a good mood on entering the pool.

> *"They are feeling relaxed and calm after hydrotherapy. And it's look like, yeah… majority of them, they enjoy. I don't have anyone, who feels like, I don't know,*

> *anxious or feels, um, um…in a bad mood after hydrotherapy, so I think it's just relax them."* (Adult LD Physiotherapist)

Paid carers tended to focus more on subthemes of confidence and understanding, alongside feelings of freedom and weightlessness.

> *"I would hope with obviously consistency of sessions, that it would give them a confidence that they're having their communication recognised."*
> (Paid carer of adults with LD)

> *"He absolutely loved it. It just gave him so much freedom. And with the support of the float, he could float around the hydrotherapy pool."* (Adult LD day centre carer)

While family members tended to particularly focus on subthemes of relaxation, calm and comfort; however the unique theme of caring proximity was raised by them too.

> *"For her having that sense of being kind of held, really, which she doesn't get that sense that much, you know or or supported, […] with without any restrictions is um, is just amazing."* (Sister of a lady with PMLD)

Both family members and paid carers reported perceptions of hydrotherapy instilling feelings of inclusion, achievement and satisfaction in their care-receivers. One family member explained their perceptions as to why feelings of achievement and satisfaction are so rare for adults with SLD/PMLD:

> *"You're a little bit worthless if you can't do what other people can do […] it [hydrotherapy] must give her that feeling of, well yeah, […] "I'm clever as well"."*
> (Mother of daughter with SLD)

Health professionals confirmed all these subthemes, but took a more practical approach to justifying these emotions; instead of discussing freedom it was freedom from support, and happiness was discussed in terms of tolerance of people and stretches. Health professionals also raised the theme of safety, in terms of safety being an important factor when attempting gait rehabilitation, but also in terms of building rapport between care-receiver and therapist.

> *"The people [caregivers] they choose are the better handlers, so that um they know that the people [caregivers] that are going to make them feel safest and best in the water."* (Adult LD Physiotherapist)

All participants had positive perspectives to share in relation to emotional hydrotherapy impact, but it is worthy to note that caregivers of multiple care-receivers were keen to highlight their experiences of when hydrotherapy isn't the right activity for an individual care-receiver, it could elicit negative emotions of sadness, fear and anger.

> *"I've got a few people [adults with SLD/PMLD] that they can't come [to hydrotherapy] because of it [the pool] being hospital based or the echoey, echoey… or other people in the room shouting or enjoying themselves and they can't cope with that."*
> (Adult LD Physiotherapist)

> *"Not everybody liked it, I will admit. […] Some didn't like it, but some did."*
> (Physiotherapy assistant in an education setting)

These caregivers were quick to follow up these perceptions by stating that in this situation caregivers would see if any immediate sensory changes could be made to the environment in order to mitigate these triggers (such as dimming lights, reducing splashing, adding calming music), or else review whether it was appropriate for that individual to continue to attend hydrotherapy. In some cases, caregivers reported these negative experiences could be avoided through graded exposure to the hydrotherapy environment before attempting to get into the water.

> *"We tried just to take some [adult with SLD/PMLD]… we thought is not gonna, not gonna like the the water… […] Err, because they were always vocal in the past when they went to swimming pools. So just to take like a slow approach, they first went went, went to the building just to have a coffee there or something, just to to feel the atmosphere, or get used to the atmosphere. And then, the next time they they they they were shown around, but didn't get changed, and and so yes, this slow approach sometimes help."* (Adult LD Physiotherapist)

The only other negative emotional impact reported by caregivers was observed when the hydrotherapy session was drawing to a close. Carers and health professionals both provided examples of care-receivers' mood changing negatively when suddenly told it was time to get out of the pool. One caregiver suggested a solution they had devised, by tailoring the hydrotherapy sessions to consistently end with a period of relaxation, so as to warn care-receivers the end of the session is coming. This made the end of the session less surprising and so care-receivers felt less frustration and sadness, and were able to continue to experience the positive emotions they had enjoyed during their hydrotherapy session.

> *"He used to get so upset and angry when it was time to finish in the hydro-pool, so […] towards the end of the session we'd quite often put on a bit of relaxation music, sort of, to change the lighting, err just to help the students recognise that it was coming to the end."* (Supported-living LD carer)

4.7 Caregiver perceptions regarding hydrotherapy and quality interaction between caregiver/receiver

During interviews, caregivers were keen to talk about their experiences of hydrotherapy impacting on relationships, communication and care-receiver alertness (Rows 5, 7 and 9 of Appendix VII). This study's "quality interaction" theme of importance draws on findings from each of these areas.

The theme of relationships was scattered throughout caregiver interviews, usually expressed through experiential examples. While some of these subthemes are discussed in sections 4.8 and 4.9 below, the relationship subtheme of particular importance to 'quality interaction' were the consistent reports of hydrotherapy affording caregivers (particularly paid carers) dedicated 1:1 time with their care-receiver.

> *"You haven't got anybody else interrupting you, they've got their- your sole attention, and you know, the interaction is second to none. You know. Because you've got to*

> *be on the ball, you've got to be awake, you've got to be alert. So they are getting the best of the best."* (Adult LD day centre carer)

Caregivers reported this opportunity for uninterrupted, undistracted, 1:1 time with their care-receiver is hard to achieve on land and so is a particularly treasured opportunity, particularly unique to hydrotherapy. They were able to explain this further through explaining the barriers they had experienced which prevent this level of devotion or quality time being achieved on land.

> *"Once you're in the pool with someone, you're not gonna suddenly be distracted by the phone ringing, or anyone else coming to grab you for a minute. […] There's no, "Oh could you just pass me this? Could you just do that?" It's not going to happen."*
> (Adult LD day centre carer)

Caregivers were also passionate in describing the high quality of the interactions achievable during hydrotherapy sessions. While some caregivers attributed this to the improvement in care-receivers' communication and social skills, other caregivers attributed this to the attention caregivers are able to give to their care-receivers' during hydrotherapy sessions: resulting in them recognising and responding to their care-receiver's existing communication attempts which previously would have been overlooked.

> *"His communication was much err more consistent and clearer.[…] And their communication skills improve um as well, because it's a very motivating activity for them [adults with SLD/PMLD]."* (Support worker for adults with PMLD)

> *"It just makes you have to think harder about how someone's like maybe facial expressions changing in the water, what they might be feeling, why they're suddenly maybe turning away and not wanting to get involved. […] I think it makes you more aware of this, of their cues of what they're giving off, of what they're, what they're trying to communicate. Or just how they're feeling."*
> (Activity co-ordinator for people with LD)

The other factor reported by caregivers to impact the quality of interactions is the positive impact perceived on care-receiver alertness in the hydrotherapy pool. Eleven caregivers reported experiencing care-receivers to be more alert both during and after hydrotherapy sessions, attributing this to factors such as the stimulation achieved through sensory input during hydrotherapy, reduced boredom, the intrigue of the new environment and the level of engagement as care-receivers can be an active participant in hydrotherapy activities rather than a passive observer.

> *"I think he probably gets the stimulation, maybe from music from lights in the pool as well, so as there's other things going on. The more, the more he can interact with things, the better."* (Father of a son with PMLD)

> *"Hydrotherapy like I said, it's got the proprioceptive deep pressure, it gives you feedback where your body is in space, um and all proprioceptive input has a regulating effect on the brain. Um, so that's going to mean that people are more alert, more able to function, more able to learn, more able to do the things that they need to do."* (Occupational Therapist for adults with LD)

Twelve participants had positive perspectives to share in relation to the unique opportunity for quality interaction that hydrotherapy provides; the only notable conflicting perspectives were from one caregiver who reported hydrotherapy being so relaxing for some care-receivers that they would fall asleep during their sessions. While this would therefore limit interaction, it is important to note that this caregiver reported this experience as a positive indicator that these care-receivers must be happy, relaxed and safe.

> *"The impact [of hydrotherapy] on them [adults with SLD/PMLD] was so different, every single one. You know, one used to go to sleep in the water. You know, he'd be nodding off."* (Physiotherapy assistant in an education setting)

4.8 Caregiver perceptions regarding hydrotherapy and family bonding

Caregivers of all types were keen to report the positive impact they perceived hydrotherapy to have on the bond between families and care-receivers. While family members passionately reported their own experiences, paid carers and professionals were keen to talk about the moment they watched as a mother happily danced with their daughter in the pool for the first time, or that moment a father realised he now had an activity he could do with his son every weekend, which could replace his broken hearted dream of them ever being able to play football.

> *"So it's like Father/son have never done anything [together], because you know stereotypical Dad's take the boys to football, or whatever, they'd never really done anything [together]. And then… […] like yeah, [observing his son in hydrotherapy] changed his perspective and he wanted to take him."*
> (Physiotherapy assistant in an education setting)

Caregivers reported these observations passionately, explaining their experience that opportunities for family bonding are particularly limited for adults with PMLD, thus making hydrotherapy all the more valuable as a rare opportunity for families to do an activity together.

> *"It's the […] lack of the physical access to other services which means that hydro is a really nice opportunity, where it is inclusive and you can be saying, "Yes you can do this. Come in. Join your family. Do a a an activity together"."*
> (Physiotherapy assistant in an education setting)

When asked to consider reasons for this paucity in adult SLD/PMLD family activities, caregivers cited the lack of physical or sensory appropriateness of 'normal' family activities (e.g. lack of hoists, noise or queuing), lack of ideas or fear (e.g. of risks associated with care-receivers particular impairments).

> *"Because they can't access "normal" activities, "normal" family activities. You know, there's no, there's no facilities anywhere that have got [an] overhead tracking hoist and things like that, to get them in and out."*
> (Physiotherapy assistant in an education setting)

Not only did caregivers perceive hydrotherapy to be a unique accessible opportunity for shared family activity, but they continued to explain their perceptions of hydrotherapy having a more meaningful and significant impact than that through providing a rare opportunity for family bonding. When asked to consider why, caregivers attributed this to the nature of neuro-hydrotherapy which demands close physical contact (in order to support the care-receiver in the water), while facilitating communication and alertness: with many caregivers reporting this combination to be entirely unique to hydrotherapy.

> *"We [the whole family] benefited it, from it, together um, as something to be able to do together. […] Us being able to bond together […] We could hire that [the hydro pool] around her birthday, or something special like that and then go as a family."*
> (Sister of a lady with PMLD)

> *"It forms positive relationships; as in our families parents have, they have, they want to come swimming with them, and they get… so… they get a session, but they also get quality time with their families, and their families really report a difference in their [adult] child."* (Manager of a PMLD residential home)

When asked to reflect on their perceived paucity of adult SLD/PMLD opportunities for close family bonding, caregivers explained the barriers they had experienced in preventing close physical contact and caring touch with their own care-receivers. While family members mostly attributed this lack of caring touch to the physical barriers presented by their care-receiver's postural management equipment (e.g. moulded wheelchair, modular armchair or even sleep system lying support), professionals and paid carers tended to attribute this lack of caring touch to time pressures and their roles as paid caregivers.

> *"If someone [with SLD/PMLD] doesn't live with their parents, they're not getting that family contact, if you only ever are supported by paid carers, they they tend to keep their distance."* (Adult LD Physiotherapist)

> *"Also, yeah, just us um us being able to bond together and also for her having that sense of being kind of held, really, which she doesn't get that sense that much, you know or or supported, but in that sense, where yeah with with without any restrictions is um, is just amazing."* (Sister of a lady with PMLD)

Twenty-two participants had positive perspectives to share in relation to hydrotherapy impact on relationships; while only seven reported on the specific family bond, the subthemes relating to wider and non-specific caregiver/care-receiver relationships (see Row 5 of Appendix VII) align with these experiences. The only negative perceptions expressed relating to hydrotherapy and relationships were in relation to negative reactions from the general public (presented in section 4.9 below). There were no negative perceptions expressed in specific relation to hydrotherapy and family bonding.

4.9 Caregiver perceptions regarding hydrotherapy and social inclusion

Table 8 illustrates the main themes and subthemes identified by caregivers in relation to their reported impact of hydrotherapy and social inclusion.

Themes	Subthemes
1. Barriers to social inclusion	• Lack of physical access • Public perception • Inability to self-advocate
2. Facilitators to social inclusion	• Accessibility • Alertness and engagement • Ability in water
3. Opportunities for social inclusion	• Community sense • Meaningful occupation • Family/peer bonding

Table 8: Themes and subthemes relating to social inclusion

4.9.1 Barriers to social inclusion

Caregivers raised the issue of social inclusion early on in the interviews, largely when asked about their general experience of hydrotherapy. They often started with a comment about the lack of activities available to the PMLD community, and used hydrotherapy as an example of a suitably accessible activity.

> *"I do think there's really a lack of activities and things for adults with PMLD […] I mean that's why I was quite passionate about swimming."*
> (Activity co-ordinator for people with LD)

When asked why they feel there aren't more activities for people with PMLD in the community, caregivers cited the lack of physical access as the predominant barrier.

> *"Because they can't access "normal" activities, "normal" family activities. You know, there's no, there's no facilities anywhere that have got [an] overhead tracking hoist and things like that, to get them in and out."*
> (Physiotherapy assistant in an education setting)

One caregiver was able to explain their views as to why these barriers are particularly challenging for adults with PMLD, compared to children:

> *"I think it's just, it's making sure that adults with PMLD aren't forgotten about. […] Because so many places cater for children with PMLD, children with learning difficulties. Um. And because they're smaller, they're easier to get into non-accessible pools, and so I think swimming pools and leisure centres tend to forget that these people grow up."* (Activity co-ordinator for people with LD)

When asked about the barriers of accessing hydrotherapy, caregivers expressed their concerns and fears of social intolerance and rejection resulting in feeling further socially excluded. In some cases this was anticipatory fear prior to attending hydrotherapy, in other cases they were speaking from experience. Fear of public perception presented as a prominent subtheme with caregivers reporting both experiences and anticipatory fears of the public staring, making derogatory comments or being upset by vocalisations, appearance or behaviours.

> *"He'd never seen that [member of the public], because like I say the facilities don't exist, you know. Or maybe because parents or carers are a bit like "I don't want to*

> *take them out in public, because they get stared at, they've got to have, you know, armbands on". They're 25 and they've got armbands on; people do look, you know."*
> (Physiotherapy assistant in an education setting)

> *"It has backfired on occasions, when I've taken somebody with challenging behaviour into the leisure centre, and um they've screamed the place down! And and the elderly people look quite perturbed."* (Adult LD Physiotherapist)

One family member cited inability to self-advocate as another barrier in overcoming social exclusion, reporting that his son often missed day centre hydro sessions because, being non-vocal, he didn't demand attention and so regularly got forgotten about while other people were prioritised.

> *"He lost out quite a lot, and if something else was going on at the centre, they would often cancel sessions. […] So there was a period when he was there that I would say that he didn't get the full benefit. And I think because of competition with other other people there, he often got forgotten because he didn't demand attention."*
> (Father of a son with PMLD)

4.9.2 Facilitators to social inclusion

Caregivers largely cited the physical accessibility of hydrotherapy facilities (e.g. hoists, ramps and changing facilities) as facilitators to social inclusion, particularly in comparison to other community activities. One caregiver referred to the Changing Places Campaign (a consortium campaign to increase the number of fully-accessible toilets - including hoist, changing-bench and shower facilities, particularly in community settings), and sounded hopeful that the number of toilets meeting these standards (Changing Places Consortium 2013) would continue to increase and subsequently facilitate better access to public hydrotherapy in the future.

> *"I'm hoping, with more "Changing Places" and things like that coming available I'd hope that swimming pools and leisure centres would would come on to-, would hopefully grab hold of that and come into it."*(Activity co-ordinator for people with LD)

Some caregivers perceived hydrotherapy to improve levels of alertness of the person they support, leading to an improvement in engagement over and above that of land-based activities (such as family visits), and cited this as another facilitator to social inclusion.

> *"Most of our families, when they see their son or daughter, they always see them asleep. Um. But when they go to a hydro session, they, the parent also comes away feeling really positive because they had 1:1 interaction with their [adult] child, who's been alert and free. […] I think the individual enjoys the interaction with their family, where on dry land, if you wanna say, they switch off."*
> (Manager of a PMLD residential home)

> *"She's going to be able to engage with the world more, because she can see things more."* (Adult LD Occupational Therapist)

Two caregivers described hydrotherapy as a disability eliminator; reporting that even though someone may require a lot of physical support (for posture and transfers) on land, in the water that same person can be as independent as the general population.

> *“You're all in the same boat, really. When you're in the water.”*
> (Adult LD Physiotherapist)

> *“This particular man, […] I’ll describe him on land. So on land: can't walk, can't talk, can't eat, can't move, he’s lifted, he’s hoisted. […] You put him in the pool: and he can float, and nobody's holding him. There's not a float on him. There's not anything supporting him, other than the water. […] All of a sudden in the water, if I was floating, he was floating, there would be no difference whatsoever.”*
> (Physiotherapy assistant in an education setting)

They reported this apparent change in abilities as a significant facilitator to social inclusion as it brings with it the power to change perception.

> *“Dad was amazed that all his life he’s told this boy, this man, that he can't do anything. And then I’ve put him armbands on, and he can, you know. […] That changed Dad’s perception, because he’s only ever seen him at home, and on land it’s a totally different viewpoint of that child or adult, when you get in the water.”*
> (Physiotherapy assistant in an education setting)

4.9.3 Opportunities for social inclusion

The theme of opportunities presented by hydrotherapy for social inclusion was scattered throughout each caregivers interview. One particular subtheme was the reporting/marvelling of caregivers that hydrotherapy is an activity out of the home, in the community, and often in “mainstream” facilities.

> *“It's a different activity, so they go somewhere different, they do something different. […] I think also the fact that it's a more mainstream activity. It's not, it's you know, it's the sort of thing everybody would do.”* (Adult LD Physiotherapist)

> *“They’re with lots of different people in the pool, and that's that's a lovely environment 'cause it's a mainstream facility, that they're they're able to access.”*
> (Adult LD Physiotherapist)

Caregivers continued to explain their perceptions that hydrotherapy being an activity in the community, and often in mainstream facilities, allows opportunity for the general public to meet adults with SLD/PMLD. Despite some fears and the previously presented negative experiences, many caregivers reported receiving positive comments from members of the public, or even experiencing changes in perception.

> *“Sometimes we’ll have other physios come into the pool, um or just come past the pool, and and and ask about [adult LD] clients who are in the pool. So that's definitely made our client group a bit more visible, to our MSK [Musculo-SKeletal] colleagues, especially who used the pool. And that's where our pool’s based, is in an outpatient setting. Um. So it’s just opened up those conversations.”*
> (Adult LD Physiotherapist)

> *"I actually had a member of public come over to me and and just start chatting to me, and say, and ask me a few questions about the man who [I] was supporting."*
> (Supported-living LD carer)

> *"You often get the parents that go, "Ooh. Don't look, don't stare." […] It is really good to sort of, chat with the children and and with the parent there, to say, you know, "this is what this means, and he's really happy 'cause he's swimming". And then you know, we've had that a couple of times where the same children have been there the next time, and then you can hear them go, "Oh Mummy, he's happy today". […] So that is great for me, because you know, and and great for the person supporting, 'cause then you've not got someone staring."* (Supported-living LD carer)

> *"I gue-, guess that is good because it's a bit educational for um the general public. […] And that one child may grow up, you know, not being scared, and and a bit more open to different people. Rather than, "Oh don't look, don't stare, it's rude"."*
> (Supported-living LD carer)

Another prominent subtheme reported by caregivers is the opportunity hydrotherapy provides for meaningful occupation. Caregivers particularly reported hydrotherapy to impact on meaningful occupation through providing opportunity to both actively be part of a community and to feel the satisfaction of engaging with and in some cases even helping others.

> *"He'll come back, and he says, "oh I've been bouncing [name]", for example, now what he means by bouncing – he holds their hands and goes like this (gesticulates holding both hands with someone in front and shakes arms up and down). That's him doing his exercises on the other person, he's trying to help the other person. […] He felt so rewarded by that."* (Father of a son with SLD)

> *"Seeing their, their child who's now an adult, um actually achieving. And it might be small thing, but that achievement can be you know just so exciting for them, and exciting for me (laughs)."* (Private hydrotherapy Physiotherapist)

Throughout the interviews, there was a shared and palpable sense from many caregivers that hydrotherapy (whether through socialising before, during or after sessions) is responsible for creating and developing a sense of belonging, inclusion and genuine support. One sister described this as a community sense.

> *"You know, that you become, kind of feel a bit supported by a community s-, in a community sense."* (Sister of a lady with PMLD)

> *"He absolutely, he loves people. He loves watching people, other people have fun, make-, you know, makes him, makes him happy."* (Supported-living LD carer)

In summary, although caregivers reported both experiences and anticipatory fears relating to hydrotherapy and perpetuating barriers in overcoming social inclusion (e.g. public perception and physical access difficulties), they were also keen to convey their positive experiences and perceptions relating to the ways in which hydrotherapy facilitates social inclusion (e.g. ability, accessibility, and engagement). There was an overall sense from the caregivers that despite the challenges and anticipatory fears, the positive opportunities hydrotherapy offered for social inclusion (e.g. family bonding, community sense and meaningful occupation) outweighed the negatives: with many caregivers ending their negative-experience narrative with a caveat of it all being worth it for the person they're supporting.

4.10 Caregiver perceptions regarding hydrotherapy and barrier/facilitators

While the main objectives of SPLASH Study were to explore caregiver experience and any perceived biopsychosocial impacts of hydrotherapy on adults with SLD/PMLD, the final objective was to explore any barriers/facilitators reported by these caregivers in accessing hydrotherapy. This objective was added during study design when following discussion with volunteer caregivers it became apparent that the barriers of accessing hydrotherapy formed a significant part of caregiver experience in relation to hydrotherapy and adults with SLD/PMLD; it would therefore have been inappropriate to attempt to gain understanding of the adult SLD/PMLD caregiver hydrotherapy experience without affording attention to this aspect. It is for this reason that, despite the fact that the barriers and facilitators of hydrotherapy do not appear within the themes of importance for this study, the following section is appropriately presented within this thesis.

The full themes and subthemes identified by caregivers in relation to their perceived barriers and facilitators of accessing hydrotherapy are set out in Row 11 of Appendix VII, however the main barriers and facilitators reported have also been summarised in Table 9 below.

Factor	Barriers	Facilitators
1. Care-receiver needs & preferences	• Health needs (e.g. epilepsy, continence and Percutaneous Endoscopic Gastrostomy feed) • Water anxiety • Sensory preferences • Fear of hospitals	• Obvious enjoyment and engagement in the water
2. Support/caregiver investment	• Caregiver body confidence • Caregiver water confidence • Caregiver motivation • Caregiver health/physical tolerance • Cognitive load of organisation	• Family able to support, advocate and organise. • Provided completely through education or specialist hydrotherapy facility.
3. Facilities	• Pool availability • Equipment and maintenance of (e.g. hoists) • Changing rooms (physical access and availability) • Pool temperature	• Having own pool at home
4. Funding	• The hydrotherapy session • Transport • Associated care (e.g. if require 1:1 when usually have shared care, or 2:1 and usually have 1:1)	• Clear agreed funding streams for both session and staffing

5. Transport	• Distance • Physical requirements (e.g. wheelchair access) • Availability (e.g. limited around school drop off/pick up times)	• Own car (e.g. Motability) or close to home.
6. Covid-19	• Concerns for the future • Infection control • Pool closure • Reduced availability/capacity • Staffing issues	

Table 9: Themes and subthemes relating to barriers/facilitators

4.10.1 Caregiver perceptions regarding the barriers in accessing hydrotherapy

As anticipated, the topic of hydrotherapy barriers was something all 23 SPLASH Study participants were keen to talk about, yet each caregiver type offered a differing perspective as to the significance of each barrier, whilst also offering some explanation for barriers reported by other caregiver types. For example, while family members were keen to highlight the reluctance of paid carers to get into the water themselves, paid carers were keen to point out the lack of engagement, time and provision from therapists.

> *"The first problem we had is we had carers complaining that the water was too cold for them. […] One of the carers at the time, who turned out to be his senior support worker then, um, basically was not a confident swimmer."* (Father of a son with SLD)

> *"Me and my staff do some stretches in the pool, but we're not actually qualified. So we don't know if we're causing more problems sometimes. […] I'll be honest, they [Physiotherapists] don't even tell us what they're doing. So not being disrespectful of any Physios, we've had one recently where they didn't talk to the individual for the whole session."* (Manager of a PMLD residential home)

While therapists reported paid carer reluctance to arrange successful community hydrotherapy sessions, paid carers were able to explain the amount of mental fatigue and physical effort that occurs from organising hydrotherapy days (e.g. staffing rotas, transport, funding, continence swimwear, medication and mealtime changes) and the physical effort required to support someone on these days (e.g. getting changed, getting into the water, supporting them in the water, carrying out hydrotherapy programmes, getting out of the water, getting washed, dried and dressed before returning home).

> *"In terms of the rapport with our carers: some of them don't want to get in water. […] If it's a self-conscious confidence thing then, you know, you can wear your t-shirt and shorts while you're in the pool […] so a lot of it… staff confidence, sometimes of just, water confidence themselves, just if they've got a staff team of, where they don't have a strong swimmers.[…] Some staff just don't want to do it. "*
> (Adult LD Physiotherapist)

> *"When I first started, I didn't realise how intense it was. Because you do have a limited time slot. […] And there is an awful lot to do before you get the person actually into the pool. I mean, if they're PEG fed [fed via a Percutaneous Endoscopic*

> *Gastrostomy tube], you've got to take them off the machine, you have to seal up everything. There there is a heck of a lot to do."* (Adult LD day centre carer)

Despite these differing perspectives, there was overall congruence in the themes reported by all caregiver types, and aside from support/caregiver investment, all other themes were reported with consistent perspectives throughout all caregiver types.

All caregiver types consistently reported the need to ensure care-receiver needs and preferences were known and considered prior to attempting hydrotherapy for the first time in order to identify any personal barriers specific care-receivers may have to hydrotherapy. Caregivers suggested these personal barriers may relate to factors such as sensory needs (e.g. controlling the lights, sounds and temperature of the environment), health needs (e.g. considering seizure risk assessments, PEG feeds and continence) or specific fears (e.g. relating to the water or hospital environments, if the hydrotherapy pool is in a hospital).

> *"I've got a few people [adults with SLD/PMLD] that they can't come [to hydrotherapy] because of it [the pool] being hospital based or the echoey, echoey… or other people in the room shouting or enjoying themselves and they can't cope with that."* (Adult LD Physiotherapist)

Caregivers were quick to advise that many of these personal barriers could be overcome with appropriate planning and consideration (e.g. controlling the environment, preparation to ensure their health needs continue to be met, and visiting the environment prior to attending a hydrotherapy session), but acknowledged the need to understand that in some circumstances hydrotherapy isn't the right intervention for some care-receivers.

> *"We tried just to take some [adult with SLD/PMLD]… we thought is not gonna, not gonna like the the water… […] Err, because they were always vocal in the past when they went to swimming pools. So just to take like a slow approach, they first went went, went to the building just to have a coffee there or something, just to to feel the atmosphere, or get used to the atmosphere. And then, the next time they they they they were shown around, but didn't get changed, and and so yes, this slow approach sometimes help."* (Adult LD Physiotherapist)

> *"And if they are [in a bad mood during hydrotherapy], this mean that hydrotherapy is not for them, so we have to find something else. […] I think it depends on the client. Maybe some of them, they can have phobia of water."* (Adult LD Physiotherapist)

The theme of support/caregiver investment as a barrier to hydrotherapy was particularly gained through family member and health professional perspectives, and described the apparent reluctance of paid carers to either arrange or support with regular hydrotherapy sessions. Participants expressed particular frustration about when the practicalities of hydrotherapy had been put in place, and yet there seemed to be a string of excuses given by paid carers as to why the session could not go ahead that day. Participants reported that these ranged from one-off excuses such as the caregiver forgetting their swimwear or transport breaking down, to longer term excuses such as the caregiver being unable to swim, the water being too cold for the care-receiver or the care-receiver no longer enjoying their hydrotherapy sessions.

> *"We tried to change the policy when I worked um at the charity, that when a new, when a new support worker coming swimming was part of the job description. […] Obviously unless you've got medical reasons and things like that, but I think that was probably about eight or nine people who were allergic to chlorine? Um. And so couldn't go swimming. […] And you kind of go, "What? I've never known that many people…?" […] I'm thinking, "Is there something in the water around here? I don't know what's going on?""* (Paid carer for an epilepsy charity)

Participants perceived these excuses to be covering up for genuine caregiver reluctance and attributed the following reasons as the real source of this caregiver reluctance: caregiver body confidence, caregiver water confidence and caregiver motivation. While the perceived barrier of caregiver motivation was often reported by therapists as laziness, both family and paid carers acknowledged this is likely to arise as a result of experiencing the physical effort and mental fatigue which comes from arranging and supporting adults with SLD/PMLD to attend hydrotherapy sessions.

> *"It's too much effort. Because you know, especially if they are severely spastic cerebral palsy, undressing is a massive challenge. And if the parent or carers dressed them in the morning, then gotta go swimming to undress them, then swimming, then dress them."* (Physiotherapy assistant in education setting)

Twenty-two participants reported quality of facilities and lack of working/suitable accessibility equipment as a significant barrier for adults with SLD/PMLD in accessing hydrotherapy. While caregivers predominantly reported experiences of issues with poolside equipment (e.g. lack of hoists, or hoists regularly left in states of disrepair for many months), another common subtheme was the lack of accessibility and availability of suitable changing areas. Paid caregivers particularly cited this as a reason for the physical fatigue they feel after hydrotherapy sessions, as they have had to support someone with severe physical disabilities to shower, dry and change all within a few minutes so as to allow the next care-receiver into the only accessible changing room before they got too cold.

> *"You have to move like the wind. You literally, they hit the thing [changing plinth], you pull the thing [changing plinth] out. You get that down. You shower them as quick as you can. You dry them with like three towels, and you're, but you're trying to get clothes on but you're semi-wet. […] Then you gotta put them in the chair (wheelchair) and like rush them out, and be like "next person in"."*
> (Manager of a PMLD residential home)

Secondary to accessibility, participants reported significant issues with the availability of hydrotherapy sessions: whether this be in terms of limited hydrotherapy pool access (privately or through the NHS), or the specificity of disabled swim sessions in public pool. Caregivers reported they had often resorted to carrying out passive/sedentary hydrotherapy programmes in swimming pools where the water temperature was too cold (but there was better availability), resulting in the session being terminated early due to it being inappropriate for the care-receiver.

> *"It was six weeks, once a week. and then we had nothing for another six weeks. […] And then it was back on again. That was the best they could do. […] It's obviously not desirable to just have six week blocks and then six weeks of nothing. It's not, not ideal, but then as they say, you've got the demand, and you've got the facilities, and the two are mismatched you know."* (Father of a daughter with PMLD)
>
> *"I tried to find somewhere else, and we went to [Town name] baths, and that was a disabled swim, and we got in the water, and it was only 29 [degrees Celsius] and [Daughter] said straight away, said "get out. Get out"."*
> (Mother of a daughter with SLD)

Family members particularly reported frustration at the reduction of hydrotherapy availability in adult LD services when compared to their experiences in children's services. These reports were supported by the 'care-receiver hydrotherapy frequency' questionnaire responses given by SPLASH Study caregivers; these responses (Figure 20) indicate that while 57% of represented care-receivers attended hydrotherapy at least weekly in children's services, only 43% of represented care-receivers continued to attend at least weekly as an adult (prior to the Covid-19 pandemic).

Nineteen participants reported funding issues as the primary barrier for adults with SLD/PMLD in accessing hydrotherapy. Participants reported the financial implications go beyond solely covering the cost of attending the hydrotherapy pool (which can cost upwards of £30 per 30mins if attending a private pool), but also include the costs of associated care, transport (often requiring wheelchair accessible taxi) and continence swimwear.

> *"[My son] needs to have appropriate swimwear, i.e. like a a nappy pad type swimming costume. […] They're not cheap these swimming costumes. […] £42 on average I pay for a swimming costume. […] Over a period of time that will deteriorate because of the chemicals in the water et cetera. So you're probably talking about every eight months you have to change them."*
> (Father of a son with SLD)

The perceived impact of hydrotherapy on care-receivers' care needs are presented in Row 4.1 of Appendix VII. While caregivers reported experiences of hydrotherapy reducing the investment/burden of care (e.g. by improving active function or passive range of movement), caregivers were largely in agreement that in order to attend the hydrotherapy session, care-receivers required at least 1:1 attention in the pool, with some care-receivers requiring 2:1 care (e.g. for washing and dressing). Participants explained their experiences of this level of care rarely matching the care-receiver's usual care package. For example, the care-receiver may live in residential care with shared support, in which case requiring 1:1 or 2:1 support for hydrotherapy sessions is a significant increase. Caregivers reported this increase in the required level of care to be a particular sticking point with funding authorities, particularly social care. Caregivers reported social care to largely consider hydrotherapy a health need, and therefore beyond their jurisdiction to fund.

> *"When [my son] was funded by social services, that was your lot […] I had to keep justifying with the budgetary people about what [my son] needed to attend to benefit from him. Whether it was from buying, um, trays for wheelchairs, head rests for wheelchairs, access to to the sort of um expensive 'cause it's not cheap to go to hydrotherapy. […] Obviously their contribution to care they didn't leave them a lot of money left. So every year, I had to go in and argue the toss about allowing to reduce that access to his care costs, so he had the money to be able to do it [hydrotherapy]. […] Now [my son]'s NHS continuing healthcare funded, it's not an issue, 'cause he now makes no contribution to his care, which makes a big difference for [my son] as well. So, it's now affordable, but for people under social care, it is not"*
> (Father of a son with SLD)

> *"I mean it's [hydrotherapy] considered like a luxury or something as far as I can see. […] You know, "Isn't it nice to have", you know, it's in the same sort of category as buckets and spades isn't it?"* (Father of a daughter with PMLD)

This belief is supported by the 'funding authority' questionnaire responses given by SPLASH Study caregivers; these responses (Figure 18) indicate that while 30% of represented care-receivers received social care funding for their usual package of care, only 17% of represented care-receivers received social care funding towards their hydrotherapy attendance.

Thirteen participants perceived the travel/distance to the pool to be a barrier in accessing hydrotherapy. Some participants reported a gradual deterioration in the number of hydrotherapy pools available to adults (e.g. through closure or restrictions introduced by pools in educational settings), resulting in care-receivers needing to travel further in order to access hydrotherapy. This was certainly the case for Dorset HealthCare University NHS Trust who used to own and run a hydrotherapy pool (with full hoist accessibility) within an adult LD residential unit. When the unit closed down in 2011 under the government funded campus reprovision project (Department of Health 2001) the NHS trust decided not to continue to offer this service.

> *"We were traveling 26 miles to get to the swimming pool."*
> (Activity co-ordinator for people with LD)

> *"Some of them are traveling for about 30-40 minutes to get to the pool."*
> (Adult LD Physiotherapist)

Participants cited the reasons for this distance being a barrier for adults with SLD/PMLD in accessing hydrotherapy to be because of the complex health needs of this population (e.g. medications required at specific times, PEG feeds requiring specific run times, seizure risk), and the fact that this population often rely on wheelchair accessible taxis to travel distances greater than can be walked. Caregivers reported this reliance on wheelchair accessible taxis largely comes from the experience of regular accessibility issues on public transport, and issues in being able to supply a regular care team who are all qualified and insured to drive a care-receiver's own Motability vehicle. Caregivers described how this subsequent reliance on wheelchair accessible taxis can prove not only expensive but challenging when the only hydrotherapy slots available for adults with SLD/PMLD tend to be around 3-4pm, and so all accessible taxis are block-booked for special educational needs school runs.

> *"Unfortunately. There's the end of school, and the start of our hydro session. So wheelchair taxis, can be a bit challenging to to find."* (Adult LD Physiotherapist)

SPLASH Study interviews were conducted in early 2021, just after the second national wave of the Covid-19 pandemic. When asked about the hydrotherapy barriers they had experienced, caregivers were forthcoming to highlight the impact the Covid-19 pandemic has had on their care-receivers' hydrotherapy attendance. All participants reported Covid-19 had prevented their care-receiver from accessing hydrotherapy in some way. While 22 of these participants cited the biggest reason being the temporary closure of pools (hydrotherapy, educational and public) in line with national lockdowns, one family member reported she had been hopeful her daughter would be able to continue to access hydrotherapy regularly throughout the pandemic due to them having their own hydrotherapy pool at home. However, this caregiver continued to explain that as the borders closed and travel restrictions came into play, many of her daughter's usual paid carers returned to their home countries. While funding authorities continued to ensure her daughter's care needs were met, the agency staff provided weren't confident or competent to support her in the water, and were particularly anxious regarding distancing and Personal Protective Equipment (PPE) requirements and the difficulty of implementing these within the hydrotherapy context.

> *"She [paid carer] didn't want to come in, she was in a panic, a young girl, she said, "ooh we're we're a big family I don't want to take or catch anything". And so she kind of actually that was it. Another carer who went in with her [daughter with SLD], err, had to go back to Spain."* (Mother of a daughter with SLD)

These PPE and infection control concerns were similarly shared by therapists and swimming club caregivers who discussed the disparity between doing what they feel is best for their care-receivers and following the ever changing government guidelines.

> *"The other question is, now with PPEs […] How the carers can can support the the the the patients in the water now, with wearing full PPE? […] Because they can wear all the PPEs on the ground [dry land], but when when in the water… […] it's gonna be a a huge burden for for hydrotherapy."* (Adult LD Physiotherapist)

Many of these caregivers reported concerns for the future of hydrotherapy in a post-covid world; concerns ranged from safety concerns for the adults with SLD/PMLD attending, whether some private hydrotherapy pools may not reopen due to the financial impact Covid-19 has had on businesses, whether local authority/public swimming pools would continue to offer disability swim sessions with the same frequency given that many of these groups have been identified as particularly vulnerable to Covid-19, and whether their care-receivers would be able to access their usual hydrotherapy pools at all if pool capacity were to be reduced when they did reopen (e.g. reduced numbers in the pool and allowances for fallow time).

> *"We don't know how long a lot of the restrictions are going to go on for. And it may well be that months or even into years that you're having to take extra precautions?"* (Father of a son with PMLD)

> *"How can we as therapists take that responsibility of saying, "you need to go back to the gym [where the public pool is]" and then they end up getting Covid. Oh my God. I would feel absolutely heartbroken and terrified."* (Adult LD Physiotherapist)

One health professional even reported Covid-19 had resulted in an increase in the level of care required as many local pools near them were now refusing to provide a lifeguard for hydrotherapy sessions, resulting in care-receivers needing to have 2:1 support in order to attend (one to support in the pool, one to remain pool-side as lifeguard).

> *"He needed an extra carer because of lockdown. [referring to the Covid-19 pandemic;…] The hydro-pool where he goes, they said that someone has to be by the side of the pool all the time with him now."* (Adult LD Physiotherapist)

4.10.2 Caregiver perceptions regarding the facilitators in accessing hydrotherapy

All participants had perspectives to share in relation to the barriers of accessing hydrotherapy. While some assumption can be made that if the opposite of these perceived barriers were to occur then this could be ascribed to being a hydrotherapy facilitator, caregivers were very rarely able to disclose specific facilitating factors in regards to accessing hydrotherapy. The majority of the facilitating factors identified in Table 9 were therefore identified through divergent caregiver discussion or practical care-receiver examples.

There was an overwhelming sense from all caregivers that although they had been able to overcome each of these reported barriers in order for their care-receiver to access hydrotherapy, that this was a unique occurrence, or that they were grateful for having been able to successfully advocate for their care-receiver's access to hydrotherapy. All 23 caregivers reported appreciation that there remain many other adults with SLD/PMLD who haven't been able to overcome these barriers, and so continue to be unable to access this therapy. There was also an overwhelming sense, from participants, of how mentally and physically exhausting it can be for caregivers of all types to have to continuously advocate for their care-receiver in order to overcome these barriers and be granted access to hydrotherapy: alongside frustration at the systems which perpetuate these barriers and an appreciation as to why other caregivers may not be able to continue to fight.

> *"There is enough system out there, with the social care support and they know they're disabled. Why do you have to go in and argue that they need this sort of input? You know what I mean, it's just mad."* (Father of a son with SLD)

This caregiver awareness of the fragility of adult SLD/PMLD access to hydrotherapy resulted in fifteen caregivers explicitly thanking the researcher for conducting this research: while expressing their hopes that this study would both facilitate further discussion among funding authorities, care planners and pool providers, as well as paving the way for future research on this under-represented population of adults with SLD/PMLD.

> *“Funding authorities just don't seem to see the importance and the benefit of this for their health, which is why this research project [referring to SPLASH Study] is amazing.”* (Adult LD Physiotherapist)

> *“Obviously this study will help them [pool providers] obviously encourage that [funding] as well so. […] Maybe even get some financial input from social care and um CHC [referring to Continuing Health Care (NHS funding)]? Who knows!”* (Father of a son with SLD)

> *“It's so lovely to see somebody doing some research on hydrotherapy, because it's so beneficial, and and there's not, there's hardly anything [research] out there at all, is there? For the learning disability group?”* (Adult LD Physiotherapist)

CHAPTER FIVE: DISCUSSION

5.1 Introduction

This study sought to answer "how do caregivers experience/perceive hydrotherapy to impact on adults with SLD/PMLD?" with aims of specifically exploring caregiver experience, any perceived biopsychosocial impacts of hydrotherapy on adults with SLD/PMLD, and any reported barriers/facilitators in accessing hydrotherapy. Where Chapter Four reported this study's findings in terms of the impacts perceived through caregiver experience; this discussion chapter will further explore and discuss this study's themes of importance in relation to the biopsychosocial framework underpinning this study.

5.2 Summary of findings

The findings of this study suggest that caregivers perceive hydrotherapy to impact on the biopsychosocial needs of adults with SLD/PMLD in many more areas than are represented within current LD-hydrotherapy literature. The full list of this study's perceived impacts is broken down into twelve overarching themes and many more themes and subthemes in Appendix VII.

It would not be appropriate to attempt to fully explore every theme and subtheme within the bounds of this thesis so the subsequent discussion will focus on the following main themes of importance: body systems, choice, motivation and inspiration, emotions, quality interaction, family bonding and social inclusion. In order to fulfil all of the study's objectives a final section is included relating to the caregiver experience of barriers/facilitators in accessing hydrotherapy.

5.3 Applying context

While the ICF (WHO 2001) illustrates the complex interplay between each component of the biopsychosocial model of disability, individual themes can align themselves more naturally to specific components. Table 10 uses this alignment to illustrate the arrangement of this study's themes of importance within the main components of the biopsychosocial model of disability.

Biopsychosocial component	Themes of importance
Biomedical	Body systems
Psychological	Choice, motivation and inspiration Emotions
Social	Quality interaction Family bonding Social inclusion

Table 10: Themes relating to biopsychosocial components

5.4 Biomedical impacts

The biomedical model of disability is built on the belief that if I know your diagnoses and demographics, I can define your level of disability (WHO 2001). The full list of biomedical themes and subthemes for this study are set out in Appendix VII.

5.4.1 Physiological findings supported by existing research

Row 1.1 of Appendix VII lists this study's reported physiological health impacts on adults with SLD/PMLD. All 23 caregivers reported experiencing hydrotherapy to have a positive physiological impact on their care-receivers; particularly regarding balance and co-ordination, core stability, function and independence, mobility and movement, pain, posture and positioning, strength and tone. These physiological findings are all supported by existing sedentary neuro-hydrotherapy studies (Table 2), including L'Huillier et al.'s study on adults with LD (2016). As previously discussed within Chapter Two, ten of the 15 existing sedentary neuro-hydrotherapy studies centred mainly on the biomedical model of disability, and consistently reported positive physiological outcomes in range of movement, balance and function (Table 2). As the physiological impacts of hydrotherapy are well documented within existing sedentary neuro-hydrotherapy research, it is important to acknowledge that SPLASH Study's findings support this previous research. However, as SPLASH Study's physiological findings do not add a unique perspective to existing knowledge, the remainder of this discussion chapter will focus on this study's unique themes of importance.

5.4.2 Biomedical themes of importance

The biomedical themes of importance, as set out in Table 10, relate to body systems and include perceived positive impacts on infection prevention (chest and urinary tract), circulation and swelling, seizure activity, bowel management, appetite, bone density and the immune system.

Body system impacts don't appear within existing sedentary neuro-hydrotherapy studies with the exception of limb circulation and breathing control which is mentioned within the narrative literature review and qualitative case study by Lotan and Barmatz (2009). Their paper talks specifically about the positive impact hydrotherapy can have on limb circulation and subsequent lower limb swelling of individuals with Rett syndrome, alongside the specific benefits hydrotherapy can have on improving breathing control within this population.

Altered breathing control is a common symptom in people with Rett syndrome; this might include hyperventilation followed by periods of breath holding, often affecting seizure activity (Lotan and Barmatz 2009). While this prevalence doesn't directly correlate with the adult LD population, breathing issues such as frequent chest infections are a significant problem. A recent report identified respiratory conditions as the leading cause of death in people with LD, with pneumonia being the cause of 41% of all adult LD deaths in 2019 (NHS England 2021). These statistics on pneumonia deaths in adults with LD, represent avoidable respiratory infections and subsequent death. The caregivers in SPLASH Study reported that hydrotherapy improved respiratory function and reduced respiratory infections; when interpreted with the evidence by Lotan and Barmatz (2009) this may suggest there is a relationship between hydrotherapy and respiratory infection that needs to be explored further.

SPLASH Study found that hydrotherapy was perceived to have a positive impact on limb swelling, which was also supported by Lotan and Barmatz (2009). Lower limb swelling is a common problem for people with Rett syndrome (shared by many adults with SLD/PMLD), which is regularly attributed to poor postural circulation with specific causes of inactivity and scoliosis or other asymmetric body shapes (Lotan and Barmatz 2009; Public Health England 2018). The care-receiver population represented in SPLASH Study illustrates this prevalence with at least 65% of caregivers reporting trunk asymmetry in the person they support (Figure 12). The postural asymmetry of adults with SLD/PMLD therefore highlights the importance of the SPLASH Study suggestion that hydrotherapy could have a positive effect on the management of peripheral oedema. Future research should therefore consider further exploring and quantitatively investigating this proposed relationship between hydrotherapy intervention, postural asymmetry and the management of peripheral oedema in order to determine/evidence any actual impact on these outcomes.

Seizure frequency, bowel motility, nutritional intake, bone health and the immune system are all areas of importance to the adult LD population due to the prevalence of co-morbidities in these body systems (NHS England 2021), and yet haven’t been considered in existing sedentary neuro-hydrotherapy literature (Table 2). This suggested relationship (between hydrotherapy and body systems such as bowel motility, seizure frequency and nutritional intake) may therefore be of importance to caregivers of individual care-receivers experiencing impairments in these areas. For example, such caregivers may want to consider these findings when deciding whether to support their care-receiver to try hydrotherapy. Future studies should also therefore consider quantitatively investigating whether hydrotherapy intervention has any actual influence on these body systems in order to evidence any actual impact and subsequently affect allocation of resources or policy change.

5.5 Psychological Impacts

The psychological model of disability is built on the belief that disability is a perception built on one’s own (often distressing) experience (Johnston 1996); this model is often combined with the social model of disability to be described as the psychosocial model of disability. The full list of psychological themes and subthemes for this study are set out in Appendix VII.

5.5.1 Psychological themes of importance

The psychological themes of importance, as set out in Table 10, relate to emotions and mental health and include perceived positive opportunities for and impacts on care-receivers' choice, motivation, and inspiration of exploration. Within this theme, caregivers also reported perceiving the facilitation/display of the following feelings in their care-receivers: happiness, relaxation, freedom, confidence, satisfaction and safety.

It is of note that this theme also encapsulates perceived positive direct and indirect impact on caregiver emotions and mental health (see Row 3.4, Appendix VII). However as the aims of this study are predominantly orientated around the perceived impact on care-receivers, this thesis discussion will continue to adopt the same focus for this psychological section.

5.5.2 Choice, motivation and inspiration of exploration

SPLASH Study's findings of perceived positive impact on care-receivers' choice, motivation, and inspiration of exploration are supported by existing LD-hydrotherapy research. L'Huillier et al. (2016) combines all of these three areas within their outcome measure of volition. They measured volition weekly over a course of 13 weekly hydrotherapy sessions using a VQ, which rated care-receivers on factors such as curiosity, task initiation and demonstration of preferences and their results indicated a statistically significant improvement in volition scores throughout the course of sessions.

Empowerment through enabling choice is a significant principle of the Care Act (Department of Health 2014). This legislation was introduced in 2015 and changed the perspective of UK social care – ensuring that the wellbeing of care-receivers is at the heart of service provision by promoting personalisation, choice and safety. As many as 151,565 adults with LD in England receive social care funding (NHS Digital 2021), so factors such as choice and safety are of particular importance to this population. Many caregivers within SPLASH Study were particularly passionate about these reported impacts of choice, motivation and inspiration of exploration, stating that these three areas are particularly difficult to provide opportunities for on land. When questioned further, many participants attributed this to the level of physical disability their care-receivers experience (therefore resulting in a restriction of autonomy on land), as well as the lack of purpose that actions/movements often serve on land for this population (e.g. the force or co-ordination required to interact with objects is much greater on land when compared to a facilitatory and forgiving body of water). The care-receiver population represented in SPLASH Study illustrates the prevalence of physical disability and movement limitations with more than 95% of caregivers reporting altered muscle tone in the person they support (Figure 11), and over 86% reporting them to have limb contractures (Figure 14).

SPLASH Study caregivers perceived little carry over of this theme (choice, motivation and inspiration of exploration) outside of the hydrotherapy environment, other than lasting positive emotional impact, as on land there continued to be limited opportunities for their care-receivers to demonstrate choice, motivation or exploration. Interestingly L'Huillier et al. (2016) did not report whether their measured volitional improvements were statistically significant during land or water-based activities, as measures were taken during both and the scores added together prior to reporting. Future studies should therefore consider further exploring if there is a link between hydrotherapy and water-based choice, motivation and inspiration of exploration, and whether it is possible to facilitate any carry over on land. These findings could be of particular relevance to social care professionals responsible for implementing the Care Act (Department of Health 2014).

5.5.3 Emotional impacts of hydrotherapy

This study's findings of perceived increase in positive care-receiver emotions include happiness, relaxation, freedom, confidence, satisfaction and safety. These findings haven't been considered in existing LD-hydrotherapy literature, but have been measured in terms of emotional functioning and enjoyment within existing paediatric sedentary neuro-hydrotherapy research (Vonder Hulls et al. 2006; Lotan and Barmatz 2009; Lai et al. 2015; Güeita-Rodríguez et al. 2017; Caputo et al. 2018). Lai et al. (2015) measured enjoyment using the physical activity enjoyment scale and reported significantly higher levels of enjoyment in children who had received hydrotherapy, compared to children who had received a land-based physiotherapy intervention. While Vonder Hulls et al. (2006) stated that all therapists responding to their quantitative survey reported their children enjoyed hydrotherapy.

Positive emotions such as enjoyment and fun are crucial motivating factors, and have been found to play a significant part in overcoming barriers of adherence to physical activity and therapy programmes in adults with LD (Temple 2008). Looking beyond the sphere of adult LD, psychological quality of life measures in adults are known to be positively impacted by factors such as enjoyment and emotional wellbeing (Medvedev and Landhuis 2018); while psychological quality of life has been evidenced to impact on health related quality of life (Mannucci et al. 2010).

No adult sedentary neuro-hydrotherapy studies could be found giving consideration of positive emotional factors. Myers et al. (2013) commented on the smile displayed by their Alzheimer's disease case report participant during his first hydrotherapy session, even including a photograph and reporting that this was an unusual occurrence for this gentleman. However they offered no further comment or investigation of this occurrence. Caregivers may want to consider SPLASH Study's suggested relationship (between hydrotherapy and facilitation of positive emotions such as happiness and relaxation) when deciding whether to support their care-receiver to try hydrotherapy, especially if they are lacking in opportunities to access activities which promote fun and enjoyment. Future studies should consider further exploring the perceived emotional impact of hydrotherapy and investigating any actual impacts on outcomes such as adherence to therapy/activity programmes and quality of life.

5.6 Social Impacts

The social model of disability is built on the belief that disability is a social construct, and is not caused by individuals' physical abilities/impairment (WHO 2001). For example, identifying the presence of stairs and lack of other access as the reason for someone being unable to enter a particular shop, rather than attributing it to their lower limb weakness or mobility limitations. The full list of social themes and subthemes for this study are set out in Appendix VII.

5.6.1 Social themes of importance

The social themes of importance, as set out in Table 10, relate to quality interaction, family bonding and social inclusion. While the themes of quality interaction and family bonding were consistently reported by caregivers as positive opportunities, the topic of social inclusion is more dichotomous and so will be discussed in more detail.

It is of note that while caregivers largely reported their experiences in relation to perceived care-receiver impact, within the context of these social themes it is almost impossible to separate caregiver impact from care-receiver; it would also be amiss to ignore their perceived impacts on wider society. This thesis discussion will therefore seek to discuss these social perceptions in the context of how they were reported.

5.6.2 Quality interaction

SPLASH Study found it was paid carers who most frequently reported a unique opportunity presented by hydrotherapy to have uninterrupted, undistracted, quality 1:1 time with the person they support. These findings haven't been considered in existing LD-hydrotherapy literature, but the themes of relationships and socialisation do appear within three existing paediatric sedentary neuro-hydrotherapy studies (Vonder Hulls et al. 2006; Lotan and Barmatz 2009; Zanobini and Solari 2019). These studies all reported hydrotherapy to both provide opportunities for and to improve the skills required for social participation. Lotan and Barmatz (2009) attributed this to the motility and independence afforded by the hydrotherapy environment. While SPLASH Study findings support these reports (see Rows 2.1, 5.1 and 5.2 of Appendix VII), there appears to be a unique perspective offered by SPLASH Study participants specifically in relation to the uninterruptable nature of the time spent with their care-receivers which hydrotherapy affords; no previous sedentary neuro-hydrotherapy studies have considered the intensity or quality of interactions received from caregivers during hydrotherapy sessions.

This is perhaps more of an indicator as to how pressured paid caregivers feel while delivering care/spending 1:1 time with their care-receiver on land. Paid carer participants regularly reported it was nice to be unable to answer their telephones and to know someone wasn't about to knock on the door and ask for their support elsewhere. In 2011, Gray-Stanley and Muramatsu reported on the correlation between over-workload and burnout in paid carers (direct care workers) supporting adults with LD, and through the researcher's own experience of working in the integrated health and social care sector, she has witnessed first-hand the pressures that were evident on paid carers prior to the Covid-19 pandemic. These pressures have only continued to exponentially increase since then (Doody and Keenan 2021). In a society where time is money (quite literally when it comes to paid support), SPLASH Study caregivers (particularly paid carers) reported hydrotherapy offered a unique haven for uninterrupted, undistracted, quality 1:1 time, and this particular perspective of hydrotherapy has not been captured by existing sedentary neuro-hydrotherapy studies.

Caregivers may want to consider SPLASH Study's suggested relationship (between hydrotherapy and unique opportunity for quality interaction) when deciding whether to support their care-receiver to attend hydrotherapy, especially if they are lacking in other opportunities to have interaction without distraction or interruption. Future studies should consider investigating the quality and prevalence of this opportunity for interaction, and whether there are any measurable impacts on care-receiver outcomes or caregiver stress and job satisfaction as a result.

5.6.3 Family bonding

SPLASH Study's findings of perceived positive hydrotherapy impact on the relational bond between caregiver and care-receiver have not been fully considered by existing sedentary neuro-hydrotherapy research. As previously mentioned, three studies (Vonder Hulls et al. 2006; Lotan and Barmatz 2009; Zanobini and Solari 2019) reported hydrotherapy to offer opportunities for socialisation and to improve the skills required for social participation. While Lotan and Barmatz (2009) primarily focussed on peer interactions, Vonder Hulls et al. (2006) and Zanobini and Solari (2019) focussed on the development of expressive social skills (such as eye contact, conversation and initiation of play).

While SPLASH Study findings support these reports (see Rows 5.1, 5.5 and 7.1 of Appendix VII), there again appears to be a unique perspective offered by SPLASH Study participants specifically in relation to the exclusive opportunity hydrotherapy provides for family bonding. No previous sedentary neuro-hydrotherapy studies have considered the role hydrotherapy might play in providing opportunity to socialise as a family unit.

When questioned further, many participants attributed the lack of wider family bonding opportunities for adults with SLD/PMLD to the inaccessibility (both physically and sensorially) of traditional family activities (e.g. going to theme parks or the cinema), but also due to the physical barrier postural management equipment presents, even for basic caring physical contact such as a hug. Conversely, in the water they reported they could be physically close without requiring equipment, and they could be face to face on the same level, with the whole family taking part in the same activity.

Many adults with SLD/PMLD require complex and bulky equipment to help them maintain an upright position or to move (Bruce and Standley 2019); the care-receiver population represented in SPLASH Study illustrates the prevalence of the need for this equipment with caregivers reporting more than 95% of their care-receivers required a wheelchair, 65% required a sleep system (indicating they need equipment 24 hours a day) and 47% required a specialist armchair, meaning their care-receivers would be unable to sit on the family sofa (Figure 15).

Caregivers of all types were keen to report the impact they had perceived hydrotherapy to have on the bond between family members and care-receivers; while family members passionately reported their first person experiences, paid carers and professionals were keen to talk about the moment they watched as a mother happily danced with their daughter in the pool for the first time, or that moment a father realised he now had an activity he could do with his son every weekend, to replace his broken-hearted dream of them ever being able to play football together. For a population where caring physical contact is scarce and family activities are often inaccessible (Dobson et al. 2002), SPLASH Study caregivers reported hydrotherapy affords a rare and treasured opportunity for family bonding, and this particular perspective of hydrotherapy hasn't been captured by existing sedentary neuro-hydrotherapy studies.

Caregivers may want to consider SPLASH Study's suggested relationship (between hydrotherapy and rare opportunity for family bonding) when deciding whether to support their care-receiver to attend hydrotherapy, especially if they are lacking in other opportunities to experience caring physical contact and are unable to access other family activities. Future studies should consider further investigating opportunities for adult SLD/PMLD family bonding and the prevalence of caring physical contact experienced by this population, alongside whether hydrotherapy impacts on any care-receiver outcomes as a result.

5.6.4 Social inclusion

The SPLASH Study social inclusion theme of importance incorporates subthemes of anticipatory public reaction, negative experiences, and opportunities within the wider community. SPLASH Study's findings of perceived hydrotherapy impact on social inclusion have not been fully explored by existing sedentary neuro-hydrotherapy research, although the associated theme of normalisation appears briefly within Lotan and Barmatz’s (2009) narrative literature review/case report. After stating the underpinning belief that swimming is a ‘normal’ activity, they conclude that hydrotherapy, as both an activity and an environment, is responsible for the facilitation of normalisation for people with Rett syndrome. Furthermore stating that due to hydrotherapy, this normalisation perception is subsequently instilled in both the care-receiver and their families.

While these views regarding hydrotherapy and normalisation are certainly congruent with SPLASH Study’s findings (see Row 6.2 of Appendix VII), there again appears to be a unique perspective offered by SPLASH Study participants specifically in relation to both positive and negative impacts on/from wider society through attending hydrotherapy in the community. No previous sedentary neuro-hydrotherapy studies have considered the role community-delivered hydrotherapy might play in either perpetuating social exclusion or promoting social inclusion. Future studies should therefore consider further investigation of how regular community-delivered hydrotherapy attendance may impact positively or negatively on public perception.

The vulnerability of adults with LD to social exclusion is well known and widely documented (Department of Health 2001; Bruce and Standley 2019; Grung et al. 2020). The reasons for this are as diverse as the heterogeneity of the LD population themselves, but common factors are thought to include: increased incidence of challenging behaviour and a lack in development of communication or social skills, alongside the complexity of their health and social care needs (Grung et al. 2020). The secondary negative effects of social exclusion are similarly well documented and include negative impacts on mental health, physical health and quality of life (Bernstein 2016).

In 2001, the Department of Health recognised that years of government funded institutionalisation had led to the widespread normalisation of social exclusion of adults with LD; this led to the publication of the ‘Valuing People’ white paper (Department of Health 2001), which aimed to tackle social inequality for people with LD by promoting their rights, independence, choice and inclusion. Grung et al. (2020) further explores United Kingdom (UK) legislation and policies relating to social inclusion and the associated health inequalities that people with LD experience. They conclude that although there have been a significant number of UK policy and legislative publications to overcome the barriers of social exclusion and to actively promote social inclusion, sadly many people with LD continue to face these inequalities and “remain a significantly disadvantaged group” (Grung et al. 2020, p. 24).

In summary, adults with LD are particularly vulnerable to social exclusion. Although SPLASH Study caregivers reported both negative experiences and anticipatory fears relating to community hydrotherapy and it's perpetuating barriers in overcoming social inclusion (e.g. public reaction and physical access difficulties), they were also keen to convey their positive experiences and perceptions relating to the ways in which hydrotherapy facilitates social inclusion (e.g. ability, accessibility, and engagement). There was an overall sense from the caregivers that despite the challenges and anticipatory fears, the positive opportunities hydrotherapy offered for social inclusion (e.g. normalisation, community sense and meaningful occupation) outweighed the negatives: with many caregivers ending their negative-experience narrative with a caveat of it all being worth it for the person they're supporting.

There's a particular dichotomy between the reporting of negative experiences and anticipatory fears (particularly in relation to public reaction) and seizing opportunity to change perceptions. Although these views oppose, there was surprising overlap between the two; for example, a family member reporting anticipatory fears initially, but being keen to take their son again after seeing them so free and independent in the pool, or a carer reporting a negative experience of people staring, followed by a compliment from a member of the public later on.

Caregivers may want to consider SPLASH Study's findings relating to social inclusion when experiencing or anticipating negative public reaction regarding hydrotherapy attendance. For example, when deciding which type of hydrotherapy environment may be best for their care-receiver. Future studies should consider further investigation of the suggested change in attitude (from anticipatory fears of negative public reaction, to seizing opportunity to change public perception) in relation to factors such as duration of hydrotherapy attendance, or type of hydrotherapy setting attended. Evidence of any actual impact in these areas could subsequently be used by policy makers to affect legislation and facilitate the government's existing aims of continuing to overcome the barriers of social exclusion and the associated health inequalities which adults with LD continue to experience.

5.7 Barriers/facilitators in accessing hydrotherapy

In order to fulfil all of the study's objectives, this final discussion section is included and relates specifically to the caregiver experience of barriers/facilitators in accessing hydrotherapy. The full list of perceived hydrotherapy barriers/facilitators for this study are shown in Table 9, and encompasses the main themes of carer-receiver needs/preferences, support/caregiver investment, facilities, funding, transport and Covid-19.

Only one existing sedentary neuro-hydrotherapy study considered the barriers/facilitators of accessing hydrotherapy. The qualitative content analysis study by Güeita-Rodríguez et al. (2017) found caregivers of children with CP perceived the following barriers: lack of pool availability, difficulty in physically accessing the pool and health services, systems and policies resulting in difficulties gaining funding and regular access to hydrotherapy. This study reported the sole facilitator of hydrotherapy to be the support and relationships offered from close family.

While Table 9 shows SPLASH Study findings support these reports of facilities, funding and caregiver investment impact on access to hydrotherapy, SPLASH Study's wider findings of care-receiver needs/preferences, transport and Covid-19 having impact on access to hydrotherapy remain unreported in existing sedentary neuro-hydrotherapy studies. Similarly, no existing sedentary neuro-hydrotherapy studies have measured the impact of these reported barriers/facilitators on access to hydrotherapy.

Caregivers may want to consider SPLASH Study's findings relating to hydrotherapy's barriers and facilitators when planning for their care-receiver to attend. For example, such considerations may enable caregivers to identify potential factors which might negatively affect their care-receiver's attendance or experience, and enable mitigating strategies to be implemented. Those responsible for designing and delivering hydrotherapy services may also consider SPLASH Study's findings relating to barriers/facilitators in order to broaden access to hydrotherapy for adults with SLD/PMLD. For example, considering the capacity and quality of accessible changing facilities, or establishing a reliable service and maintenance contract for all hoist equipment.

Future studies should consider measuring any actual impact of these reported barriers and facilitators in relation to hydrotherapy attendance, and consider identifying whether there are any factors which are successful in overcoming any identified barriers. Such evidence could then be used to inform formal service standards, policies and procedures.

5.8 Discussion summary

This chapter has explored SPLASH Study's themes of importance in relation to the main components of the underpinning biopsychosocial model of disability, and has discussed the position of these themes in relation to existing sedentary neuro-hydrotherapy literature. This discussion has alluded to indications for application and considerations for future research, which will be further explored Chapter Six to follow.

5.9 Study strengths and limitations

5.9.1 Study design

When considering the strengths and limitations of this study, quantitative researchers may be critical of the limitations imposed through the study's interpretivist and qualitative methodologies. Interpretivist qualitative research cannot measure impact, but instead reports specific perceptions and experiences which participants experience as their reality (Saunders et al. 2016). However, as demonstrated in Chapter Two through the development of this study's research question, the paucity of biopsychosocial adult SLD/PMLD hydrotherapy research demanded an exploratory approach in order to first understand the perceived impacts of hydrotherapy on this population. These perceived impacts can now be used to inform future research which could measure actual impact (thus providing evidence regarding the effectiveness of hydrotherapy on specific outcomes). Tables 4 and 5 illustrate the strategies implemented prior to and during study design in order to strengthen the trustworthiness of this study.

5.9.2 Sampling and recruitment

As discussed in Chapter Three, the self-selected volunteer convenience sampling method used within SPLASH Study may weaken the internal validity of quantitative research; yet is entirely appropriate within exploratory research as the resultant participant sample are likely to be more motivated and keen to share their views, perceptions and experiences (Saunders et al. 2016). While other non-probability sampling methods could have been implemented, self-selected convenience sampling was identified as the most appropriate sampling method for SPLASH Study in order to minimise researcher bias (which would have been increased through purposive sampling) and maximise credibility (which would have been weakened through haphazard sampling).

Recruitment for SPLASH Study was achieved through public advertising and use of a Diverse Abilities gatekeeper. Prior to the Covid-19 pandemic, a third stream for recruitment had been identified through an NHS gatekeeper, which would have allowed distribution of study information (e.g. the participant information sheet (Appendix VI) and poster) to caregivers via the Dorset Community LD Teams. This wasn't possible within the study's recruitment window as due to the impact of Covid-19 the NIHR closed NHS ethics submission to masters level studies. While the researcher was concerned that this may negatively impact on the recruitment of paid carers and family members, the study was still able to achieve data saturation in both of these participant types largely due to the facilitation of recruitment achieved through the Diverse Abilities gatekeeper.

Although SPLASH Study recruitment materials (posters, leaflets and social media) specifically sought health and social care professional participation, no social care professionals or nurses were recruited within the recruitment window. This therefore means the resultant SPLASH Study professional perspectives are only represented by therapists (eight Physiotherapists and one Occupational Therapist). Future studies should consider specifically seeking the participation of social care professionals, nurses and a wider variety of allied health professionals to ensure no new perspectives are present within these participant types.

5.9.3 Study implementation: data collection and analysis

SPLASH Study was initially designed prior to the Covid-19 pandemic, yet recruitment began in January 2020 during the second national wave of Covid-19. As explained in Chapter Three, prior to Covid-19 SPLASH Study methods included face to face interviews. As discussed by Saarijarvi and Bratt (2021), face to face interviews have a long-standing history of being the best format for qualitative research interviews: with historic positives of accessibility, non-verbal understanding and facilitation of participant trust and rapport with the researcher.

In the context of SPLASH Study, the researcher had been concerned that attempting to conduct interviews virtually in place of face to face would negatively impact both on recruitment (through discouraging potential participants who were less technologically confident or capable) and data collection (through data loss, loss of non-verbal understanding through poor quality connection, or participant inhibitions due to lack of participant-researcher rapport). However, through offering virtual interviews SPLASH Study recruitment was positively impacted, as it wasn't solely limited to participants who were able/willing to travel to Dorset: participants were able to take part from across the United Kingdom, therefore strengthening the diversity of participants and reach of study findings.

In addition, Covid-19 increased societal dependence on videoconferencing for socialising, working and even accessing healthcare (Saarijarvi and Bratt 2021). SPLASH Study found most participants were both competent and confident with using videoconferencing software, and had a reliable internet connection. However, not all virtual interviews were conducted without incident or delay; while two participants consented to take part in the recorded virtual interview using videoconferencing software, they requested for the camera to be turned off, one participant requested a telephone interview due to being unable to access videoconferencing software, and one participant experienced significant internet quality issues initially until they resolved an issue with their router. Some participants requested to pause the interview temporarily due to a disruption in the privacy of the interview at their end (e.g. the telephone ringing, someone entering the room to ask a question). In all cases, the participant was keen to continue with the interview after the disruption had been resolved. Subsequently no SPLASH Study data was lost, and it was still possible for the researcher to discern the non-verbal communication of 20 out of 23 participants.

Table 5 sets out the reflexivity strategies considered prior to SPLASH Study implementation. These strategies were all executed throughout the study without deviation. While these mitigations ensured researcher bias was appropriately minimised during study design through to data collection; a converse strength of SPLASH Study lay in the researcher's extensive LD and hydrotherapy background. This prior experience and understanding in the field of adult LD hydrotherapy facilitated the ease of immersion into participants' experiences; enabling the researcher to fully empathise with their points of view and subsequently improve understanding of their perspectives (Saunders et al. 2016).

Table 4 sets out the trustworthiness strategies considered prior to SPLASH Study implementation. These strategies were all executed throughout the study without deviation. While such mitigation strategies were implemented to strengthen this study's credibility, Korstjens and Moser (2018) suggest another mitigation factor would have been for participants to self-verify their own transcripts (often referred to as participant validation). Although some may argue the lack of transcript participant validation weakens the credibility of SPLASH Study, Birt et al. (2016) suggest the opposite can be the case if participants request changes/corrections to be made to the content due to their subsequent post-interview self-reflections rather than a misrepresentation of their honest perceptions. An example within SPLASH Study context could be a participant reporting laziness as a perceived reason for caregiver reluctance, then later reflecting on how this sounds and wishing to remove it, even though their honest perception of laziness remains. For this reason, instead of offering participants the opportunity to verify their transcripts post-interview, SPLASH Study sought to gain participant verification during interviews through implementing active listening techniques such as paraphrasing which enabled the researcher to ensure the correct inference was understood.

As previously discussed, thorough biopsychosocial description of sample populations is vital in strengthening the transferability of LD study findings. The transferability of SPLASH Study is therefore strengthened through the detailed descriptive caregiver and care-receiver biopsychosocial data which was gathered through administration of the electronic questionnaire.

Chapter Two highlights the paucity of biopsychosocial sedentary hydrotherapy research relating to populations with complex-neurological conditions and how the heterogeneity of hydrotherapy interventions can limit transferability. The transferability of this study's findings have therefore been strengthened through collection of caregiver description of hydrotherapy frequency, water temperature and activities undertaken during a typical hydrotherapy session.

The detailed care-receiver biopsychosocial description not only strengthens this study's transferability, but also evidences the contribution made to both the paucity of adult SLD/PMLD hydrotherapy research and that of the wider field of complex-neuro hydrotherapy. SPLASH Study caregivers reported 19 of their care-receivers to fit the descriptor for GMFCS level V, the highest level of physical disability and two fitting the descriptor for level IV. Chapter Four highlights the particular paucity of participants with the highest levels of physical disability in existing CP-hydrotherapy research, with only two studies including participants of GMFCS level IV and no studies including participants with GMFCS level V (Gorter and Curry 2011; Lai et al. 2015). Therefore highlighting the contribution this study is making not only to the paucity of adult SLD/PMLD hydrotherapy research, but also that of the wider field of complex-neuro hydrotherapy research.

While some may dispute the credibility of caregiver self-report in relation to care-receiver biopsychosocial description, Chapter Three explains why such physiological assessments were identified to be beyond the scope of SPLASH Study and in contradiction to the exploratory nature of the research question and subsequent interpretivist underpinning. Future studies should consider measuring such biopsychosocial factors when carrying out future quantitative adult SLD/PMLD hydrotherapy research.

CHAPTER SIX: CONCLUSION AND RECOMMENDATIONS

6.1 Conclusion

Through qualitative interviews, this interpretivist study sought to explore caregiver experiences and perceptions of hydrotherapy and adults with SLD/PMLD, with particular focus on any perceived biopsychosocial impacts and any reported barriers/facilitators.

This study found caregivers perceived hydrotherapy to impact on adults with SLD/PMLD within the ten broad brush themes of health, function, mental health and wellbeing, support needs, relationships, social inclusion, communication, sleep and tiredness, alertness and engagement and sensory preferences. Caregivers were also keen to report their experiences relating to the barriers and facilitators of accessing hydrotherapy for this care-receiver population, as well as their perceptions regarding the impact of Covid-19.

While SPLASH Study findings support existing knowledge regarding the physiological health impacts of sedentary complex-neuro hydrotherapy (specifically outcomes such as range of movement, balance and mobility), SPLASH Study identified six new themes of importance which have not been identified within existing sedentary complex-neuro hydrotherapy research.

The six unique themes of importance identified by SPLASH Study are body systems, choice, motivation and inspiration, emotions, quality interaction, family bonding and social inclusion. These were identified as themes of importance as they contribute to the knowledge-gap in existing research, were important to the study’s research question, participants and to the researcher, they illustrate the potentially unique opportunities hydrotherapy presents, and they have potential to impact on adults with SLD/PMLD, their care networks and even wider society. Participants reported experiences of hydrotherapy having positive care-receiver impact on each of these themes, as well as perceptions that the opportunities presented by hydrotherapy to impact on these themes are particularly rare for adults with SLD/PMLD.

By recognising that biomedical outcomes both support and are supported by psychological and social impacts, funding authorities and caregivers can consider SPLASH Study’s findings when developing services or making a case for hydrotherapy in this client group. Those responsible for designing and delivering hydrotherapy services may find it particularly helpful to consider the SPLASH Study findings relating to barriers/facilitators in order to broaden access to hydrotherapy for adults with SLD/PMLD. For example, considering the capacity and quality of accessible changing facilities, or establishing a reliable service and maintenance contract for all hoist equipment. These findings have been of particular interest to Diverse Abilities as they are currently fundraising to build hydrotherapy facilities at their day opportunities centre for adults with LD.

As explained in Chapter One, due to the paucity of adult-LD physiotherapy evidence, clinical practice is often informed by (rather than based upon) the best available evidence (Oliver et al. 2003). This results in clinicians adopting a "trial and error" approach in order to determine the best therapeutic intervention for each specific client. SPLASH Study's qualitative findings may therefore be sufficient to inform the practice of individual caregivers. Caregivers may consider SPLASH Study's themes during discussion at individual care-receiver's best interest decision meetings; for example, a client with recurrent chest infections, poor bowel motility or chronic peripheral oedema.

Through exploring caregiver perceptions of hydrotherapy and adults with SLD/PMLD, this study offers unique biopsychosocial insight into the experiences of a population underrepresented in hydrotherapy research literature. While SPLASH Study's qualitative findings may be sufficient to inform the practice of individual caregivers, further research is needed in order to evidence any actual hydrotherapy impact on clinical outcomes for adults with SLD/PMLD, and subsequently effect policy change. The themes explored through this study should therefore be used to form the foundation for future studies to further investigate; with the aim of generating evidence which could be used to underpin wide-scale practice, policies and procedures.

6.2 Recommendations for future research

Recommendations for future hydrotherapy research based on this study's themes of importance have been made throughout Chapter Five, and are summarised in this section. Further research hypotheses can be drawn from this study's full catalogue of findings in Appendix VII.

In relation to population sampling, future qualitative SLD/PMLD and other complex-neuro hydrotherapy research should consider specifically seeking the participation of social care professionals, nurses and a wider variety of allied health professionals to ensure no new perspectives are present within these participant types. Future adult SLD/PMLD and other complex-neuro hydrotherapy research should also consider quantitatively measuring biopsychosocial needs/factors in order to provide accurate contextual description of their sample. This accurate biopsychosocial description would strengthen the generalisability/transferability of future studies, which could better inform caregivers and policy makers when choosing whether to consider hydrotherapy intervention for specific populations. For example, if the needs of a specific care-receiver group matched the study's detailed biopsychosocial sample description, it may affect decision making regarding the allocation of funding or staffing resources in order to enable access to hydrotherapy.

As concluded in the previous section, while SPLASH Study's qualitative findings may be sufficient to inform the practice of individual caregivers, further research is needed in order to evidence any actual hydrotherapy impact on clinical outcomes for adults with SLD/PMLD. The themes explored through SPLASH Study should therefore be used to form the foundation for future studies to further investigate; with the aim of generating evidence which could be used to underpin wide-scale practice, policies and procedures. Table 11 illustrates the proposed biopsychosocial hypotheses identified by SPLASH Study, in relation to this study's themes of importance. These hypotheses could be further investigated with adults that have SLD/PMLD or other complex neurological conditions who take part in hydrotherapy.

Model of disability	SPLASH Study suggested hypotheses
Biomedical	Investigation of sedentary hydrotherapy and any effect on incidence of chest infections and associated hospital admissions in adults with SLD/PMLD.
	Investigation of sedentary hydrotherapy and any effect on postural symmetry or peripheral swelling in adults with SLD/PMLD.
	Investigation of sedentary hydrotherapy and any effect on seizure frequency, bowel motility, nutritional intake, bone health and the immune system in adults with SLD/PMLD.
Psychological	Investigation of sedentary hydrotherapy and any effect on choice, motivation and inspiration of exploration (water and any carry-over onto land) in adults with SLD/PMLD.
	Investigation of sedentary hydrotherapy and any effect on emotional impact, and whether there is any subsequent impact on outcomes such as adherence to programmes and quality of life, in adults with SLD/PMLD.
Social	Investigation of the quality of 1:1 interaction during sedentary hydrotherapy sessions, and whether this has any subsequent impact on adult SLD/PMLD outcomes.
	Investigation of family bonding and caring physical contact during sedentary hydrotherapy sessions, and whether this has any subsequent impact on adult SLD/PMLD outcomes.
	Investigation of whether regular community sedentary hydrotherapy has any impact on public perception of adults with SLD/PMLD.
	Investigation of whether regular community sedentary hydrotherapy has any impact on caregiver fears and motivation/inspiration in wanting to change public perception of adults with SLD/PMLD.
Barriers and facilitators	Investigation of whether this study's reported barriers and facilitators have any impact on adult SLD/PMLD hydrotherapy attendance.

Table 11: The biopsychosocial hypotheses proposed by SPLASH Study

6.3 Dissemination and impact

One anticipated outcome of this study was the publication of SPLASH Study's findings in a peer-reviewed journal. Due to the range and breadth of SPLASH Study's findings, the researcher anticipates these findings would be of interest to multiple journals with different focusses and so is aiming to submit this study's findings for publication in the following: the Journal of Clinical Rehabilitation (preliminary findings), Physiotherapy Journal (perceived biomedical impacts), British Journal of Learning Disabilities (perceived psychosocial impacts) and the Journal of Aquatic Physical Therapy (themes of importance, and barriers/facilitators).

Table 12 evidences the events and conferences to date where SPLASH Study has been presented.

Event /Conference and date	Organiser	Audience	Format	Content
Café Scientifique 03/11/20	Café Scientifique	General public: all caregiver types	Virtual 30 minute oral presentation and 30mins questions and answers	Work in progress SPLASH Study presentation with aim of gaining social media followers in anticipation of recruitment.
Rehabilitation 2020 10-11/11/20	British Society of Rehabilitation Medicine (BSRM), The Society of Research in Rehabilitation (SRR), and the Association of Chartered Physiotherapists for People with Learning Disabilities (ACPPLD)	Rehab-neurologists, LD Physiotherapists and rehabilitation researchers	3 minute electronic poster presentation, with 10 minute oral presentation during an LD workshop	Work in progress SPLASH Study presentation with aim of gaining social media followers in anticipation of recruitment.
Postgraduate Research Conference 2020 02/12/20	Bournemouth University	University students and staff	Electronic poster	Work in progress SPLASH Study presentation with aim of gaining social media followers in anticipation of recruitment.
South West Allied Health Professional Massive Network Event 15/06/21	South West Allied Health Professional Massive	Allied health professionals	Electronic poster	Presentation of SPLASH Study preliminary findings.
Physiotherapy UK 2021 5-6/11/21	The Chartered Society of Physiotherapy	Physiotherapists	Electronic poster	Presentation of SPLASH Study findings.

Rehabilitation 2021 9-10/11/21	BSRM, SRR, and ACPPLD	Rehab-neurologists, LD physios and rehabilitation researchers	Virtual 10 minute presentation in the main auditorium and abstract publication in the journal of Clinical Rehabilitation	Presentation of SPLASH Study findings specifically relating to health.
ACPPLD South West Region Study Afternoon 14/11/21	ACPPLD South West	LD Physiotherapists	Virtual 30 minute oral presentation and 30mins questions and answers	Presentation of SPLASH Study findings.

Table 12: SPLASH Study's dissemination opportunities to date

These events have enabled dissemination of SPLASH Study findings to a wide range of health care professionals and clinical researchers. However, in order to further disseminate these findings to family and paid/volunteer carers, the researcher also plans to present SPLASH Study's findings through public virtual presentation, advertised through the SPLASH Study social media accounts and Diverse Abilities. Therefore fulfilling the study's final anticipated outcome of enabling caregivers to consider these findings when developing services or making a case for hydrotherapy in this client group.

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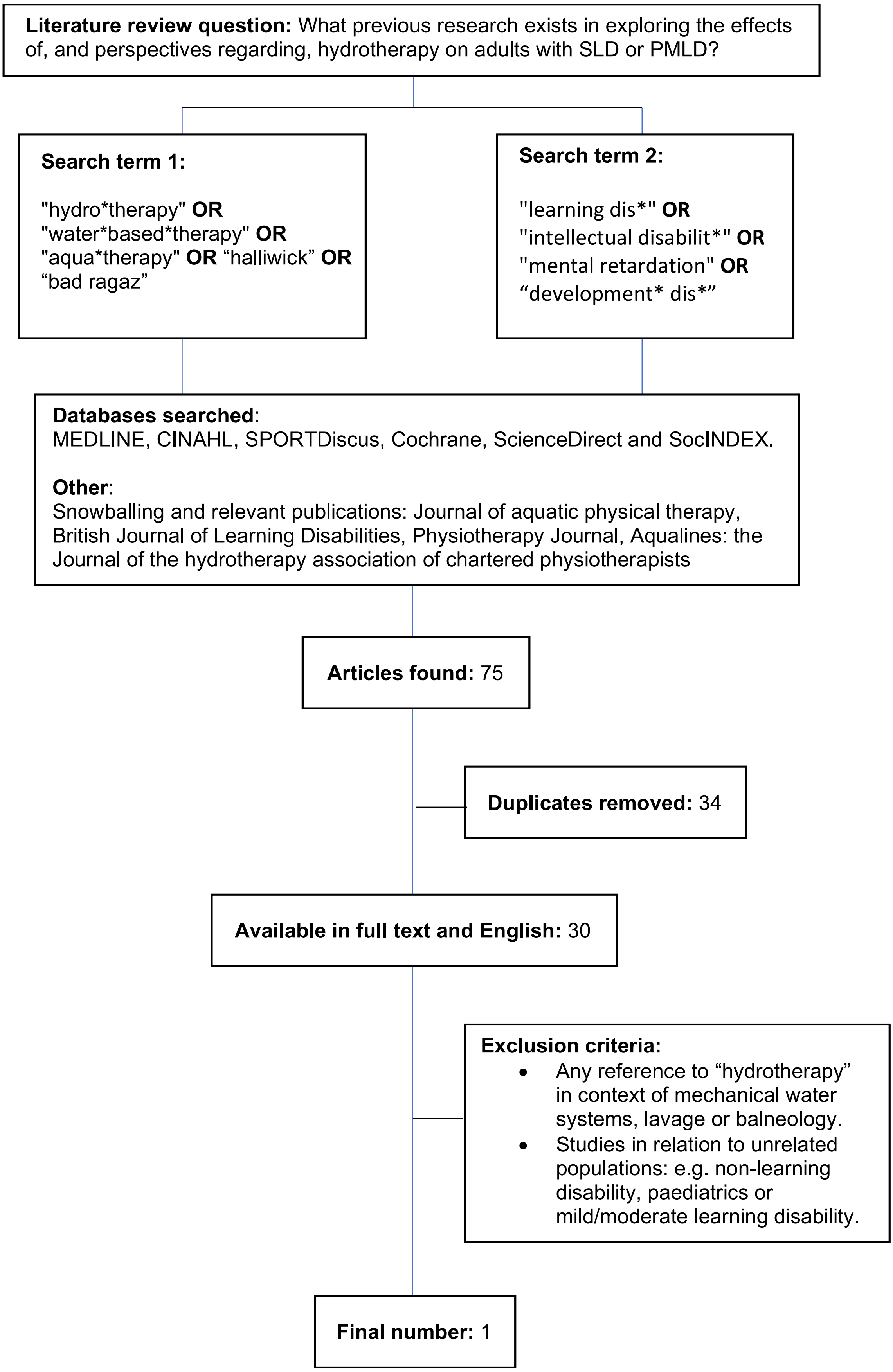
Appendices

Appendix I	Literature search flowchart: hydrotherapy and adult SLD/PMLD
Appendix II	Literature search flowchart: sedentary hydrotherapy and complex neurological populations
Appendix III	SPLASH Study question topic guide for semi-structured interviews
Appendix IV	SPLASH Study caregiver contextual questionnaire (including consent and screening questions)
Appendix V	Ethical approval letter
Appendix VI	Participant information sheet
Appendix VII	SPLASH Study’s full catalogue of themes: caregiver perceptions of hydrotherapy and adults with SLD/PMLD

Appendix I: Literature search flowchart: hydrotherapy and adult SLD/PMLD



Literature review question: What previous research exists in exploring the effects of, and perspectives regarding, hydrotherapy on adults with SLD or PMLD?

Search term 1:

"hydro*therapy" **OR**
"water*based*therapy" **OR**
"aqua*therapy" **OR** “halliwick” **OR**
“bad ragaz”

Search term 2:

"learning dis*" **OR**
"intellectual disabilit*" **OR**
"mental retardation" **OR**
“development* dis*”

Databases searched:
MEDLINE, CINAHL, SPORTDiscus, Cochrane, ScienceDirect and SocINDEX.

Other:
Snowballing and relevant publications: Journal of aquatic physical therapy, British Journal of Learning Disabilities, Physiotherapy Journal, Aqualines: the Journal of the hydrotherapy association of chartered physiotherapists

Articles found: 75

Duplicates removed: 34

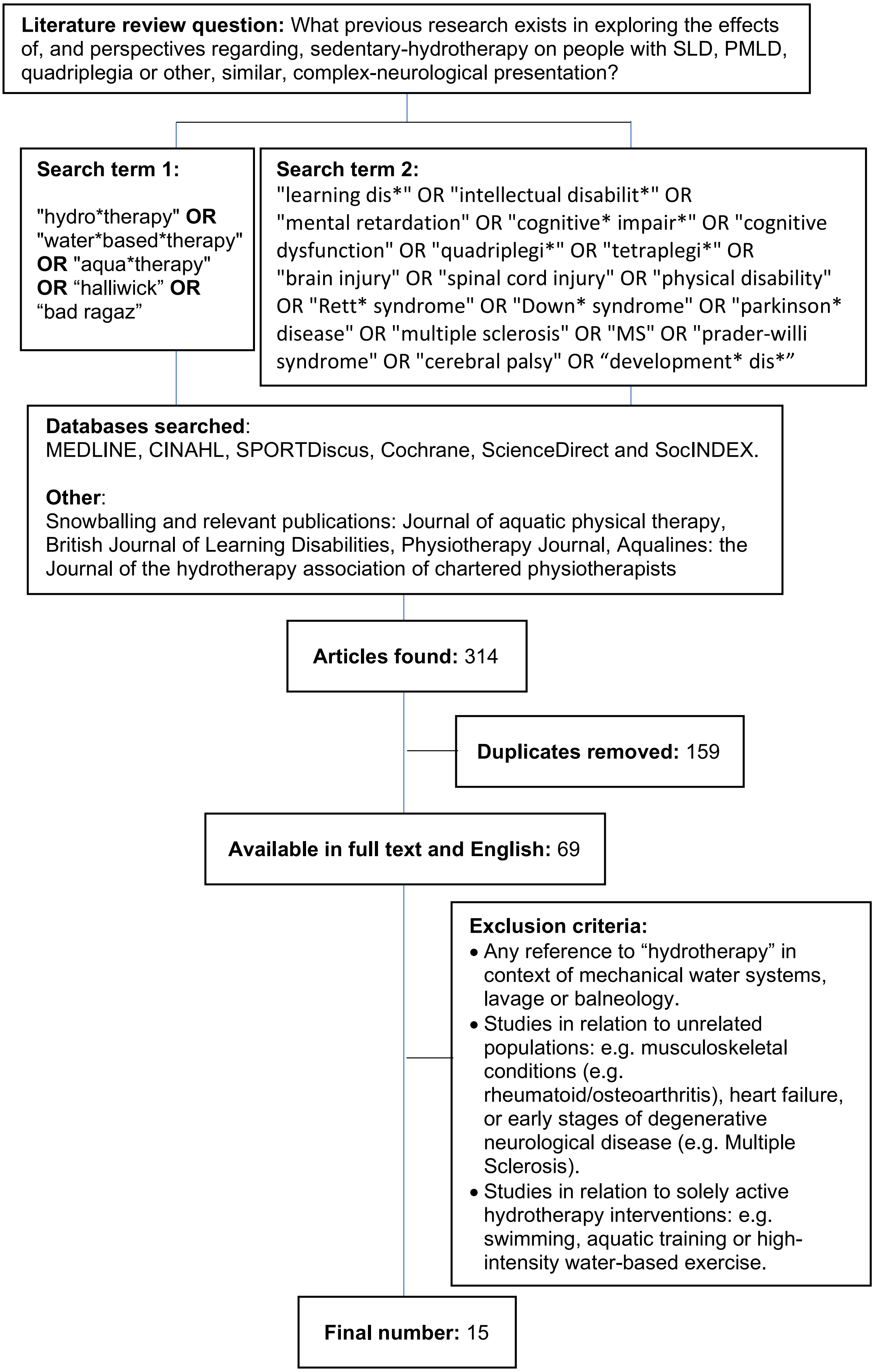
Available in full text and English: 30

Exclusion criteria:

- Any reference to “hydrotherapy” in context of mechanical water systems, lavage or balneology.
- Studies in relation to unrelated populations: e.g. non-learning disability, paediatrics or mild/moderate learning disability.

Final number: 1

Appendix II: Literature search flowchart: sedentary hydrotherapy and complex neurological populations



Literature review question: What previous research exists in exploring the effects of, and perspectives regarding, sedentary-hydrotherapy on people with SLD, PMLD, quadriplegia or other, similar, complex-neurological presentation?

Search term 1:

"hydro*therapy" **OR** "water*based*therapy" **OR** "aqua*therapy" **OR** “halliwick” **OR** “bad ragaz”

Search term 2:
"learning dis*" OR "intellectual disabilit*" OR "mental retardation" OR "cognitive* impair*" OR "cognitive dysfunction" OR "quadriplegi*" OR "tetraplegi*" OR "brain injury" OR "spinal cord injury" OR "physical disability" OR "Rett* syndrome" OR "Down* syndrome" OR "parkinson* disease" OR "multiple sclerosis" OR "MS" OR "prader-willi syndrome" OR "cerebral palsy" OR “development* dis*”

Databases searched:
MEDLINE, CINAHL, SPORTDiscus, Cochrane, ScienceDirect and SocINDEX.

Other:
Snowballing and relevant publications: Journal of aquatic physical therapy, British Journal of Learning Disabilities, Physiotherapy Journal, Aqualines: the Journal of the hydrotherapy association of chartered physiotherapists

Articles found: 314

Duplicates removed: 159

Available in full text and English: 69

Exclusion criteria:
- Any reference to “hydrotherapy” in context of mechanical water systems, lavage or balneology.
- Studies in relation to unrelated populations: e.g. musculoskeletal conditions (e.g. rheumatoid/osteoarthritis), heart failure, or early stages of degenerative neurological disease (e.g. Multiple Sclerosis).
- Studies in relation to solely active hydrotherapy interventions: e.g. swimming, aquatic training or high-intensity water-based exercise.

Final number: 15

Appendix III: SPLASH Study question topic guide for semi-structured interviews

Topic Guide for SPLASH Study interviews

Semi-structured interviews will be conducted with consenting participants found to be eligible. Recruitment will continue until data saturation has been reached within each of the 3 participant areas of family members, paid carers, and qualified/registered professionals.

Questions will be asked to explore each participants' perspectives on the themes below. The flow of each interview and exact questions asked will be bespoke for each participant, based on their responses. There will also be opportunity for participants to discuss anything else they feel relevant to the study. This flexibility allows for a more comprehensive capturing of their experiences, thoughts and perceptions relating to hydrotherapy and the adult severe/ PMLD population.

The themes of priority are highlighted below.

1. **Health**:
    - medical/health/diagnoses/LD specific needs (sensory/behaviour)
2. **Function**:
    - functional ability/meaningful occupation
3. **Welfare:**
    - wellbeing/freedom/control/quality of life
4. **Connections**:
    - family/personal relationships/communication
5. **Support**:
    - care/support needs/carer burden
6. **Night time:**
    - sleep/night support
7. **Negatives**:
    - barriers/challenges/safety

Examples of specific questions include:

Note: when interviewing families/carers of specific service users XXX is used to represent client’s name, when interviewing qualified professionals or carers of multiple service users XXX is used to represent “service users”.

- Tell me a little about XXX, and your last experience of them accessing hydrotherapy?
- How does hydrotherapy impact on XXX’s life?
    - Are any of these impacts unique to hydrotherapy?
    - Is this the same in the pool and out of the pool?
    - (if no) Could you tell me some more about XXX and your experience of them accessing hydrotherapy?

- Could you tell me about hydrotherapy and XXX's health?
- Can you describe any affect hydrotherapy may have on XXX’s ability to do things?
- How does hydrotherapy impact on XXX's wellbeing or quality of life?
- How does hydrotherapy have on the way XXX connects with you or others?
- How does XXX accessing hydrotherapy impact on you/XXX’s carers?
    - What impact, if any, does hydrotherapy have on XXX’s support needs?
- Can you describe any affect hydrotherapy may have on XXX’s night time routine or sleep?
- Could you tell me a bit more about any negative thoughts/experiences/perceptions you have regarding XXX and hydrotherapy?

- We’re nearly done now; I’ve just got a couple more questions. Can you give me an example of any surprises/anything unexpected relating to XXX and hydrotherapy?
- Is there anything else we haven't covered, which you would like to share, or feel is relevant?

Examples of specific probes include:

- Could you tell me a bit more about …?
    - Could you tell me a bit more about hydrotherapy and XXX's health?
    - Could you tell me a bit more about hydrotherapy and how XXX's is able to take part meaningfully?
    - Could you tell me a bit more about hydrotherapy and XXX's quality of life?
    - Could you tell me a bit more about hydrotherapy and XXX's relationship with you/carers?
    - Could you tell me a bit more about hydrotherapy and XXX's support needs?
    - Could you tell me a bit more about hydrotherapy and XXX's sleep?
    - Could you tell me a bit more about the barriers, risks or challenges of hydrotherapy and XXX?
- Have you experienced the same thing in any other environment? / Is this the same out of the pool?
- Can I just check what you mean when you say …?
- What do you feel was the reason for that?
- Active listening principles will also be applied in terms of body language, facilitative responses and paraphrasing.

Appendix IV: SPLASH Study caregiver contextual questionnaire
(including consent and screening questions)

Caregiver Questionnaire

Participant Information

You are being invited to take part in a research project. Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following Participant Information Sheet carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

BU's Research Participant Privacy Notice 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 and 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 within the Participant Information Sheet.

Participant Information Sheet

Click here to read and download the Participant Information Sheet

I confirm that I have read and understood the information provided and I agree to take part in this study. ✱ *Required*

○ I agree

Participant Agreement

Researcher name and email: Carrie Tbaily, MRes Student,
ctbaily@bournemouth.ac.uk
Supervisor name and email: Dr Louise Fazakarley, BU Physiotherapy Program Leader,
lfazakarley@bournemouth.ac.uk

Agreement to participate in the study
You should only agree to participate in the study if you agree with all of the statements listed below and accept that participating will involve the listed activities.

- I have read and understood the Participant Information Sheet (Version 2.0) and have been given access to the BU Research Participant Privacy Notice which sets out how we collect and use personal information.
- I have had an opportunity to ask questions.
- I understand that my participation is voluntary. I can stop participating in research activities at any time without giving a reason and I am free to decline to answer any particular question(s).
- I understand that taking part in the research will include the following activity/ activities as part of the research:
  - being video/audio recorded during the project.
  - my words will be quoted in publications, reports, web pages and other research outputs without using my real name.
- I understand that, if I withdraw from the study, I will also be able to withdraw my data from further use in the study **except** where my data has been anonymised (as I cannot be identified) or it will be harmful to the project to have my data removed.
- I understand that my data may be included in an anonymised form within a dataset to be archived at BU's Online Research Data Repository.
- I understand that my data may be used in an anonymised form by the research team to support other research projects in the future, including future publications, reports or presentations.

Enter your initials in the box below to agree: ✱ *Required*

Please enter a response that contains only upper case letters.

☐

I confirm my agreement to take part in the project on the basis set out above.

Name of Participant: ✱
Required

Date: ✱
Required

Dates need to be in the format 'DD/MM/YYYY', for example

(dd/mm/yyyy)

Screening

Which of the following statements describes you best? ✱
Required

○ I am an unpaid carer (e.g. family member/volunteer) of an adult (over 18) with either severe LD or PMLD, who has attended hydrotherapy as an adult.

○ I am a paid carer for at least one adult (over 18) with either severe LD or PMLD, who has attended hydrotherapy as an adult.

○ I am a health or social care professional working with at least one adult (over 18) with either severe LD or PMLD, who has attended hydrotherapy as an adult.

○ None of the above.

Contact details

Thank you for your interest and willingness to participate in SPLASH Study.

Please answer the questions below to indicate how we can contact you and which interview format you would prefer.

Email address:

Please enter a valid email address.

Telephone number:

Please enter a valid phone number.

Postal Address:

Please indicate your preferred interview format: ✱ *Required*

○ Zoom
○ Microsoft
○ Teams Skype
○ Telephone

○ I would like a member of the research team to contact me to discuss other options.

After you have completed this questionnaire, a member of the research team will be in touch with you to arrange a suitable date and time for the interview.

How would you prefer for us to contact you to arrange this? ✱ *Required*

Questions about you

What is your relationship with the person/people with Severe LD/PMLD you care for?

(e.g. son, daughter, sister, brother, 1:1 support worker, or physiotherapist in community adult LD team)

How often/many hours per week do you care for them?

(e.g. 37.5 hours per week, evenings and weekends, monthly visit)

Questions about the person you care for

Thinking about the adult with Severe LD or PMLD you support, please answer the following questions as accurately as possible.

If you support more than 1 adult with Severe LD or PMLD, please tell us about the adult you know best.

Age: *(if you would prefer not to say, please type this in the box below)*

Gender: *(if you would prefer not to say, please type this in the box below)*

Diagnoses:

Level of Learning Disability:

○ Severe
○ Profound and Multiple

Thinking about their muscles, how might you describe their tone?

(e.g. high (hypertonic), low (hypotonic), spasticity, rigidity, variable, unknown/unsure)

Which limbs are affected by altered tone and how?

(e.g. increased tone in both arms / both legs / left side / right side, unknown/unsure)

Do they have any issues affecting the position/posture of their trunk?

(e.g. bent forwards (kyphosis), bent to their left / right (scoliosis), unknown/unsure)

Do they have any contractures (unable to fully bend or straighten any joints)?

○ Yes
○ No
○ Unknown/unsure

If yes, where and what movement are they unable to do?

(e.g. unable to straighten their right elbow, unable to bend either knee)

Questions about the person you care for

What postural equipment do they have in place at home or use at day centre?
(e.g. wheelchair, armchair, sleep system, pacer/body support walker, unknown/unsure)

Can they walk or transfer at all? *(Please select the answer which best fits)*

○ Yes - able to walk independently, more than 10m, both indoors and outdoors.

○ Yes - able to walk with some support, or walking stick/frame. Difficulty walking outdoors. Able to manage stairs but need a rail or support.

○ Yes - short distances and indoors only, with walking stick/frame. Able to transfer.

○ Yes, but - only using a full pacer/body support walker, or with a lot of physical assistance.

○ No - they are unable to weight bear and need equipment to sit/stand upright.

○ Unknown/unsure

Do they have any specific communication support needs?

(e.g. easy read, pictures/onjects of reference, TaSSeLs, communication aids, unknown/unsure)

What type of accomodation do they live in?
(e.g. family home, supported living, residential care, unknown/unsure)

What care packages are in place?
(e.g. at home / day centre, unknown/unsure)

Who funds their care?

☐ Health / Continuing Health Care (CHC)
☐ Social Care / Local Authority / Council
☐ Self-funded
☐ No paid care needs
☐ Unknown/unsure
☐ Other

If you selected Other, please specify:

Questions about their hydrotherapy

Did they access hydrotherapy as a child?

○ Yes
○ No

If yes, how often?

Do they access hydrotherapy now?

○ Yes
○ No

Hydrotherapy Questions Continued

How regularly did they used to access hydrotherapy as an adult?

When/why did they stop attending hydrotherapy?

Hydrotherapy Questions Continued

How regularly do they access hydrotherapy now?

Have they ever accessed hydrotherapy more or less often than they currently do?

○ Yes
○ No

If yes, could you explain how often they used to access hydrotherapy and the cause for this change?

Final Hydrotherapy Questions

Who pays for their access to hydrotherapy as an adult?

☐ Health / Continuing Health Care (CHC)
☐ Social Care / Local Authority / Council
☐ Self-funded
☐ Unknown/unsure
☐ Other

If you selected Other, please specify:

When they last accessed hydrotherapy, was the water:

○ Hydrotherapy pool temperature (e.g. hotter than a public swimming pool)
○ Warm but not hydro pool temperature (e.g. about the same as a public pool)
○ Cool (e.g. colder than a public swimming pool)
○ Unknown/unsure

What did they do during the hydrotherapy session?

☐ Active swimming/exercises without support (e.g. no support needed)
☐ Active movements (e.g. kicking, splashing, moving) with physical support
☐ Passive movements (e.g. swishing in the water/sea weeding) from caregiver in the water
☐ Passive stretching (e.g. someone giving hands on stretches) from caregiver in the water
☐ Unknown/unsure
☐ Other

If you selected Other, please specify:

Final page: Thank you

Thank you for taking the time to complete this questionnaire. Your answers have now been submitted and are important in helping us to fully explore the impact of hydrotherapy on adults with Learning Disabilities.

A member of the research team will now be in touch with you to arrange a suitable date and time for the interview.

You can keep up to date with the progress of this study via the SPLASH Study Facebook and Twitter social media accounts.

If you have any further questions, please use the contact details below:

Carrie Tbaily, Postgraduate Researcher,
Faculty of Health and Social Sciences,
Bournemouth University,
S601 Studland House,
12 Christchurch Road,
Bournemouth,
BH1 3NA.
Email: ctbaily@bournemouth.ac.uk Tel: 01202 961150

Appendix V: Ethical approval letter

From: Research Ethics
Sent: 14 January 2021 17:02
To: Caroline Tbaily
Subject: 30905_Caroline Tbaily (Research Ethics Submission)

Dear Carrie

Thank you for responding to the Science, Technology & Health Research Ethics Panel's request for further information and submitting revised documentation.

The further information has now been considered on behalf of the Panel by the Chair and I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the ethics checklist and supporting documentation as revised.

After ethical review:

Study Files:

- Research Development & Support suggested index for your study files. This document clearly sets out which documents a study monitor would expect to see in your files.
- Version log for your documents held in study files

Amendments:

Should you need to make any modifications to your project e.g. request an extension, increase of planned recruitment of participants, requests for Amendments should be made via the online ethics checklist (https://ethics.bournemouth.ac.uk/). If recruiting additional research participants, you may need to revise your current participant information sheet and agreement form, please do visit the research ethics blog to make sure you are using the most up to date versions. Requests will be considered by the Panel Chair and approved by Chair's Action. Changes cannot be implemented until relevant approvals are in place.

Monitoring:

In line with BU's research ethics code of practice, the University may carry out monitoring visits to ensure research projects are being carried out in accordance with good practice, legal and ethics requirements. Studies will be selected at random and you will be notified by the Governance Team in advance of their intention to monitor. Should your project be selected, please make available all the requested documents for review during the monitoring visit e.g. master project file, consent forms (see recommended index form).

I will approve your checklist online shortly.

With the Panel's best wishes for the success of this project

Kind regards
Sarah

Sarah Bell
Research Governance Advisor
Research Development & Support

To keep up to date on Clinical Governance and Research Ethics @ BU – visit the Research Governance and Integrity website

Appendix VI: Participant information sheet

Participant Information Sheet

SPLASH Study

Exploring caregiver perspectives of adults with Severe or Profound and multiple Learning Disabilities Accessing Sedentary Hydrotherapy

You are being invited to take part in a research project. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Who is organising/funding the research?

This study is being sponsored by Bournemouth University (BU) and it is funded by Diverse Abilities. Bournemouth University has set up the study.

What is the purpose of the project?

Hydrotherapy is frequently used in children's services, and there is some research to support its use. But in adult Learning Disabilities services, access to hydrotherapy is limited as research is scarce. This research aims to find out how carers, family members and professionals perceive hydrotherapy to impact on the lives of adults with severe or profound and multiple Learning Disabilities.

Why have I been chosen?

All formal carers (such as paid carers), informal carers (such as family members) and qualified professionals (including health and social care) who care for at least one adult with either Severe Learning Disability (SLD) or Profound and Multiple Learning Disabilities (PMLD), who has accessed hydrotherapy in their adult life, are being invited to consider taking part. There is no set number of participants for this study.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part, you will be able to download a copy of this information sheet to keep and be asked to sign a participant agreement form. We want you to understand what participation involves, before you decide whether to participate. 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.

Can I change my mind about taking part?

Yes, you can stop participating in study activities at any time and without giving a reason.

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. Regarding 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.

What would taking part involve?

If you agree to take part in this study you will be asked to complete a short questionnaire, which will ask you about your caring role and the person/people you care for. The questionnaire is available in electronic or paper format and should take approximately 10 minutes to complete. On completing the questionnaire you will be invited to attend an interview, at a date and time suitable for you. Participants will be encouraged to attend these interviews virtually, but alternative arrangements can be discussed with the research team if necessary. The interview will be recorded, and a researcher will ask you questions about your experiences of hydrotherapy, and any impact it has had on the person/people you care for. It is expected that the interview will last no longer than 1 hour.

What are the advantages and possible disadvantages or risks of taking part?

Whilst there will be no immediate benefits to you participating in the project, it is hoped that this work will contribute to knowledge and research in the area of adult LD. Whilst we do not anticipate any risks to you in taking part in this study, you may find the questions in this interview tiring and it will take up time. There are no other associated disadvantages or risks from taking part.

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?

Through the questionnaire and interviews, information about caregivers and adults with LD will be collected. This information will include personal health information, as well as demographics data. This is to allow the research team to understand and explore each caregiver's unique lived experience. The information you provide will only be identified by your unique reference number, not by personal information such as your name. If during the interview you disclose poor practice, you will be encouraged to raise this directly with the care provider. However, if safeguarding disclosure is made this will be reported to your local safeguarding adults board. We do not anticipate any topics to cause distress, however if this happens you will be given opportunity to pause or discontinue the interview. If necessary, you will be sign posted to primary care services or your local 'Improving Access to Psychological Therapies' service.

Will I be recorded, and how will the recorded media be used?

Yes, the interview will be video/audio recorded. The recording of your interview will be used only for analysis, and the transcription of the recording 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. The video/audio recordings will be destroyed as soon as the transcript has been approved by the research team.

How will my information be managed?

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 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.

Publication

You will not be able to be identified in any external reports or publications about the research. Your information will only be included in these materials in an anonymous form, i.e. you will not be identifiable.
Research results will be made available via presentation at conferences, written papers, and summaries distributed to interested parties and via social media. You can keep up to date with the progress of the study on the
@SPLASHstudy Facebook and Twitter social media accounts.

Security and access controls

BU will hold the information we collect about you in hard copy in a secure location and on a BU password protected secure network where held electronically.
Personal information which has not been anonymised 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 in the Privacy Notice. 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.
After consenting to take part in this study you will be allocated a unique reference number. The information you provide will therefore only be identifiable by your unique reference number, not by personal information such as your name.

Sharing your personal information with third parties

Your personal information will only be shared in non-anonymised form between Carrie Tbaily and BU staff working on the research project. No third parties, including Diverse Abilities, will have access to your non-anonymised information.

Further use of your information

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.

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. This may include your personal identifiable information. 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.

Retention of research data

Project governance documentation, including copies of signed participant agreements are kept for a long period after completion of the research, so that we have records of how we conducted the research and who took part. 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.

Research results

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.

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.

Who do I contact for further information?

If you have any questions or would like further information, please contact:

Carrie Tbaily, Postgraduate Researcher,
Faculty of Health and Social Sciences,
Bournemouth University, S601 Studland House,
12 Christchurch Road, Bournemouth, BH1 3NA.

Email: ctbaily@bournemouth.ac.uk **Tel:** 01202 961150

In case of complaints

Any concerns about the study should be directed to Dr Louise Fazakarley, BU Physiotherapy Program Leader, lfazakarley@bournemouth.ac.uk. If your concerns have not been answered by Dr Fazakarley, you should contact Professor Vanora Hundley, Deputy Dean for Research & Professional Practice, Faculty of Health & Social Sciences, Bournemouth University, by email to researchgovernance@bournemouth.ac.uk

Finally

You may download a copy of this information sheet to keep and if you do decide to take part, you will be given a copy of a signed participant agreement form to keep.

Thank you for considering taking part in this research project.

Appendix VII: SPLASH Study's full catalogue of themes: caregiver perceptions of hydrotherapy and adults with SLD/PMLD

SPLASH Study's full catalogue of broad brush themes, themes and subthemes, as reported by caregivers in relation to the perceived impacts of hydrotherapy on adults with SLD/PMLD.

Section Theme	Themes	Subthemes
1. How hydrotherapy impacts on health needs	1. Physiological health impacts	a) Balance & co-ordination b) Core stability c) Function & independence d) Maintenance e) Mobility & movement f) Pain g) Posture & positioning h) Strength i) Tone
	2. Body system impacts	a) Appetite b) Bone density c) Bowel movements & constipation d) Circulation e) Immune system f) Infection g) Seizure activity h) Sleep
	3. Opportunities to impact on health	a) Challenging behaviours b) Disability c) Passive movement and stretching d) Physiotherapy assessment & treatment e) Promotes health-routine f) Relaxation
	4. Secondary impact due to health impacts	a) Hospital admissions reduced b) Medication reduced
	5. Negative effects on health	a) Change to health-routine b) Skin integrity c) Rushed washing & dressing
2. How hydrotherapy impacts on function	1. Function in the water	a) Activity & exploration b) Independence c) Mobility & movement
	2. Function on land	a) Activities of daily living b) Better sleep c) Core stability d) Maintenance e) Mobility & movement f) Posture & positioning g) Reduced falls h) Upper limb use & activities
	3. Opportunities impacting on function	a) Cause/effect & control b) Learning & achievement c) Meaningful occupation & purpose d) Motivation to choose e) Playing with others
	4. Secondary impacts on function	a) Communication b) Relationships c) Tolerance

3. How hydrotherapy impacts on mental health & wellbeing	1. Facilitation of feelings	a) Inclusion & satisfaction b) Confidence & understanding c) Freedom & weightlessness d) Happiness & excitement e) Relaxation, calm & comfort f) Safety & caring proximity
	2. Enabling autonomy	a) Choice & control b) Facilitation of independence c) Inspiration of exploration d) Motivation
	3. Opportunities impacting on mental health	a) Caregiver attention b) Demonstrate/observe ability c) Different position/eye level d) In the community e) Meaningful occupation f) New experience g) No external support h) Not clinical/personal care i) Sense of humour j) Sensory experience k) Routine l) Secondary impact on health
	4. Positive impact on caregivers	a) Observed impact & ability b) Quality & fun time c) Positive effect on mood
	5. Negative impact on mental health	a) Caregiver cold/exhausted b) Inconsistency c) Proximity d) Session ending e) Travel f) Washing & dressing
4. How hydrotherapy impacts on support needs	1. Level/amount of care	a) Allowed reduction b) Required increase c) Neutral impact
	2. Investment/ burden of care	a) Reduction in water b) Reduction on land c) Increased burden
	3. Secondary impact on level & investment of care	a) Confidence, motivation & skills b) Inspiration c) Quality of care
5. How hydrotherapy impacts on relationships	1. Developing relationships	a) Care-receiver & caregiver b) Caregiver & physio c) Carer & family d) Community e) Peer relationships f) Support networks
	2. Negative impacts on relationships	a) Caregiver communication b) Existing assumptions c) Public perceptions
	3. Changing perceptions	a) Care-receiver's view b) Challenging assumptions c) Eliminating disability d) Fear & confidence
	4. Relationship impact on caregivers	a) Confidence & skills b) Observing activity & independence c) Observing happiness d) Observing posture & movement

	5. Opportunities impacting on relationships	e) Family bonding f) Fun & humour g) Interaction while alert h) Physical proximity i) Quality attention j) Social inclusion
6. How hydrotherapy impacts on social inclusion	1. Barriers to social inclusion	a) Lack of physical access b) Public perception c) Inability to self-advocate
	2. Facilitators to social inclusion	a) Accessibility b) Alertness and engagement c) Ability in water
	3. Opportunities for social inclusion	a) Community sense b) Meaningful occupation c) Family/peer bonding
7. How hydrotherapy impacts on communication	1. Care-receiver's communication	a) Engagement & alertness b) Expression of emotion c) Motivation d) Physical communication e) Trust & confidence
	2. Caregiver's communication	a) Consistency b) Eye contact c) Intensive interaction d) Quality attention
	3. Negative impacts on communication	a) Acoustics b) Care-receiver refusal c) End of session
	4. Opportunities for communication	a) Meaningful use of TaSSeLs (Tactile Signing for Sensory Learners) b) Proximity & position c) Social communication
8. How hydrotherapy impacts on sleep & tiredness	1. Positive impacts on sleep	a) Ease of sleep system use b) Physical tiredness c) Quality & duration d) Sensory regulation
	2. Neutral impacts in relation to sleep	a) Nap during the day/session b) No effect c) Not reported or considered
	3. Negative impacts on sleep	a) Impacts on night-time routine b) Reduced sleep at night
9. How hydrotherapy impacts on alertness & engagement	1. Causes of increased alertness	a) Engagement b) Involvement & interaction c) Reduced boredom d) Sensory input
	2. Consequences of increased alertness	a) Awareness of the environment b) Function c) Rate of learning d) Reduced tiredness e) Relationships
	3. Negative impacts on alertness & engagement	a) Sleeping in the pool b) Drowsiness & lethargy afterwards
10. How hydrotherapy impacts on sensory preferences	1. Positive sensory input	a) Sight b) Sound c) Tactile/touch d) Vestibular e) Proprioception f) Deep pressure g) Interoception

	2. Negative sensory input	a) Noise b) Turbulence c) Splashing
	3. Opportunities for sensory experience	a) Sensations b) Movements & positions c) Person-centred flexibility d) Communication
	4. Secondary impact due to sensory input	a) Emotional regulation b) Sensory modulation c) Tactile tolerance
11. The barriers/facilitators of accessing hydrotherapy	1. Facilities	a) Availability b) Changing facilities c) Equipment use & maintenance d) Physical access e) Pool temperature, size & depth
	2. Care-receiver needs & preferences	a) Health needs b) Location c) Previous experience d) Sensory
	3. Funding	a) Funding authority & need to advocate b) Multiple costs
	4. Support	a) Confidence & competence b) Caregiver investment c) Flexibility d) Motivation e) Organisation
	5. Transport	a) Distance b) Requirements & availability
	6. Covid-19	a) Concerns for the future b) Infection control c) Pool closure d) Staffing
12. How Covid-19 has impacted on hydrotherapy	1. Availability & access to facilities	a) Pool closure b) Reduced capacity c) Resourcefulness d) Non-prioritisation
	2. Care-receiver deterioration due to Covid-19	a) Challenging behaviour b) Mental health c) Night terrors d) Physical health e) Social isolation
	3. Caregiver burden due to Covid-19	a) Harder to use postural management equipment b) Infection control c) Less access to support network d) Responsibility & risk e) Staffing difficulties
	4. Concerns for future hydrotherapy provision	a) Increased costs b) Pool closure c) Reversibility of physical deterioration d) Risk of catching Covid-19