

**An Interpretative Phenomenological Analysis of
the role of social media in the lives of young men
with neuromuscular conditions**

George Peat

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Abstract

Background

Young men with Duchenne Muscular Dystrophy (DMD) are now living longer due to advancements in medical technologies such as developments in support for breathing and gastronomy feeding. However, daily life for young men with DMD can be a challenge, particularly as they enter into adulthood, where services and provision may change and are not always suited to their needs. Anecdotal evidence has illuminated the capacity of social media as an alternate lifeworld for young men with DMD. Few studies however, have explored how social media is experienced by young men with DMD.

Aim

To explore the lived experience of social media from the perspective of young men with DMD.

Method

An Interpretative Phenomenological Analysis was undertaken, involving sequential in depth interviewing with eight young men aged 18-28 with DMD. Novel methods of data collection were used, including the use of video gaming to support engagement during the interview.

Findings

Three superordinate themes were identified: 'Existence outside social media; navigating offline lifeworld', 'Transcending into an alternate reality, life within video gaming' and 'The meaning of social networking platforms, blogs, and spaces'. The lived experience of social media appeared to be grounded in the interplay between the offline and online existences of participants. Video gaming provided an alternate reality for many participants to immerse themselves, and to engage in experiences unavailable 'offline'. Social networking sites, and blogs facilitated a sense of group identity, belonging, and autonomy over decisions related to their care.

Conclusion

The meaning of social media to young men with DMD appears at its most harmonious when it is experienced as an activity for enjoyment, connectivity, discovery, and occasional refuge. The findings of the study have implications both for social media development, and for the care provided to young men with DMD.

Outputs of the study to date

Conference presentations

- Peat, G., Rodriguez, A., Smith, J. 2018. Exploring the lived experiences of young men with life-limiting conditions: making sense of identity through social media. *University of Leeds. School of Healthcare Conference*, November, 6th, University of Leeds, (first prize for oral presentation).
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- Peat, G., Rodriguez, A., Smith, J. 2018. Mobilising the self through social media: themes from a Twitter Chat. *Faculty of Medicine and Health PGR Conference 'Making a Difference'*. June, 5. University of Leeds.
- Peat, G., Rodriguez, A., Smith, J. 2017. The use of social media in palliative care and its wider intergenerational impact: A scoping review. *International Family Nursing Conference*, June, 14-17, Pamplona, (highly commended in poster competition).
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Publications

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- Peat, G., Rodriguez, A., Smith, J. 2018. Social media use in adolescents and young adults with serious illness: an integrative review. *BMJ Supportive and Palliative Care*. **19**(9), pp. 235-244.
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Chapter 1 Introduction

Young men with Duchenne Muscular Dystrophy (DMD) are living longer due to advancements in medical technologies such as improvements in support for breathing such as mechanical ventilation (Birnkrant, Bushby, et al, 2018). However, the daily life for young men with DMD can be challenging, particularly as they enter into adulthood, where services and provision may change and are not always suited to their needs. Consequently, young men with DMD may turn to an alternate lifeworld provided by social media in the search for experiences otherwise deprived to them. This thesis explores the lived experience of social media from the perspective of young men with DMD.

Several studies (e.g. Gibson, Young, et al, 2007; Abbott, 2012; Skyrme, 2017) have alluded to the presence of social media (including video gaming) in the daily lives of young men with DMD. It is suggested that up to 20% of video gamers live with an impairment, including people with a neuromuscular condition such as DMD (Porter, Keinz, 2013). Similarly, a plethora of online content related to DMD exists within the many pages, groups, and profiles found among social networking sites such as Facebook, Instagram, and Twitter. However, little is known about the lived experience of social media from the perspective of young men with DMD.

This study reported herein adopted an Interpretative Phenomenological Analysis (IPA) approach (discussed in Chapter 3) to explore the lived experience of social media from the perspective of eight young men with DMD. The findings of the study offer a unique contribution to knowledge that have implications for practice, and the application of future social media interventions.

This chapter first outlines the background context to exploring the lived experiences of young men with DMD. A definition of DMD and a trajectory of the disease accompanied with appropriate care options is provided. A summary overview of the literature that has highlighted key issues of daily living with DMD is then discussed. Reflections on my role as a volunteer carer at a children and

young adult hospice are described including observations that alerted me to the frequency young men with DMD engaged with social media. A definition of social media and the range of platforms and activities associated with the term are offered, before a discussion on social media use in the context of young men with DMD. Finally, an outline of each chapter of the thesis is provided.

1.1 Background context to the study

In order for the reader to understand the purpose of the study, background context is provided, including an outline of DMD and care provision. A summary of the extent DMD impacts on different aspects of the daily lives of young men diagnosed with the condition is provided.

1.1.1 Duchenne Muscular Dystrophy

DMD is a life-limiting neuromuscular condition (Mendell, Shilling, et al, 2012).

Life-limiting conditions are defined as those that currently have no cure and therefore will result in premature death (Widdas, McNamara, et al, 2013).

Together for Short Lives (2020) categorise life-limiting conditions, of which over 300 have been identified that affect children and young people into four categories, with DMD falling into category two:

1. Life-threatening conditions for which curative treatment exists but may fail. Examples include cancer and irreversible organ failure.
2. Conditions whereby treatment is available to prolong life, but where a premature death is inevitable. Examples include Duchenne Muscular Dystrophy and Cystic Fibrosis.
3. Progressive conditions where curative treatments do not exist and therefore treatment is exclusively palliative. Examples include Batten disease.
4. Irreversible but non-progressive conditions that cause severe disability and an increase susceptibility to health complications. Examples include severe Cerebral Palsy.

Neuromuscular conditions (NMCs) describe a range of progressive disorders that impair muscle functioning, primarily as a result of muscle dystrophy or disruption of neuromuscular junction process (Royal College of Nursing, 2020).

In the UK it is estimated prevalence of NMC in adults and children is 37 per 100,000 (Woodcock, Fraser, et al, 2016). NMCs include muscular dystrophies (MDs), which are a group of inherited conditions, characterised by muscle weakness and/or fatigue, loss of motor control, muscle spasm and altered sensations such as numbness, tingling and pain, and include Duchenne Muscular Dystrophy (Landfeldt, Lindgren, et al, 2015).

Duchenne Muscular Dystrophy (DMD) is the most common MD, with a prevalence of 15.9-19.5 per 100,000 births, usually affecting boys and results in a shortened life expectancy (Woodcock, Fraser, et al, 2016). DMD is the result of a genetic mutation on the X chromosome that prevents the production of the protein dystrophin essential for muscle development and function. Early symptoms of DMD usually present with delayed motor development between 1 and 3 years of age, and can include difficulty in performing activities involving the trunk of the body such as walking or climbing stairs. Typically children use a wheelchair by about 12 years of age because of progressive weakening of muscles resulting in fatigue when walking. Children often have an associated scoliosis develop around this age, and by mid to late-teens, some young people with DMD develop breathing problems due to the weakness of intercostal muscles and the diaphragm. When respiratory muscle weakness compromises breathing both non-invasive and invasive mechanical ventilation are used to prolong life (Muscular Dystrophy UK, 2020). The next sub section details the disease trajectory and related care needs of DMD.

1.1.2 Disease trajectory and related care needs

DMD is a complex condition that requires multidisciplinary care across services from initial diagnosis to end of life (Hill, Phillips, 2005). International and nationally accredited clinical guidelines for DMD were published in 2010, and later updated in 2018, with the aim to provide a comprehensive guide to best practice for care of patients with DMD (Bushby, Finkel, et al, 2010; Birnkrant, Bushby, et al, 2018).

Care typically begins in primary care where a General Practitioner (GP) will initiate the process that leads to a diagnosis of DMD, by referring the patient on to a neuromuscular specialist. From confirmation of diagnosis to end-of-life, a

patient with DMD will interact with multiple different clinicians and specialists dependent on the stage of the disorder. For instance, in the earlier stages of diagnosis termed 'early to late ambulatory' (Landfeldt, Lindgren, et al, 2015, p.65) care is predominately focused on neuromuscular management. However, as the disease progresses the requirement for cardiac and respiratory specialist care, alongside neuromuscular and orthopaedic management results in a multi-disciplinary approach (Landfeldt, Lindgren, et al, 2015).

Specialists in physiotherapy, occupational therapy, and speech and language therapy should also play an active role in the care of young men with DMD (Hill, Phillips, 2005). Several neuromuscular clinics or centres exist in the UK, whereby multi-disciplinary care is situated in one geographical location. However, not all parts of the UK have a dedicated neuromuscular centre, with the majority based in large regional centres (Hill, Phillips, 2005). Nevertheless, estimates suggest a significant majority of children, and up to 70% of adult patients with DMD visit a neuromuscular centre (Landfeldt, Lindgren, et al, 2015, p.70). Routine appointments and contact with a GP should underpin the care package, ensuring the coordination of care between care specialists and continuity of care (Birnkrant, Bushby, et al, 2018).

Outside of clinical settings evidence suggests care for young men with DMD, with support from health services, is largely provided at home, with parents and family members often providing a significant contribution to their child/young person's care. Other support options for care include an external carer visiting the home for an agreed time on agreed days (for instance 9am-3pm 5 days a week), an external carer providing 24/7 care, paying for support with housework to facilitate time for parents to support their son. However, these options are dependent on funding and local provision that can often vary (Abbott, Carpenter, 2010). Some of these services and care delivered are often provided as part of a package of palliative care. Palliative care can be defined as care that aims to "prevent and relieve suffering and to support the best quality of life for patients and their families" (Birnkrant, Noritz, 2008, p. 265). While there has been debate about the role of palliative care in the care package of young men with DMD (e.g. Bach, 2007), national clinical guidelines emphasise the value of palliative care across the lifespan of a person with DMD (Birnkrant, Bushby, et

al, 2018). Palliative care services can offer support at the time of diagnosis, during significant decisions related to treatment, and provide respite care and support at end of life.

Palliative care is delivered across community, specialist and hospice settings. Children and young adult hospices, and adult hospices each provide palliative care to patients and their families. A UK wide survey in 2011 found young men with DMD form a significant part of the case load in children and young adult hospices (Fraser, Aldridge, et al, 2011, p.329). However, in contrast, other studies suggest a low uptake of palliative care services by young men with DMD (Abbott, Prescott, et al, 2017). The variability in evidence may be attributed to the criteria to access hospice provided palliative care. A report into hospice provision found the majority of children and young adult hospices state an upper-age limit in the early 20's, with only a selection offering services up to the age of 35 (Fraser, Aldridge, et al, 2011). As the life expectancy for young men with DMD continues to increase, these young men may have fewer age-appropriate palliative options available to them.

A review into whether clinical practice is compliant with guidelines for the care of young men with DMD identified several shortcomings (Landfeldt, Lindgren, et al, 2015). For example, patients often experience difficulties in obtaining essential medical devices and aids such as wheelchairs, appointments to see a neuromuscular specialist can be inconsistent, and access to services such as physiotherapy is poor in comparison to other European countries. Psychosocial care for young men with DMD was also found to be particularly poor. Of a sample of 770 patients, less than 15% (n=110) reported engagement with a psychologist or therapist in the last six months (Landfeldt, Lindgren, et al, 2015).

Social media as a tool to benefit the wellbeing of young men with DMD is under-acknowledged in the clinical guidelines (Birnkranz, Bushby, et al, 2018). Furthermore, platforms and types of social media such as video gaming are regarded as a potential cause, rather than alleviator of social isolation (Birnkranz, Bushby, et al, 2018, p.453). It is unclear what evidence the guidelines draw on to come to such conclusions, with no studies on social media use by young men with DMD referenced. Studying and reporting the lived experience of social media from the perspective of young men with DMD

is therefore necessary to inform future clinical guidelines on psychosocial support for the population.

1.1.3 Living with DMD: A summary overview of the literature

Young men with DMD represent a new cohort of adult patients, who are now expected to live into their 30's or 40's, a prospect that would not have been considered at birth until relatively recently (Pangalila, Geertrudis, et al, 2015). A growing corpus of literature has explored the impact of DMD for young men, which is summarised below.

1.1.3.1 The wellbeing of young men with DMD

To understand the wellbeing of young men with DMD, studies have used both quantitative and qualitative methods. Quantitative studies (e.g. Vuillerot, Hodgkinson, et al, 2010; Landfeldt, Lindgren, et al, 2015; Lue, Chen, et al, 2017) have used measures associated with health-related quality of life (HRQOL), defined as a person's perception of the significance of their health or illness on their physical, mental, and social wellbeing (Landfeldt, Lindgren, et al, 2015, p.508). Despite the daily physical challenges they face, young men with DMD reported in studies that have measured HRQOL suggest their quality of life to be good (Pangalila, Geertrudis, et al, 2015; Graham, Rose, 2017. Vuillerot, Hodgkinson, et al, 2010; Lanfeldt, Lindgren, et al, 2015). Studies have posited that young men with DMD may perceive their overall quality of life as good, because they have learnt to reassess and reevaluate their lived world and circumstance, referenced as a 'response shift' (Pangalia, Geertrudis, et al, 2015, p.47). Consequently, satisfaction and meaning may be found in activity that others might view as a hardship, such as the use of a wheelchair to move around (Pangalia, Geertrudis, et al, 2015). It is important to note that there are exceptions, for example Lue, Chen, et al (2017) reported that young men with DMD in Taiwan reported a low quality of life, with difficulties in establishing social relationships and engaging in social activities cited.

Engagement in meaningful activity has been associated with quality of life and life satisfaction in young men with DMD (Graham, Rose, 2017). While participants in studies stated their QOL to be largely satisfactory, few rated the meaningfulness of their life as high (Graham, Rose, 2017. Pangalia, Geertrudis,

et al, 2015). Transition into adulthood can result in fewer opportunities to engage in meaningful activity. In England, all young people with disabilities should be actively involved in the development of an Education, Health, and Care (EHC) plan with support from their local authority (Birnkrant, Bushby, et al, 2018). An EHC plan aims to ensure young men with DMD transitioning into adulthood have access to developmentally appropriate care, and are provided with the support and provision to engage in further education or employment should they wish to do so. For young men with DMD who do not wish to pursue further education or enter employment, 'a programme of meaningful daily activities' should be developed based on the strengths and talents of the individual (Birnkrant, Bushby, et al, 2018,p. 451).

Qualitative research on the lived experience of transition from the perspective of young men with DMD has found that, contrary to guidelines, barriers to engagement in meaningful activity are regularly encountered. For example, few young men with DMD experience paid employment, and while further education such as going to university may be possible, it is not always suited to the ambitions of the young men, who may prefer to experience employment. Outside of further education and employment, participating in leisure or social activities can be largely family-centred, with limited opportunity to develop independent social lives (Abbott, Carpenter, 2010).

Without effective coordination and planning to ensure the needs of young men with DMD as adults are met, daily life post education can largely evolve around time at home, with limited opportunity to engage in meaningful activity (Abbott, Carpenter, 2014). Nevertheless, it remains the case that in some studies young men with DMD have rated their quality of life as good, it may be the case that engagement in home activity such as video gaming or the use of social media platforms offer purpose and meaning to young men with DMD.

1.1.3.2 Physiological impact of living with DMD

The physiological impact of DMD can have a profound influence on daily living. Qualitative studies with young men with DMD found that the feeling of pain held a consistent presence in their everyday lives (Abbott, Carpenter, 2014; Hunt, Carter, et al, 2016; Finkelstein, Marcus, 2018). Daily movements such as sitting, lying down, or moving position were pain triggers, with pain located around the legs, back, or head (Hunt, Carter, et al, 2016, p.634). The use of certain equipment such as bathing chairs were described as pain triggers. Similarly, engagement in activity such as video gaming could exacerbate pain as a result of the requirement to rapidly respond to game demands using a controller (Hunt, Carter, et al, 2016).

The management of pain was described by participants in one study as difficult (Hunt, Carter, et al, 2016). Young men with DMD tried to self-manage their pain through methods of distraction, such as reading or watching television.

However, the parents of a sample of young men with DMD described how they became aware of their son's pain either through emotional outbursts (shouting, swearing, crying), or by their behaviour (withdrawn, distant) (Hunt, Carter, et al, 2016).

Major surgery on the spine, tendons, or respiratory system are common in young men with DMD to prolong their life. However, the frequency of surgery and medical interventions may impact on their ability to engage or participate in everyday life (Abbott, Carpenter, 2014). For example, substantial time outside of education due to illness or periods of recovery can hinder engagement in educational activities and potential academic attainment. Anxiety and worry related to the risk of infection, particularly chest infections can also restrict young men with DMD to participate in outside activity (Gibson, Young, et al, 2007). Furthermore, as young men get older, fatigue can also impact their ability to engage in activities (Abbott, Carpenter, 2014). Consequently, the physical deterioration of young men with DMD can significantly impact their daily lives.

1.1.3.3 Impact of lengthened disease trajectory

The lengthened life trajectory expectations for young men with DMD has raised questions about how they interpret and make sense of their existence. As previously highlighted the life expectancy for young men with DMD is now 30-40 years of age (Abbott, Prescott, et al, 2017). Studies have explored how young men with DMD manage their shortened life existence and how with medical and technical advances, their expectations and ways of living have altered throughout their life-times, summarised below.

Young men with DMD and their families focus on finding meaning in the here and now and 'living for the day' (Abbott, Carpenter, 2014, p.1199), as opposed to what life may hold in the future (Gibson, Young, et al, 2007; Abbott, Carpenter, 2014; Pangalila, Geertrudis, et al, 2015; Finkelstein, Marcus, 2018). Nevertheless, the prospect of death can hold presence in their everyday lives particularly during times of crisis, such as major surgical interventions, or news of the death of a friend with DMD bringing the prospect of death into focus (Abbott and Carpenter 2014). A case study of one man living with DMD in Israel described how death was treated as 'the white elephant in the room' among peers in an independent-living neighbourhood (Finkelstein, Marcus, 2018, p.447).

Broaching the topic of death and dying can be challenging for young men with DMD, both within the clinical and family setting. Concerns about upsetting or troubling family members have been voiced by young men with DMD (Abbott, Carpenter, 2014). An interview based study on end-of-life planning with young men with DMD found that none of the participants were able to remember a conversation with a health professional about end of life, despite revealing that conversation regarding end of life would have been valued. Participants could only recall experiencing conversations regarding resuscitation (Abbott, Prescott, et al, 2017). It appears that young men with DMD have few opportunities to discuss and share plans, thoughts, anxieties, or wishes related to death and dying. It may be the case that social media presents an avenue for young men with DMD to discuss and share issues pertinent to them, including those related to death and dying.

1.1.3.4 Self-Presentation

Self-presentation or 'impression management' relates to a person's attempt to convey an image of the self to others (Goffman, 1959). Studies with young men with DMD or physical disabilities found that portraying an image of self in keeping with how they wish to be viewed can be difficult (Gibson, Young, et al, 2007; Skyrme, 2017; Wästerfors & Hansson 2017). These studies revealed how teasing and bullying often began in school, suppressing the multidimensional selves of the young men. The use of a wheelchair or the presence of breathing equipment were instant markers of difference, confirmed through invasive gestures such as pointing or staring (Wästerfors & Hansson 2017). Therefore, the identities of young men with DMD may be 'labelled' before they had opportunity to influence how their self is perceived. Certain contexts may enable self-presentation in line with how they wished to be perceived, for example, engagement in sports such as wheelchair football can transform the wheelchair from a symbol of impairment, into one of power and strength (Gibson, Young, et al, 2007). Social media offers relative anonymity to users, and therefore may offer young men with DMD agency over their self-presentation.

1.1.3.5 Independence

Young men with DMD are dependent on medicines, machines and people to stay alive (Skyrme, 2017). Gibson et al (2007) refer to the 'techno-body' (p. 507) to convey how the bodies of young men with DMD are intertwined and interconnected to technology and equipment such as ventilators or wheelchairs, both of which they are dependent on to breathe and move. A sense of privacy can be difficult for young men with DMD to experience, with a dependence on others for daily activity such as washing and bodily function (Abbott, Carpenter, 2015). The exposure of the body can become routinised (Finkelstein, Marcus, 2018), particularly because the requirement for assistance in daily tasks may have existed from early childhood (Abbott, Carpenter, 2015).

Despite their total dependence on people and technology, studies have shown how young men with DMD express independence in their daily lives (Skyrme, 2017; Finkelstein, Marcus, 2018). For example, ensuring that decisions related

to their care remain in the authority of the young person can enable young men with DMD to still feel independent. Furthermore, being heard and listened to during encounters with healthcare professionals was identified as central to feelings of independence (Finkelstein, Marcus, 2018). Establishing a sense of independence at a young age can also foster independence as young men with DMD transition to adulthood. Participants in one study described how their parents encouraged engagement in daily activity such as going to the shops without their assistance, providing a viable means to experience independence (Skyrme, 2017).

The option of independent-living should be discussed with young men with DMD as part of their Education, Health, and Care Plan (EHC) (Birnkrant, Bushby, et al, 2018). Local authorities should facilitate independent living if requested by the young person, providing suitable accommodation and carer arrangements (Disability Rights UK, 2020). However, changes to social policy have made the prospect of living independently increasingly difficult. For instance, the introduction of Personal Independent Payments (PIP) in replacement of the Disability Living Allowance (DLA) saved the UK Government a reported 2.2 billion, while removing, or substantially decreasing financial support for young people with disability (Cross, 2013). Consequently, living at home with their parents is a common prospect for young men with DMD (Abbott, Carpenter, 2014). Further research is needed to understand how young men with DMD may establish independence through their use of social media.

1.1.4 Summary

Young men with DMD are now expected to live into their 30s and 40s, albeit with complex needs that require multidisciplinary care. Living with DMD can be a challenge, owing to the physiology of the condition and the social barriers that can prevent a meaningful and fulfilling life. Social media may provide an alternate space for young men with DMD to 'Be'. However, little is understood about how or why young men with DMD may engage with social media.

1.2 Reflections on my role as a volunteer carer at a Children and Young Adult Hospice

Pangalila, Geertrudis, et al (2015) highlight that it is difficult for people who do not live with DMD to understand, grasp, or imagine what life as a young man with DMD is like. Those words resonated with me as I began to develop the study described in this thesis. Despite reading and interpreting the literature on life with DMD discussed in this chapter, I questioned to what extent could I, a young man without impairment who prior to the study had not interacted or encountered someone with DMD, actually grasp what living with the condition was like. I concluded that inevitably I knew relatively little and was troubled by how I could begin to understand the lived experience of social media from the perspective of young men with DMD, without any experience of daily life of people with the condition. Therefore I decided to secure a volunteer role as a carer at a children and young adult hospice, where young men with DMD and their families received respite care.

The role afforded me the opportunity to observe first-hand the challenges of daily living with DMD. Experiences of assisting young men to go to the toilet or to eat, left me to ponder how these experiences were interpreted by the young person, who was often of a similar age to myself. How did such experiences of assistance by the non-disabled male 'other' impact on their view of their masculinity? I often left the hospice questioning if I had assisted the young man in a way that maintained his dignity and preserved his masculinity. On one such instance, after spending the majority of the morning with one young man, he asked, quietly, if I could help him to go the toilet. This involved him urinating into a bottle provided by a care worker who assisted me. I vividly recall him passing the bottle back that now was filled with a vast amount of urine. I pondered afterwards why he had not felt able to go to the toilet sooner. Had my presence as a male restricted him from doing so? Had I not made it clear that I could assist him if he needed me to? These experiences provided insight into the challenges of daily living with DMD, and served to remind me that in future interactions with participants, I was an active and present member in our exchanges.

Engagement in the role also provided me with insight into the prevalence of social media in the lives of young men with DMD. The 'gaming room' in the hospice was frequently used, as were the individual video gaming consoles that lined the common room walls. Social networking sites and apps provided some of the young people with an opportunity to share their existences outside of the hospice with carers. On one particular occasion, I remember fondly how a young man proudly showed me and other members of the care team pictures on his Facebook account of him attending his school prom. The role was also beneficial in developing an understanding of how care staff interpreted the use of social media by young men with DMD. On one occasion, I observed a doctor enquire about the age rating of a video game a young man was playing, questioning whether the video game was appropriate for his age. Whilst undoubtedly well meaning, this questioning ultimately dismissed the importance of the video game to his Being, and suppressed his autonomy over which video game he chose to play. In contrast there were also observations of carers and young people playing together, or discussing content posted on social networking sites.

The challenges of contemporary children and young adult hospice care were clearly visible. While the hospice common room was a space for engagement and thoughtful conversation between young people of similar cognitive ability, on occasions, it could be a tense and awkward environment. For instance, staff shortages meant staff often cared for young people with different cognitive abilities in one shared space. In these circumstances, the importance of modern technologies to the young men with DMD such as mobile phones and gaming consoles would often surface as objects to become immersed in and thus remove the self from the environment they were present in.

To summarise, the role provided invaluable insight into the experience of respite care from the perspective of young men with DMD. Repeated 'hands on' interaction with residents forced me to confront and challenge my prior preconceptions and presumptions, which in turn led to a newfound openness and comfortability towards the hospice environment and people I was to be in regular contact with.

1.3 Definitions of Social Media

Any definition of social media encompasses two concepts, namely 'Web 2.0' and 'User Generated Content' (UGC). Web 2.0. is reflective of the changing landscape of the web in the manner that is designed and used (Anderson, Hepworth et al, 2007). Furthermore, the term denotes the transition from user interaction with the web purely on a 'read-only' basis (Web 1.0.), to the participatory engagement of users in the design and modification of content, and the emphasis on interaction with other users (Kaplan and Haenlein, 2010). User Generated Content (UGC) is used to describe web content that is created by users (Daugherty, Eastin, et al, 2008). Drawing on the two concepts, social media can be defined as a group of internet-based applications that facilitate collaboration, connection, and interaction of users (Web 2.0.) through the creation, modification, sharing and engagement with user-generated content (UGC) (Sloan, Quan-Haase, 2017). While the term is synonymous with social networking sites such as Facebook, Instagram, and Twitter, it is inclusive of a wider spectrum of applications, platforms, and activities as outlined below.

1.3.1 Discussion boards/forums

Discussion boards/forums are terms used to describe online bulletin boards where a user can post a message and expect to receive a response/s to the message they have posted. Alternatively users can browse and read posts and subsequent discussion that have already been posted (McCay-Peet, Quan-Haase, 2016). Discussion boards/forums are often established for the purpose of discussing a particular topic of interest. Popular sites that host discussion boards and forums include 'Reddit' and 'Quora'.

1.3.2 Online blogging

Online blogging refers to a website developed by a user, and often contains their personal reflections and comments (Merriam-Webster, 2020). They facilitate author-reader interactivity, and allow users to archive their entries, and publish posts in 'real time' (Heilferty, 2009). Popular blogging sites include 'WordPress' and 'Tumblr'.

1.3.3 Social networking sites

Social networking sites are defined as “web based services that allow individuals to: 1. Construct a public or semi-public profile within a bounded system; 2. Articulate a list of other users with whom they share a connection; 3. View and traverse their list of connections and those made by others within the system” (Boyd, Ellison, 2007. Pg. 211). Created in 2004, ‘Facebook’, is the most widely used site with an average of 2.38 billion monthly users (Statista, 2020). This popular social networking site allows the user to post their ‘Facebook status’, share photos or videos, and join open and closed groups. Similarly, ‘Instagram’ allows users to share photos with tools to edit and apply filters to content before posting. Photos posted on the site can also be shared, and posted onto social networking profiles held by the user, such as their Facebook profile. A widely used social networking site is ‘Twitter’. Launched in 2006, the site has an average of 100 million daily users, with the primary purpose of sharing information and opinions rapidly and succinctly. Users post micro blog or ‘tweet’ formed of no more than 280 characters, to their Twitter profile page.

Crucially, the platforms highlighted create a ‘feed’ of content for users, constructed of content posted by other users whom they follow. This function facilitates social activity by allowing users to like, share, comment on, and in the case of Twitter retweet content posted by other users. Further features such as using a unique ‘hashtag’ within ‘tweets’, that allows content to be grouped together, increases the ability to search for topics and visibility of the users profile. Social networking sites are available across a range of internet devices and are typically used with smartphone or tablets.

1.3.4 Video sharing platforms

‘YouTube’ is the most visited and used video sharing platform, the site and apps slogan ‘broadcast yourself’ is summative of the site’s purpose to post and view video content (YouTube, 2020). The intertwined nature of social media has become more prominent since the ability to share content across platforms. ‘YouTube’ is a good example, with content posted on YouTube able to be

shared across popular social networking platforms such as Facebook, Instagram, and Twitter.

1.3.5 Online messaging applications

The main function of online messaging applications are to provide instant messaging, and the sharing of photos or videos (Webwise, 2020). Popular applications such as WhatsApp or Facebook Messenger are free to download and therefore amass a huge number of users, with over 1.5 billion monthly active users (Statista, 2020).

1.3.6 Video Gaming

Since their inception, video games have been loosely defined, due to their ever-evolving nature (Etchells, 2019). For example, the release of the SEGA Mega Drive in 1989 provided an experience different to the recently released Xbox One X, due to technological advances. Nevertheless, the dictionary definition of video gaming is 'An electronic game in which players control images on a video screen' (Merriam-Webster, 2019). While vague, the definition highlights the use of electronics, signifying a difference to other types of 'games' such as board or card games. Associated with this broad definition, are a typology of video game genres. For example, 'sandbox' video games are those that provide an open world for the player to explore, interact with others, and explore in an unrestricted manner (Etchells, 2019). At the other end of the spectrum, and with many other categories in between, are visual novels which feature a narrative that guides the player through the video game in a linear fashion (iD tech. com, 2018). A range of devices can be used to engage in video gaming, including a smart phone, personal computer, and gaming console.

1.4 Social media use by young men with DMD

The following extract is from an online blog of a Swedish young man with DMD who died in 2014:

"My handicap doesn't matter, my chains are broken and I can be whoever I want to be. In there I feel normal. (Mats Steen, 1989-2014)

The extract, cited in Shaubert (2019), is a description of the meaning of video gaming to the blogger and acknowledged the role and centrality of social media in the daily lives of many young men with DMD, which I also observed in my care working role. However, glimpses into the meaning of the phenomena of social media have largely been restricted to the hidden blog posts of these young men.

Charities and organisations developed to support the wellbeing of young men with DMD such as 'DMD Pathfinders' (2020) and 'Action Duchenne' (2020) have a presence across social media platforms. For example, 'DMD Pathfinders' a user-led charity which promotes choice and control for young people with DMD have a closed Facebook group that exists for the benefit of adults living with Duchenne, and advertises the group as a 'parent and professional free zone'. The group to date has almost 350 members (DMD Pathfinders, 2020). However, it is not understood why young men with DMD access these online spaces.

To understand the empirical evidence base in relation to social media use by young men with DMD, a preliminary scoping of key health and psychology databases including MEDLINE and PsychInfo was undertaken. No articles that directly addressed social media use by young men with DMD were returned. As outlined in section 1.1.1 of this chapter, DMD is one of 300 life-limiting conditions related to children and young people. In the absence of identified research on social media use by young men with DMD, it was appropriate to broaden the search criteria to all life-limiting and life-threatening conditions, that may also include a range of disabilities. In broadening the search strategy, the aim was to understand how and why social media is used by young people with

life-limiting and life-threatening conditions, to provide an evidence base to contextualise the study and draw on when discussing the findings. Chapter 2 outlines the published literature review methods and findings.

1.5 Outline of the Thesis

This thesis explores the lived experience of social media from the perspective of young men with Duchenne Muscular Dystrophy (DMD). Chapter 2 presents an integrative review that aimed to understand how and why adolescents and young adults with life-limiting/threatening conditions, or disabilities use social media. The findings of the review highlighted gaps in the current evidence base, and provided comparative insight into convergence/divergence between social media use by young men with DMD, and young people with life-limiting/threatening conditions more broadly, discussed in Chapter 6.

Chapter 3 outlines the philosophical underpinnings of the study, and provides a rationale for adopting an Interpretative Phenomenological Analysis (IPA) approach to the study. The methods of recruitment, data collection, and data analysis and rationale for choices are outlined in Chapter 4. Findings from eight participant narratives and the three superordinate themes: 1. existence outside of social media; navigating the offline lifeworld; 2. Transcending into an alternate reality; life within video gaming; 3. The meaning of social networking platforms, blogs, and spaces, are presented in Chapter 5. A discussion of the key findings in relation to existing literature and theory is presented in Chapter 6. Chapter 7 concludes with the key messages that have arisen from this research for us to better understand the lived experience of social media in the lifeworlds of young men with DMD and implications for practice, policy and future research.

1.6 Summary

This chapter has outlined the background context to the study through a description of DMD, and an overview of the literature on living with DMD. The phenomena of interest to the study, namely social media, has been outlined, with reference made throughout to the possible ways that it is experienced by

young men with DMD. Currently, little empirical evidence exists on the use of social media with this group. To understand how social media is used by young people with life-limiting, threatening conditions more broadly, a review of the literature was undertaken and presented in Chapter 2. Concepts relevant to online behaviour are outlined in the discussion of Chapter 2.

Chapter 2 Literature Review

2.1 Chapter Overview

An initial scope of the literature suggested few published studies on social media use by young men with DMD. As outlined in Chapter 1, DMD is one of over 300 conditions that are classified as life-limiting or threatening (Together for Short Lives, 2020). It was therefore appropriate to summarise the current body of empirical evidence on how and why adolescents and young adults (AYAs) with life-limiting/life threatening conditions or disabilities interact with social media. The term AYAs typically relates to people 15-39 years of age (Live Strong Young Adult Alliance, 2006). A broad age category was chosen to reflect the disease trajectory of conditions similar to DMD. This chapter will first outline the aim of the review, before presenting the context, design, search methods, search outcomes, results and discussion of the integrative review. Gaps in the literature and limitations of the review are considered. Reference to the wider literature will be made in relation to the themes identified and discussed, including other relevant reviews, studies, and theoretical concepts, to support the critical evaluation of studies and to provide rationale for the current study.

2.2 Aim of the Review

The aim of the integrative review was to identify and evaluate the empirical evidence base on social media use by adolescents and young adults (AYAs) with life-limiting, or life-threatening conditions, or disabilities. The following questions guided the review:

- Why are AYAs with life-limiting, or life-threatening conditions, or disabilities motivated to engage with social media?
- What types of social media are used by AYAs with life-limiting, or life-threatening conditions, or disabilities and how are they interacted with?

2.3 Review design

Adopting the most appropriate review design should be guided by the aims and purpose of the review. Many types of review have been identified including scoping, integrative, narrative, systematic, meta-analysis and rapid structured reviews (Grant, Booth, 2009). A shared feature across review typologies is the synthesising of findings from primarily empirical studies to inform future research direction (Jackson, 1980). However, each review type has a unique purpose and method (Whittemore, Knafl, 2005). For instance, a meta-analysis uses statistical methods to combine the evidence of quantitative studies using rigorous methods, differing from a rapid structure review typically characterised by a detailed search but streamlined review process with the focus being to generate a knowledge synthesis in a timely manner (Grant, Booth, 2009).

Referring to the aims of the review, review types that advocate the inclusion of both experimental and non-experimental research were sought. A scoping review is a common review approach within healthcare research for identifying and summarising existing evidence to identify gaps, and thus contribute to the development of future research questions (Davis, Drey, et al, 2009). An integrative review is closely associated to a scoping approach, consisting of a five-stage process to identify, analyse, and summarise a broad corpus of evidence, including a range of research methodologies and study designs (Whittemore, Knafl, 2005). While both approaches have a shared purpose, to synthesise and evaluate existing knowledge to identify gaps and highlight strengths and weaknesses, typically integrative reviews analyse study findings in greater depth to scoping reviews (Noble, Smith, 2018). In addition, the two approaches differ in their approach to the quality assessment of studies; integrative reviews typically systematically undertake an appraisal of studies using a tool appropriate to the sampling frame such as the Mixed-Method Appraisal Tool (MMAT) while scoping reviews typically do not appraise the quality of included studies (Noble, Smith, 2018).

To address the aims of the review using systematic methods, while incorporating a broad range of evidence to comprehensively answer the specific

review aims, an integrative review using the process approach outlined by Whitemore and Knafl (2005) was adopted.

2.4 Methods

This section will describe the methods used to undertake the literature review using the five-stage framework integrative review framework outlined by Whitemore and Knafl (2005). The design, sampling strategy, and procedures are presented.

Adopting the five-stage framework for an integrative review ensured the process was undertaken systematically to achieve rigour. The initial stage of the review involved problem identification where the variables were identified; the target population and phenomena of interest to clearly define the purpose of the review (Whitemore and Knafl, 2005). Outlining the review purpose was essential to ensuring clarity and direction to the subsequent review stages. The second stage involved undertaking a comprehensive literature search, with the strategies adopted to ensure a comprehensive search outlined in the next section. The third stage involved an evaluation of the data and a quality appraisal of all included studies. The fourth stage of the framework was analysis of the studies identified. Data extracted from the studies was ordered, coded, and themed using an iterative process of grouping the themes identified in individual studies to produce a thorough interpretation of the data, accompanied by a synthesis of the evidence. Finally, the results of the review were presented in the form of two tables to represent the synthesis of data (Table 2.3, 2.4), and a narrative commentary of the results, represented through identified three themes.

2.4.1 Sampling methods

The sampling methods were directed by stage two of Whitemore and Knafl's (2005) framework: performing a literature search. To develop a robust search strategy, inclusion and exclusion criteria and search terms were clearly identified using the 'Population, Exposure, Outcomes' (PEO) framework outlined in Table 2.1.

Table 2.1: The PEO Acronym (Bettany-Saltikov, 2012)

| | Suggested | Review aims |
|-------------------|---|--|
| Population | Who are the affected population? E.g. families, patients, age, gender? | Adolescents and young adults with life limiting/threatening conditions OR disabilities |
| Exposure | Is the population exposed to condition or illness? Or Service? | Social Media |
| Outcome | What are the outcomes or themes? E.g. experiences, attitudes, feelings. | Experiences, motivations |

2.4.1.1 Selection criteria

Selection criteria was purposefully broad to encompass a diversity in study designs and methodological approaches in relation to social media use and to incorporate a broad range of platforms used by AYAs with life-limiting/threatening conditions, or disabilities. The inclusion and exclusion criteria are outlined below:

Inclusion criteria:

1. Studies that included Adolescents and Young Adults (AYAs) aged between 15 and 39 years of age, with life-limiting, life threatening conditions or a disability, who interacted with a form of social media.
2. Studies that explored social media use by AYAs with life-limiting, threatening conditions or disabilities from a professional perspective, e.g. a healthcare professional reflecting on the use of social media by the population.
3. Studies published after 1989 in recognition of the birth of the internet.
4. Studies published in the English language.

Exclusion criteria:

1. Studies exploring social media use from the perspective of people with long-term conditions associated with the elderly such as dementia.
2. Studies exploring social media use from the perspective of parents or siblings of AYAs with life-limiting/threatening conditions or disabilities.

Preliminary searches of the literature identified that some studies did not provide in-depth demographic data such as age, owing to the relative anonymity of social media. Therefore, where studies did not define the age demographic of the sample, a decision was made as to whether the study met the other inclusion criteria, and therefore suitable to be included in the review. Three studies included did not specify age range. An initial search was undertaken in 2017. In recognition of the focus of the empirical study on DMD, the terms 'physical disabilities' and 'intellectual disabilities' were added to the selection criteria in subsequent searches updated in 2018, 2019, and 2020.

2.4.1.2 Sampling strategy

To identify studies that met the inclusion criteria, a range of health and social care databases was searched as detailed in the PRISMA diagram (figure 2.1) Databases included MedLine, PsychInfo, and Cochrane. The latter was searched to determine whether systematic reviews on a similar topic had been published. Additional searches were also performed using Google Scholar. To interrogate the databases, a search strategy was developed with the support of an Information Specialist from the University of Leeds. Past search strategies relevant to the search topics were drawn upon to gather appropriate search syntax. For instance, previous search strategies on social media were used to identify syntax related to the term.

The final search syntax composed of three key words and their synonyms:

1. Adolescents and young adults, with synonyms reflective of the age bracket such as 'teenagers', 'young adolescent', or 'young adult'.
2. Life-limiting and life-threatening conditions or disability, with synonyms encompassing the diversity of conditions such as, 'neuromuscular conditions', 'cancer', 'organ failure', 'physical disability', 'intellectual disability', with

synonyms reflective of care pathways also used such as 'end-of-life care' and 'palliative care', 'advanced care planning'.

3. Social media with synonyms encompassing the diverse platforms associated with the term such as 'social networking sites', 'Facebook', 'video gaming', 'online gaming'. All syntax factored the difference in UK and US spelling.

Every effort was made to ensure all relevant studies were identified through the use of database-specific search syntax. When performing a search solely using databases, relevant studies may be missed due to differences in the indexing of key words (Aveyard, 2007). Consequently, it was necessary to supplement database searches with further search methods to ensure a comprehensive search. Additional methods included the searching of identified study reference lists, and the identification of articles through existing academic groups and networks (Arksey and O'Malley, 2005). In addition, searches of the grey literature were also undertaken, to identify unpublished material. The outcomes of the search of grey literature yielded clinical guidelines for best practice (e.g. Bushby, Finkel, et al, 2010; Birnkrant, Bushby, et al, 2018) that are reported in Chapter One, rather than empirical research.

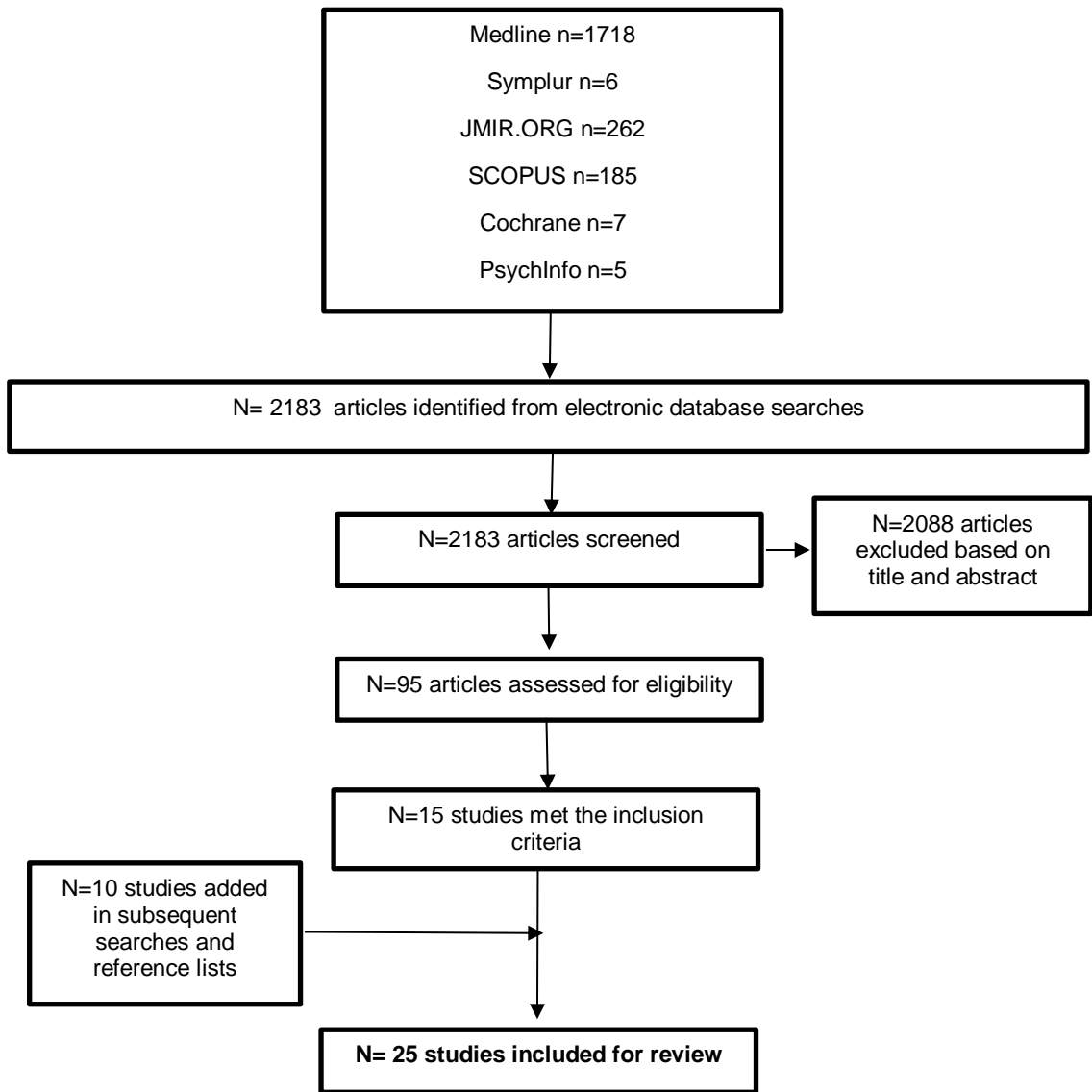
2.4.1.3 Data Extraction

To manage the search outputs, EndNote and Covidence software packages were used. EndNote facilitated the storage and management of references, while Covidence was used for title and abstract screening. A data extraction form was also developed in advance to ensure consistency in the extraction of data.

2.4.1.4 Selection of papers

An initial search of the databases in 2017 identified 2183 titles for initial screening. Full title and abstract screening using Covidence software resulted in 95 articles eligible for full text review. Of those articles, 15 met the inclusion criteria. Further searches following the same processes in 2018, 2019, and 2020 identified an additional 10 studies. This resulted in a total of 25 studies include in the review, which are detailed in the two summary tables (Table 2.3. and 2.4). The process of study selection is detailed in the 'Preferred Reporting Items for Systematic Reviews' (PRISMA) flow diagram below.

Figure 2.1: PRISMA flow diagram of the process of study selection



2.4.2 Quality appraisal

All studies reviewed were published in peer-reviewed journals, and therefore met the minimum standard for quality. The studies identified adopted a diverse range of research methodologies and methods, therefore the Mixed Methods Appraisal Tool was considered the most appropriate to guide the quality appraisal of studies. The tool offers criteria to assess the quality of quantitative, qualitative, and mixed-method studies against (Pluye, Robert, et al, 2017). An overview of the results of the appraisal is outlined in Table 2.2. Limitations of reviewed studies in terms of design are discussed in the discussion (section 2.6.2) of this chapter.

2.4.3 Synthesis of data

Descriptive data from the reviewed studies such as date published, methods, sample, and key findings was first synthesised using the summary tables (Table 2.3 and 2.4). Mapping the data from studies enabled descriptive patterns across the data to be identified. An in-depth iterative cross-comparison of the data was performed, which involved the individual coding of articles, with codes then compared across studies. Codes were then grouped into themes. An iterative process of moving between the themes identified, and the codes from individual articles ensured data from studies were appropriately represented by the emerging themes. A sample of studies, and the coding and thematic framework were shared and discussed with the supervisory team, to improve the rigour and transparency of the process.

Table 2.2: Mixed Method Appraisal Tool

| Methodological Quality Criteria: Qualitative Design | | | | | |
|---|--|--|---|--|---------------|
| Reference | Are the sources of qualitative data relevant to address the research question? | Is the process for analysing data relevant to address the research question? | Is consideration given to how findings relate to the study context? | Is appropriate consideration given to how findings relate to researcher's influence? | Overall Score |
| Bers, Gonzalez-Heydrich , Raches, <i>et al.</i> (2001 | 1 | 1 | 1 | 1 | 100% |
| Crook and Love (2016) | 1 | 1 | 1 | 0 | 75% |
| Griffiths, Panteli, Brunton, <i>et al</i> (2015) | 1 | 1 | 1 | 0 | 75% |
| Keim-Malpass and Steeves (2012) | 1 | 1 | 1 | 1 | 100% |
| Keim-Malpass, Albrecht, Steeves, <i>et al.</i> (2013) | 1 | 1 | 1 | 1 | 100% |
| Keim-Malpass, Adelstein, Kavalieratos. (2015) | 1 | 1 | 1 | 0 | 75% |
| Love, Thompson, Knapp (2014) | 1 | 1 | 1 | 1 | 75% |
| Wästerfors & Hansson, (2017) | 1 | 1 | 1 | 1 | 100% |
| Furr, Carreiro, McArthur (2016) | 1 | 1 | 1 | 0 | 75% |

| Reference | Are the sources of qualitative data relevant to address the research question? | Is the process for analysing data relevant to address the research question? | Is consideration given to how findings relate to the study context? | Is appropriate consideration given to how findings relate to researcher's influence? | Overall Score |
|--|--|--|---|--|---------------|
| Lowney and O'Brien (2012) | 1 | 1 | 1 | 0 | 75% |
| Nesby and Salamonsen (2016) | 1 | 1 | 1 | 0 | 75% |
| Pounders, Stowers,. (2017) | 1 | 1 | 1 | 0 | 75% |
| Winterling, Wiklander, Obol, et al. (2016) | 1 | 1 | 1 | 0 | 75% |
| Rasid, Nonis. (2015) | 1 | 1 | 1 | 0 | 75% |
| Stewart, Hansen, Carey. (2010) | 1 | 1 | 1 | 0 | 75% |
| Porter and Keintz (2013) | 1 | 1 | 1 | 1 | 100% |
| Griffiths, Cave, et al, (2012) | 1 | 1 | 1 | 1 | 100% |
| Chadwick, Fullwood. (2018) | 1 | 1 | 1 | 1 | 100% |

| Methodological Quality Criteria: Quantitative Design | | | | | |
|---|------------------------------------|--|-------------------------------|--|---------------|
| Reference | Is the sampling strategy relevant? | Is the sample representative of the population under study | Are measurements appropriate? | Is there an acceptable response rate (60% or above)? | Overall score |
| Crook, Glowacki, Love, <i>et al.</i> (2015) | 1 | 1 | 1 | 0 | 75% |
| Myrick, Holton, Himmelboim, <i>et al.</i> (2016) | 1 | 1 | 1 | 1 | 100% |
| Thompson, Crook, Love, <i>et al.</i> (2016) | 1 | 1 | 1 | 0 | 75% |
| Beeston, Power, <i>et al.</i> , (2018) | 1 | 1 | 1 | 0 | 75% |
| Shpigelman, Gill (2014) | 1 | 1 | 1 | 1 | 100% |

| Methodological quality criteria: Mixed method design | | | | |
|---|---|---|--|---------------|
| Reference | Is the research design relevant to address the qualitative and quantitative research questions? | Is the integration of qualitative and quantitative data (or results) relevant to address the research question (objective)? | Is consideration given to the limitations associated with this integration, e.g. divergence of qualitative and quantitative data (or results)? | Overall score |
| Donovan, LeFebvre, Tardiff, <i>et al.</i> (2014) | 1 | 1 | 1 | 100% |
| Lee, Cho, (2019) | 1 | 1 | 1 | 100% |

2.5 Results

This section first reports the descriptive findings of the review, before providing a critical discussion of the three themes: 1. Motivations for engagement with social media; 2. Disclosure of disability online; 3. Barriers to engage with social media identified from the process of data synthesis.

2.5.1 Description of the studies

Of the 25 studies identified, 16 were published in the USA, the remaining studies were published in the UK (n=3), Sweden (n=2), Ireland (n=1), Norway (n=1), Singapore (n=1), and South Korea (n=1) (Table 2.3). Articles were published between the years 2001 and 2019, with the majority published either in 2015 or 2016 (Table 2.3). A range of methodological designs was evident across studies, however a qualitative design was most common (n=18), with methods including a thematic analysis of online content from blogs or discussion boards/forums (n=8), face to face interviews (n=8), participatory design (n=1), or intervention design (n=1). Two studies were mixed method and commonly featured the use of interviews and survey design. Five studies adopted a quantitative approach to the analysis of content featured on discussion boards and forums that were part of online communities (Table 2.4).

All studies included AYAs with a life-limiting/life threatening condition or disability. The most common condition was cancer (n=14), or physical disability/condition such as cerebral palsy (n=8). A range of social media platforms was studied, including discussion boards/forums (n=5), blogs (n=5), video gaming (n=3), twitter (n=1), and website design (n=3). Other studies referred to social media without defining individual platforms (Table 2.4).

Table 2.3: Characteristics of studies

| Author(s) | Title | Country | Participants |
|---|--|---------|--|
| Bers, Gonzalez-Heydrich, Raches, <i>et al.</i> (2001) | Zora: A pilot virtual community in the pediatric dialysis unit | USA | 4 females, 4 males with end stage renal disease: mean age 15.4 years |
| Crook, Glowacki, Love, <i>et al.</i> (2015) | Hanging by a thread: exploring the features of nonresponse in an online young adult cancer survivorship support community | USA | AYAs with cancer age range undefined. |
| Crook, Love. (2016) | Examining the light and dark of an online young adult cancer support community | USA | AYAs with cancer age range undefined |
| Donovan, LeFebvre, Tardiff , <i>et al.</i> (2014) | Patterns of Social Support Communicated in Response to Expressions of Uncertainty in an Online Community of Young Adults with Cancer | USA | AYAs with cancer age range undefined |
| Griffiths, Panteli, Brunton, <i>et al.</i> (2015) | Designing and evaluating the acceptability of Realshare: An online support community for teenagers and young adults with cancer | UK | 7 females, 5 males previously had cancer aged between 16-30 yrs. |
| Keim-Malpass, Adelstein, Kavalieratos. (2015) | Legacy Making Through Illness Blogs: Online Spaces for Young Adults Approaching the End-of-Life | USA | 5 women with advanced cancer aged 25-39 yrs |
| Keim-Malpass, Albrecht, Steeves, <i>et al.</i> (2013) | Young women's experiences with complementary therapies during cancer described through illness blogs | USA | 16 women living with cancer. Aged 20-39yrs |
| Keim-Malpass, Steeves (2012) | Talking with death at a diner: young women's online narratives of cancer | USA | 16 women living with cancer. Aged 20-39yrs |
| Love, Thompson, Knapp (2014) | The need to be Superman: The psychosocial support challenges of young men affected by cancer | USA | Young men affected by cancer. Mean age 31 |
| Lowney, O'Brien. (2012) | The landscape of blogging in palliative care | Ireland | One 30yr old male with cancer receiving palliative care |
| Myrick, Holton, Himelboim, <i>et al.</i> (2016) | #Stupidcancer. Exploring a typology of social support and the role of emotional expression in a social media community | USA | Young adults impacted by cancer, age range undefined |
| Nesby, Salamonsen, (2016) | Youth blogging and serious illness | Norway | Two young women who died of cancer aged 15, and 17 |

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|--|---|-------------|--|
| Pounders, Stowers. (2017) | Exploring gender and identity issues among female adolescent and young adults who connect in an anonymous platform | USA | Young adults with cancer, age range undefined |
| Thompson, Crook, Love, et al. (2016) | Understanding how adolescents and young adults with cancer talk about needs in an online and face to face support groups | USA | Young adults with cancer, age range undefined |
| Winterling, Wiklander, Obol, et al. (2016) | Development of a self-help web-based intervention targeting young cancer patients with sexual problems and fertility distress in collaboration with patient research partners | Sweden | 11 young adults who had undergone treatment for cancer |
| Rasid, Nonis. (2015) | Exploring communication technology behavior of adolescents with cerebral palsy in Singapore | Singapore | 9 Singaporean young people aged 14-18 living with cerebral palsy |
| Wästerfors & Hansson, (2017) | Taking ownership of gaming and disability | Sweden | 15 young people aged 16-27 living with disabilities. 14 male. 1 female. |
| Beeston, Power, et al, (2018) | Characteristics and motivations of players with disabilities in digital games | UK | 230 respondents with a range of disabilities |
| Lee, Cho. (2019) | Social media use and wellbeing in people with physical disabilities. Influence of social networking sites and online community on social support, depression, and psychological disposition | South Korea | 128 participants with a range of physical disabilities |
| Furr, Carreiro, McArthur (2016) | Strategic approaches to disability disclosure on social media | USA | 16 participants. 12 females. 4 males. Aged 20 -52 yrs with physical disabilities |
| Stewart, Hansen, Carey. (2010) | Opportunities for people with disabilities in the virtual world of Second Life | USA | People who engage with 'Second Life' who live with a physical disability |
| Porter and Keintz (2013) | An empirical study of issues and barriers to mainstream video game accessibility | USA | 55 video gamers with disabilities. 69% with a motor disability. |
| Shpigelman, Gill (2014) | Facebook use by person with disabilities | USA | People with disabilities who completed an online survey about using Facebook |
| Griffiths, Cave, et al, (2012) | Social networks: The future of healthcare delivery | USA | Patients and health professionals |
| Chadwick, Fullwood. (2018) | An online life like any other: identity, self-determination, and social networking among adults with intellectual disabilities | UK | 11 AYAs with intellectual disabilities |

Table 2.4: Summary of studies

| Author/s | Aims | Methods | Key Findings |
|--|---|---|--|
| Bers , Gonzalez-Heydrich , Raches , <i>et al.</i> (2001) | To trial interactive software (Zora) in a paediatric dialysis unit to explore if it aids self-understanding of illness | Ethnographic approach to understand how Zora was used. | Zora was used to escape as oppose to confront illness. Young people consciously avoided any mentioning of their condition on Zora. |
| Crook, Glowacki, Love, <i>et al.</i> (2015) | To examine how the use of discourse, pronouns, tense, and verbs impacts the extent to which an online post receives a response. | Quantitative analysis using linguistic inquiry word count software | Posts without replies included more words per sentence. Posts with replies included more words that express negative emotion, anxiety, and anger |
| Crook, Love (2016) | To explore the challenges that young people face when participating in an online cancer support forum. | Qualitative analysis of content posted on an online support forum | AYA expect to disclose cancer to others in discussion forums. However, disclosure comes with positive and negatives. E.g. undesired response vs facilitating of friendship |
| Donovan, LeFebvre, Tardiff, <i>et al.</i> (2014) | To understand the social support young adults with cancer receive on an online discussion group. | Mixed methods analysis of 510 responses to posts in an online discussion group. | In response to uncertainty posts users received informational (82%), emotional (55%), esteem (50%), and network support (24%). |
| Griffiths, Panteli, Brunton <i>et al</i> (2015) | To design the Realshare website based on young people's input and preferences. To determine the acceptability of Realshare among young adults with cancer. | Participatory design Qualitative interviews | Participatory design led to a website tailored to the needs of the population and therefore increased the likelihood of its use. Informational support shared. Emotional support needed facilitator engagement |
| Keim-Malpass, Adelstein , Kavalieratos . (2015) | To explore the blogs of five women with advanced cancer who all passed away to explore key elements of legacy making and grief processing. | Qualitative narrative analysis of online illness blogs. | Blogs facilitate legacy making by offering young women with cancer a unique opportunity to be remembered through the public sharing of words, pictures, and life experiences |
| Keim-Malpass, Albrecht , Steeves , <i>et al.</i> (2013) | To explore the narratives shared by young women online with cancer. | Qualitative analysis of 16 online illness blogs | Sensitive issues such as fertility, and financial difficulties were the main themes that arose from the data suggesting women found blogging |

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| | | | to be a safe space where they could divulge and discuss sensitive topics. |
| Keim-Malpass, Steeves (2012) | To explore the experiences of young women with cancer through an analysis of their illness blogs. | Qualitative analysis of online illness blogs | Blogs provided an online space for women to express themselves. All participants used their blogs extensively, and as such were able to reveal their whole narrative. |
| Love, Thompson, Knapp (2014) | To investigate how gender specific issues shape the experiences of young adult men with cancer and what they report to be problematic | Qualitative analysis of content of online forums Focus groups with 6 men Individual interviews with 4 men | Young men have a desire to be emotionally expressive online Appropriate emotional support is severely hindered by cultural expectations of masculinity. The pressure to be strong is an overarching barrier that prevents young men receiving or offering emotional support. |
| Lowney, O'Brien. (2012) | A case study of a 30 year old male receiving palliative care who maintained an illness blog | Qualitative case study | Blogging facilitates legacy making and allows for experiences and narratives to be shared and preserved online. |
| Myrick, Holton, Himmelboim, et al. (2016) | To investigate which forms of social support will be the most common on a twitter-based cancer community. | A quantitative analysis of tweets containing #stupid cancer over a period of two years. | 64.7% of tweets contained informational support whilst only 12% contained emotionally expressive content. |
| Nesby, Salamonsen,. (2016) | To explore the blogs of two young women who died of cancer | Qualitative analysis of the posts from two illness blogs | Blogging allowed the women to maintain a presence online. Both women felt empowered through blogging. |
| Pounders,. Stowers, (2017) | To better understand gender and identity issues among young females with cancer | Qualitative analysis of posts on a discussion board. | Women posted content relating to gender and identity such as issues relating to motherhood, physical attractiveness, and romantic relationships |
| Thompson, Crook, Love, et al. (2016) | To explore why adolescents and young adults might choose to seek support in either a face to face or online scenario. | Transcripts from an online discussion board and face-to-face support group analysed using linguistic | Discussions relating to sex were more prominent on the online group compared to the face to face group. Ratios of emotive words were higher online |

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|---|--|--|--|
| | | inquiry and word count computer based software. | |
| Winterling, Wiklander,, Obol, et al. (2016) | Developing an interactive website designed to support young cancer patients with sexual problems and fertility distress | Participatory research with young adults. Qualitative analysis of interview data | Participant involvement impacted on the quality of website content and relevance to potential users. Motivation to participate was to share experiences and support others in a similar situation |
| Rasid, Nonis. (2015) | To explore how Singaporean adolescents (aged 14-18) with cerebral palsy use communicative technology. | Questionnaire-based face to face interviews | Social media used to communicate, and view information about the activities of peers, both with and without disabilities, seek informational support, and overcome social and environmental barriers. |
| Wästerfors & Hansson, (2017) | Explore how disabled video gamers experience digital inaccessibility, and the way such in accessibilities infiltrate their experience of video gaming. | Interviews and field notes. | Having a disability complicates, distracts, and disturbs video game engagement, while also providing extra meaning to the activity. Gamers with disabilities face several obstacles to immersion in character and game play, but respond with inventive tactics, and workarounds to maintain engagement with video gaming. |
| Beeston, Power, et al, (2018) | To collect the demographics of disabled players who engage with the 'Able Gamers' charity. | Demographic survey | Disabled gamers engage with the activity for various reasons including for escapism, for the challenge, and to aid mental health and wellbeing. |
| Lee, Cho. (2019) | How does the use of social networking sites influence social support among people with disabilities? | Mixed methods. Quantitative survey design. Focus Groups | Interaction with online communities is associated with dimensions of social support. Instrumental and informational support was more frequently mentioned, nonetheless emotional support was facilitated through offline-groups, first established through meeting others in online communities. |
| Furr, Carreiro, McArthur (2016) | Explored how and why people with disabilities choose to disclose their disabilities on social media platforms | Qualitative. 16 semi-structured interviews. Grounded theory. | 3 approaches to disability disclosure: open, secured, and limited. |

| | | | |
|--------------------------------|---|--|---|
| Stewart, Hansen, Carey. (2010) | To explore how people with disabilities interact with the virtual world 'Second Life'. | Qualitative semi-structured interviews | Massive Multiplayer Online Worlds (MMOWs) provide players with disabilities the opportunity to engage in activity they would be unable to do offline. |
| Porter and Keintz (2013) | How do disable gamers respond to barriers to accessibility. How do video game developers perceive accessibility guidelines | Online survey completed by 55 video gamers with disabilities. Semi-structured interviews with 6 people who work in the video game development industry. | Consoles present more accessibility issues for players than computers. Multiplayer video games are pushing away video gamers with disabilities. Video gamers work hard to develop strategies to continue to video game. |
| Shpigelman, Gill (2014) | To understand how people living with disabilities use Facebook. | Online survey completed by 172 people living with disabilities | 48% members of disability groups Primarily use Facebook for interaction with non-disabled friends. Connecting with friends via Facebook reduced feelings of isolation. |
| Griffiths, Cave, et al, (2012) | To understand whether social networks composed of patients and their social circles may complement existing professional networks in assembling health-related information to improve healthcare. | Framework analysis of patient and professional interviews | Social networking provides sourcing of health information free of traditional healthcare restraints. Social networks can be a vital support for people living with rare conditions. |
| Chadwick, Fullwood. (2018) | To explore the experiences of social media from the perspective of adults with intellectual disabilities. | Qualitative interviews with 11 participants. | Social media facilitated development of social capital, relationship maintenance, and identity expression and development. |

2.5.2 Themes

A comparison of studies revealed three themes:

1. Motivations for engagement with social media, had four sub-themes:
 - Making sense of illness and leave a legacy
 - Provide support
 - Socialise and reduce feelings of social isolation
 - To escape illness
2. Disclosure of disability online
3. Barriers to engage with social media, had two sub-themes:
 - User response
 - Accessibility

2.5.3 Theme One: Motivations for engagement with social media.

The review found a diversity in motivations for engagement with social media from the perspective of AYAs with life-limiting/threatening conditions or disabilities. Theme one presents a critical overview of the most salient motivations identified.

2.5.3.1 Making sense of illness and leave a legacy

Social media has cathartic value to AYAs with cancer approaching end-of-life. Engagement with online blogging facilitated a form of life review offering the space to either exclusively focus on their illness experience, or reflect on their wider lived experiences (Keim-Malpass, Adelstein, et al, 2015; Nesby, Salamonsen, 2015; Lowney, O'Brien, 2011). Posting their life review online can develop into a form of legacy making because content posted online holds an eternal presence. AYAs with cancer, particularly those with their own children, drew comfort from knowing the posts on their blogs would exist beyond their death, and be available for their family and friends to read (Lowney, O'Brien, 2011). In addition, posthumous blog posts were found to provide comfort to the family and friends of the deceased, with instances of close-family members continuing to blog from the same account of the original poster, and interact with the blog followers (Keim-Malpass, Adelstein, et al, 2015).

Two young women with cancer used online blogging as a platform to promote their advocacy and charity based activities prior to their deaths (Nesby and Salamonsen, 2015). Both their blogs have attracted national attention resulting in both women receiving awards for their charity work and awareness based activity. In these cases blogging provided a platform to be heard and in some instances leave a legacy, whether for family or friends, or the wider community. Blogging has potential for AYAs with life-limiting/threatening conditions, or disabilities to be a space to make sense of their condition through writing posts related to their condition, and in some instances post the content publicly. The current evidence base suggests engagement with blogging for the purpose of legacy making is associated with end-of-life (Keim-Malpass, Adelstein, et al, 2015; Nesby, Salamonsen, 2015; Lowney, O'Brien, 2011). Further research is required to understand whether legacy making is a motivator for engagement in blogging for AYAs with life-limiting/threatening conditions or disabilities who are not approaching end-of-life.

Beyond blogging, video gaming was also reported by studies as a platform to make sense of illness. For example, Wasterfors and Hansson (2017) based on experiences of AYAs with physical disabilities concluded that video gaming can represent a 'metaphorical site' (p.1151) to make sense and internally process their condition. One participant relayed how the good fighting evil element of the video games played facilitated a processing of their condition as 'my monster, the evil that is inside me' (p.1152), kindling a desire to 'fight' towards an acceptance of their condition. The concept of 'insight' has been identified as a core psychological need as proposed by Self-Determination Theory, which can be met through video gaming in the literature on gaming in the general population (Oliver, Bowman, David, et al, 2015). Insight is defined as "the feelings associated with contemplating, introspecting, and experiencing greater understanding of essential values, fundamental beliefs, and important life lessons" (Oliver, Bowman, et al, 2015, p9). It is posited that video games that feature a strong narrative provide an immersive environment to make sense of existential concerns akin to Being such as identity, death, and freedom (Oliver, Bowman, et al, 2015). However, further research is required to understand

whether 'insight' is a salient motivator for engagement in social media platforms by young men with DMD.

2.5.3.2 Provide support

Across the studies reviewed, a range of platforms of social media were identified as spaces for AYAs with life-limiting/threatening conditions, or disabilities to source and provide support related to their illness. Social networking sites have altered the way social support is offered and received. For example, the ability to engage with a broad audience, and provide/receive varied information from diverse networks has opened up new avenues of social support (Liu, Wright, et al, 2018). Zeilke, Roome, et al, (2009) highlight that the underlying principle of support groups is that people who share similar experiences, or disease condition, possess a richer understanding of others' experiences, and therefore are able to provide mutual emotional and informational support.

Informational support was frequently highlighted across studies that explored the content of discussion boards, forums and Twitter (Donovan, LeFebvre, et al, 2014; Lee, Cho, 2019; Myrick, Holton, et al, 2016) For instance, in response to posts on an AYA cancer support forum regarding uncertainty about medical care, 82% of response posts featured informational support. Posts related to personal and social uncertainty featured a balance of both informational and social support. While 67% of posts contained more than one type of support. For example, a post would begin with informational support about where to source equipment, followed by a statement of emotional support, then a reminder of the network of support available (Donovan, LeFebvre, et al, 2014). A similar pattern was evident in a study on the content of tweets analysed related to the #stupid cancer thread on Twitter. Of the tweets analysed, 66.6% contained informational support (Myrick, Holton, et al, 2015).

Motivations for sharing informational support may be related to a desire to source information about their condition themselves. A qualitative interview study by Chadwick and Fullwood (2018) with people with intellectual disabilities found the ability to exhibit agency through sourcing information about their disability themselves, and supporting others with similar disabilities were

benefits of social media engagement. In specific reference to young men with DMD, a study by Skyrme (2017) found that young men with DMD are not always included in decisions related to their care, despite a desire to be more active agents in such decisions. It may be that young men with DMD use social media to source and share information about DMD.

In contrast to the informational support offered on discussion boards, forums, and Twitter, emotional support appears to be more frequently provided through online blogs (Lowney and O'Brien, 2012; Keim-Malpass, Steeves, 2012; Keim-Malpass, Albrecht, et al, 2013; Keim-Malpass, Adelstein, 2015; Nesby and Salamonsen, 2016). Themes of family, relationships, financial worries, and the emotional processing of illness were found across studies that performed qualitative analysis of online blogs by AYAs with cancer. Consequently, the type of support sourced and shared by AYAs with life-limiting/threatening conditions or disabilities appears to differ dependent on the social media platform used. Part of this difference in use may be related to the intercommunicative properties of blogs, when compared to discussion boards and forums. While online blogs are often accessible to online users, two studies (Nesby and Salamonsen, 2016. Keim-Malpass, Adelstein, 2015) reported blogger to user interaction. Intercommunication through blogging is the result of users interacting with the posts of the blogger.

Discussion boards and forums by their very definition, are dependent on user to user 'discussion', to develop threads of content from multiple user input. Consequently, their appeal to AYAs with life-limiting/ threatening conditions or disabilities may relate to their capacity to facilitate the identification, receiving, and sharing of content, as opposed to the journaling of illness narrative. Similarly, the 280 character limit of Twitter, and the platforms emphasis on thread development, does not promote cathartic in depth life review reported by studies that analysed online blogs.

Comparisons between the support sourced and offered via different social media platforms is however limited by the scope of the articles reviewed. Despite anecdotal evidence suggesting the use of social networking platforms such as Facebook and Instagram by AYAs with life-limiting/threatening conditions or disabilities, none of the studies identified explored their use. In

addition, the reviewed studies all identified support in relation to illness/condition, with little acknowledgement of the support sourced and offered outside the illness remit, such as via groups related to interests or hobbies. Finally, all studies that explored concepts of support exclusively did so focusing on AYAs with cancer. Therefore, differences in illness trajectories and experiences were not accounted for. It is more likely that a more varied use of different social media platforms is used to source and provide support than presented in the current articles reviewed.

2.5.3.3 Socialise and reduce feelings of social isolation

Social isolation can have a central presence in the offline worlds of young men with DMD (Gibson, Young, et al, 2009; Abbott, Carpenter, 2014). Understanding whether social media provides an alternate space for socialisation, based on a review of social media use by AYAs with life-limiting/threatening conditions, or disabilities was of interest to the study. Studies included in the review alluded to the capacity of social media to facilitate online socialisation with others. The majority of studies reviewed explored the activity of discussion boards, forums, blogs, Twitter, or interactive websites where the focus was on the intercommunication of AYAs based on a condition or illness. Consequently, socialisation was reported in the context of sharing illness-specific informational and emotional support (e.g. Donovan, LeFebvre, et al, 2014; Myrick, Holton, et al, 2016; Keim-Malpass, Adelstein, 2015), interaction with individual illness journeys, and dialogue on a subject matter related to illness such as fertility (Keim-Malpass, Steeves, 2012). Social media was viewed as a safe and exclusive space for socialisation with others with similar lived experiences (Keim-Malpass, Albrecht, et al, 2013). Furthermore, Griffiths, Cave, et al (2012) found that condition-specific groups that exist on social media sites such as Facebook for rare conditions can be one of the only means of connecting with others who share similar lived experiences.

Four studies found that online socialisation encompassed interaction with both social groups of people with and without disability (Rasid and Nonis, 2015; Shpigelman and Gill, 2014; Griffiths, Panteli, et al, 2015; Chadwick, Fullwood, 2018). One study exploring social media use by adolescents between 14 and 18 years of age with cerebral palsy in Singapore found that social media

enabled participants to form and maintain friendships with people, both with and without disabilities who they had met online, or through their school/college (Rasid, Nonis, 2015). In addition, 67% of participants stated that social media enabled them to keep up to date with the activity of friends via news feeds (Rasid and Nonis, 2015). Similarly a study with a sample of 172 participants with disabilities found that participants engaged with Facebook to maintain friendships, stay up to date with the activity of peers, and keep peers up to date with their activity through status updates (Shpigelman and Gill, 2014). While 48% of participants engaged in illness-specific groups, they described their Facebook activity as predominately focused on engagement with non-disabled friends. A study that involved the co-design of a website aimed to support AYAs with cancer found that an appeal to the website was its entity as a separate space away from other online activity (Griffiths, Panteli, et al, 2015). Consequently, seeking social support online is not necessarily associated with a desire to engage with others with similar lived experiences. AYAs with life-limiting/threatening conditions, or disabilities may also socialise online with friends, groups, and pages unrelated to their condition.

Since the introduction of online video gaming, 'multiplayer' mode has been a popular game type in the general population, connecting video gamers to one another to facilitate the social playing of video games (internetmatters.org, 2020; Jones, 2020). A study that explored the characteristics of video gamers with disabilities (majority upper or lower limb disability) found that online multiplayer video games were played by 114 out of a sample of 230. Conversely, single player video games were played by over 80% (195) of the participants, suggesting single player game types are preferred over multiplayer video games (Beeston, Power, et al, 2018). Similar findings were also reported by a survey undertaken by Porter and Keinz (2013). Further research is required to understand why multiplayer video gaming may be less appealing to AYAs with life-limiting/threatening conditions, or disabilities, despite its capacity to connect players.

Drawing on the wider literature, the player-avatar relationship (PAR) represents a dynamic of single player video gaming that may offer insight into how socialisation can be achieved without the presence of other 'real-life' players.

Owing to the immersive quality of video gaming, and the emphasis on character development within genres, studies on PAR in the general population have reported that players can form relationships with avatars akin to human-to-human friendship (Banks, Bowman, 2013). However, no studies identified explored the dynamic with a sample of AYAs with life-limiting/threatening conditions, or disabilities.

2.5.3.4 To escape illness

Social media can provide an alternate space for AYAs with life-limiting/threatening conditions or disabilities to escape their illness. A seminal intervention study that aimed to create a virtual environment for adolescents with a mean age of 15.4 requiring kidney dialysis to connect with each other found that they used the space to escape their dialysis treatment (Bers, Gonzalez-Heydrich, Raches, et al, 2001). Adolescents perceived that the virtual environment was an opportunity to exhibit and share aspects of self they felt were hidden as a result of their illness. Notably, they revealed aspects of self, such as hobbies and interests that kindled the building of friendship between the adolescents on the dialysis unit, who previously had only been known as a 'dialysis patient'. The preconceptions of the researchers who undertook the study were challenged through the findings of the study; the research team hypothesised that the virtual environment would be used by adolescents to discuss their condition with other dialysis patients. In reality, adolescents involved in the study used the space to escape illness and explore and show other aspects of self.

Subsequent research found similar findings, for example, a survey of video gamers with disabilities (majority upper or lower limb disabilities) found a core motivation for engagement with video gaming was to 'escape reality' (Beeston, Power, et al, 2018). The use of a survey design did not facilitate further exploration of what 'escape reality' meant. However a qualitative study by Stewart, Hansen, et al, (2010) found 'massively multiplayer online worlds' (MMOWs) such as 'World of Warcraft' (2010) ¹ enabled engagement in activity

¹ World of Warcraft is a massively multiplayer online role-playing game set in a Warcraft fantasy universe.

that otherwise would be unavailable to some AYAs with life-limiting/threatening conditions, or disabilities, such as the ability to walk, fly, or socialise. Consequently, 'escaping reality' may mean a departure from everyday offline experiencing, to existence within an alternate reality where the ability to engage in activity otherwise denied can be realised.

Wästerfors & Hansson, (2017) outline an additional interpretation of 'escaping reality', offering the notion of 'situational refuge'. Drawing on the experiences of 15 Swedish AYAs with a range of disabilities, the study found that the immersive nature of video gaming made participants offline world's temporarily irrelevant, allowing a sense of escapism. Video gaming appeared to represent a space of 'situational refuge', which was particularly useful during times when their disability was most salient within their offline world, such as during intense treatments. Video gaming was often combined with other activities such as watching movies, and reading fantasy and science fiction to supplement and support an escapism from their everyday reality of living with a disability. The nature of escapism in the context of social media use is multifaceted, it can mean a departure from an environment (Bers, Gonzalez-Heydrick et al, 2001), an escapism of the body to engage in activity otherwise denied (Stewart, Hansen, et al, 2010), or as a situational refuge (Wästerfors & Hansson, (2017). There is lack of evidence whether escapism is a salient factor in the lived experience of social media from the perspective of young men with DMD, and what the term means to the population.

2.5.4 Theme Two: Disclosure of disability online.

Five of the studies included in the review detailed findings that illuminate how AYAs with life-limiting/threatening conditions, or disabilities process and action a disclosure of their disability to other users online (Furr, Carreiro, et al, 2016; Nesby and Salamonsen, 2015; Lowney and O'Brien, 2012; Love, Thompson, et al, 2014; Griffiths, Pantelli, et al, 2015) Based on interviews with 16 participants with physical disabilities, Furr, Carreiro et al, (2016) identified three approaches to disability disclosure online; open, secure, and limited. An open approach was characterised as a full disclosure of disability, including both visual and textual representations, to an audience of both disabled and non-disabled peers. The study found that participants who engaged in open disclosure felt empowered, citing the process as one of 'coming out' and a means of facilitating an acceptance of self (Furr, Carreiro, et al, 2016, p.1360). Notably, no participants under the age of 35 engaged in full disclosure. Furthermore, no participants who had lived with their disability from birth engaged in full disclosure. These findings are contradictory to those published by Nesby and Salamonsen (2015) who found that two young women with cancer, aged 15 and 17 engaged in open disclosure of their condition through online blogging. In addition, further studies reviewed suggest that open disclosure via online blogging was largely engaged with by women between the ages of 20 and 39(Keim-Malpass, Steeves, 2012;Keim-Malpass, Albrecht, et al, 2013). While one study reported open disclosure by a 30 year old male who publicly documented his illness journey via an online blog (Lowney and O'Brien, 2012), no other studies reviewed published findings of young males engaging in the open disclosure of their disability on social media. Love, Thompson, et al (2014) allude to cultural masculine expectations of Being such as the requirement to show strength as a barrier to young men engaging in full disclosure of disability. The current evidence suggests age and gender are factors in how confident individuals are to openly disclose their disability to others within public social media spaces.

A secure disclosure approach has been defined as both disclosure of disability on a platform that featured an audience of disabled peers, and carefully orchestrated disclosure with a purpose to open audiences (Furr, Carriero, et al,

2016, p.1360). Participants under the age of 35 reported secure disclosure more than those over 35 years of age. Participants who engage in secure disclosure shared strategies such as withholding information about their disability from public social media profiles, and posting subtle cues to public online audiences to assess how 'safe' it would be to disclose their disability. Notably, participants profiled illness specific discussion boards, forums, and groups as safe spaces to disclose and discuss their disability with others who shared similar lived experiences, a finding shared by Pounders and Stowers (2017) and Donovan, LeFebvre, et al (2014) who found that closed discussion boards and forums are actively engaged with by AYAs with cancer to exchange support and discuss condition.

Video games may provide a suitable environment for disability disclosure in instances where AYAs wish to disclose or talk about their disability to others. A study by Sibilla and Mancini (2018) found that players feel more protected and less judged when video gaming, and are able to build trust with other players through avatar to avatar relationships. Nevertheless, Wästerfors & Hansson (2017) allude to the notion of 'disability stickiness' (p.1146) referring to the challenge AYAs with life-limiting/threatening conditions, or disabilities face in disclosing their disability to others. Despite the anonymity provided by video gaming, with players able to interact with other players as avatars as opposed to persons multiplayer video gaming can lead to players forming long-standing bonds. Consequently, players with disabilities practice secure disclosure to determine the 'stickiness' of their disability within social interaction with other players (Wästerfors & Hansson (2017)). For example, a participant described how a dialogue about her disability with in-game team-mates led to one gamer offering unwanted and unhelpful advice, while identifying the participant as having a physical disability in front of other gamers (Wästerfors & Hansson, 2017). Outside of closed illness or disability specific social media groups, pages, forums, or discussion boards, AYAs with life-limiting/threatening conditions, or disabilities are typically cautious when deciding when/who/and how to disclose their disability to others if they wish to do so.

For some AYAs with life-limiting/threatening conditions or disabilities, a strategy of limited disclosure characterised as disclosure only through private channels

is the preferred option (Furr, Carreiro, et al, 2016.p. 1362). Participants using this approach alluded to past experiences of face-to-face rejection and bullying on account of their disability. Furthermore, one participant remarked that he had to 'share too much too soon' in previous online encounters (Furr, Carreiro, et al, 2016. p.1363). Other reviewed studies offer further factors to why a strategy of limited disclosure may be adopted. For example, Crook, Glowacki, et al. (2015) highlight the issue of non-response, while Nesby and Salamonsen (2015) allude to the presence of negative behaviour online. Both factors may inhibit AYAs with life-limiting/threatening conditions or disabilities from disclosing their disability to others on social media should they wish to do so. A previous study with a sample of young men with DMD found that they did not wish to interact with their peers because 'they remind me of things I don't want to talk about' (Sanger, 2019, p.66). Consequently, further research is required to understand if this viewpoint is shared by other samples of young men with DMD.

2.5.5 Theme Three: Barriers to engagement in social media

Two barriers to engagement with social media were identified, namely 'user response' and 'accessibility'.

2.5.5.1 User response

Three studies reviewed found that the behaviour of users online can be a barrier to engagement with social media (Crook, Glowacki, et al, 2015; Crook, Love, 2016; and Nesby and Salamonsen, 2016). A statistical analysis of initial posts posted on a AYA online cancer community discussion board highlighted a high number of posts do not receive a response (Crook, Glowacki, et al, 2015). The study found the style of the post was a factor in whether other responded, posts with longer sentences were less likely to generate a response . Social media platforms all provide the potential for user to user communication, however this potential is not always realised. Users may be left without a response or acknowledgement to a post, deterring future engagement and heightening feelings of isolation (Crook, Glowacki, et al, 2015). Further research is required to explore the reasons for non-response and whether it is experienced as a barrier to social media use by young men with DMD.

The role of user behaviour in creating a barrier for AYAs with life-limiting/threatening conditions or disabilities has been explored using qualitative methods. A qualitative analysis of a sample of posts from an AYA online cancer support group discussion board found that initial posts received responses that featured inaccurate or conflicting information, often related to medical advice. Similarly, posts that required emotional support on topics such as relationships received unwelcome advice or a dismissive responses (Crook and Love, 2016). Hurtful and negative comments to blog posts were also reported in one study (Nesby and Salomonsen, 2015). These findings suggest seeking informational and emotional support via social media may not always result in the desired outcome. Furthermore, blogs that are made publicly available may be susceptible to potentially hurtful and distressing responses. All 3 studies reported featured a sample of AYAs with cancer. The evidence base on the role of user response as a barrier to accessing informational/emotional support would therefore benefit from the experiences of other population groups.

2.5.5.2 Accessibility

The 'digital divide' refers to, and is akin to general inequalities in society, that are present within the digital arena, including social media (Hacker and van Dijk 2001). Studies included in this review explored the digital divide in relation to accessibility barriers associated with video gaming (Porter and Kientz, 2013 and Wästerfors & Hansson, 2017). AYAs with physical disabilities can find participation in video gaming challenging, due to the physiology of their condition/s and the poor suitability of video gaming equipment to their needs. For example, one study found that AYAs with physical disabilities experience breathlessness and fatigue when video gaming (Wästerfors & Hansson, 2017). Consequently, becoming immersed in video games can be difficult, owing to the consistent presence of the body. Nevertheless, the resilience of AYAs with life-limiting/threatening conditions, or disabilities is evident in the strategies they deploy to maintain an active video gaming lifestyle despite accessibility challenges.

Studies included in the review found that AYAs with life-limiting/threatening conditions, or disabilities develop several strategies to engage in video gaming. For example, one study found that discussion boards, forums, and social

networking pages were highlighted as spaces to gather information about a video game, in order to assess whether it was playable (Wästerfors and Hansson, 2017). The requirement to be educated on coding and software adjustment to remap and reconfigure video game controllers to enable user interaction was highlighted as essential to overcoming accessibility barriers without external support (Porter and Keinz, 2013. Wästerfors and Hansson, 2017). Nevertheless, despite developing an inventory of skills and processes to mitigate against accessibility barriers, enjoying video games can be challenging.

Several intervention studies evaluated video gaming as a form of rehabilitative therapy to improve balance and motor control for AYAs with conditions or disabilities that effect physical movement(Rowland, Malone, et al, 2016;Rinne, Mace, et al, 2016). Findings suggest video gaming has merit as a potential tool to complement existing physical therapies. However, the development of specialised video games risks labelling and marginalising AYAs as ‘treatment receiving objects’ (Wästerfors and Hansson. 2017 p.1143) as opposed to equal players in the video gaming world. Furthermore, studies have found that video game developers are largely unaware of the challenges faced by AYAs with life-limiting/threatening conditions, or disabilities face when video gaming (Porter and Keintz, 2013; Wästerfors and Hansson, 2017). The launch of the Microsoft Kinect console in 2010 that required players to be stood up to interact with the console is illustrative of the industry’s failure to acknowledge the presence of disabled video gamers amongst the video gaming community (Wästerfors and Hansson, 2017). Consequently, further research is necessary to illuminate the prevailing issues that AYAs with life-limiting/threatening conditions, or disabilities may face when playing commercial mainstream video games.

Tentative steps have been made in recent years by developers to ensure their products are accessible to all gamers. A notable example being the partnership between Microsoft and the charity ‘Able Gamers’ (2020) to develop the Xbox Adaptive Controller (Bailey, 2019). Furthermore, legislation such as the 21st Century Communications Act (2010), passed to ensure technology companies delivered software and products that ‘increased the access of persons with disabilities to modern communications’ is representative of a drive to make video gaming more inclusive. Nevertheless, on the whole it seems that design

recommendations for game developers to improve accessibility are often based on laboratory studies that lack ecological validity and undermine the complexity of the user population (Porter, Kientz, 2013). Research that explores the unique everyday challenges faced by disabled video gamers would be a useful contribution to an evidence base that is largely unrepresentative of their needs. In addition, the current corpus of evidence on online accessibility barriers is situated within the remit of video gaming. Future research should be considerate of the potential for barriers to accessibility existing across social media platforms.

2.6 Discussion

This section discusses the key messages of the review and the limitations of studies reviewed and the review approach. Gaps in the literature are identified, and theoretical concepts of relevance to the study are outlined. The chapter concludes with the aims and objectives of the study.

2.6.1 Key messages

Two questions guided the review, the first asked what motivates AYAs with life-limiting/threatening conditions, or disabilities to engage in social media. The second asked what types of social media are used by the population and how do they interact with them? Findings from the 25 reviewed studies provided answers to both questions. AYAs with life-limiting/threatening conditions, or disabilities are motivated to engage in social media to make sense of their illness and leave a legacy, provide and receive support, socialise with others, and escape their illness.

Differences appear to exist in motivations for engaging with social media use and the participants' illness type and trajectory. Studies with a sample of AYAs with cancer who were approaching end of life exclusively reported a motivator for engagement being to leave a legacy via the use of online blogs (Keim-Malpass, Adelstein, et al, 2015; Nesby, Salamonsen, 2015; and Lowney, O'Brien, 2011). No studies that included samples of AYAs with disabilities or other life-limiting/threatening conditions found that legacy/meaning-making was a motivator for social media use. This finding suggests legacy/meaning-making

via social media is associated with end-of-life. Studies exploring daily life with DMD found that living in the 'here and now' is a common strategy adopted by young men, but equally some AYAs wish to talk about end of life (Abbott, Carpenter, 2014; Abbott, Prescott, et al, 2017). The use of social media to make sense of illness was a more widely shared motivator across reviewed studies. There appears to be a paucity of research focussing on understanding the salience of the motivation of sense and legacy making among young men with DMD who engage with social media.

Providing and receiving social support via online discussion boards, forums, and blogs was a primary motivator for social media use across the findings of reviewed studies. Informational support was offered on discussion boards, and forums, with emotional support more affiliated with online blogs. The physiology of DMD can result in daily experiences of pain and discomfort; seeking support on how to alleviate pain via support groups that exist on social media platforms may be a motivator for social media engagement (Finkelstein, Marcus, 2018). Similarly, young men with DMD want to be active agents in decisions related to their care, but often felt ignored during consultations (Skyrme, 2017). Support about their condition via social media platforms may provide young men with DMD with a sense of agency and empowerment

Socialisation on social media occurs both between AYAs who share experiences of living with the same/similar conditions, and between AYAs and their peers or friends who do have a disability. One study included in the review suggest AYAs with life-limiting/threatening conditions, or disabilities preferred to discuss their condition in illness-specific spaces, as oppose to more openly across their social media profiles (Griffiths, Pantelli, et al, 2015). Socialisation appeared to exist between persons and their video gaming avatars. Studies on the dynamic between player and avatar with the general population suggest players can form relationships with avatars akin to human-to-human friendship (Rigby, Ryan, 2011; Przybylski, Weinstein, et al, 2012). However, the significance of video gaming avatars to AYAs with life-limiting/threatening conditions, or disabilities including DMD remains underexplored. Young men with DMD can experience social isolation, whether social media provides the

ability to socialise with others remains underexplored (Skyrme, 2017; Abbott, Carpenter, 2014).

AYAs with life-limiting/threatening conditions, or disabilities are motivated to use social media for the purpose of escapism. Experiences of escapism varied across reviewed studies. However, studies were unified in escapism meaning to be removed from their condition, or disability; via a departure from an environment, to escape the body, or as a situational refuge. It is unknown whether escapism is a prominent motivator for social media use by young men with DMD.

Whether AYAs with life-limiting/threatening conditions, or disabilities wish to disclose their disability to others, and how they choose to do so appeared to be influenced by multiple factors including gender, age, and condition type (Furr, Carreiro, et al, 2016; Nesby and Salamonsen, 2015; Lowney and O'Brien, 2012; Love, Thompson, et al, 2014; Griffiths, Pantelli, et al, 2015). A theory of online disability disclosure posits that three strategies of disclosure exist; open, secure, and limited (Furr, Carreiro, et al, 2016). Further research is required to understand if young men with DMD wish to disclose their disability to others online and what strategies they adopt to do so.

Barriers to engagement with social media appear to take the form of negative user response, and accessibility issues associated with the 'digital divide' (Hacker and van Dijk 2003). Experiences of non-response to posts and hurtful or abusive messaging were reported as a barrier to social media use. Young men with DMD can experience bullying and derogatory and offensive behaviour in their daily lives (Gibson, Young, et al, 2007; Skyrme, 2017; Wästerfors & Hansson 2017). It is unknown whether similar behaviour is experienced by young men with DMD online. DMD progressively impacts muscle development and function, it is therefore likely that young men with DMD face accessibility barriers to engagement in social media related activity such as video gaming (Landfeldt, Lindgren, et al, 2015). The findings of the review highlighted both the accessibility barriers AYAs with physical disabilities (conditions not specified) face to video gaming, and the strategies developed to overcome such barriers. These findings offer insight into the barriers young men with DMD face and the strategies they may adopt.

In summary, preliminary searches of key databases returned no studies that specifically explored social media use by young men with DMD. Drawing on the wider body of evidence into social media use by AYAs with life-limiting/threatening conditions, or disabilities has yielded empirical insight into the motivations for social media use, and the types of social media platforms used. The findings of the studies reviewed informed the direction of the study outlined in this thesis, and the methods adopted to understand the lived experience of social media from the perspective of young men with DMD.

2.6.2 Limitations of studies included in the review

All studies were critically appraised using a mixed methods analysis framework with all articles meeting the quality criteria, but had limitations. First, the qualitative studies lacked an account of a reflexive processes, albeit recognising the constraints of journal word limits. Reflexivity is a practice necessary to improving the transparency of study designs, through the acknowledgement of the role of authors' assumptions and beliefs on the study aims, design, analysis, and outcomes (Finley,2017). Second, there is a paucity in face-to-face methods of data collection, with studies largely analysing online data. While online data can provide insights into the content posted and interacted with by the group members, it is limited in its capability to understand the motivation and circumstances around the content published. Third, several studies reviewed did not include participants characteristics, such as age, gender and condition, owing to the relative anonymity of social media. Consequently, the review was restricted in the conclusions it could draw relating to the role of variables such as age, gender, and condition on the use of social media. Fourth, there was an underrepresentation of the breadth of life-limiting/threatening conditions, or disabilities with a dominance in study samples featuring AYAs with cancer.

2.6.3 Limitations of the review

The review has several limitations. First, while a robust search strategy was developed with the support of an information specialist, and a range of appropriate healthcare related databases were searched and substantiated with a review of Google Scholar, a wider search of databases may have resulted in further articles identified. Second, the review strategy would have benefited

from the deployment of two-person iterative approach to the selection of studies to increase its robustness. However, the practicalities of a PhD programme did not facilitate a two-person approach. Furthermore, the strategy employed enabled the retrieval of 25 studies, with diverse methodologies and methods to facilitate an in-depth review of the literature.

2.6.4 Gaps in the literature

Several gaps were identified in the literature. First, the current corpus of evidence focuses largely on the experiences of AYAs with cancer. Of the studies that explored social media use from the perspective of AYAs with disabilities, few specifically outline conditions. Further gaps in sample were identified, with the perspective of AYA males in relation to their social media use underexplored. Second, the majority of studies reviewed undertook a quantitative or qualitative analysis of the content of illness-specific discussion boards, forums, online blogs, or interactive websites. Consequently, few studies exist that have explored social media use for non-illness related purposes. Third, of the 25 studies reviewed, only three were published in the UK. As a result, the evidence base does not representative the unique experiences of AYAs with life-limiting/threatening conditions, or disabilities living in the UK.

2.6.5 Theoretical concepts of relevance to the study

The integrative review identified several theoretical concepts that could facilitate the interpretation of the lived experience of social media from the perspective of young men with DMD. Concepts of relevance broadly related to self-presentation (Goffman, 1956), self-discrepancy (Higgins, 1987), and self-disclosure (Furr, Carreiro et al, 2016) were identified. Each are discussed in the context of supporting literature.

2.6.5.1 Self-Presentation

The notion of self-presentation relates to how individuals continuously exhibit behaviour with the intention of creating or altering an impression of the self in line with how they wish to be viewed by others (Brown, 2009). In his book 'Presentation of Self in Everyday Life' (1956) Goffman provides a useful dramaturgical model of self-presentation in which he presents everyday social interactions as a theatrical performance. Based on this model, social

interactions feature on stages in which actors aim to control the impressions that others, or the 'audience' form of them, also termed 'impression management' (Hogan, 2010).

In outlining all social interactions as featuring on stages, Goffman (1956) went further to distinguish between the front and back stage (Hogan, 2010). On the front stage individuals, or 'actors' are conscious of their audience and will therefore act in a way that adheres to context dependent social conventions or rules (Billingham, Vasconcelos, 2013). Failure to do so risks distorting the impression they wish to create. For example, a person attending a job interview will likely be aware of the social norms surrounding interviewing, such as the requirement to dress smart and act punctually to form the desired impression. Whether people consciously act in a way to form desired impressions has been debated in the literature. Some studies suggest self-presentation is habitual and therefore the way we present ourselves occurs as a taken for granted action (Jones, Pittman, 1982). Conversely, other studies suggest people consciously adapt their behaviour to fit specific contexts (Schlenker, 1980). The back stage refers to the private spaces of individuals, whereby no audience is present and therefore no performance is required (Billingham, Vasconcelos, 2013). The backstage has also been described as a space of solace from what can be the intense and stressful performances of the front stage (Wood, 2004).

As outlined in Chapter One, young men with DMD are often denied the opportunity to present the self in a way that is on par with the impressions they wish others to form of them. Staring, pointing, and offensive remarks, can suppress the self, and nullify attempts at self-presentation (Skyrme, 2017. Wästerfors & Hansson 2017). Social media presents an alternate 'stage' with different properties to traditional social encounters such as the ability to withhold or present aspects of self through privacy settings and the user-generated nature of social media content (Pempek, Yermolayeva, et al, 2009).

Goffman (1964) was sceptical of emerging technology such as the telephone, positing that it represented a suppressed version of social interaction (Goffman, 1964, p. 70). Consequently, there is some debate as to whether Goffman's (1964) theory still holds relevance in the digital age whereby social interaction takes place within non-physical environments (Billingham, Vasconcelos, 2013).

For example, Arundale (2010) suggests that Goffman's dramaturgical model is outdated and therefore needs to be updated in line with advancements in communication technology. However, several studies have argued and shown the utility of Goffman's theory (1964) to the study of online communication behaviour (e.g. Billingham, Vasconcelos, 2013; Laughey, 2007; Miller, Arnold, 2009).

While Goffman's (1964) theory offers a useful theoretical position to understand how social media may offer an alternate 'front stage' for young men with DMD to action self-presentation. Certain aspects of his theory appear to have particular relevance to the study of online communication behaviour. For example, Goffman (1964) refers to the 'mask' as a metaphor to how individuals may look to bring forth aspects of self during interactions while seeking to nullify others. One study on avatar personalisation found that the customisable nature of avatars within video games and online virtual worlds enable their users to create characters that represent aspects of self they deem more favourable to others (Sibilla, Mancini, 2018) Similarly, the concept of 'identity tourism' relates to how the anonymity and social mechanisms of social media enable users to adopt different identities online (Nakumara, 2002). For example, one study found users of an online virtual world adopted avatars of a different gender or race to their own (Sibilla, Mancini, 2018). Both concepts may be applicable to understanding how young men with DMD present themselves on social media.

As outlined in Chapter One, the term 'social media' now incorporates a plethora of different platforms, sites, and activities. Each of these feature separate and distinct social norms and goals. For instance, the norms of a violent video game differ from those of a subject-specific forum or discussion board. However, the distinction between social norms becomes more blurred in the context of social networking sites (Davis, Jurgenson, 2014). Sites such as Facebook promote the active generation of networks. Where an individual's network is small and well known, self-presentation may be straightforward, for instance the user will likely feel confident about the types of status to post to form the desired impression among their network. However, as a user's network grows in diversity, managing impressions may become challenging as social groups and spheres integrate and collide within the same network, referred to as 'context collapse'

(Gil-Lopez, Shen, et al, 2018). Consequently, users must manage their self-presentation across diverse audiences. Studies suggest that users with larger and more diverse networks post less than users with smaller heterogeneous networks (Vitak, 2012; Gil-Lopez, Shen, et al, 2018). Young men with DMD may have multiple social media accounts with different audiences, the concept of context collapse may therefore be useful to understanding how they manage their self-presentation across their social media accounts.

Goffman's (1964) self-presentation offers an interesting theoretical viewpoint to understand how young men with DMD may engage in impression management on social media. Concepts related to the theory such as identity tourism and context collapse may also be useful to understand how young men with DMD manage their identities online.

2.6.5.2 Self-Discrepancy

The notion that individuals may hold conflicting beliefs about the self has been well explored in the field of psychology (e.g. Rogers, 1961). In particular, the idea that people differentiate between their 'actual' self, and 'ideal' self, and that conflict arises as a result of this differentiation is the basic assumption of Self-Discrepancy Theory (Higgins, 1987). The 'actual' self refers to the attributes a person believes they hold. By contrast, the 'ideal' self represents the attributes a person, or others, would wish a person to possess (Higgins, 1987, p. 320). A person's self-discrepancy equates to the gap that exists between the two. Where a gap exists, negative emotions may manifest such as anger, jealousy, and frustration (Higgins, 1987).

Discrepancy between the actual and ideal self was outlined by Higgins (1987) as manifesting as a result of person's wishes or hopes remaining unfulfilled, resulting in feelings of disappointment, frustration, and dissatisfaction. The advent of video gaming has brought the notion of the actual and ideal self into a new realm. Users may no longer wish or imagine an ideal self, but can create and embody the ideal self through avatars. Video games feature 'ready-made' idealised roles for players to embody within highly immersive environments (Przybylski, Weinstein, et al, 2012).

Previous research has drawn on Self-Discrepancy Theory (Higgins, 1985) to study the player-avatar-relationship (PAR) (Rigby, Ryan, 2011; Przybylski, Weinstein, et al, 2012). Studies have found that video games can provide players with the opportunity to connect with, or display aspects of their 'ideal self' that may be otherwise difficult to access outside of this medium (Rigby, Ryan, 2011). Significantly, the ability to experience ideal-self characteristics through avatar engagement is associated with increased motivation to engage in video gaming (Przybylski, Weinstein, et al, 2012) In addition, a further study found that users tend to seek video games that allow them to create avatars that are more akin to their idealised self, rather than their actual self, with the greatest discrepancies associated with physical attributes such as fitness levels or perceived attractiveness (Sibilla, Mancini, 2018).

The discrepancy between a player's actual self, and their ideal self played through their avatar can result in 'avatar idealisation' (Sibilla, Mancini, 2018, p.15). Studies have reported negative outcomes associated with avatar idealisation including feelings of jealousy, low self-esteem (Molesworth, 2009; Dengah, Snodgrass, 2020). However, studies to date appear to have focused on samples of able-bodied gamers. Consequently, whether concepts such as 'avatar idealisation' feature in the lived experiences of young men with DMD is worthy of exploration.

2.6.5.3 Self-Disclosure

Self-Disclosure refers to the process of sharing information, experiences, and feelings with others (Liu and Brown, 2014). It is suggested that self-disclosure has become somewhat of a prerequisite of social media, with users encouraged to post and share information about themselves or others (Bazarova and Hancock, 2011). It has also been suggested that the act of online self-disclosure is necessary for connectedness with others and can increase relational closeness (Vitak and Kim, 2014). The therapeutic benefits of self-disclosure within therapeutic and interpersonal relationships have been highlighted in the literature (Pennebaker, 2012). However, there appears to be less evidence on the lived experience of self-disclosure online and its potential benefits.

The contexts and social cues surrounding social media may encourage self-disclosure. For example, associations between anonymity and self-disclosure have been found, with individuals more likely to self-disclose information anonymously (Clack-Gordon, Bowman, et al, 2019). Furthermore, personal disclosure online to others through avatar to avatar relationships has previously been associated with a sense of trust among users (Sibilla, Mancini, 2018). However, the same properties have also given rise to offensive behaviour and cyberbullying that may understandably deter users from disclosing aspects of self online (Davis, Randall et al. 2015). Studies have also posited associations with gender, with findings suggestive of women being more openly self-disclosing in comparison to men (Petronio, 2002. Kleman. 2007). Nevertheless, there are likely to be multidimensional factors that surround self-disclosure such as culture, motivation, and risk (Waters, Akerman, 2011).

Online self-disclosure by adolescents and young adults (AYAs) with life-limiting/threatening conditions/and or disabilities is generally under-researched (Furr, Carriero, 2016). The findings of this integrative review have illuminated the prominence of illness-related disclosure on platforms such as blogs, discussion boards, and forums. However, few studies have explored how AYAs with life-limiting/threatening conditions, or disabilities may engage differently in self-disclosure across platforms, and the factors that influence the aspects of self they disclose to others. Furr, Carriero, et al (2016) conceptual framework of online disability disclosure outlined in section 2.5.4 of this chapter provides a useful framework to explore how young men with DMD may engage in disability disclosure through social media.

2.7 Summary

The integrative review outlined in this thesis found three broad themes that underpin social media use by adolescents and young adults (AYAs) with life-limiting/threatening conditions, or disabilities. First, the population is motivated to engage with social media for purposes of sense making, seeking support, socialising and reducing social isolation, and escaping their illness. Second, for those who wish to disclose their disability to others, how they chose to do so was influenced by factors including gender, age, and condition. Finally, AYAs

with life-limiting/threatening conditions, or disabilities face barriers to using social media related to the behaviour of others online, and issues of accessibility.

Several gaps in the current body of evidence were identified. First, and of most significance to the current study, is that no studies have specifically focused on social media use by young men with DMD. Second, studies that have explored social media use by AYAs with life-limiting/threatening conditions, or disabilities have largely focused on the analysis of online content. Consequently, there is a current paucity in evidence on the broader context of populations that lead them to engage in social media. To address these gaps in knowledge, the following aim and objectives were developed:

Aim: To explore the lived experience of social media from the perspective of young men living with Duchenne Muscular Dystrophy (DMD).

Specific objectives:

- Understand the role of social media in the daily lives of young men with DMD
- Identify how the impact of living with the condition may influence the way young men with DMD interact with social media.
- Understand what motivates young men with DMD to engage with social media.

Chapter 3 Philosophical and Methodological Underpinnings of the Study

A phenomenological approach was adopted to explore the lived experience of social media from the perspective of young men with DMD. This chapter outlines why a qualitative approach was appropriate, and the rationale for adopting a phenomenological approach. A critical discussion of the three tenets of phenomenology is provided, namely, descriptive, existential, and hermeneutic phenomenology, and key phenomenological concepts are highlighted. The chapter continues to detail the chosen methodology of the study, namely Interpretative Phenomenological Analysis (IPA).

3.1 A Qualitative Approach

To understand the lived experience of social media from the perspective of young men with DMD it was necessary to explore the epistemological and ontological underpinning of qualitative research. Qualitative research, is grounded in the assumption that knowledge is generated through the unique and subjective meanings individuals attribute to phenomena (Cresswell, 1998). However, there exists a plethora of qualitative approaches each underpinned by different epistemological and ontological positions. Those considered suitable to explore the lived experience of social media from the perspective of young men with DMD included Grounded Theory (Glaser, Strauss, 1967), Netnography (Kozinets, 2002), and Phenomenology (Smith, Flowers, et al, 2009):

- Grounded Theory is particularly well suited to phenomena that are under researched, or where a new perspective would be beneficial (Miller, 2015). Multiple approaches to Grounded Theory exist, however, broadly the aim of the approach is to generate theory or a conceptual framework that explains the phenomena of interest and is 'grounded' in the data provided by participants (Miller, 2015, p.197). A possible question underpinned by Grounded Theory could have been 'How do young men with DMD use social media?'. While this question would have led to fresh and valuable insight into an area of research that, as identified, is

underexplored, it would not meet the aim of the study. The aim of the study described in this thesis was to uncover the lived experience of social media from the perspective of young men with DMD.

Consequently, a Grounded Theory approach was disregarded and other approaches were considered.

- Netnography originates from the well-established discipline of ethnography. However, it is distinguished by its interest in social interaction that occurs online through the observation of online communities (Kozinets, 2002). A plethora of online spaces dedicated to young men with DMD now exist. However, as outlined in Chapter 2 little is understood about how or why the population interact with such spaces. A possible research question to approach the gap in knowledge underpinned by Netnography would have been 'How do young men with DMD interact with each other in a closed online community'. However, it was important to remain open to the potential multi-faceted meaning of social media to young men with DMD. A focus on observing the social interaction and behaviour of the population within a specific online space was therefore unsuitable to the aims of the study.
- Phenomenology as a research approach broadly aims to explore lived experience, and the meanings individuals derive from their everyday experiences (Smith, Flowers, et al, 2009). It is therefore well suited to the aims of the study, that seek to understand the meaning of social media derived from the lived experiences of young men with DMD. Phenomenology offers a 'radical' alternative to viewing the world, and the phenomena that exist within it: in this context radical denotes a significant shift in thinking, or a departing from the familiar. Phenomenology in general is a shift away from viewing objects such as social media 'just as they are', embracing the perspective of the individual who lives that experience (Idhe, 1986). Consequently, phenomenology offers the necessary openness required to understand the many possible meanings of social media as uniquely lived by eight young men with DMD.

3.2 Descriptive Phenomenology

Any discussion of phenomenology must first start at the descriptive approach; the descriptive phenomenology of Husserl (1970) laid the foundation for further strands of phenomenological thinking. The central philosophy is first discussed, before a Giorgi's (2009) descriptive psychological methodology is pondered as a suitable methodology for the study.

3.2.1 Philosophical Underpinnings

Descriptive phenomenology is largely attributed to the work of Edmund Husserl (1859-1938), who is viewed as the father of phenomenology. Husserl's background as a mathematician led him to approach human behaviour in an objectivist fashion and developed a phenomenological philosophical method, outlined in his book *Logical Investigations* (Husserl, 1970). The core aim of the method was to examine experience to understand the way in which phenomena provide meaning. In order to pursue this aim, Husserl developed a number of phenomenological concepts. What follows is an overview of the concepts relevant to the aim of the current study.

3.2.1.1 Intentionality

Phenomenology in its primal philosophical and descriptive state is concerned with how consciousness presents itself. This interest is based on the assumption that consciousness is intentional, it is always directed towards something (an object, phenomena, memory, mental image) (Idhe, 1986). Husserl termed this correlational relationship 'Intentionality' (Husserl, 1970). The object which consciousness is in correlation with may physically exist (the Xbox console positioned on a table), may no longer be a physical entity (the once well used SEGA mega-drive), or may exist as a floating thought (an image of a blog post read in the past). Crucially, to be conscious, is to always be conscious of 'something'. Intentionality exists within a pre-reflective conscious state, prior to any apprehending or perception of the phenomena being encountered (Idhe, 1986). For example, when typing a response to a thread on an online discussion board, it is likely that if the individual was conscious of their encounter with every key on the keyboard they may struggle to type quickly or at all.

Husserl developed terminology for what he deemed to be two aspects of this correlation. The object of experience or consciousness he named the noema (Noematic). The way in which that object is experienced he named the noesis (Noetic) (Ihde, 1987). It is within what Husserl termed the 'noetic correlate' that the meaning of the object (the noema) can be found. Therefore the concern is not the object itself, but how it is experienced. Social media viewed as an object that exists independently is not of concern, rather the way social media is encountered and experienced is the concern. Intentionality is a layered process dependent on the phenomena presenting itself to consciousness. For example, a video game disc is experienced as a disc for video gaming as opposed to a floppy disc. However, the noetic experience has further layers that reveal the disc to be more than simply text and images on a piece of circular metal. This layering reveals the noetic quality of the phenomena, its meaning. Within the pre-reflective state, the meaning of the object to the experiencer is also made up of the everyday beliefs, thoughts, and biases that Husserl collectively terms 'the natural attitude'.

The 'natural attitude' is the dominant position of everyday consciousness and experiencing, to the extent whereby the individual is unaware of its existence (Luft, 1998). To adopt the 'natural attitude' takes no effort and in this sense it is a natural state of being. The meanings of objects within this attitude are presumed, with a significant bias towards the familiar (Ihde, 1986). Fact is considered to be that which feels most familiar and homelike. There is a taken for granted essence to the natural attitude, in the sense that there is little questioning of that which appears as familiar. The makeup of the natural attitude includes all that is known to the individual such as their beliefs, interests, opinions, and knowledge (Spinelli, 1989). To become aware of the natural attitude is to enter a reflective attitude. In order to view the relationship between the noema and noesis objectively, Husserl believed that the individual must transcend their natural attitude. That is, step outside of it in order to view it thematically (understandable chunks of subject matter), this process is part of what he termed the phenomenological reduction (Husserl, 1970).

3.2.1.2 The Phenomenological Reduction

In order to be active within the phenomenological reduction a phenomenological attitude must be first adopted. This attitude signifies the first layer of the reduction that Husserl referred to as the *Epoché*. The epoché is an attitudinal shift from the natural attitude to the phenomenological. Within the phenomenological attitude the phenomenologist's beliefs, knowledge, prior understandings, thoughts, and experiences are made known. It is a process of breaking free from the bonds of familiarity in order to see the phenomena from a neutral and fresh state (Idhe, 1987). The process is often attributed negatively as a shutting off process. However, Husserl (1970) offers it as an enlightening activity, in that it allows the full range of possible appearances of the phenomena to show themselves. For example, a parent may withhold within the natural attitude a concern of social media as negatively affecting the health and wellbeing of their child. In practicing the epoché, those concerns that exist within the natural attitude are withheld, allowing the many other possibilities of social media as phenomena to be illuminated. The epoché is an ongoing and constant process within Husserl's method, a note to the phenomenologist not to impose or conclude something about a phenomena too early (Idhe, 1986). The purpose of the epoché is to fulfill the first stage of Husserl's philosophical method, to turn towards the phenomena, 'to the things themselves' to allow the object to show itself on its own terms (Husserl, 1970).

In practicing the epoché and adopting the phenomenological attitude, what Husserl terms the phenomenological psychological reduction or the 'reflexive move' can be engaged with. This 'reflexive move' facilitates the second stage of Husserl's method, to describe the phenomena through an examination of the intentional relationship between the noema and noesis (Giorgi, 2009). Key to this process is to describe as opposed to explain and is distilled in Husserl's belief, and the phenomenological philosophical belief in general that truth is constructed by the experiencer. Therefore the philosophy should only seek to describe what it is to the experiencer as opposed to explaining how or why it is (Spinelli, 1989).

The final stage of Husserl's method is the transcendental reduction. This reduction requires a transcendental attitude whereby the philosopher is required to go 'above' all consciousness that has been touched by empirical reality (including human consciousness) to reach a state of pure consciousness. It is from this position, that the phenomena can be examined 'purely' in order to reveal its universal essence, a process referred to as the eidetic reduction (Mohanty, McKenna, 1989). The essence of a phenomena are the essential and necessary constituents of the phenomena, that without which it would not be that phenomena (Mohanty, McKenna, 1989).

3.2.1.3 The Lifeworld

Husserl faced criticism of his phenomenological reduction and sought to address these criticisms in his later work "*The crisis of European Sciences and Transcendental Phenomenology*" through the concept of the lifeworld (Moran, 2000).

"This textured, embodied, experienced world of colored trees, sparkling stars, alternative ways home, remembered seasons, happiness, joy, anguish and sadness. It is this lifeworld that any number (or word) refers to, without which numbers or words would have no meaning or living context". (Todres, Galvin, et al, 2007, p.55).

The concept lifeworld arose from a further Husserlian term 'horizon'. The horizon is the background or context to the objects of consciousness. All objects are perceived against a context, a 'horizon'. It is the lifeworld (horizon/context) that gives the object its meaning (Idhe, 1986). For Husserl, the lifeworld is not the focus of inquiry, rather it provides context to experience. Husserl terms the lifeworld as 'a pre-given world' and therefore indicates that it occurs in a pre-reflective state within the natural attitude (Husserl, 1970). Through an engagement with the phenomenological reduction, the lifeworld can be made thematic and its meaning explored (Moran, 2000). The significance of the lifeworld concept to this study will become clearer in its existential and hermeneutic interpretations. However, Husserl's positioning of the lifeworld as the context that surrounds experiences speaks to the study aim to understand

the phenomena of social media against the backdrop of being a young man living with DMD.

3.2.2 Descriptive Psychological Methodology

The central tenet of this study is an exploration of the lived experience of social media from the perspective of young men with DMD. Therefore, in exploring a methodology to meet this aim required an attitudinal shift from a philosophical to a psychological perspective. Giorgi's descriptive approach (2009) offers a well-established and renowned methodology that is grounded in the philosophy of Husserl, but applied to a psychological analysis. As such, in drawing on some of the key phenomenological concepts of Husserl it was appropriate to also assess the applicability of methodology associated with the descriptive position to the aims and objectives of the study.

Giorgi's approach involves Husserl's philosophical method, but does so from a psychological scientific perspective (Giorgi, 2009). For example, the account of others is analyzed as opposed to the philosopher analyzing their own intentional relationship with phenomena. Furthermore, a psychological attitude is adopted and so the focus is on the human subject. Nevertheless, the concept of the epoché is practiced with the intention of developing a complete eidetic picture of the phenomena in line with Husserl's method (Robinson, Giorgi et al, 2012).

Giorgi's descriptive phenomenological methodology has been applied to understand aspects of lived experience relating to healthcare such as the lived experience of dementia (Beck, 2013) and the experience of social anxiety (Robinson, Giorgi et al, 2012). If the study was to adopt the descriptive approach as its methodology, the aim would be to develop a descriptive synthesized summary of the general structure of social media as described by young men with DMD. However, the aim of the current study is to explore how the phenomena of social media is made sense of, and lived by young men with DMD. To meet this aim, there must be a move towards experience as lived and embodied.

3.3 Existential Phenomenology

Existential phenomenology is representative of the phenomenological turn towards experience as embedded within the world. The phenomenological position has an ontological insistence on understanding what it means to be in the world, to exist (Thomas, 2005). It is a branch of phenomenology that recognises young men with DMD as Beings who exist and whom cannot help but question their existence. As with phenomenology in general, there are many strands of thinking associated with the existential position. The philosophies of both Sartre (1956) and Merleau-Ponty (1945/1962) are of relevance.

3.3.1.1 Intentionality and the Lifeworld

Merleau-Ponty's work considers how the body interacts with the world and details the intentional correlation as '*body-subject*' as opposed to '*consciousness-subject*' as posited by Husserl. Merleau-Ponty rejects Cartesian thinking that argues a mind-body detachment, and instead proposes the mind and body as intertwined. Therefore, the body is in itself intentional; it 'reaches out towards the world' (Reuter, 1999). The body is therefore not an object to be viewed and observed through a natural science lens, but as a lived and experienced body (Reuter, 1999).

The body as lived means the body negates the potentialities of lived experience. For example, an able bodied person has many potentialities open to them; the body is able to interact with phenomena in the way that mind intends it to, and is therefore seemingly absent in the interaction (Leder, 1990). By comparison, a diagnosis of a degenerative condition such as DMD foregrounds the body so that it is present even if the self wishes it be ignored (Charmaz, 1983). Furthermore, the present body can lead to 'restrictive potentialities' (Merleau-Ponty, 1945/1962). The role of social media has potential to alleviate such restrictions, and offer new ways of 'getting around the world' (Tombs, 1995) by allowing the body to act in ways it would not be able to do within the 'everydayness' of the world.

The philosophical relevance of Merleau-Ponty's work on the intertwining of mind and body can be further reflected on in relation to the current study. The online world can present young men with DMD with the opportunity to have multiple 'online avatars' all performing for the mind in unique ways. In this sense, it could be assumed that the lived body, the body that has DMD, is able to be dissociated from or transformed within the online realm. Whether social media facilitates a renegotiation of 'bodily intentionality' (Merleau-Ponty, 1945/1962) is a source of inquiry for the study.

Merleau-Ponty (1945/1962) was also concerned with 'situated perspectives' in relation to the embodied relationship with phenomena. To understand the meaning associated with a phenomena, it must be described as a meaningful whole, made up of the figure or form (that which is most prominent) against a background (that which surrounds it) (Moran, 2000). The figural and the ground are co-creative entities, in that the figural aspect of experience can only be illuminated against the background. Merleau-Ponty posits the background as containing 'major grounds' that include body, time, other people, and world (Thomas, 2005). As such, in seeking a description of an experience one must consider the phenomena under investigation in light of these major grounds. For example, when encountering the phenomena of social media, it is likely that the presence of others will be most prominent, with time and the body in a state of fuzziness in the background. The figure and background are always in a state of interchanging as the phenomena is experienced against different backgrounds on numerous occasions. This interchanging also illuminates the uniqueness of meaning of phenomena to the individual (Thomas, 2005). Two young men with DMD, will experience social media in intrinsic ways, as the background against which the phenomena appears is unique to the experienter.

Sartre's renowned statement 'existence precedes essence' (Sartre, 1956) also holds philosophical value to the narrative of the study. Metaphysical thinking, particularly in relation to religion, often determines that individuals possess a predetermined essence, or inherent identity. Sartre contended this stance by positing that there is no fixed way of human 'Being'. Rather, individuals have freedom in defining their own essence, developed through the 'projects' they engage within the world and throughout life (Sartre, 1956). Therefore, in line

with Sartre’s philosophy, there is no predetermined essence that defines a way of ‘Being’ a young man with DMD. Instead there are many possibilities of Being and the individual has freedom ‘by oneself to determine oneself’, interpreted further by Sartre as ‘freedom to choose’ (Sartre, 1956, p 483). That is, an individual has freedom to define their essence based upon the projects they engage with in life. This aspect of Sartre’s existential philosophy speaks to the attempt to explore how social media may aid young men with DMD in defining their essence beyond that of a pre-assumed existence, through embarking on projects with the aim of becoming who they wish to be.

3.3.2 The Lifeworld as a Psychological Methodology

The Sheffield School led by Ashworth (2015) see value in drawing on a set of universal fractions of the lifeworld to enhance the analysis of phenomenological descriptions (Ashworth, 2003). The methodology proposed draws on the work of Giorgi (2009) and therefore maintains a strong commitment to the epoché in allowing the phenomena to speak on its own terms. However, Ashworth (2015) acknowledges the existentialist position that the lifeworld is intrinsically part of any experience and therefore cannot be bracketed. As Ashworth states, “*were we to bracket it, it would inevitably reappear as soon as an experience was opened up for description*” (Ashworth, 2015, p. 23). Therefore, according to Ashworth the lifeworld has certain fractions that are always present in any experiential encounter. Each fraction is described in the following table:

Table 3.1: The fractions of the lifeworld according to Ashworth (2015)

| Fraction | Meaning/Description |
|-------------------------------|--|
| Self-hood | The self does not exist internally but is revealed through one’s concerns with one’s world. Therefore, an analysis of an experiential encounter can reveal something about the participant’s identity and sense of agency. |
| Sociality | The presence of others, and relationships with others impact self-hood. |
| Embodiment | How is the body perceived and understood by self and others? This fraction is linked to project, how is the body able to perform projects? |
| Temporality and its events | How is the meaning of time and biography understood and present within the experiential encounter? |
| Spatiality and its things | How space is made sense of in terms of a person’s own geography. Not just the physicality of places, but the social norms and meanings associated with a place. |
| Project | How is the person able to fulfill the tasks and activities that are of meaning to them and are fundamental to their self-hood? |
| Discourse | How is language used to describe a lived experience? |
| Moodedness-mood as atmosphere | A feeling-tone exists within any experiential encounter. Objects and events that exist within the lifeworld are endowed with emotional meaning. |

Ashworth (2015) emphasised that each fraction is not strictly distinct, but has overlapping meanings. However, certain fractions may be more salient than others when presented within varying experiential accounts. For example, sociality and spatiality may be more salient in the experiential account of social media, while other fractions would still be essential but less salient. In applying the fractions to the analysis of data the lifeworld is recognized as an operationalized concept. In operationalizing the lifeworld the Sheffield School offer a methodology that focuses on the person experiencing as oppose to the object experienced. Ashworth (2015) therefore offers an approach to understanding how young men with DMD experience social media in the context of their lifeworld. However, the methodology advocates a strict commitment to the epoché in terms of ensuring the researcher is bracketed as far as possible. Difficulties with this are called into question in the acknowledgement that not just the participant, but the researcher are 'Beings in the world' and therefore an interpretive lens is warranted.

3.4 Interpretive Phenomenology

Interpretive phenomenology illuminates the ontological focus of the study, to understand what it means to 'Be' a young man with DMD in the world of social media. In addition, the phenomenological strand introduces hermeneutics, and in doing so positions the study as one grounded in interpretation (Pringle, Drummond, et al, 2009)

Heidegger's work '*Being and Time*' (1927, 2011) highlights the ontological origins of his phenomenology and beginning of interpretive phenomenological thinking. Heidegger first and foremost was interested in 'Being', that is, what does it mean to be, to exist within the world. Existence for Heidegger was an inescapable and embedded nature of 'Being in the world' (Horrigan-Kelly, Miller, et al, 2016). That is, humans exist and interact within a meaningful world.

3.4.1.1 Dasein (Being in the World)

To illustrate Being-in-the-world Heidegger developed the concept of Dasein; a Being that is concerned with and able to question its existence (Heidegger, 1927, 2011). To explore the structure of Dasein, Heidegger cast upon 'average

everydayness'. It is through everyday interactions that Dasein develops an understanding of Being. Heidegger's Dasein speaks to the pursuit of exploring how young men may make sense of their existence, their 'Being' through their interactions with social media.

For Heidegger, Dasein exists as an entity among others as opposed to alone, therefore a fundamental concept of Dasein is 'Being-with'. By 'Being-with', Heidegger illustrates that Dasein's existence is shaped by the presence of the 'they' or the 'Das Man' (Heidegger, 1927, 2011). The 'Das Man' refers to Dasein's perception of their social reality understood by the presence of nature, structures, and other Dasein (Horrigan-Kelly, Miller, et al, 2016). The structures and processes of social media and their influence on Dasein's (young men with DMD) existence in their everydayness can be pondered when viewed in light of Heidegger's Das Man.

Dasein is posited as having alternative ways of Being in relation to Das Man, namely the authentic or inauthentic existence. The inauthentic existence represents a passiveness and unquestioned conformity to societal norms and values, to the collective norms of the 'they' (Das Man), resulting in a loss of self-hood. By contrast, authentic existence is that of pure self-hood and understanding (Horrigan-Kelly, Miller et al, 2016). Heidegger therefore presents Dasein as having two modes of being in the world, the inauthentic 'they self', that which conforms to the Das Man, and the authentic self, 'that which is mine'. (Horrigan-Kelly, Miller et al, 2016). An authentic self does not relate to any moral goals, but to an understanding of one's unique capabilities and potential (Sherman, 2009).

Dasein's fundamental 'totality of Being' is based upon what Heidegger refers to as the 'care structure'. For Heidegger, "*Dasein's Being reveals itself through care*" (Heidegger, 1927/2011 p. 227). The care structure has ontological value, in that it exposes what is of most importance to Being, and that which is of most concern to Dasein (Horrigan-Kelly, Miller, et al, 2016). The care structure is articulated as three fundamental temporal aspects of Dasein's existence, the past, present, and future. However, Heidegger does not view them in the conventional form, but as future, past, and present (Horrigan-Kelly, Miller, et al, 2016). The stipulation of the future and past occurring before the present casts

Dasein as a Being thrown into a world that already exists and that is 'ready to hand', and a Dasein that is already ahead of itself (Willig, Rogers, 2017). It is the 'being toward the future' that reveals what matters to Dasein in terms of their existence, termed as 'mattering' (Yancher, 2015). Mattering reflects Dasein's ability to have agency in their existence, to act upon and make judgements based on what matters most to them (Yancher, 2015). Furthermore, Heidegger's care structure emphasizes meaning and agency as structures of Dasein. In this sense, Dasein (young men with DMD) exist in a world in which they cannot help but find meaningful, with a concern towards the future that reveals what matters most to them (Eautough, Smith, 2017).

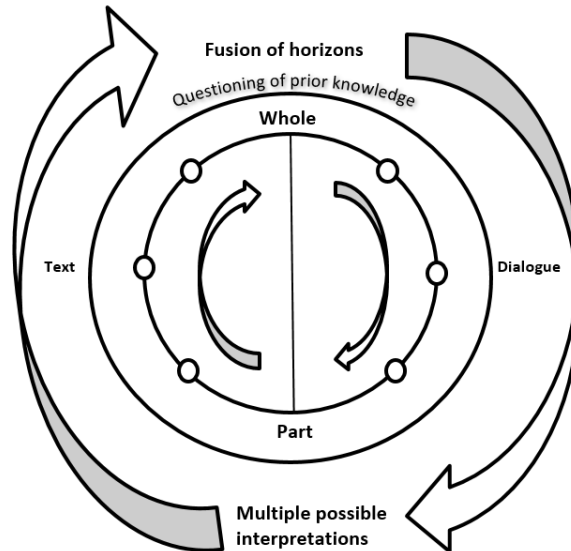
Heidegger posited that to be human, is to interpret (Heidegger 1927/1962). That is, as humans we have an innate desire to make sense of, and find meaning in our existence and experiential encounters with phenomena, and the method of doing so is through interpretation. In this sense, young men with DMD are not merely spectators of their intentional interaction with social media, but consciously look to interpret in order to understand and find meanings from those experiences. By the same merit, the researcher who encounters the experiential account cannot help but interpret and make sense of the account in light of their own Being in the world. The acknowledgement of such leads into a related discussion of a branch of philosophy referred to as hermeneutics.

3.4.1.2 Hermeneutics and the Epoché

Hermeneutics is the philosophy of interpretation and predates phenomenology in its origin. However, Heidegger fused the two positions together to form a hermeneutic phenomenology in his positing that experience is only understood through interpretation. Interpretation is the dynamic and iterative relationship between the fore-structure, and the new phenomena at hand (Smith, Flowers, et al, 2009). The fore-structure are the pre-understandings, experiences, attitudes, and socio-cultural context that make up an individual's being in the world (Smith, Flowers, et al, 2009). The inevitable and constant presence of the fore-structure presents a complete commitment to the epoché as difficult. That is not to say that the intention of the epoché of allowing a phenomena to speak on its own terms is not sought. Rather, an alternative process of doing so is put

forward that advocates awareness as opposed to bracketing, presented graphically as the hermeneutic circle (Peat, Rodriguez, et al, 2019).

Figure 3.1: Diagram of the hermeneutic circle (Peat, Rodriguez, et al, 2019)



The hermeneutic circle represents a process through which the fore-structure meets the new phenomena in an iterative, circular, and constant fashion. The iterative nature of the circle means that the biases, pre understandings and structures of the interpreter are constantly revealed, elaborated, and revised as they interact with the new phenomena to hand (Tappan, 2010). In first reading the transcript of an account of social media from the perspective of a young man with DMD. The preunderstandings present within the initial encounter with the transcript will evolve, adapt, but always be ever present as the transcript is reread and revisited, assisting the interpreter in making sense of the account. The circle also represents the dynamic between the part and the whole (Peat, Rodriguez, Smith, 2019). The dynamic between the transcript and the single extract demonstrates this. When reading a transcript, the reader is only able to understand the meaning of the transcript in relation to the cumulative extracts that make up the transcript. Likewise, the meaning of the extract only makes sense in relation to the complete transcript (Horrigan-Kelly, Millar, et al. 2016). Gadamer's projection of meaning further illustrates the part/whole dynamic of

the circle. As interpretative Beings we are drawn to project meaning onto something as a whole at the earliest opportunity. However, through careful questioning of the parts, the projection of meaning onto the whole is constantly evolving and changing (Lavery, 2003).

“Hermeneutics must start from the position that a person seeking to understand something has a bond to the subject matter that comes into language through the traditional text and has, or acquires, a connection with the tradition from which it speaks” (Gadamer, 1960/1998, pg. 295)

The above quote highlights the hermeneutic aim to interpret and understand meaning through text. For the influential hermeneutic phenomenologist Gadamer, *“Language is the universal medium in which understanding occurs, understanding occurs in interpreting”* (Gadamer, 1960/1998, p. 389). The meaning of a phenomena therefore lies within the language in which it is delivered, and the text in which it is written. It is the role of the phenomenologist, to examine and question the text, in order to bring the meaning of phenomena, which may be hidden or concealed to light (Smith, Flowers, et al, 2009). This questioning is not performed within a transcendental space, but within the world in which the fore structure and pre conceptions are ever present (Lavery, 2003). More so, the presence of pre conceptions may not be known prior to interaction with the text, only becoming known as the phenomenologist makes sense of their emergent interpretations (Smith, Flowers, et al, 2009). Therefore, rather than putting one’s preconceptions up front prior to interpretation as advocated by the epoché, the interpreter seeks awareness and transparency of what they are ‘bringing’ to the encounter with the text, through an interaction with the hermeneutic circle (Smith, Flowers, et al, 2009).

3.5 The Methodological Approach to the study; Interpretative Phenomenological Analysis

Whilst the approaches so far outlined are all relevant and potentially applicable to the study in their broad aims to interpret the lived experiences of participants, Interpretative Phenomenological Analysis is most appropriate, Interpretative Phenomenological Analysis commitment to the inclusion of theoretical concepts, and it's positing of the participant as reflective Beings that makes it a suitable to an exploration of how social media is experienced by young men with DMD.

Interpretative Phenomenological Analysis (IPA) has a fundamental concern in how a particular phenomenon has come to mean something to a particular person, in a particular situated context (Smith, Flowers, et al, 2009). It is the focus on meaning making as a reflective process that relates IPA to cognition, thus separating it from other hermeneutic phenomenological approaches in its commitment to psychology. IPA posits reflection as being a layered process, beginning in the pre-reflective natural attitude and moving to a 'phenomenological reflection' (Smith, Flowers, et al, 2009). It is the objective of an IPA study to situate participants within the 'phenomenological reflection'. Therefore, the intention of this study, through methods outlined in the next chapter, was to provide participants with an opportunity to contemplate and make sense of the meaning of their experiences of social media that prior to reflection, had existed within the taken for granted everydayness of their Being in the world.

The first aim of IPA is to adhere to its descriptive foundation and provide a rich description of 'what it is like' for an individual to interact with a phenomena. Within this endeavour, the IPA researcher acknowledges that a direct first person account of an experience is not attainable. Rather, the account is a construction between participant and researcher, and therefore the objective is to produce a third person description of the intentional experience, that aims to get as close to the participant's account as possible, to see the world as they do (Smith, Flowers, et al, 2009).

The second aim of IPA and perhaps its most distinguishable from other phenomenological approaches is to attend to the interpretative nature of the experiential account. The hermeneutic underpinnings of the methodology position the researcher as an integral part of the sense making process. For IPA, both the participant and researcher are 'Beings in the world' and therefore any description is influenced by the pre conceptions, past experiences, and lifeworld of both the participant and the researcher. Smith, Flowers, et al (2009) refers to the process as a double hermeneutic, with the researcher making sense of the participant making sense of their experiences. For IPA, this sense making process is layered and dependent on the participant's willingness to reflectively engage with their experiences (Smith, 2018). Reflective engagement begins at the literal, a participant may for example ask what is the literal definition of the word being considered. The participant may then reflect on what does the text actually mean. This could be from a pragmatic perspective, such as what did they mean when they said that. Or it could be at the experiential level, for example how do I experience social media in my everyday Being in the world. Finally, participants may engage in existential experiential reflection, what does the experience of social media mean for my identity and existence. It is the role of the IPA researcher to guide the participant to engage in the layers of reflection in order to make sense of the meaning they attribute to the phenomena (Smith, 2018, p.2).

Despite being interpretative, IPA still maintains the phenomenological principle 'to the things themselves'. That is, whilst IPA has been developed to allow the researcher to undertake an extensive interpretive repertoire to examine the account, such as relevant theory, there is still a commitment to ensuring the interpretation is grounded in the text and can be traced back and recognizable to the core account (Smith, 2004). In addition, the researcher keeps an open 'polymorphic mindedness' to the text being examined (Idhe, 1984, p.15). That is, the researcher remains open to the many possible meanings of the phenomena.

IPA recognizes the participant as being embedded in their world, therefore an account of social media can be legitimately used to reveal an account of the person who produced it. In pursuit of gaining a glimpse into the lifeworld of the

participant, revealed through their account of social media, the IPA researcher also adopts a critical and investigative lens. Questions such as ‘what is the person trying to achieve here? Or ‘is there something appearing that wasn’t intended’ may be used to get to the hidden meanings that exist within the participant account, in order to reveal something about the participant. Furthermore, IPA with its philosophical grounding within the three strands of phenomenology outlined, offers the researcher philosophical freedom in attaining to the concepts akin to each strand and to make them operational throughout the study. For example, Ashworth’s (2003) universal notions of the lifeworld can be drawn upon to aid interpretation, as well as the philosophy of Sartre and Merleau-Ponty noted within the chapter.

Idiography relates to a commitment to examining the unique and particular (Smith, Flowers, et al, 2009). IPA is idiographic in that the analysis always begins with, and is retained and grounded in the particular. In this sense, whilst the development of general themes is of importance in capturing an overall understanding of the lived experience of social media, the root to such general themes should be coherent back to the particular account. The application of the commitment to the particular will be outlined within the method chapter.

IPA recognizes the importance of language within the mean-making process, through the use of narrative, discourse, and metaphor, and within the way it performs within certain contexts such as during an interview (Smith, Flowers, et al, 2009). However, IPA views language in a different way to established discursive approaches such as Foucauldian Discourse Analysis (Arribas-Ayllon, Walkerdine, 2017) and Discursive Psychology (Potter and Wetherell, 1987). Discursive approaches have a general interest in the effects of language and discourse (Willig, 2017). In comparison, IPA in viewing individuals as ‘existential world disclosers’ is interested in how language is used to disclose or reveal a participant’s experiential encounter (Yancher, 2015).

3.6 Summary

This chapter has explored the rationale and choice of phenomenological approach, highlighting the philosophical principles of relevance to the current

study. Interpretative Phenomenological Analysis (IPA) encompasses and makes operational these principles. The next chapter will outline the study methods, influenced by IPA

Chapter 4 Method

This chapter presents the methods undertaken to address the study aims and objectives. The aims and objectives of the study are again outlined, then details of the methods of sampling and recruitment, data collection, and data analysis are outlined. The steps taken to ensure the quality and rigour of the study are then discussed. The chapter concludes with an overview of the specific ethical considerations of the study and how each was addressed.

4.1 Aims and Objectives of the study

The overarching aim of the study was to explore the lived experience of social media from the perspective of young men living with Duchenne Muscular Dystrophy (DMD). Specific objectives of the study were to:

- Understand the role of social media in the daily lives of young men with DMD
- Identify how the impact of living with the condition may influence the way young men with DMD interact with social media.
- Understand what motivates young men with DMD to engage with social media.

4.2 Study Setting

As outlined in Chapter One, as the life expectancy for those with DMD increases, providing hospice care that is developmentally appropriate can be difficult. Many children's hospices state an upper-age limit of 19 years or to the early 20's, with only a few hospices offering care up until the age of 35 (Fraser, Aldridge, et al, 2011). Nevertheless young men with (DMD) 'form a large proportion of the cases cared for by children's hospices in the UK (Fraser, Aldridge, et al, 2011). Consequently, a children and young adult hospice based in Yorkshire provided a suitable setting for the study. Initial enquires with the hospice were made regarding the appropriateness of the setting for the study.

Young men with DMD and their families form a large proportion of their cases, with respite care offered up to the age of 35. The hospice has two distinct areas, one cares for children and young people up until the age of 13 and their families. The other is a purpose built 'lodge' for teenagers and young adults, that includes six en-suite rooms. The lodge includes a variety of rooms for young people to engage in a range of activities, including a music studio, computer, and games area, and a multimedia recreation centre with cinema and video gaming capabilities. The hospice was keen to support the study, and engaged in all aspects from study development through to dissemination activity. An email outlining an agreement for the hospice to support the study is provided in Appendix 1.

4.3 Patient Public Involvement Activity

Patient and Public Involvement (PPI) is a central and essential component of health research and can have positive impact on all stages of the research process to ensure the research is patient centred (Chalmers, Glasziou, 2009; Ocloo, Matthews, 2016). PPI is defined as 'research that is carried out with members of the public (including people from organisations that represent people who use services) rather than to, about, or for them' (NIHR INVOLVE, 2020). PPI in health related research can help to ensure that the aims of the research are focused on topics that are most pertinent to healthcare users (Crowe, Fenton, et al, 2015). In recognition of the importance of PPI activity, guidance on how to incorporate PPI activity into research studies exist (NIHR INVOLVE, 2020). More specifically, guidance on PPI activity as a component of doctoral research has been published and followed by the study outlined in this thesis (Tomlinson, Medlinskiene, 2019).

To ensure the study was relevant to young men with DMD, and that the methods of recruitment and data collection were suitable to the sample, two healthcare professionals involved in the hospice care of young adults and a well-established Young Person's Advisory Group were consulted. In addition, a twitter chat involving young people with life-limiting conditions was undertaken to gauge young people's views and opinion on the area of study. This helped me to further shape the study aims and objectives.

The two PPI health care representatives that could advocate on behalf of the study participants held nursing roles at two different children and young adult hospices. They each had extensive experience of working with young men with DMD. They assisted in the following tasks:

- Identifying and developing the aims of the research. Both representatives described that staff were unclear of how to best cater for the online needs of young men with DMD. To address the gap in practice understanding, they perceived that a broad exploratory aim was appropriate.
- Developing and reviewing recruitment materials such as the Participant Information Sheet (appendix 3). The well-established Young Person's Advisory Group, also reviewed all recruitment documents to ensure they were age appropriate.
- Developing and reviewing the interview guide (appendix 7)
- Engaging in developing appropriate dissemination strategies for of research findings (discussed in-depth in section 7.5).

The 'Twitter Chat' focused on the role of social media as a mechanism for psychosocial support for young people with life-limiting conditions and was also attended by academics associated with the field and healthcare staff. A summary of that chat has been published (Peat, Smith, et al, 2018).

Key findings from the chat included:

- Health professionals recognised the importance of understanding how young people with life-limiting conditions use social media.
- Health professionals were unsure of the platforms of social media to engage with, and the type of content to share, to best support young people with life-limiting conditions.
- Academics discussed the limited evidence base on the use of social media by young people with life-limiting conditions.
- Young people perceived that in general their psychosocial needs are not met or included in their care plans.

Reference will be made throughout the chapter to the impact of PPI at different stages of the research process.

4.4 Sample and Recruitment

This section details the sampling approach adopted to identify participants, and the processes followed to recruit participants to the study.

4.4.1 Sample selection strategy

To meet the aims of the study a sampling approach was required that was consistent with the qualitative paradigm, and specifically IPA (Smith, Flowers, et al, 2009). Theoretical and purposeful sampling approaches are well adopted approaches to sampling in qualitative research (Moser and Korstjens, 2018). Both sampling strategies aim to identify participants who have an interest, or shared experience in a particular phenomenon. However, they differ in their application of selection criteria. In a purposeful approach to sampling the selection criteria are predetermined. While in theoretical sampling the sampling criteria are abroad at the start of the study, sampling criteria are refined and adapted in line with emerging theory, consequently the approach is synonymous with Grounded Theory (Moser and Korstjens, 2018).

Purposeful sampling has sub categories including 'referral', where participants are identified by gatekeepers, or 'snowballing', where participants may refer others to engage with the study (Smith, Flowers, et al, 2009). In line with the idiographic principles of IPA, the aim is to purposefully identify a sample of participants that share experiences of a particular phenomenon. Consequently, a degree of homogeneity is expected and sought, with the focus on representing a particular perspective, rather than generalising to a wider population (Smith, Flowers, et al, 2009). As a result, in keeping with the principles of IPA and in order to meet the study aim, a purposeful approach was adopted. Inclusion and exclusion criteria were defined in advance of recruitment (figure 4.1). Being a novice researcher in this study area and not a clinician was a consideration when identifying potential participants to take part in the study. It was decided that only young men with DMD who had capacity to confirm

consent verbally and to participate without the aid of others, would be invited to the study.

Figure 4.1: Inclusion and exclusion criteria

| Inclusion Criteria | Exclusion Criteria |
|--|---|
| <p>Young men aged 16 to 35 living with Duchenne Muscular Dystrophy who interact with social media (including video gaming)</p> <p>Young men aged 16 to 35 living with Duchenne Muscular Dystrophy who received respite care from a Children and Young Adult hospice.</p> | <p>Young people who did not speak fluent English</p> <p>Young men with Duchenne Muscular Dystrophy who were approaching end-of-life</p> |

The primary purpose of an IPA study is to provide a rich and detailed account of individual experience (Smith, Flowers, et al, 2009). Therefore, as with other qualitative approaches, sample sizes are often small in comparison to quantitative research. A small sample size reflects the need to commit time to engage with each participant in order to collect the depth of data required to understand their perspectives and ensure the analysis does justice to the accounts offered (Smith, Flowers, et al, 2009). It is not always possible, nor desirable, to predict precise sample sizes at the start of a qualitative study. Data collection and preliminary analysis occur simultaneously which guide the final sample size ensuring the study aims are met.

While sample size of between three and twelve participants for student projects and doctoral studies are suggested (Smith, Flowers, et al 2009), it is also important to be flexible and adopt a sample that is appropriate to meeting the aim(s) of the study. However, large sample sizes are generally not advocated in IPA, owing to the necessity to perform a rich in-depth account of each participant case (Smith, Flowers, et al, 2009).

4.4.2 Recruitment materials

This section outlines the development of recruitment materials that included a: cover letter, participant information sheet, information sheet for parents/guardians, carer information sheet, and consent form. All materials were first reviewed by the PPI representatives, as well as a young person's advisory group to ensure the appropriateness, readability, and sensitivity of the materials. All materials were approved by the University of Leeds School of Healthcare Research Ethics Committee (SHREC). Study materials are presented in Appendix 2-6.

4.4.2.1 Invitation letter

An invitation letter (appendix 2) that informed potential participants about the opportunity to take part and information pack was sent to participants (described further in section 4.4.3). The PPI representatives advised that an invitation letter should be signed by a representative of the hospice to complement the recruitment materials and offer reassurance that the hospice settings were supportive of the study.

4.4.2.2 Participant information sheet

Participant information (appendix 3) was developed in line with guidelines provided by the University of Leeds School of Healthcare Research Ethics Committee (SHREC). The involvement of PPI representatives and a young person's advisory group was fundamental to ensuring the document was appropriate for the sample of young men. Several versions were developed prior to a final document being agreed. Duchenne Muscular Dystrophy can affect cognitive function, therefore it was essential that participants were able to fully understand the information provided, and therefore the document was reviewed by PPI representatives who had extensive experience of caring for young men with DMD, to check readability was appropriate for the target sample. An online readability calculator (Gunning-Fog index, 1968) was also used.

4.4.2.3 Information sheet for parents/guardians

The study PPI representatives advised that the participant information pack that were posted to participants who lived with their parents should also include information for parents/guardians. The purpose of the document was to request parents/guardians to support participants in reading information about the study, should they have needed assistance (appendix 4). The purpose was not to affirm consent from parents/guardians for their son to participate in the study. The information sheet was reviewed by PPI representatives to check for appropriateness

4.4.2.4 Information sheet for carers

Information was also produced for carers at the hospice where recruitment and data collection took place (appendix 5). The information sheet was, developed with the support of the study PPI representatives and provided an overview of the study. To develop a level of trust with the people who provided care for participants during their respite stay it was important to be transparent and clear about why the study was taking place, who it would involve and why, and what involvement would be expected by the carers. The information primarily provided an overview of the study and asked carers to support participants during interview if necessary. In addition to the information sheet, I attended the hospice on multiple occasions to explain the research study to hospice staff.

4.4.2.5 Consent Form

Seeking informed consent from participants is a fundamental process in any research study (Streubert, Carpenter, 2011). The process of consent and the ethical issues are explored in section 4.8 of this chapter. Guidance from the University of Leeds School of Healthcare Research Ethics Committee (SHREC) was used to develop the consent form. The study PPI representatives reviewed the consent form (appendix 6) in particular whether the content of consent form was reflective of the information provided to participants in the participant information packs. Due to the impact of Duchenne Muscular Dystrophy on fine motor skills, particularly related to the hands, it was assumed that the consent form would be read to the participant, with a carer present who confirm that verbal consent had been taken.

4.4.3 Process of recruitment

This section outlines the recruitment of participants. The initial recruitment strategy focused on the hospices with later recruitment using social media, both strategies are described.

4.4.3.1 Children and Young Adult Hospice

A children's and a young adult hospice located in Yorkshire supported the recruitment of participants. The recruitment strategy was designed in consultation with a senior nurse and the administrative team at the hospices. A purposive sampling strategy was used to identify potential participants who met the inclusion criteria. Eligible participants were sent a participant information pack (that included a cover letter, participant information sheet, parent/guardian information sheet (Appendix 2-4) one month prior to a booked planned stay at the hospice. The hospices posted the pack which negated the need to share addresses with me. The majority of the planned stays booked by eligible participants were clustered around school/college term holidays. Therefore, most participant information packs were sent one month prior to each term holiday, beginning in October 2018 and ending in July 2019.

My university email address was provided in the participant information to enable people to contact me that were interested in the study. Postal contact details and a pre-stamped envelope were also provided for the same purpose. Posting information packs to potential participants one month prior to their planned stay at the hospice, provided sufficient opportunity for participants to contact me in advance of their hospice stay. A dialogue between participants who were interested in taking part in the study was established via email with a date and time agreed to meet during their stay at the hospice. One participant opted to be interviewed at their home.

Recruitment via the hospice occurred over a period of eight months. The progress of recruitment was reviewed on a monthly basis with the hospice administrative team, with further eligible participants identified and contacted via post as necessary. The process was repeated until all eligible participants had been contacted. Throughout this recruitment strategy period a total of seven

participants were recruited . While further eligible participants were booked to attend the hospice at later dates in the year, it was decided in line with the study timeline, that an alternate method of recruitment should also be utilised

4.4.3.2 Twitter

The use of Twitter as a method of recruitment has grown in popularity in recent years (Hendricks, Düking, et al, 2016). The properties of Twitter lend themselves well to recruitment purposes because it is a commonly used medium to share ideas and promote widespread conversation (Forgie, Duff, et al, 2013) and less than 10% of user accounts are private (Wasilewski, Stinson, et al, 2019). Consequently, the open access nature of user accounts facilitate purposive sampling approaches such as the ‘snowball’ technique, whereby ‘retweets’ can enable the rapid sharing of recruitment tweets (Wasilewski, Stinson, et al, 2019). Therefore, Twitter presented a viable method of recruitment for the study.

A ‘recruitment tweet’ was developed in consultation with the study PPI representatives (figure 4.2). An additional sample of five young men with DMD to compliment the seven participants recruited using the hospice recruitment method was sought. To obtain a degree of variance in the sample, it was also decided to focus recruitment via Twitter on participants aged 21-35. Hospice recruitment had been successful in recruiting young men predominately aged 16-21.

Figure 4.2: Twitter recruitment tweet

“I am keen to talk to five young men aged 21-35 with DMD (muscular dystrophy) about their experiences of using social media and gaming as part of my PhD research. If you are interested or have any questions please contact me via email (address) #DMDPathfinders”.

An ethical amendment to the original approved ethics application was submitted prior to the start of recruitment via Twitter to the University of Leeds School of Healthcare Research Ethics Committee (SHREC). The amendment detailed the use of Twitter as an additional method of recruitment, and considered the ethical implications associated with this method of recruitment (detailed in section 4.8). On approval from SHREC, the tweet was posted from my Twitter

account. Various hashtags associated with charities and organisations that support young men with DMD and have a Twitter presence were added to the tweet. Research suggests that the use of hashtags can benefit the visibility and distribution of a tweet (Hamad, Wu, et al, 2014). The tweet was also 'pinned' to the researchers Twitter profile. This feature of Twitter is designed to increase tweet visibility by 'pinning' the tweet to the top of the users profile.

The tweet received a total of 88 engagements, was retweeted 18 times, and had 12 likes. Among the retweets were organisations and charities related to DMD, meaning the tweet was also shared among their followers. The tweet was reposted from the researchers account on a monthly basis over the period of three months. One participant responded to the recruitment tweet by emailing the researcher. Email dialogue between myself and participant was established. The participant information pack was sent as an email attachment to the participant. The participant then confirmed that they were willing to participate in the study, and the date of the first interview was agreed. In total eight participants recruited over a 12 month period. Participant characteristics are described at the beginning of Chapter 5.

4.5 Data Collection

Data collected comprised of sequential semi-structured interviewing with participants. This section first outlines the process of developing rapport between myself and participants, before the rationale, and delivery of the chosen methods of data collection are described.

4.5.1 Developing rapport between researcher and participant

The notion of 'rapport' is well established within the qualitative paradigm (Willig, Rogers, 2017). However, the term has been widely interpreted resulting in a range of interpretations. For some authors, rapport refers to the ability to recognise and be responsive to the feelings and opinion of the other, and in doing so build a sense of trust and understanding (Knight, 2009). Morgan and Guevara (2012) suggest rapport relates to the degree of comfort in the relationship between researcher and participant. This position was most resonant with my experience of prior email engagement with participants before

data collection. Contact between myself and the participant/s prior to data collection was beneficial in that it provided the necessary time and space to build a sense of familiarity and shared commonality with one another.

Establishing a line of communication prior to data collection, also afforded the ability to organise the most ideal environment for the interview/s to take place from the perspective of the participant. The majority of participants (n=6) opted to be interviewed at the hospice they were initially recruited through, during a period that they were receiving respite care. One participant wished to be interviewed at his flat, whilst another participant opted to be interviewed via Skype from his family home.

Prior to interview, email communication was established between the majority of participant's and myself. This afforded the opportunity to share aspects of ourselves such as our hobbies and interests, outside of the context of an interview. Much of this dialogue was often related to video gaming. On reflection, the tendency to focus on this phenomenon may have been influenced by both parties' search for 'safe-ground' in our initial interactions. In circumstances whereby email communication was not possible, I arranged to meet the participant the day before, or morning of the interview at the hospice. Video gaming also took centre stage during these initial interactions between myself and the participant. The presence of video gaming provided a neutral topic to begin to form a level of rapport with one another.

4.5.2 Chosen method of data collection

A range of data collection approaches can be adopted in qualitative research, including interviewing, focus groups, observations, and diaries (Willig, Rogers, 2017). Each approach has been used in studies guided by an Interpretative Phenomenological Analysis (IPA) approach. However, overwhelmingly IPA researchers adopt interviewing as the primary method of data collection (Smith, Flowers, et al, 2009).

Semi-structured interviews provide the necessary structure to stay close to the phenomena of interest, while facilitating the equally essential freedom for the participant to draw on their own unique lived experiences of the phenomena (Smith, Flowers, et al, 2009). In comparison to structured interviews whereby

the questions and structure of the interview are fixed (Arksey, Knight, 1999). Semi-structured interviewing values the participant as the 'experiential expert' (Smith, Flowers, 2009). Therefore, while a topic guide is developed it is applied loosely in order to enable the participant to arrive at the meaning of the phenomena on their own terms. Consequently, semi-structured interviews can provide the rich in-depth data necessary to perform an IPA (Smith, Flowers, et al, 2009). While unstructured approaches to interviewing are often advocated in IPA (Smith, Flowers, et al, 2009), it was decided in consultation with PPI representatives that a semi-structured approach was most appropriate. Several of the participants involved in the study had cognitive impairment and therefore the use of a topic guide with questions and prompts was necessary to support them to describe and make sense of their experiences.

Sequential semi-structured interviewing was used as the primary method of data collection. This involved participants being interviewed on average twice, over an average one week period. The different approaches undertaken to semi-structured interviews by the study are discussed. First, a description of the development of the interview topic guide is provided.

4.5.2.1 Development of the interview topic guide

An interview guide was developed in consultation with the study PPI representatives, the young person's advisory group and discussion with supervisors. The purpose of the guide was to provide a loose structure to the interview to ensure that the aim of the study was addressed. Prior to asking the participant any questions, it was recommended by the young person advisory group that I provide a descriptive background of myself. It was felt that in doing so, participants may feel more comfortable and relaxed in describing their own lived experiences. A further intent of the interview guide was to facilitate an interview that was as participant-led as possible (Smith, Flowers, et al, 2009). Consequently, the questions were not designed to be prescriptive, but to be used as a guide to facilitate the participant to make sense of the varied aspects of their lived experience of social media. Two pilot interviews were undertaken, with iterations made to the guide based on feedback. For example, prompts were added to questions related to social media and the self. It was felt that

these questions may have been challenging for participants to initially make sense of.

Prior research, theory, and PPI activity influenced the development of the interview guide. Table 4.1 provides an overview of the guide and how it was informed by previous research, theory, and PPI activity.

Table 4.1: Overview of the influence of previous research and theory on the development of the interview topic guide.

| Interview guide sections | Influence of research/theory/PPI Activity |
|--|---|
| Introducing the researcher and the interview | PPI Activity: Importance of providing participant insight into researcher's lifeworld |
| Understanding the participant | Merleau-Ponty: Understanding the 'situated perspectives' of participants. |
| Social media activity | Findings of the integrative review suggested AYAs with life-limiting/threatening conditions, or disabilities use social media for purposes of making sense of illness and leave a legacy, provide and receive support, socialise with others, and escape their illness. Do young men with DMD engage with social media for similar reasons? |
| Social media and the self | Self-Presentation Theory (Goffman, 1959). How might social media enable young men with DMD to have agency over the online self they present to others? Self-Discrepancy Theory (Higgins, 1987). Do discrepancies exist between the offline/online self? |
| Social media and self-disclosure | Disability disclosure Furr, Carreiro et al, (2016). Do young men with DMD wish to disclose their disability online? How is this experienced? |
| Social media and accessibility | Findings of the integrative review suggest young men with DMD may encounter accessibility challenges. If so, how are these experienced? |

4.5.2.2 Video gaming as an integral part of the interview encounter

The use of video gaming during interviews has been alluded to by authors who have carried out research with young men with DMD (Abbott, 2012; Wästerfors & Hansson, 2017). In both studies, the authors described how video gaming had been present at the start of the interview encounter. However, limited information was provided about the impact of the activity on the interview

encounter. This study developed an approach to semi-structured interviewing that engaged video gaming as a tool to enable participants to illicit their lived experiences of video gaming specifically, and more generally social media.

I was keen to be led by the participant in relation to the format and structure of the interviews. During my time as a carer at a children and young adult hospice I witnessed the prevalence and importance of video gaming as a daily activity for some young men with DMD. It was therefore perhaps unsurprising that several participants asked for the interview to take place whilst they also engaged in video gaming.

All interviews that involved video gaming took place at the hospice, in a 'gaming room' that featured a large screen and several video gaming consoles. Prior to the start of the interview, consent was confirmed verbally, and was witnessed by a member of the hospice care team. The care team member then left the room if the participant were happy for them to do so. The interview then started with the participant choosing a video game they wished to play. The video games chosen by participants influenced the flow and structure of the interview. For instance, the video game 'Grand Theft Auto¹' was a popular choice with participants. The game sees the player take control of a character who is free to engage in a broad range of activities. These activities ranged from the mundane, such as going shopping, to the extreme of engagement with acts of violence. Participants during interview described their actions in the game, and at times reflected on their meaning. For example, on entering into a nightclub in the game, the participant engaged in a comparative discussion about their social life within, and outside of video gaming. Similarly, the importance of player customisation was described both verbally, and through the in-game action of the participant's character:

'Yeah it kinda shows what type of person you are kinda like from the way you, like customise things like and how they look and stuff'.

¹ An action/adventure role play video game that features a narrative of a crime underworld that players engage with through missions.

Maintaining a balance between respecting the apparent reverie of participants while they video gamed, and staying attune to the interview schedule was on occasion a challenge. I reflect on interviews where I attempted to draw the participant back to the focus of the interview by asking a question removed from what was taking place during the video game. The consequence was a return to the literal meanings of social media, a sign that the participant had possibly withdrawn back from the interview. I learnt to trust the flow of the narrative, and with the aid of subtle prompts from the interview guide, led the participant to uncover the holistic meaning of social media to their Being.

Certain genres of video games did not compliment the desired in-depth nature of the interview. Fast-action sports video games in particular presented difficulties, with the participants attention primarily focused on the demands of the video game. The following dialogue is reflective of the disharmony between the interview and video game. In this example, a question asked resulted in the opposition team scoring on the football video game 'Fifa'²:

I: Oh sorry....

(opposition team scores on the game)

P: (laughs) It's cool what were you saying?

In instances where participants opted to play fast-paced video games, it was agreed that the researcher and participant would spend time between episodes in the video game, and that where appropriate the video game would be paused to engage in a more focused dialogue. Interviews using this style of interviewing lasted on average 1hr 10 minutes. At the end of each interview I would briefly reflect with the participant about what we had discussed. This was for the purpose of ensuring the participant was happy and comfortable with the interview, and provided a further opportunity to affirm consent to my use of their data. A follow-up interview was also offered. All participants who agreed to be interviewed again opted to do so without the presence of a video game in subsequent interviews. I later pondered whether a degree of trust had been

² Fifa is a series of annual football simulation video games developed by Electronic Arts

established between participant and researcher in the initial interviews that included video gaming. I reflect further on this interview technique within Chapter 7, section 7.2.

4.5.2.3 Interviewing without video gaming

As previously stated, the format of the interviews was dictated where possible by the participant. Some participants chose to be interviewed without the involvement of video gaming (for first and second interview, n=2, for second interview, n=6). Interview location varied, from a private conservatory attached to the hospice, to the front room of a participant who lived in an assisted living apartment.

During these encounters, void of the presence of a video game, the interview guide took a salient role and provided a guide to the interview. However, participants were rightly viewed as the experiential expert, and therefore directed the interview through the experiences that mattered most to them. Prompts were used throughout to help bring to light aspects of experiential accounts that may have previously been hidden. Providing the space and opportunity for participants during this format of interview to discuss experiences that were most resonant to them, rather than being dictated by a strict interview guide, also afforded the opportunity for several teachable moments to arise. For example, one participant informed me about the tactics of the sport of wheelchair football. These interactions enriched the rapport between the participant and myself, and led to an openness from the participant to further questioning:

“Ask me anything it is fine”.

Interviews that used this format lasted for an average of forty minutes, with the shortest interview fifteen minutes long, and the longest lasting for just over ninety minutes. In total (combined interviews including video gaming and without) 18 interviews were undertaken with participants.

4.5.2.4 The presence of others during the interview/s

Throughout data collection, on occasion the carers of participants, including family members and hospice staff were present during interview to respond to the care needs of participants. Within the hospice setting, as an initial outsider, I was greeted with caution and hesitancy, with my 'agenda' repeatedly questioned by some carers who understandably sought to protect and shield the participant. I was grateful for these interactions, as they led to detailed discussions about the nature of the research, beyond what I could convey in the carer information sheet, and the group meetings I held. Established relationships between myself and the hospice team developed during my time as a volunteer, also helped to nurture trust.

The aim of the hospice to 'offer independence and dignity' to its residents, was reflected in the behaviour of carers who were attuned to the autonomy of the participant. As such, for the majority of interviews that took place at the hospice, carers would only interject when necessary (administer medicine, assist participant to get comfortable). Indeed, on occasion the carer questioned the participant as to why their intervention was necessary. In the following quote the carer interrupted the interview to move the participants head to make him more comfortable. After doing so the carer remarked:

"I'm sure George could have done that for you if you had asked him".

Understandably the participant may have not felt comfortable asking me to do so. Nevertheless, the above dialogue depicts the level of trust established between myself and those who provided care for the participant, that ultimately led to interviews for the most part being exclusive to just myself and the participant (although interviews always took place in view of a member of staff, such as in the hospice conservatory). For the two participants who chose to be interviewed at home, the involvement of others was limited. For the participant who was interviewed via Skype at his family home, his mother was only present at the start of the interview, to help set up the Skype video call. For the participant who was interviewed at his flat that he shared with his 24-hour carer, whilst said carer was present during the interview, he rarely interjected in the conversation between myself and the participant.

4.5.2.5 Commonalities across interviews

Each interview with participants was a unique event, depictive of the contextual lifeworld of the participant and make-up of the interview. In addition, the cognitive ability of participants varied and influenced the discourse shared. For example, the meaning of social media to several participants was conveyed through literal descriptive responses. By contrast, other participants were able to draw on discourse to convey the existential meaning of their lived experiences of social media. I reflect on the 'meaning-making' (Smith, 2018) process between myself and the participant in Chapter 6, section 6.1. Nevertheless, shared commonalities also existed across interviews.

Every interview was an 'interactional event' with meaning communicatively assembled through the 'double hermeneutic' between researcher and participant (Smith and Flowers, et al, 2009). On occasion, the 'coming together' of researcher and participant led to mutual disclosure. For example, experiences of being bullied were expressed by both parties during one interview. During this event, I was mindful to not overshadow the participants lived experience of bullying. Rather, I hoped that revealing my own vulnerability helped to balance the inherent power imbalance inherently at play. It is important to note that the participant's account of being bullied was a historical event. Ethical plans were put in place and adhered to regarding the disclosure of information that would have led me to believe the participant was at risk of harm.

I worked with each participant to reach a fusion of meaning, whereby I understood the meaning of the lived experience of social media that each participant attempted to convey to me. It was made clear to participants, both at the start of the interview and throughout, that there was no set or right answer to any of the questions I may pose, and that my interest was in their own unique, subjective experiences of social media. Doing so, encouraged participants to explore the varied and unique meanings of the phenomena (social media) as it appeared to them.

4.5.3 Management of data

Audio data from the interviews was transcribed by myself to facilitate the start of a knowingness and immersion within the data . Nonverbal as well as verbal behaviour was noted. Capturing both verbal and nonverbal interaction aided my understanding of the meaning of social media to participants whose verbal responses were literal. Nonverbal behaviour was illustrated in the transcripts within brackets, such as (pause), (laughter), (quiet tone of voice). Multiple interviews from each participant were transcribed into one document, to aid data analysis. As well as audio recorded data, I also kept a journal of field notes throughout data collection. These notes were pivotal in developing a layered interpretative account of the data. The storage of data is discussed in section 4.8. of this Chapter. A description of the data analysis undertaken follows.

4.6 Data Analysis; An Interpretative Phenomenological Analysis (IPA) approach

In line with the philosophical and methodological underpinnings presented in Chapter 3, Interpretative Phenomenological Analysis (IPA) (Smith, Larkin, et al, 2009) governed all aspects of the study, including data analysis. IPA offers a seven-staged process to analysis that begins at a case level (individual transcript), before moving to an analysis across cases (all transcripts), which are now described.

4.6.1 Initial Case-Level Data Analysis

Working first at a case level, I initially engaged in a process of data familiarisation, that involved reading the participant's transcript and field notes, and listening to audio-recordings of interviews (stage one). The longevity of data collection meant that in some cases, I had not returned to the data of participants for a period of time. Therefore, this first stage of data familiarisation was necessary to become re-immersed into the participant's account.

Following this initial familiarisation of the data, I moved to developing an 'exploratory commentary' (Smith, Flowers, et al, 2009, p.84) of the transcript, coding at a descriptive, linguistic, and conceptual level (stage two). Central to this activity was a 'slowing down' of my analytical thinking, mindful not to force my own assumptions onto the data, but to instead remain open to the data, and allow it to speak freely to me. Coding the data was an inductive process, with a continuous revisiting of the transcript, to develop the codes identified, and search for codes previously hidden. Codes were recorded in the left-hand margin of the transcript, with a different coloured pen distinguishing between descriptive, linguistic, or conceptual codes, and notes were made on my initial thoughts.

Descriptive codes highlighted the content that appeared to 'matter' most to the participant. Sections of the transcript where the participant was describing the key aspects of their lived experience of social media were highlighted. Engaging in the process of descriptive coding helped to structure the participant's

narrative. Linguistic coding focused on how the participant's use of linguistics to convey their narrative. Examples included the coding of pronoun use, laughter, pauses, repetitive discourse, and metaphors.

Conceptual coding involved an interpretative probing and questioning of the data. Inevitably, I fell upon my own pre-experiencing and assumptions during this process, as my imaginative dwellings sought to place me in the participant's shoes. At times, my interpretations and questioning went beyond the data, as I lost myself within my interpretative musings. However, much of this questioning remained grounded in the data and led to a richer and deeper understanding of the participant account. The process of coding is illustrated in table 4.1.

I then progressed towards grouping the descriptive, linguistic, and conceptual codes identified into emergent themes, that were summarised in the right-hand margin of the transcript (stage three). Each emergent theme aimed to capture a particular aspect of the text, so that the transcript was summarised into a set of chronological parts. At this stage transcripts, annotated with codes and emergent themes, were shared with the supervisory team who questioned my analysis to ensure I wasn't being led by the 'talk' (Abbott, 2012), that I wanted the accounts to produce, forcing data into themes, rather than remaining open to the data. I then sought to identify patterns across emergent themes (stage four). A process of abstraction was central to stage four, as emergent themes were compared and grouped together where appropriate. Engagement in stage four helped to summarise the transcript, in preparation for analysis across cases discussed in section 4.6.2. Table 4.1 provides two examples of case analysis.

Stages one to four were then repeated for each participant account (stage five). Prior to beginning the analysis of a new transcript, I would spend time noting the 'fore-meanings' (Gadamer, 1960/1998, p.271) of the lived experience of social media I had developed as a result of engagement with previous transcripts. I was mindful to adopt a 'polymorphic mindedness' (Idhe, 1987, p. 15) towards the participant's account, in order to remain open to new meanings and perspectives of social media previously undiscovered. As I engaged in stages one and two of analysis with a new transcript, I noted in a journal any premature links I was making between cases. Doing so, helped me to maintain focus on

each participant account to view it 'on its own terms' (Smith, Flowers, et al, 2009, p. 100). Once all participant cases had been analysed on their own merit, a cross case analysis was performed.

Table 4.1: Example a case study analysis.

| Transcript: Mohsin | Exploratory comments (descriptive, linguistic, conceptual) | Emergent Themes |
|---|--|--|
| <p><i>“Ever since I was little I have always really liked Martial Arts. And I used to go to a youth club, which was just like to meet other lads with similar conditions, ye know muscular dystrophy. But underneath the youth club was a boxing gym. And I used to sneak off downstairs and watch them train. And a few times they used to, I used to make comments when they were training like ye doing it wrong. Or you’ve got too much weight on one leg. And on one occasion the trainer actually said to me I know what I am talking about”.</i></p> | <p>Mohsin’s experiencing encourages an imaginative dwelling: It is akin to Lucy entering Narnia through the wardrobe, ‘sneaking’ into an alternate world to that previously known. I also picture myself in the youth club with Mohsin, the faint but nonetheless audible sound of chains from repeatedly hit boxing bags permeating through the floor. Mohsin’s presence and Being within this boxing gym is accepted, his knowledge and wisdom related to boxing locked in upstairs, is set free, listened to, and valued within this downstairs, previously hidden space. His use of discourse such as ‘underneath’ conjures up a sense of two separate spaces. One in which his presence is a young man with a NMC, the other whereby he can be a boxing coach. I wonder how this offline experiencing is transferred into his online aspirations and desires? Further, how does Mohsin contend with his two identities within these spaces? Upstairs he is a young man with a NMC, downstairs he is seemingly a boxing coach.</p> | <p>Contrasting spaces Separated spaces Sneaking into an alternate space Identity as a boxing coach recognised, valued, and acknowledged</p> |

| Transcript: Zahid | Exploratory comments (descriptive, linguistic, conceptual) | Emergent Themes |
|---|---|--|
| <p><i>"I think what it is with gaming is I get <u>into a space where I forget</u>, kind of not just that I am in a wheelchair but <u>kind of an astral projection in a way like I am kind of transformed</u>. You are in a space where you are kind of <u>enjoying yourself</u>".</i></p> | <p>I am initially drawn to Zahid's description of forgetting through gaming, what is he forgetting? And why does he feel a need to forget? The term 'astral projection' is rich and packed full of meaning. It's literary meaning is grounded in a separation, of two spaces. This meaning appears to be true to Zahid's experiencing, as he talks of a transformation, and being within 'a space', separate to that he occupied prior to this video gaming experience. How is this transformation experienced? And who, what, where is he transforming to?</p> | <p>'Astral projection' Transformation Entering into an alternate space Video gaming as a place for enjoyment</p> |

4.6.2 Cross-Case Analysis

This stage of analysis was extremely iterative, consistently going back and forth between cases in the search for patterns as well as divergence across cases (stage six). Rather than using computer software, a process of writing case emergent themes onto 'post-its' (small pieces of paper with sticky backs) that I could arrange on a wall to provide me with an analytical overview, was the preferred method of visually making sense of the data as a whole. Throughout this stage of analysis, I continuously engaged with the hermeneutic circle (Peat, Rodriguez, et al, 2019), as my fore conceptions generated from individual case analysis, were questioned and reworked, resulting in previously separate emergent themes being subsumed to create new established cross-case themes. Linking newly established cross-case themes led to the emergence of superordinate themes, that structured the overall narrative. This process of moving through participant accounts, to developing emergent themes, to established themes and a superordinate theme is illustrated in Table 4.2. The end result of the cross-case analysis is provided in a master table of themes that is indexed with participants data (Appendix 8).

To add a further layer to the interpretative analysis of participant data, an artist was invited to read extracts of the participant's narratives. The artist, Robert Maida, was sent extracts from each participant account, and was asked to draw his interpretation of the meaning of extracts that were most resonant to him. Two illustrations were developed and are illustrated in Figure 6.3 and 6.4 in the Chapter 6 of the discussion.

Table 4.2: Example Cross-Case Analysis

| Extract One Mohsin | Extract Two Mark | Extract Three Zahid | Emergent themes across cases | Theme | Superordinate theme |
|--|--|---|---|--|--|
| <p><i>“Well I’m a member (of DMD pathfinders), I do, like if someone puts a request on and they are looking for answers like erm, <u>where can I get this equipment</u> from or whatever, I will put something in the comments if I know the answer and ye know <u>help them</u> choose stuff”.</i></p> | <p><i>“Well I’m on a DMD...my disability we’ve us own pathfinders’ group. Yeah so we chat to one another ye know if people have problems like ye know to do with ventilators or....they will put it on (the group) and everybody will comment on it and yeah we just discuss whatever”.</i></p> | <p><i>“Then I realised through social media and talking to other people, that a lot people are having similar issues, cos I thought I was alone in those issues...but you’re not there are a lot of communities. I think it has helped me deal with things really, and now I find solutions and I find charities that can kind of help me”.</i></p> | <p>Group identity, belonging, and togetherness through social networking sites.</p> <p>Findings peers with similar experiences to own</p> <p>Autonomy and independence in seeking solutions to healthcare</p> <p>Supported and empowered by others to find solutions</p> <p>Providing rather than receiving healthcare advice; changing the narrative</p> | <p>#DMD; group identity, empowerment, and making the other aware</p> | <p>The meaning of social networking platforms, blogs, and spaces</p> |

4.7 Quality in Interpretative Phenomenological Qualitative Research

The qualitative research discipline features a plethora of different methodologies, ranging from discursive approaches (e.g. Potter and Wetherall, 1987), to Grounded Theory (Glaser, Strauss, 1967), to approaches informed by phenomenology such as IPA (Smith, Flowers, et al, 2009). Unlike quantitative approaches whereby the guidelines for appraising the quality of studies have been well established and feature little divergence due to standardised universal measures. The diversity in qualitative approaches means a standardised strict framework for assessing quality would be both inappropriate and ineffective (Yardley, 2008). Rather, it is more appropriate to appraise quality in line with the particular qualitative approach undertaken, while also remaining open to the broad characteristics that constitute 'good' qualitative research (Yardley, 2017). In this vein, I have drawn on the criteria for assessing quality in IPA studies proposed by Smith (2011), while also subjecting the work to Yardley's (2008) broad criteria for assessing quality in qualitative research.

Demonstrating sensitivity to the context of the study is deemed as a key characteristic of good quality qualitative research (Yardley,2008). For instance, IPA has philosophical underpinnings, recognising and articulating this context (see Chapter 3) is paramount to demonstrating the synergy between philosophy, methodology, and method. Moreover, sensitivity towards IPAs phenomenological and (double) hermeneutic foundation is necessary to go beyond the descriptive, to offering an interpretative analysis that draws on such philosophy to produce an in depth evocative account of the data (Chapter 5,6) (Smith, 2011). However, the inclusion of theory to produce an interpretative account, must be balanced by a continuous sensitivity towards the data (Yardley, 2008; Smith, 2011). The supervisory team, as well as the study PPI representatives provided feedback on my interpretations of the data throughout stages of the analysis, thereby ensuring that the data guided the interpretation, rather than being led by it.

Sensitivity to context as described by Yardley (2008) and adopted by this study as a means of ensuring quality is at odds with the notion of transferability. Lincoln and Guba (1985, p.290) outline transferability as 'how one determines the extent to which the findings of a particular inquiry have applicability in other contexts or with other subjects/participants'. The methods and findings of this thesis depict an idiographic sensitivity to the unique contexts of the eight young men involved in the study. Furthermore, the study was guided by an Interpretative Phenomenological Analysis (IPA) approach that values the subjective experience of a phenomena, situated in the unique lifeworld of a person. Thus, applicability of the findings to other contexts/participants was not an aim of the study. However it is still recognised that others to some extent, may be able to read similarities in experience and see how tenets of the experience reported may hold resonance to features of current practice/support/recreational needs of young men with DMD. While this work hopes to generate further inquiry, further research would require a sensitivity to the context of the aims, and sample of said research.

Commitment and rigour are essential components to establishing trustworthiness and confidence in the study (Yardley, 2008). Phenomenological qualitative enquiry requires a prolonged commitment to the topic under exploration, in order to develop findings that demonstrate rigour as a result of their 'depth, detail, emotionality, and coherence' (Denzin, 1997, p.283). Volunteering at a children and young adult hospice was also demonstrative of my commitment to understand the context of the research. Data saturation is regarded as 'the most frequently touted guarantee of qualitative rigour offered by authors' (Morse, 2015, p.587), and has therefore obtained a degree of orthodoxy (Saunders, Sim, et al, 2017). While the concept is widely defined, the definition of when new data is redundant of data already collected is well cited (Saunders, Sim, et al, 2017). It is however, an inappropriate measure of rigour in relation to this study. While convergence existed across cases, each participant offered a unique account, with experiences of social media distinctive to their context. New and previously underexplored experiences would continue to arise as the number of participants increased. Saturation was therefore focused upon each participant with data collection stopping with each

participant after agreement between myself and the participant that we had reached an account of their lived experience of social media.

In writing this thesis, transparency and coherence, further components of quality in qualitative research and indeed good quality IPA work, were continuously close to mind to ensure trustworthiness in my research (Yardley, 2008; Smith, 2011). Drawing on the hermeneutic underpinnings of this work my aim was to ensure that each 'part' described in this thesis, such as the findings chapter, worked coherently as a 'part', but also fit to 'whole' that is the complete thesis. Transparency in the research process was assured by first articulating the rationale for the aims of the study, followed by a coherent detailing of the methods undertaken to collect the data, before outlining the process of analysis with the use of examples (see section 4.6.1 and appendix 8) to demonstrate clarity, and thus trustworthiness in the findings developed as a result.

Central to the researcher's role in the study was a constant commitment to reflexivity. Finley (2017) claims that it is not enough to only know the background of the researcher such as their gender, age, occupation, and prior assumptions, what needs to be made clear is *how* the researcher's prior experiencing and background influences the decisions they make throughout the research, and the narrative that unfolds as a result. Applying a critical, self-aware lens to my intrinsic involvement in the research, and acknowledging the complexity and messiness of this involvement, was paramount to displaying transparency. In practicing reflexivity, I drew parallels with Sally Goldspink's (2018) experience of being aware of the 'echoes' both in my experiencing as a carer, and also within the data offered by participants that held meaning and were resonant with my own experiencing. IPA by its hermeneutic nature, pushes for deep interpretative inquiry, and therefore I was keen to use these 'echoes' in ways that illuminated further meaning to the data offered by the participant. To demonstrate, I offer an extract from my research journal related to my first shift as a carer at a children and young adult hospice, where I felt like an outsider and intruder:

'Today I was the awkward one, I was the one who was ignored and stared at. I was the one left out. My prior experiences of being bullied amplified these feelings, sat in the hospice common room, I was back in secondary school. I

could feel my awkwardness amplifying off me, what to say? How to be? What to do? I fixate on the video game 'set up' to the left of me, as conversations between young people and carers continue. At last, I am offered a lifeline 'Jamie, why don't you go on the Xbox with George'. Relief'.

Prior experiences of being bullied echoed throughout my first shift at the hospice, and provided a knowingness and understanding of the participant narratives of bullying and isolation that I would come to interpret. Therefore, journaling such echoes, and reflecting on them during analysis demonstrated the 'relational intricacy between the interpreter and interpreted constantly exercised' (Goldspink et al, 2018, p.6). Ultimately, any piece of research must also be assessed for quality in terms its impact and utility (Yardley, 2008). I reflect on the contribution of this study to practice and research in the conclusion chapter (7) of this thesis.

4.8 Ethics and Research Governance Approval

This sub-section of the method chapter presents the ethical considerations related to undertaking a study that involved young men with the life-limiting condition, Duchenne Muscular Dystrophy. These included the wellbeing of participants, avoiding coercion, and researcher wellbeing. Ethical considerations related to procedure are also explored including obtaining informed consent, maintaining confidentiality and anonymity, and data management and storage.

4.8.1 Ensuring the wellbeing of participants

Disclosing and making sense of any lived experience has the potential to evoke an array of emotion. The researcher developed strategies to ensure the wellbeing of participants involved in the study. First, all correspondence sent to participants was reviewed by the study PPI representatives and members of the hospice care team to check the appropriateness of the content. Drawing on the expertise and knowledge of the representatives and care team was crucial to developing participant-facing documents that were sensitive to the participant's wellbeing. For example, initial versions of the documents included the term 'life-limiting condition'. It was made clear by the hospice team that the use of such

terminology could be distressing for some participants, who may not equate DMD as a life-limiting condition.

Second, the methods of data collection were designed to support participant wellbeing. Fatigue and tiredness are common symptoms of daily life with Duchenne Muscular Dystrophy (Landfeldt, Lindgren, et al, 2015). It was therefore appropriate to adopt an approach to data collection that was attuned to the needs of participants. The adoption of a single-interview technique may have proved physically and mentally challenging. By contrast, sequential interviewing enabled the participant to voice, discuss, and make sense of their narrative over a series of interviews; allowing periods of time in between for rest. Dates and times of interviews were led by the participant, often participants wished to be interviewed during the late evening, so arrangements were made with the hospice to facilitate. During interview, I repeatedly reminded the participant that the interview could be paused or stopped at any point.

Third, it was important that participants felt able to talk about the interview to others (excluding researcher) during their hospice stay. All hospice staff involved in the care of participants were made aware of the study through carer information sheets, a presentation by the researcher, and frequent conversations with the researcher. Participants were told that staff were aware of the study, and would be happy to discuss their study involvement if they wished to do so.

4.8.2 Avoiding coercion

A benefit of recruiting participants through a children and young adult hospice was it enabled the researcher and the study to be guided by clinicians and administrative staff who had extensive experience of caring for young men with DMD. However, the direct involvement of the hospice also raised ethical implications that warranted consideration. In particular, the potential for participants to feel coerced into taking part in a study supported by the hospice they received respite care from was acknowledged. To mitigate against any perceived coercion, several strategies were put in place in consultation with the study PPI representatives.

First, potential participants were contacted via post one month prior to their planned hospice stay. Doing so provided ample opportunity for discussion with friends, family, carers about whether they would like to participate. It was made clear in the participant information packs, that their planned hospice stay would not change if they decided to not take part in the study. For those who chose not to take part in the study, no reference to the study was made when they first arrived at the hospice. Only participants who contacted the researcher to take part in the study were met by the researcher at the hospice.

Inevitably, participants who had agreed to take part in the study on occasion were staying at the hospice at the same time as other young men with DMD who had declined to take part. Several instances occurred whereby the study was raised as a topic of conversation around the hospice common room table. A strategy of transparency was adopted where I openly discussed the study, but it was reiterated that there was no obligation for any of the young men to participate. Prior to, and after interviews with participants, their right to withdraw from the study was stated. Furthermore, as part of the ethical process devised by the myself and hospice team. Participants were asked by a member of the care team about their involvement in the study after the researcher had left the hospice, to provide a further opportunity to withdraw their data should they have wished to do so.

4.8.3 Researcher Wellbeing

In any research study, the wellbeing of participants should be a key priority. However, it is also important to be mindful of the impact of the research on the researcher, particularly in studies that explore lived experience that have the potential to evoke emotive response. During initial meetings with the hospice involved in the study, the importance of supporting my own wellbeing throughout the study was made clear. As a researcher who was new to the study area, I was on reflection naïve to the potential impact of the study on my wellbeing. Nevertheless, on the advice of the study PPI representatives, and my supervisory team, three strategies were put in place to protect my own wellbeing that proved to be invaluable.

First, engagement in journaling throughout data collection proved to be a cathartic, and sense making process. I reflect on my experience of journaling in Chapter 6, section 6.1. Second, regular appointments were scheduled during data collection and analysis with a close family member who also practices as a Vicar at the local parish. These appointments took the format of walks where I was able to make sense of my experiences. Alternatively, I drew comfort from silent meditation facilitated by the church I attend. Third, regular academic supervision provided a safe space to discuss my experiences and receive both pragmatic and emotional support.

4.8.4 Ethical Approval

Ethical approval for the study was granted by the University of Leeds School of Healthcare Research Ethics Committee (SHREC) on the 09.03.18. One further amendment was approved that related to changes to the recruitment procedure.

4.8.5 Informed consent

Research governance outlined by The University of Leeds 'SHREC' (as above) states that informed consent must be provided by all participants prior to data collection. An exemplar consent form provided by SHREC was drawn on to develop the study consent form (appendix 6). A symptom of DMD is the gradual loss of hand movement and dexterity (Muscular Dystrophy UK, 2020). Mindful of the possibility that the participant may have been unable to sign the consent form themselves, it was arranged that where necessary a carer would confirm verbal consent. Consent was confirmed prior to the start of each interview, and was affirmed at the end of the interview. All participants consented for the interview to be audio-recorded. Participant's right to withdraw from the study was also outlined both in writing (participant information sheet), and verbally.

4.8.6 Maintaining confidentiality and anonymity

Participant confidentiality was maintained using several strategies. First, all recruitment information was sent to participants via the hospice administrative team. Therefore, the researcher did not require access to the personal information of participants such as their address and telephone number. Email dialogue established between researcher and participants was communicated via a secure server, with the researcher using their University of Leeds email

account that is password protected. All email correspondence was deleted from the researcher's email inbox and stored in a password protected word document.

During interview, if it was necessary for a carer to present, they were asked to sign a confidentiality form, with all parties present during the interview agreeing to not discuss or share any information disclosed with others. The use of pseudonyms is a well-used method of maintaining participant anonymity, while keeping the data 'personable' (Orb, Eisenhauer, et al, 2004). Participants were explained the rationale behind the use of pseudonyms, and were asked what pseudonym they would like to be associated with their data. One participant wished to use their own name as opposed to a pseudonym, however, the use of pseudonyms to maintain participant confidentiality was an agreed ethical condition of the study, therefore this was not possible. Participants were made aware through the participant information sheet, consent form, and verbally that confidentiality would be broken if the participant disclosed anything that would suggest they/or anyone else was at risk of harm.

4.8.7 Data management and storage

Guidelines related to data management and storage stated within the General Data Protection Regulation (GDPR) were adhered to throughout the study (Gov. UK, 2020). Data provided by participants such as consent forms, email correspondence, audio data, and transcripts were appropriately stored. For instance, consent forms and transcripts were filed in separate locked cabinets located within an office at the University of Leeds. Audio data provided by participants was removed from the recording device at the earliest opportunity and transferred to a password protected audio file on the researcher's University of Leeds hard drive.

4.9 Summary

This chapter has outlined the rationale and application of the methods undertaken by the study. The study methods were underpinned by an Interpretative Phenomenological Approach (IPA) (Smith, Flowers, et al, 2009). Throughout a continuous commitment was made to the ethical principles of the

study, and an awareness of the ethical considerations specific to the study context were adhered to. The next chapter outlines the study findings, developed as a result of the methods outlined in this chapter.

Chapter 5 Cross Case Findings

5.1 Introduction

This chapter presents the findings of the cross case analysis of participant interviews. The findings are discussed thematically. First, participant characteristics will be presented and then the three overarching superordinate themes are detailed: 'existence outside social media: navigating the offline lifeworld', 'life within video gaming: transcending into an alternate reality', and 'the meaning of social networking platforms, blogs, and spaces'.

5.2 Participant Characteristics

Eight participants were recruited to the study. At the time of interview/s, the age of participants ranged from 18 to 28. Three participants identified as Asian British, with remaining participants self-identifying as White British. All participants lived with the condition Duchenne Muscular Dystrophy (DMD). Participants were at different stages of disease progression, two participants were dependent on a ventilator to support breathing. All participants used a mobility chair.

Table 5.1: Participant characteristics

| Participant Number | Participant Name | Age | Ethnicity |
|--------------------|------------------|-----|---------------|
| 1 | Zahid | 28 | Asian British |
| 2 | Kez | 18 | Asian British |
| 3 | Simon | 21 | White British |
| 4 | Tom | 18 | White British |
| 5 | Lee | 22 | White British |
| 6 | Mark | 28 | White British |
| 7 | Mohsin | 23 | Asian British |
| 8 | Craig | 25 | White British |

All but one of the participants lived at home with their family, one participant lived in an assisted living flat, supported by a 24 hour carer. All participants had attended mainstream secondary school. At the time of interview, one participant was attending university, one participant attended a special needs college, two participants were enrolled at a mainstream college, the remaining four participants spent the majority of their time at home. Only one participant had experienced employment, and worked as a freelance writer for a video gaming magazine. All participants described social media as having presence in their daily lives.

5.3 Overview of the study findings

This section presents the three superordinate themes and their accompanying sub-themes. Each superordinate theme is completed by between two and five sub-themes. Direct extracts from the original data have been used to both illustrate the findings and to enable judgements to be made about their credibility. An overview of the thematic structure is provided in Table 5.2

Table 5.2: Overview of thematic structure

| Superordinate theme | Themes |
|---|--|
| Existence outside social media; navigating the offline lifeworld | Being-with others |
| | Factors that influence Being |
| Life within video gaming; transcending into an alternate reality | An altered sense of Being through video gaming |
| | A questioning of Being through playing video games |
| | Video gaming as cathartic; A welcomed intrusion |
| | The importance of video gaming to Being; An enforced companion |
| | Video gaming as a fragile reality; A persistent intrusion |
| The meaning of social networking platforms, blogs, and spaces. | #DMD; group identity, autonomy, and making the other aware |
| | Online blogging; a variation of meaning |
| | Online blogging as a process towards the acceptance of self |
| | Seeking a sense of belonging within online spaces |
| | Revealing the self online |

5.4 Superordinate theme one: existence outside social media; navigating the offline lifeworld

The lived experience of social media was embedded in the daily lives of young men with DMD. Superordinate theme one describes the offline lifeworld of participants as portrayed in their interview data. Two sub-themes underpin theme one, 'Being-with others', and 'Factors that influence Being'. The two sub-themes are linked in their description of how the people participants encountered in their daily lives, and the factors that surrounded their lifeworld influenced and shaped their daily existence.

5.4.1 Being-with others

Being-with, as described in Chapter 3 is a phenomenological term that alludes to the presence of others shaping the existence of the self (Heidegger, 1927, 2011). Being-with included being among others in educational, family, social, and hospice settings.

The education setting was a prominent feature of participant's narratives. All participants attended 'mainstream' education up to 16 years of age, but described different experiences of their time within educational spaces. For some participants, education provided the opportunity to establish and kindle friendships. Kez attended a mainstream secondary school with non-disabled peers. Kez described how the appeal of school was due to being able to be among his non-disabled friends. By contrast, other participants' experiences of Being-with peers in educational spaces were negative, with accounts of being bullied, often attributed to their disability being recounted. These different perspectives are highlighted in the following accounts:

"Erm, yeah just cos all of my mates are there, it is the only reason I like school to be honest with ye". Kez.

"I got bullied at high school, I didn't tell anyone". Mohsin.

"Okay and was the bullying related to...?" Interviewer

"My disability and everything". Tom

Whereas Kez spoke of education as a space for friendship. Tom and Mohsin described experiences of isolation that were sustained throughout their time in secondary education:

Well secondary school was just awful erm like we were so isolated as well like. Like everyone with either summet wrong with them or anything like that went on a different break always and I think it all stems back to that really". Tom.

Tom made sense of his isolation as the result of being marginalised into a category of people who had 'summet wrong with them'. It appears that Tom's isolation was confounded by school policy, whereby those with 'summet wrong with them' went on 'a different break always'. The impact of Tom's negative experience of school led him to sever ties with the limited friendships he developed at school, in order to try and protect the self, as evident in this account:

"...basically I suppose you would word it as I let a lot of bridges burn. Ye know what I mean just to get rid of them. Erm just to forget about secondary". Tom

Discourse used by Tom such as 'get rid of' and 'forget' accompanied by his analogy of letting 'a lot of bridges burn' suggest Tom was attempting to close a chapter of his life synonymous with his time in secondary education, even at the cost of a loss of friendship. On finishing mainstream education, some of the participants went on to attend college. For example, Mark enrolled onto an A Level Arts and Graphics course at a 'normal college' but boarded at a college that had facilities to support his needs:

"I went to one down South, it was like a boarding college, for disabled. But basically I stayed there but I went to a place called (name) College. Which was just down the road. Which was a normal college". Mark

Opportunities to attend educational spaces with peers who shared similar cognitive ability appeared to not be offered to all participants. Tom described how after a period of illness his only option was to enrol at a 'specialist college' where his educational capability and aspiration were suppressed, and occupy a space with others who did not share his cognitive ability. Consequently, there were few opportunities for him to be challenged educationally:

"I went back to a...they got me into this specialist college, after I was ill, cos they have like physios and everything on site, but, to be honest I am the most intelligent one there. And I feel like it is making me more, like, less intelligent because cos it's like ye know.

I: Not challenging you?

Yeah. So that's how I feel, and it's only like me and two others, who are at my sort of, cognitive sort of ability". Tom

In contrast, a different participant spoke of being initially accepted onto a college course before being 'kicked off'. Mohsin described how prior to submitting the application to enrol on a music course, he outlined to the college what his capabilities were and what he was unable to do. He was initially accepted onto the course before being transferred onto a different course without his consent:

"I got kicked out of college, because of my disability. I got kicked off my course, because of my disability". Mohsin.

"Before I applied for the course, I told them my condition, I told them what I was capable of, and I told them everything right I was straight up with them. Anyway right a third of the course is playing an instrument which I physically can't do.

And I said to them I can rap, I can sing, I can do vocals but I can't play instruments. And because of that reason, they didn't even tell me, they took me off the course, and they put me in media studies". Mohsin.

Mohsin's experience of being 'kicked off' a college course that was aligned to his interest in music 'put him off' continuing with his education, and thwarted his ambition to be a nightclub DJ. His experience is reflective of how the presence and decisions of others can impact on a person's self-concept. Mohsin appeared to perceive opportunities to become a nightclub DJ as unattainable, not as a result of a lack of ambition or skill, but because of an unspoken message from the college institution that he was not able. More so, the decision of the college not to consult Mohsin in their decision draws parallels to Tom's experience of being enrolled to attend a 'specialist college'. In both instances, the future aspirations of the young men were suppressed, with decisions made for them rather than by them.

Participants also reported good examples of educational transition planning whereby the necessary provision was provided to enable participants to attend University. For example, at the time of interview Simon was working towards a university degree in media production. When asked to describe himself, Simon highlighted his degree-level education within the first sentence:

Erm, well I am 'Simon' I study at, I am in second year at (name) University, studying media production. So I am into doing a lot of filming and stuff like that.

Simon

The proximity of his education to his description of self was suggestive of its importance to his Being, and demonstrative of the importance of Being-with others who support young men like Simon to achieve their potential. Due to diversity in age within the sample, each of the participants were at different stages of their education. For participants who were no longer in education, opportunities to be with others was limited to interaction with family members or carers in the home environment:

"I don't go to college anymore, I am just at home". Craig

Limited opportunities to interact with others were also described by participants who were still enrolled in some form of education. Even if participants did not experience social isolation directly, they were aware of others who were in 'the same situation' as the participant and had 'no chances' to socialise with others. Participants described how inadequate facilities or disabled access meant establishing a presence within 'typical' social venues was a challenge. These limited opportunities are highlighted in the following accounts:

"Whereas when I am at home I don't really go out or anything, I just stay in so..." Tom.

"Whereas I know other lads who are in the same situation as me, but they've got no friends because they've had no chances..." Mohsin.

"Yeah because it is like people who can go to I don't know the gym or do sport and things you get to know people through that stuff ye know going out, but I can't really go out on nights out and stuff like that. Cos there is just no facilities or disabled access and stuff it all comes down to that..." Tom.

Some of the participants such as Tom highlighted that social and sporting venues were spaces in which the self could ‘*get to know*’ other people, but also perceived these spaces were denied to their Being-with others. It could be interpreted that Tom’s experience of exclusion from social venues led to a reduced sense of belonging; a sense that the self was not welcome. Consequently, establishing agency and autonomy over their social lives may be a challenge for young men like Tom. The impact of limited avenues to develop and sustain a social life appeared to be the reason some of the young men had few friendship groups. For example, Tom described when discussing the limited access to social spaces that he had few friends:

“Erm, I don’t mind saying but I don’t have a lot of friends really”. Tom

Tom’s discourse use of the term ‘*I don’t mind saying*’ in his description of having few friends, appeared to convey a reluctant acceptance or hopelessness toward his social situation.

Even in circumstances where opportunities to converse and be among others existed, some participants felt uncomfortable conversing with others. This was particularly the case in relation to able-bodied peers. For example, Zahid described how he perceived his self as the lesser Being when compared to able-bodied people, and disclosed how he had often perceived able bodied others were more ‘*clever*’ and ‘*better*’ than him, which emanated from a culture and society that had ‘*taught him how to feel*’, and how to be. Where these feelings were internalised, the young men felt unable to interact with able bodied others, as in Zahid’s account:

“Disabled people forget that sometimes they have biases as well. Cos I used to have biases like able bodied people are more clever and that kind of thing. And they are better than you but then you learn that, that is not true. It is just society has taught you how to feel.” Zahid.

*“...but I think when I was younger it probably would have been because I was bit sort of scared of kind of able bodied people, I thought oh my god I can’t...”
Zahid.*

Zahid appeared to perceive a boundary between those who were disabled and those who were non-disabled, based upon the non-disabled being the superior

Being. As such, to overcome this boundary, and interact and 'Be' among non-disabled others was 'scary' for participants, who may have received an education in their inferiority to the non-disabled other. However, not all participants described a suppressed social self. For instance, Mark described an active and nourished social existence. His everyday Being in the world consisted around social activity, and involved attendance at football matches, visiting friends, or going shopping. When asked to describe himself during the interview, Mark referred to himself as a:

"Social animal". Mark

"To be honest I'm more of a social person, I prefer just to go out and go shopping and do something". Mark.

The term '*animal*' implied a Being who is attuned to, and in keeping with his habitat and environment. Despite recounted experiences of being bullied, Mohsin too spoke of Being-with others socially who valued his self and sought to include him in everyday activities:

"And I've been blessed in a sense where I've got really good friends, they don't like not include me in stuff". Mohsin.

Interaction with family members also appeared to influence the confidence of participants to be independent. Some participants described how their parents encouraged them to engage in everyday activities independently such as going to the shops, and '*been pushed*' in general. Conversely, other participants described disparities between the messages they received from parents:

"I have always been pushed ever since I was younger. Cos I once said to my mum oh I need to get a card for my friend. And she goes, well go get it yourself. She has always been like that with me so". Mark

"But my mum and dad are very different parents. Like my mum she will send me to the shop on my own ye know for me to get her cigs or summet. My dad won't even let me cross the street on my own". Mohsin

For the majority of participants Being-with others who were not family members or carers was difficult. Organised respite stays at their local young adult hospice provided opportunities to interact with others. Participants voiced the

importance of their hospice stays, and described how visits enabled them to engage in social activity with peers that was otherwise difficult to facilitate. The young men described a range of opportunities during their hospice stays such as festivals hosted at the hospice, visits to the cinema and or shopping centres during stays. In addition, field trips such as a visit to a local brewery were described. For example:

“It’s not so much as when I come here (hospice), when I am here I always just like try and communicate and talk with other people...” Tom

“Yeah I mean you’ve got comedians, er music, food, but last time it was torrential, torrential downpour so we were all stuck in the mud and everything. It was quite fun actually”. Mark

“Every Tuesday for over 18’s with (name) hospice we made us own beer with a brewery. So he’s invited us to his thing to have a party but it’s on his farm is his brewery in one of the barns and it is all there and he has his own bar”. Mark

I: And you brewed like your own beer?

“Yeah it’s called legless (laughs)”. Mark.

Engagement with hospice organised social activity enabled participants to ‘Be’ young adults. However, it was not always possible to engage with hospice organised social activity. Participants described how hospice stays with other young people who were non-verbal and had severe disabilities did not always offer opportunity to socialise. The young men highlighted that staff to patient ratios could result in limited opportunities to engage in social activity. Furthermore, Being-with other young people who were non-verbal meant that it could be difficult to establish friendships, as participants perceived that they shared little in common with them, as described in the following accounts:

“There are sometimes that it is a bit boring, because there are certain people there who can’t talk, or are really severely disabled. And they have to have one on one staff so it cuts the staff down sometimes”. Mark.

“Yeah like, I’m not been funny but the 3 who are here now, like I’ve nothing in common with them. Like me and (name) yesterday, we never shut up and erm I prefer to come in with people like that.” Tom.

Participants reported how the hospice would try and book them in to stay when other young people whom they had formed friendships with were also staying, however this was not always possible. In these instances, it could be difficult for participants to socially engage with the young people they were staying with. Nevertheless, on the whole, respite care provided by hospices was described as important to engage in social activity and interact with others.

In summary, participants descriptions and experiences of Being-with others offline varied. Examples of marginalisation, discrimination, and bullying were described with social isolation a common experience shared by some participants. Conversely, other participants shared largely positive experiences of Being-with others. The next sub-theme presents participants descriptions of the factors that appeared to influence their perceptions of Being.

5.4.2 Factors that influence perceptions of Being

Participants revealed how the way they interpreted their Being, and in particular their disability, was influenced by a range of factors, including the availability of funding, provision, and periods of illness.

Engagement in sporting activities was highlighted as important in facilitating a positive perception of self. Mark was an avid football player with future ambitions to be a coach. The captain of a city-based wheelchair football team who played in the highest division, Mark’s hunger to win and be successful was championed by the team, and supported through the opportunity to go beyond ‘*playing for fun*’, to a level that satisfied his Being:

“I used to play for them but they have no ambition and just wanted to play for fun. But this team actually play for winning. So then I moved to them”. Mark.

Beyond his current successful career as a wheelchair football player, Mark spoke in depth about his pathway to be a football coach once he had retired from playing. Access to funding from a bursary meant that Mark was able to build the foundations for this career. At the time of the study, Mark was

undertaking training to complete his first coaching badge. These experiences enabled Mark to interpret his disability not as a barrier, but as a part of his Being that was still able to fulfil its interests and vocational aspirations. Exposure to people who recognised and championed his abilities ultimately facilitated Mark's positive perception of his capability. Similarly, Mohsin, a keen mixed martial artist (MMA), relayed encounters where his abilities in martial arts were recognised. The following extract detailed a particular experience that illuminated how the presence of others can determine the perception of self:

“Ever since I was little I have always really liked Martial Arts. And I used to go to a youth club, which was just like to meet other lads with similar conditions, ye know that have got muscular dystrophy. But underneath the youth club was a boxing gym. And I used to sneak off downstairs and watch them train. And a few times they used to, I used to make comments when they were training like ye doing it wrong. Or you've got too much weight on one leg. And on one occasion the trainer actually said to me I know what I am talking about”. Mohsin.

Mohsin recounted how the upper floor of the youth club he attended was dedicated to meeting other young men with similar conditions. Within this space Mohsin's Being was that of a young man with Muscular Dystrophy. However, downstairs existed a boxing gym, the playground of the martial artist, a space in which the sport of MMA is crafted and developed. It is not beyond the imagination to envisage that at moments whilst he was upstairs, Mohsin may have been able to hear the clanging of chains, or thuds of impact of the bags being manipulated by the fists of the athletes below. Mohsin recounted how he used to 'sneak off' downstairs, an utterance that could be aligned with the moment that Lucy enters the wardrobe into Narnia in *The Lion, the Witch, and the Wardrobe*. To enter and firstly observe a space in which his interest in MMA is accessible, approachable, and lived. Mohsin discussed how he would offer advice to those training, specific to the degree to which his knowledge of the sport was evident. Crucially, this advice was respected and well received with one trainer verbally recognising Mohsin's ability. Consequently, for those moments in which Mohsin was downstairs in the boxing gym, his perception of self was altered, by virtue of Being-with others who recognised his ability as an MMA coach.

Where Mark portrayed a narrative of sustained funding and service provision that enabled him to continue to attend to his commitment to football. In contrast, Mohsin's experience as a valued MMA coach was conveyed as a singular event. This was made evident through the utterance that followed the detailed description of his experience as an MMA coach. When asked if he continued to coach after the initial experience, his response was:

"It (the boxing club) shut down years ago". Mohsin.

This response provided interpretative insight into his perception of his disability. It appeared that for Mohsin, the experiences he enthusiastically conveyed as an MMA coach were confined to the boxing club and the people present within that unique space. There was a sense that the stars aligned for Mohsin during the experience of coaching; the right location, and more so the right people enabled a becoming of his Being into that of the trainer. Outside of that space, Mohsin's response suggested a lack of belief that in a different gym, and with different others, the experience would be the same. Therefore, when the club closed, so did the opportunity to coach MMA.

For some participants, their impairment prevented engagement in activity that could have supported a positive perception of self. For example, Tom disclosed how a recent period of illness left him to question whether he could participate in sports that he was aware other young men with DMD were involved in, for example wheelchair football:

"I was going to get into it...that was just before I was ill. So now I don't think I could do it like" Tom.

Tom's perception of not being able to 'do it like' after a period of illness in which he lost much of his muscle tone and strength, relayed the impact of his impairment on his confidence to participate in sports. Away from engagement in sport, inadequate equipment led other participants to view their impairment as all consuming:

'Well the thing is when I was younger about 13 to about 15 I was kind of stuck in bed, I couldn't sit in my wheelchair'. Zahid.

Zahid revealed how for two years his existence was confined to his bed, due to being unable to sit in his wheelchair. The term '*stuck*' poignantly summarised Zahid's position during this period.

5.4.3 Summary of Superordinate Theme One

Existence outside of social media involved navigating various offline spaces. Participants described how Being-with others in educational, family, social, and hospice environments shaped the self and their daily existence. Similarly, factors such as funding and provision, and the physiological impact of living with DMD influenced the daily opportunities provided to participants.

5.5 Superordinate theme two: Transcending into an alternate reality; life within video gaming.

To consider transcending into an alternative reality, is to go above or beyond the range of normal human experiencing. Superordinate theme two is supported by five sub themes that each describe the lived experience of video gaming from the perspective of participants. A narrative is threaded throughout each sub-theme to illuminate how video gaming transcended participants to experience that which was outside of their 'normal human experiencing'.

5.5.1 An altered sense of Being through video gaming

The accounts of some participants revealed that video gaming had the capacity to alter their sense of Being. Video gaming facilitated a space in which their Being took on a different meaning through a transcendence beyond what they associated with their 'normal experiencing' of living with DMD. Participants expressed a desire to transcend and enter an alternative way of Being through video gaming, reflected in discourse such as *'taking attention away'*, *'shutting out'*, and *'escape'* as described in the following accounts:

"...so I think through that period gaming kind of helped me to I don't know take my attention away from negative things all the time about my weakness because it felt like I was grieving each time I had a little bit of deterioration, but having the game there and being kind of able to play that I forget about that (deterioration)". Zahid.

"In the sense of shutting out from the real world kinda thing. And instead immersing yourself in something that is not there". Mohsin.

"Also just to escape everyday life". Tom.

Participants described their desire to divert attention, shut out, escape, and forget their offline world. This drive to *'escape everyday life'* facilitated an immersion into *'something that is not there'*. An alternate space to that which usually exists. Participants used discourse such as *'I got so into that world'* and *'another universe'* to convey how video gaming provided an alternate space to

be. Furthermore, the use of *'into'* and *'another'* in the description of their experiences signified a separation of spaces. A departing of one space in order to enter into another world or universe:

"And I got so into that world it was amazing". Mohsin.

"Well it feels like they have created another universe for you." Zahid

For some participants, immersion was dependent on the type of video game, narrative video games where the self could become absorbed in the story provided immersive experiences. The lived experience of immersion was not a one-off occurrence, but was a consistent part of their video gaming experience. Participants described the lived experience of immersion as a *'zoning out'* of the offline world into a *'zoning in'* of the online lifeworld provided through video gaming. The following accounts reflect the immersive experience of video gaming:

'But I am kind of into narrative games, that is a big thing I need to enjoy the narrative'. Zahid.

"...and the same thing happened to me." Mohsin

'...so I think when you are playing you slowly erm kind of zone out and kind of focus on the game so afterwards...I don't know I just, you just embody the character so because I am zoned in I forget about kind of the disability but not even that, I am just experiencing the game so it is like you don't really realise what I am doing. It is like I am watching myself play something where I have been transported into the game'. Zahid.

Central to the lived experience of *'zoning out'* appeared to be the embodying of a character within the video game. Participants described how they were *'transported'* into the video game through this embodiment, but at the same time were able to observe themselves playing the video game. This description denoted a separation of the body from consciousness that one participant went on to further make sense of within the following extracts:

'I think that is what it is with RPGs you just...I feel a sense of transformation, so that transformation is like I am a different person through the game. So I am looking at somebody playing a game and that is how I feel I am able to

understand what I am doing in the game. Like I can observe and find meaning like something to teach me or if something really interesting and I have felt I have learnt a lot I can remember...so I think it helps me to understand gaming at a deeper level. Like time slows down...' Zahid.

"I think what it is with gaming is I get into a space where I forget, kind of not just that I am in a wheelchair but kind of an astral projection in a way like I am kind of transformed. You are just in a space where you are kind of enjoying yourself".

Zahid.

'I kind of think in a way it is like accessing a parallel universe or something'.

Zahid.

The term '*astral projection*' is synonymous with 'out-of-body' experiencing and was used by Zahid to project the sense of '*transformation*' he experienced through video gaming. This transformation, appeared to result in a rising above from the video game denoted in his reference to '*accessing a parallel universe*', so that Zahid is '*looking at somebody playing a game*' who is both himself and the character combined. Zoning into the video game to the degree that he was transformed into this state of Being, enabled Zahid to make sense of and find meaning in the actions of the character, facilitating an understanding of the video game at a '*deeper level*'. At the same time, zoning in allowed Zahid to enter a space of enjoyment. Zahid did not define the cause of that enjoyment, but there is an evident aura of tranquillity and peacefulness that reverberated throughout Zahid's description of this experiencing. In the first extract above, Zahid made reference to role-playing games (RPGs) as central to this experiencing. RPGs require the player to control and become familiar with a character. This emphasis on coming to know another Being could be a contributor to why Zahid associated his experiencing with RPG video games in particular.

A sense of transformation was also experienced by participants as a transcendental state, whereby participants experienced an altered sense of Being beyond their normal experiencing:

"Like in games I can do stuff that I wouldn't be able to do in real life and stuff, so it's just a bit escapism I think, from just, life really". Simon.

This 'beyond experiencing' took many forms and was often unique to the individual. For example, Mohsin was a keen Mixed Martial Artist. However, opportunities to practice this sport and be recognised for his ability within his 'normal experiencing' were brief and short lived as revealed in superordinate theme one (5.4.2). Therefore, the video game Tekken provided him with the space in which to transcend, to experience being a Mixed Martial Artist. The practice room that once existed downstairs in a youth club, came to exist through a video game. Mohsin was able to practice and mould his art, developing and learning 'every combo' in order to excel at his sport:

"I always say to my mum and dad if I was able bodied, I would be an MMA fighter. I would be in martial arts, hence that's why I play a lot of Tekken".

Mohsin.

"Ye know but I am the kind of person that used to spend hours in a practice room learning every combo. I am that kind of devoted to it". Mohsin.

Video gaming therefore provided Mohsin the space to experience what otherwise would not feature in his normal experiencing. This sense of transcendence was not confined to experiences of practicing sport, but applied to activities that to others maybe everyday experiences such as driving:

"I like the driving ones obviously I don't drive so it's like a thing I get to know actually what it is like to drive, well ye know not quite exactly but..." Simon.

Opportunities to experience driving within the non-gaming world were not within reach for Simon. Despite doing so via a controller and a monitor, Simon revealed how he got to know 'actually what it is like to drive'. The lived experience of driving via a video game held a sense of realness for Simon noted in discourse 'actually what it is like'. Simon then relayed an awareness that his experience of driving may differ to that of someone who is able to drive a car in the offline world; 'well ye know not quite exactly but (pause)'. In doing so, he acknowledged that for the person who is able to drive offline, driving through video gaming may lack realism. However, for Simon, video gaming offered a route to get as close to the experience of driving possible to his Being as a young man with DMD. The experience of driving was not just limited to Simon's account. Other participants also described similar experiences:

*“Have you ever played GTA so much where you actually follow the speed limit?
Ye know indicate n that ye know what I mean?” Mohsin.*

Mohsin’s use of discourse such as *‘have you ever played GTA so much’* suggested that an immersion in a video game, and subsequent transcendental experiencing occurred gradually. In addition, to reach this state required a level of commitment and desire. The casual video gamer who plays leisurely, and to whom to follow the speed limit on a video game is trivial and pointless may view video gaming in a different light, as a passive rather than immersive activity. However, for young men like Mohsin, who to follow the speed limit was an experience otherwise unattainable in his offline world and therefore holds meaning, to become immersed is seemingly effortless. Once this immersive state was achieved, Mohsin’s Being was altered from that of a young man who was wheelchair bound, to that of a young man who is driving, consciously following the speed limit, and being courteous to other drivers through the use of indicators.

The experiences sought by participants through video gaming shed light on their unique interests. While the ability to drive was salient for Mohsin and Simon in particular, for Zahid, being outdoors and partaking in horse riding appeared to matter to him:

“Like I enjoyed Red Dead Redemption, I’ve still not finished it but I just kind of like the riding around, and doing a lot of things that physically I wouldn’t be able to do. Cos in a way it is like a simulation in a way like kind of, regular life in that era really, and I like nature so yeah I am able to do things I can’t physically do which is really good”. Zahid.

Zahid’s description of *‘just riding around’* was however on par with Mohsin’s account of driving. There was a sense from both participants that activities that provided them with enjoyment and meaning were often tranquil and relaxed in nature. Whilst some of the activity engaged in by the young men through video gaming was frantic and action based such as MMA fighting, for the most part it appeared that to transcend was to experience what to the non-disabled were mundane and everyday experiences. This was further illuminated in how participants found meaning in experiencing through video gaming acts such as

growing a beard and washing. The lived experience of washing and grooming their avatar appeared to hold meaning to participants. They represented 'new things' to experience, and enabled a sense of agency in how their characters looked and appeared, as described in the following account:

"And also like Arthur's beard, it's strange that I enjoy that bit, kind of how it grows in real time and it is just really bizarre but I think it is just such a good way to customise your character." Zahid

'...but when you fall you get muddy, yeah and then you can wash yourself, whereas I wouldn't be able to do that in real life, so it is just experiencing new things'. Zahid

Transcending also appeared to enable the salience of self traits that may otherwise be nullified offline. Participants described how video gaming provided a purpose and structure to their day to 'just do something'. Similarly, organising 'street races' provided a sense of responsibility to participants. Furthermore, video gaming provided a sense of spatial freedom that may be in contrast to their offline world. The following extracts summarise these meanings:

"and just to do something like". Tom

"But if you're the one that's hosted it you try and deal with it yourself as best you can. Then other people will try and help you or whatever". Lee.

"It's like I just find it amazing that you can go wherever you want...". Lee.

The lived experience of video gaming provided participants with a sense of agency and autonomy. Participants described the ability to 'create your own character and own narrative'. These experiences appeared meaningful because outside of video gaming there were 'a lot of things that I can't really control'. Consequently, they provided 'another kind of perspective' on life. While participants described several video games, the game 'Grand Theft Auto' was highlighted as particularly enjoyable because it enabled participants to 'control three characters in the same world'. Participants valued the ability to express agency over 'how to experience the world'.

The following two extracts describe the lived experience of agency through video gaming:

'Cos a lot of games now are RPG's (Role-Playing Games) so you are creating your own character and own narrative really. So yeah I feel you are more in control in a way cos in my life there is a lot of things that I can't really control whereas in the game you can, so it gives you another kind of perspective yeah'.

Zahid

'I think the other thing is with GTA 5 is having three characters was quite a unique experience because I don't think there has been another game where you control three characters in the same world. I kind of liked Michael the best because I kind of identified with him more but I did like Trevor cos he was really insane. But it is like they gave you different...again a choice of how to experience the world which is very unique in gaming that you can embody each character and still feel connected to them in different ways. Like if you were in a certain mood you would pick a certain character'. Zahid

In comparison to other forms of media such as films, video gaming was described by participants as the only kind of entertainment in which they were in control of their enjoyment, distinguishing it from other forms of media such as films or TV. An important component of control appeared to be its active nature; a sense of 'doing' as opposed to being a passive observer:

'Yeah I think with the game that is the only kind of entertainment where you are in control as well, you are controlling your enjoyment whereas if you watch a series or film, you are kind of very passive and that can get boring'. Zahid

Participants attempted to describe and make sense of their altered sense of Being and 'new experiencing' during interview/s. For some participants, conveying the meaning of this experience was difficult. Inevitably, participants were trying to convey a meaning that could only be understood by persons who shared similar lived experiences to their own. The ability to drive a car, or practice a sport are activities of daily living readily available to the able-bodied other. Consequently, attempting to convey why these experiences via video gaming carried so much meaning to participants was a challenge. The following extract from Simon's account is representative of this finding:

“Well yeah like when I was younger I used to do it because it was just something to do, but I do just really think it’s I don’t know, I am just really into it, and I don’t know, It’s just, well yeah that mainly is what is yeah” Simon.

Other participants were seemingly more comfortable in making sense of why the activities they engaged with through video gaming were meaningful. Participants such as Zahid described how video gaming had ‘*opened up opportunities in real life*’ through being enlightened to interests that beforehand may have been nullified by virtue of the limited opportunity to experience them within his offline world:

“It is not a conscious thing cos suddenly you think oh that is why I wanted to learn, like oh I can’t really do that in real life, like horse riding”. Zahid

“I mean cos I think a lot for me afterwards I got into wanting to do things in the outside world a lot more because of the game. Like I wanted to do falconry which I have actually done but I would never considered doing that kind of thing. So it seemed like it opened up opportunities in real life, it’s bizarre”. Zahid

In summary, video gaming enabled participants to facilitate an alternate way of Being in the world. This alternate existence was subjective to each individual, and was reflected of their aspirations of Being. Participants described being an MMA fighter, or experiencing horse riding, driving, walking, or falconry. Video gaming therefore appears to provide engagement in experiences that would otherwise be unavailable.

5.5.2 A questioning of Being through video gaming

The distinction between the offline and online lifeworld experienced through video gaming was at times murky. This murkiness existed as a result of a questioning of Being; whereby video gaming stirred some of the participants to contemplate their offline existence. For instance, the ability to embody a character within a video game, or ‘*pretend to be someone else*’ facilitated a reflective comparison between the self who exists through video gaming, and the self that exists outside of video gaming. Participants described how the ability to transcend within a video game led to a questioning of their existence outside of video gaming:

“Just something you can...like when I’m playing I can pretend to be someone else for a change ye know”. Mohsin.

“Yeah would I drive like I do on GTA and do the stuff I am doing in the game. Ye know what I mean that’s the thing. Cos in my case I have never been able to walk. Ye know what I mean I have never had that. So there is always that thing of what would I be like if I could walk?” Mohsin.

Mohsin initially pondered if his actions and behaviours within the video game would be replicated offline if he could do activities like driving. This led to further existential questioning, focused on the ability to walk. It appeared that experiencing movement such as walking through video gaming, stirred Mohsin to question ‘*what would it be like if I could walk*’. This musing did not suddenly appear to Mohsin, but held a constant presence ‘*always*’. For other participants, reflection was focused on a comparison between the characters they embodied when video gaming, and the self within their offline existence:

“I just think I would love to be some of the characters that I am in the games and stuff. I just think ugh, probably because their life is a bit more exciting than mine ye know what I mean. It’s quite hard for me to explain but yeah”. Simon.

The characters who Simon came to be through video gaming had existences that extended beyond his interaction with them ‘*because their life*’. They were to Simon more than simply software developed avatars who only served to be controlled and manipulated by the user; but Beings in their own right. More so, they appeared to encompass the Being who Simon wished to be, by virtue of the exciting life they appeared to lead. When compared against his own offline existence, Simon yearned to become the characters he encountered and came to know through video gaming.

Participants described how questioning their Being in the world as young men with DMD led them to develop a deeper understanding of the self. For example, Zahid relayed how video gaming continuously shaped him as a person as he came to understand his Being more:

‘I think gaming, and oh I read comic books and things that is very reflective, yeah I have always found kind of reflection in characters’. Zahid.

'I think with everything I do like gaming or, I kind of start to understand myself more, it is kind of a way to like create an identity and kind of shape it, so yeah I think that is what I think gaming is, it is shaping you as a person'. Zahid.

In summary, video gaming appeared to awaken a questioning of self by providing young men with DMD an alternative way of Being in the world, in which they could question and compare their offline Being against. Engagement in this questioning led to a deeper understanding of self, that continuously shaped the identity of participants who embraced this reflective practice.

5.5.3 Video gaming as a cathartic space; A welcomed intrusion

The narratives of participants revealed how the alternate lifeworld accessed through video gaming provided a space to make sense of emotion that manifested within the spaces participants occupied offline:

"Yeah so it started from there really, and I kind of used it (video gaming) as sort of a coping mechanism as I got older. Mainly because as a kid I was confused, I had a lot of anger, ye know about myself and the position I am in. I just didn't understand why, so I used Tekken (game) as a way to vent out my frustrations".

Mohsin.

"Well I think like for Xbox it is a way of like sort of taking out my stress and stuff". Simon.

"Yeah it is (emphasis), cos like, I suppose some games where you can get quite involved, like angry at so it is quite a good way to like get rid of anger as well".

Tom.

The cathartic nature of video gaming is revealed through discourse such as 'vent out' 'taking out' and 'get rid of'. Such phrases used by participants appear to denote a sense of cleansing the self of emotion such as frustration, stress, and anger that may negatively impact wellbeing. Video gaming appeared to provide space/s that acted as a retreat for participants to make sense of their offline Being, and the emotions that manifest as a result of that process. Video gaming encompassed a retreat or 'coping mechanism', a space to momentarily withhold and relieve emotions that otherwise may be all too consuming in their ever presence and existence in their offline Being in the world. These emotions

were a welcomed intrusion into a video gaming reality that provided participants the autonomy and safe space to actively make sense of, and work through such emotion; as oppose to having to suppress and 'bottle it up' for fear of upsetting significant others:

"Ye know cos they (parents) might think I don't know they've failed you or something like that. When they haven't but...". Tom.

As articulated in the above extract by Tom, speaking to significant others such as his parents about matters related to his condition and the emotions associated was not viable, as he feared doing so would cause his parents to feel they had failed him. Video gaming provided the space to make sense of these feelings and emotions away from the presence of others who may have internalised such emotion as a failure of care on their part.

For participants, emotion they wished *'to get rid of'* such as anger and frustration was done so not through the sharing of experience with others, but through action. This was evident in how participants discussed engaging in the mixed martial arts video game Tekken as a way to *'vent out frustrations'*. The frantic tapping of buttons to punch or kick an opponent within a video game can facilitate a *'venting out'* that is comparable to the punching of a boxing bag. The need to vent frustration and anger are by products of an offline world in which some of the participants were isolated, with little control over their Being (superordinate theme one). The lived experience of *'getting rid of'* *'venting out'* or *'taking out'* of emotion such as frustration, anger, and stress was situated within the temporality of the participant's lifeworld:

'But I think in the past when I was younger gaming helped to get my frustration and anger out because I used to play completely different games to what I play now. Cos I used to play games like Call of Duty, sort of those kind of shooting games because it helped me to get my frustration out but then I have turned into a person that is a lot calmer which changes what you need'. Zahid.

Video games such as 'first person shooters' were Zahid's go-too when he was younger as a means *'to get'* his *'frustration and anger out'*. Zahid then described a transition where he *'turned into'* a person who *'is a lot calmer'*. This

metamorphosis attuned Zahid's video gaming toward more cerebral and relaxing genres:

"There is a lot of games that are more cerebral, and kind of relaxing where you are not really doing anything, like the game Journey. Which like you hardly do anything, but it connects you emotionally in a way. I think games that are open to interpretation like Gris, like I played it then after a while, I think like a couple of weeks later I kind of think oh, ye know something pops into my head about the game that makes me think deeply more kind of about how I was feeling at the time. So it leaves, sort of plants a seed into my mind that grows and just helps me to process things in a way". Zahid.

While first-person shooters conjure up a sense of hyper-action and intensity. Zahid's video gaming behaviour as an older self appeared to be more calming. Potentially harmful emotion is not so much 'got rid of' but processed and made sense of gradually. With the content of the video game stirring Zahid to contemplate and consider his emotion at the time of interacting with the video game, often weeks later. The meaning of video gaming as a cathartic space therefore appeared to be influenced by the individual and unique lifeworld's of participants.

5.5.4 The importance of gaming to Being; an enforced companion.

For many of the participants video gaming had occupied a consistent presence within their Being-in-the-world:

"Well I have been gaming forever really, like as young as I can remember really I have always played it" Tom.

"Well, I've always liked, gaming and films have been my top two things I like doing, since forever" Simon.

"I mean I've always gamed since I was really little" Mohsin.

The eternal presence of video gaming, signified through discourse such as 'since forever' captured the importance of video gaming to participants. More so, participants appeared to have grown up with video gaming, alluded to in particular by Tom and Mohsin. This ever presence denoted a sense of

companionship, of a friendship developed at a young age, and consistently attended to on a daily basis as illustrated:

“Mm about 6 (hrs) from whatever time I get up till when I go to sleep. Sometimes it can be like more than 6 but on a regular day, it is normally 6”. Lee.

“I game...everyday (emphasis). So it could be hours so I would say each day it is at least 4 hours at least”. Tom.

“Err, I get up and watch telly for a bit at home, and then in the afternoon I go on my computer (to game)” Craig.

While much of the relationship between participants and video gaming was based on enjoyment and an ability to take on an altered sense of Being, its origins, as described in superordinate theme one, appear to born out of a lack of opportunity ‘to Be’ outside of video gaming. In this sense, there was an enforced quality to the companionship that existed between participants and video gaming. This was particularly well articulated in the following two extracts:

“I mean you don’t understand if you’ve got a disability, and you’ve got an overprotective family, that don’t let you play out because they are scared that you are going to get hurt, or ye know, or that you are going to get picked on, or ye know, ye not going to fit in, the only thing you can do is gaming”. Mohsin
And they’ve got nothing else to do with their life except for gaming. So it helps so many people ye know that are isolated from the real world”. Mohsin.

Both extracts illuminate how Mohsin’s Being was funnelled into the world of video gaming as a result of restricted opportunities ‘to Be’ within his offline world. These restrictions were the product of his parent’s concerns over how his Being would be interpreted by others. In a bid to protect him, Mohsin was contained inside, and denied opportunities to ‘play out’. Isolated ‘with nothing else to do’, video gaming was a consistent companion that maintained its presence against a backdrop of limited offline opportunity. The enforced quality of this dynamic is further evidenced by Tom:

“If I could, I would not just game, if I could get out and do all that stuff I would hardly ever go on my Xbox”. Tom.

“And I find it really annoying when people say ‘well is that all you do, sit on that all day’ that is the one line that I really, really (don’t like), cos like I have said to you ye know I can’t pick an instrument up and start playing it, or go walking ye know what I mean it really winds me up”. Tom.

‘If I could get out and do all that stuff’ poignantly summarised the position of participants. If life outside of video gaming offered a glimpse of what life inside video gaming provided, then the companionship between them and the video game would perhaps hold an alternate meaning. A meaning built upon choice rather than enforced Being. The position of participants was further compounded by the lack of understanding by others on the importance of video gaming to his Being.

For some participants, this companionship between themselves and video gaming evolved and changed over time. This development appeared to be in line with an increase in opportunities within their offline world. Both Mark and Mohsin in particular discussed how their relationship with video gaming had become less dependent and defining of their Being over time:

“I used to do a bit of gaming, not too much of it now”. Mark.

“If you’d have asked me say 10 years ago I would have said yeah it probably does define me. But now I am older I would probably say no, My outlook, I’m not as stuck in a rut anymore. I don’t just spend all my time on it because I do try and get out of the house now”. Mohsin.

Mohsin alluded to how a change in his outlook had led to a gradual reduction on the amount of time he spent video gaming, with more of his time spent outside. The wider narratives of participants also shed light on this change of relationship. Mark for example had a busy social lifestyle that evolved around following and participating in sport. As such, he had less of a need to video game when his offline lifeworld was rich with experiences that he would otherwise be forced to source through video gaming.

For others, untangling themselves from their companionship with video gaming could be challenging:

“I am sure it is not just people with disabilities who get ye know either haven’t been out for ages or being ill, and they start playing Xbox and then they can’t

really reconnect with people. It is a bit of a...in a way it can be quite a vicious circle. Cos once you're in it, it is hard to get out of it ye know". Tom.

Tom highlighted how life within video gaming could create a struggle to exist outside of it. His use of discourse such as *'once you're on it, it is hard to get out of it'* summarised his position. For Tom it seemed, existence within a video game offered much of what his offline lifeworld was deprived of. Therefore, *'getting out of it'* became a detachment from a reality that attended to his Being, in order to attempt to exist in an offline reality in which a meaningful existence is less assured.

The struggle described by Tom to come *'out of'* video gaming in order to develop a meaningful existence offline, was marred by low expectations of self relayed by others. For instance, Zahid, a successful blogger and accessibility consultant, discussed how his respiratory consultant was unable to grasp that he had an existence beyond his condition:

'Cos in the past when I go to the respiratory consultant, when I used to say I go to London and Parliament, and I do blogging and gaming they were like 'oh my god do you do all that, how do you manage'. Like yeah I do have a life not just Duchenne. I think that's what it is just education, people are ignorant but not in a terrible way, they've just not been educated properly'. Zahid

The failure of others to recognise that young men with DMD *'do have a life not just Duchenne'* can hamper their attempts to form a meaningful existence outside of video gaming. Whilst ever others are *'ignorant'* to the multifaceted existences of young men with DMD, the appeal of video gaming as a space in which the self is understood, and ability is recognised may remain greater than the appeal of life offline.

5.5.5 Video gaming as a fragile space; A persistent intrusion

Participants described an awareness of the potential for their condition to intrude into the reality they had created through video gaming. Their online realities therefore were represented as fragile spaces that were consistently and progressively intruded on by the degenerative nature of their condition/s. Intrusion was frequently experienced as a reduced ability to immerse themselves in their video gaming reality:

“Whereas like Red Dead Redemption, and for like when you have to slow time down or like track animals I can’t press both analogue sticks in. So I am a bit stuck there so it’s sort of hindered me playing a game to like its fullest ability cos I can’t do what’s quite important in the game”. Tom.

“It is a standard controller but I’ve recently been having trouble with the L3 and R3 buttons, ye know the analogues, like the ones you have to push in, I can’t do that at all. I just haven’t got the amount of strength to press it. So I am at a disadvantage now when I play”. Mohsin.

“The options button I can never press, cos there are a lot of games that I can play but they always have the map or whatever on the options button which I can never press so it limits the game”. Zahid

This presence of condition was experienced through the loss of strength and subsequent ability to manipulate the controller in order to perform necessary commands within the video game. Not being able to do so ‘*hindered*’ and ‘*limited*’ participant’s ability to engage in video gaming to its ‘*fullest ability*’, leaving them at a ‘*disadvantage*’ when playing. Some participants described how the degenerative nature of their condition progressively infiltrated their video gaming reality to the point where it could no longer be ignored:

“Yeah cos I did try and get into the harder levels but it just got like really annoying I used to be better at it. I am not as good as I was, it is a bit harder to play now. I get tired a lot quicker, and I am not as good as I used to be. So...”
Tom.

In the above extract Tom described the gradual reduction in his ability to play a football video game. His use of the discourse *'not as good as I used to be'* was akin to perhaps the dialogue of a retiring footballer justifying their decision to hang up their boots. Participants described their frustration at not being able to play video games to the level they desired:

"Oh it can be trust me". Mohsin.

Other participants came to understand video gaming as a fragile space through observing the devastating impact of degenerative conditions on the lives of their friends who also lived with similar condition/s:

"Honestly it was the best thing ever, he is the best player I have ever seen play. And then recently he lost the ability to use his fingers. And I thought if that happened to me, I would probably lose the plot". Mohsin.

Being witness to the decline of his friend's ability from the *'best player I have ever seen play'* to losing all ability to play forced Mohsin to confront how he would cope if *'that happened to me'*. The gravity of what life without video gaming would mean to Mohsin is poignantly illustrated in his realisation that he *'would probably lose the plot'*. Something he goes on to make further sense of:

"But I've never stopped gaming ye know, if I couldn't game, like if someday I was to lose the movement in my fingers, I don't know what I would do because gaming is like my go too thing". Mohsin.

His use of discourse such as *'I don't know what I would do'* illustrated the sense of lostness Mohsin associated with the prospect of a life without video gaming, something that is his *'go too thing'*. Mohsin's affiliation with not being able to video game as a result of a loss of movement in his fingers revealed the meaning of his fingers to his Being. They represented the last remaining muscle group to not succumb to the degenerative nature of his condition. Without their dexterity, his ability to video game is fundamentally threatened, by virtue of the necessary synergy between fingers and controller in order to video game.

In an attempt to scaffold and support the fragility of their video gaming space, participants sought assistance from others:

“Yeah well the company that I know are called Special Effects, they are a charity, and what they do is help people with disabilities, they will talk to ye, ask you what the problem is, ye know and what needs doing, and they will take the controller, and they will try and customize it for you. To help you out”. Mohsin.

“Yeah I have had Special Effects in touch for quite a while, they did try and actually put some extra buttons on my remote”. Tom.

“But then I found like Special Effect, and I have had kind of adaptive controllers, it is amazing cos it is like a normal PS4 controller but the buttons are larger to press and I have got switches so that had kind of really helped me in a way”.

Zahid.

The charity ‘Special Effects’ adapt and customise video gaming controllers, in addition to using a range of technologies from modified joypads to eye-control software (Special Effects, 2020). The majority of participants were aware of the charity, and some actively engaged with the charity to develop and find solutions to enable them to continue to video game. As well as assistance through charities, some participants invested in adaptive controllers:

“But I’ve seen this new controller and it has got 4 buttons at the back. They cost a bomb though”. Mohsin.

“But now Xbox has brought out like there special like remote. And you can plug like different things into it. So I have got one of them now”. Tom.

“But recently I have got an Xbox because I was using an Xbox adapted controller, and Microsoft gave that to me so I had to kind of use it but with that I, even though they have adapted it I find it difficult to use...but I have bought this device called a Titan One which you can plug your PS or Xbox and you can use whatever controller you have”. Zahid.

The development of assistive controllers by video gaming companies signified an awareness of the disabled gaming community, as well as an openness to develop technology to meet their needs. However, the cost of such controllers ‘they cost a bomb though’ highlighted a discriminatory attitude that preys on the

importance of video gaming to people with disabilities, and seeks to profit on their resilience to seek out technology that provides access to their video gaming reality. In addition, there was a sense from participants that efforts to make video gaming more inclusive could often be tokenistic:

“What people don’t seem to understand is that everyone is different. You can’t just adapt one controller for everyone, it’s got to be catered for each person. Do you get where I am coming from?”. Mohsin.

In response to expensive technology that may not be suitable to their unique needs, participants turned to developing their own strategies to maintain their video gaming reality:

“FIFA is the easiest yeah because like, basically you can put it down to the trigger, the analogue stick, A and B and that is it really”. Tom.

“But with voice control it has kind of helped me to play games more”. Zahid.

“...but recently on the PS4 they’ve done this thing where you can change the buttons on the settings. Yeah, but then again it’s sort of the same thing cos you’re just swapping one thing for another”. Mohsin

Strategies included manipulating the commands of buttons on the controller in order to reduce the number of buttons needed to partake in the video game. This was not always successful, particularly with video games that required each of the buttons for multiple commands. The use of voice control was a further strategy described, with the technology enabling participants to use their voice to reduce pressure on hand movement. Each of these strategies, helped to enable the young men to re-establish a sense of control, particularly over the video game controller:

“Also if you write some code then you can adjust things, like faster fire rate, or like toggling a button for it to do a different thing. So I have learned that which has really enabled me to have some more control back, it is like I am controlling the controller not the other way round”. Zahid

Re-establishing this sense of control, provided young men such as Zahid with a sense of satisfaction, and highlighted his resilience to find a solution to continue video gaming:

“But I think as I get weaker, I have found it does, there are more problems but I enjoy these problems because I get to find a solution. So sometimes it is nice to have a challenge, you feel a sense of satisfaction, you feel a bit weaker but you have still managed to play”. Zahid

As illustrated in the abstract, Zahid applied a positive outlook onto what understandably can be a distressing realisation of getting progressively weaker. Focusing on the solution, and recognising the sense of satisfaction he feels when identifying a solution, preserved his wellbeing. However, even when participants had access to a repertoire of solutions to continue video gaming, the threat and at times reality of life without video gaming was still ever present:

*“Well I think it does worry me in a sense, when they say maybe a new console is coming out, and when the PS3 changed to the PS4 controller. That is when I couldn’t play games because the controller I just couldn’t use it at all, so I bought a PS4 but I couldn’t play it, so that was like the worst time for me”.
Zahid.*

In the above extract Zahid described how the introduction of the Playstation 4 rendered him unable to video game, a result of a controller that did not meet his needs. His experience reflects how disabled gamers can be marginalised and forgotten. Left behind by advancing technology, and having to find their own solutions, or pay ‘a bomb’ to purchase adaptive controllers that do not always suit their needs. Disabled gamers can be forced to exist in a world that depicts a landscape of ableism. Whereby the announcement of a new video gaming console is met with dread and fear, rather than excitement. This led to some participants to leave console video gaming behind:

“Well I can’t do it anymore”. Craig.

“No, well I struggle to use the controller so”. Mark.

Applying an interpretative lens to the above extracts, Craig and Mark may have felt reluctant to seek help from charities such as ‘Special Effects’, or to invest in

an assistive controller, for fear of being further labelled as 'the needed' or 'less able'. Asking for help, can also come with a sense of humiliation, particularly for young men who also have to contend with and find their place among masculine expectations of Being. Furthermore, emotions that are potentially harmful to wellbeing such as frustration, anger, and upset, manifest as a result of making sense of the realisation that an activity that provided so much meaning, is no longer accessible. Therefore, it may be that to preserve the self, Mark and Craig dismiss all possibility of console video gaming, depicted in their dismissive and 'final' discourse. As a result, some participants sought alternative technologies that enabled access to their video gaming reality:

"Yeah online games, games that are on my computer... I mainly play on the computer now". Craig.

Craig described how a computer mouse was much easier for him to use in comparison to a video gaming console. Craig's account is testament to both the resilience of participants to seek solutions to video game, and further illuminates the importance of video gaming in their lives. However, for others, the drive to seek assistance or alternative methods to video game appeared to be less important:

"I can probably get someone to help me adapt one but I just can't be bothered really". Mark.

Mark's narrative depicted an offline lifeworld rich with opportunity, purpose, and relative independence. Consequently, it may be the case that because his offline lifeworld was meaningful, the desire to engage in video gaming was less intense in comparison to other participants. By contrast, other participants were clear of the significance of technology to their Being:

"So I think I realised how kind of for me technology err kind of makes my life because if I didn't have the technology or ways to communicate I would just be in bed kind of not doing anything which I never really wanted for myself so..."
Zahid.

Life without technology for these participants would mean an existence '*in bed kind of not doing anything*'. Therefore, the importance of technology as a medium to a meaningful existence was evident. While much of the discourse on

video gaming and accessibility centred on strategies to alleviate the impact of muscle weakness on the ability to video game. Some participants also described the benefit of video gaming as a form of physio:

'I feel like I am doing physio because after I play my hands feel a lot more stretchy, and they feel like I can use them a bit more which is a nice feeling as well. Like I think a lot of boys we never used to do hand exercises cos you think what it is the point but now I wish I did a bit more of that physio'. Zahid.

'Cos a lot of my friends who are in a wheelchair but can stand up and walk a bit, they said that gaming has been like a form of physio for them. So they kind of, it physically heals them in a sense, cos mental enjoyment does heal you and relax you'. Zahid.

Video gaming can therefore be as physically *'healing'* as it is significant to their overall wellbeing as described. More so, video game provided meaning and purpose to hand exercises that otherwise could be viewed as pointless.

The physical impact of living with a progressive disease can persistently intrude on the experience of video gaming. This intrusion ultimately can prohibit the level of immersion and subsequent transcendence that participants enjoyed. Nevertheless, the degree to which participants developed solutions to continue to video game relayed how crucial it was to their Being in the world.

5.5.6 Summary of superordinate theme

Video gaming, to the majority of participants provided an alternate reality which they could immerse themselves within, and transcend to engage in experiences that were beyond their 'normal experiencing'. Participants described a range of activity experienced through video gaming that were otherwise inaccessible offline. Furthermore, video gaming offered cathartic value to participants, a space to question their Being and make sense of emotion that manifested within their offline world. However, participants described the continuous threat of not being able to video game by virtue of the degenerative nature of their condition/s, and the lack of awareness from video gaming companies to address their unique needs.

5.6 Superordinate theme three: The meaning of social networking platforms, blogs, and spaces.

Superordinate theme three attends to the meaning of social networking sites, and online blogs, two platforms of social media that featured in the lived experiences of participants. Five sub themes each describe the lived experiences of participants in relation to their interaction with these spaces.

5.6.1 #DMD; group identity, empowerment, and making the other aware

Social networking sites and apps such as Facebook, Instagram, and Twitter are host to a plethora of pages, groups, and profiles that are related to DMD. The majority of participants identified being a member of, or following a page designed to encourage discussion relating to living with the condition:

“Well I’m a member (of DMD pathfinders), I do, like if someone puts a request on and they are looking for answers like erm, where can I get this equipment from or whatever, I will put something in the comments if I know the answer and ye know help them choose stuff”. Mohsin.

“Well I’m on a DMD...my disability we’ve us own pathfinders group. Yeah so we chat to one another ye know if people have problems like ye know to do with ventilators or....they will put it on (the group) and everybody will comment on it and yeah we just discuss whatever”. Mark.

The use of discourse such as ‘we’ve us own’ and ‘I’m a member of’ conveyed how these online spaces provided participants with a sense of group identity, belonging and ownership. The existence of closed social media groups facilitated on sites such as Facebook aided participants in attaining a sense of togetherness with others who shared similar lived experiences to their own. Several participants described how the online spaces were one of the limited avenues available to encounter other young people with ‘similar issues’. The realisation of not being alone and feeling part of a community spurred participants to seek solutions to issues that otherwise they would have felt alone in confronting:

“Then I realised through social media and talking to other people, that a lot of people are having similar issues, cos I thought I was alone in those issues...but you're not there are a lot of communities. I think it has helped me deal with things really, and now I find solutions and I find charities that can kind of help me”. Zahid.

Away from the gaze of significant others and healthcare professionals, conversations regarding the practical matters of living with DMD were highlighted as commonplace online. For instance, advice on where to source pieces of equipment or assistance in solving problems with ventilators featured. Participants described the benefits of being able to source queries related to their condition themselves. Furthermore, participants described assisting and aiding others who had similar lived experiences:

“Yeah, yeah, I like to comment and help people with other stuff so it is quite good yeah”. Mark.

“And I think that has helped me through the online community. That is why social media is so good cos you can read a lot of other comments and identify with them a lot. So I think that you really do feel empowered in a way because you can type ‘oh I am having this problem does anyone have a solution to this?’” Zahid.

“Yeah connecting to other people. Actually (emphasis) interacting with another person, that you can feel helpful towards that other person...” Mohsin.

Participants also described how sourcing information about their condition themselves from others who shared similar lived experiences aided the processing of this information:

“And also with Duchenne, and I think all disabilities sometimes you want to learn the information without kind of having to ask professionals or parents in a way. You feel a bit I don't know almost more confident with that. So I think that is also...if you've been given the information it is harder to admit to yourself I think. But if you've just come across that information then it doesn't feel as bad in a sense”. Zahid.

Achieving a sense of group membership and identity through interaction with others in illness-specific online spaces aided the confidence of some

participants, particularly relating to communicating with others. For example, Zahid discussed how his confidence within group situations had increased as a result of engagement with a DMD charity:

“And feeling part of a group and communicating, cos I am part of a charity MD UK and they’ve helped me to become more confident. Because if you met me about ten years ago, I would never speak I was so quiet, and I was really stressed a lot of the time”. Zahid.

The security of being ‘part of a group’ of others with similar lived experiences pushed some of the participants to test the waters and engage in discourse that may be considered ‘taboo’ offline. For instance, participants described how they would ‘take the mic out of each other’ about their disabilities. This light hearted discourse alleviated some of the tension and worry related to their diagnosis that reverberated within offline spaces. However, the use of humour was not always appropriate or well received:

“There are a lot of us who take the piss out of our disabilities and each other. But then some who, you say anything, and it’s like the end of the world to them”. Mark.

Mark’s experiences evidenced the individual differences across the sample, likely reflective of the wider population. Illness specific Facebook groups and pages also provided a platform for participants to voice their opinions and feelings about living with a disability or on matters such as the distribution of funding to charities:

“I follow a few people who erm just post awareness for like my condition and stuff. And I like comment and share and bits”. Simon.

“And yeah if there is anything I feel strongly about I will talk about it (online) ye know what I mean if it is something about my life like with my disability and stuff I do often voice stuff”. Simon.

“That’s what it was, it wa to do with erm cancer charities. I was saying why do they always get the money when there are other charities out there. Cos they (cancer charities) waste money on adverts and stuff like that. So I said summet like that and people were like ‘ugh ugh’. Mark.

The above extracts signified a sense of making others aware of DMD and what life living with the condition is like. For Simon, this was achieved through the sharing and commenting on posts and content he affiliated with, by virtue of it representing *'something about my (his) life'*. Mark's approach was to challenge, question and voice the sense of injustice he felt regarding the use of charitable funds particularly by charities who raise money to support cancer patients. In doing so, making others aware that a wider spectrum of charities exist, specifically those related to DMD who also require funding.

Closed Facebook groups were also described as spaces to become aware of the possibilities of life with DMD:

"Yeah I mean I have been friends with (name) and the other guys from Pathfinders for a while. And like with me, when I first saw (name) he was like kind of my inspiration cos I thought oh god, with Duchenne you can do a lot of things, it was just amazing. So through that it has pushed me to think yeah you can do it". Zahid.

Participants spoke of being enlightened and inspired by the lives of other young men with DMD whom they came to know of online. Being aware that they could do *'a lot of things'* aided an altered perspective on what was possible, and pushed participants to *'think yeah you can do it'*. However, not all participants were aware of how to access and become members of closed Facebook groups related to their condition:

"I mean I don't know I've tried to like research other people with disabilities but it comes up with nothing really" Tom.

Tom described how he actively researched online to find *'other people with disabilities'* but was unable to identify the closed groups, and social media spaces that other participants were frequent visitors of. Tom's perspective was illustrative of the importance of ensuring support, guidance, and signposting exists on how to access the content and people described. Tom was not the only participant to describe the experience of not been connected to others online:

"Yeah I do think cos for a long time I was very isolated and I didn't have a lot of real friends and that kind of thing so I think slowly I have built up, over the years

you build a community and it is only recently in the past kind of couple of years where I have connected with people online". Zahid.

For Zahid, the experience of being connected to others online was relatively recent. He described the process of developing a community as slow, with a large part of his life spent socially isolated prior. Both participant's accounts act as reminders that while social media is an ever-growing, expanding, and developing phenomena, it is not always accessible to those who may benefit from its potential capacity to bring users together. Nevertheless, for participants able to engage in closed Facebook groups associated to their condition they were described as useful spaces to meet others with similar lived experiences, and express autonomy and independence over healthcare decisions.

5.6.2 Online blogging; A variation of meaning

Online blogs are defined as a webpage that features a person's own experiences, opinions, and observations (Merriam-Webster, 2020). Its meaning to participants was less clearly defined, with varied interpretations expressed as to what online blogging meant to participants. For some participants, online blogging was highlighted as useful for raising awareness of what living with DMD was like, and dispelling connotations that can surround the condition:

"I have been thinking about maybe doing that. To just talk about my life, and for awareness, I definitely am thinking about doing that. And I might do a bit about university cos I know there is people that might be scared to because of their disabilities and stuff and I just want people to know what it is like". Simon.

Simon described how blogging offered a platform to detail his experience of going to university, in order to convey to others what the experience was like. Simon shared an awareness of the concerns and worries other young people with disabilities harbour regarding higher education. This awareness appeared to be a motivator for him to contemplate blogging, in order to reduce concerns and fears by demystifying the experience through his account of *'what it is like'*. For Simon, blogging provided a platform to offer a different narrative to life with DMD to what he felt was portrayed by *'some scientist'*: Providing an accurate representation of the self that included the *'good parts'* of life with DMD was perceived as being *'helpful for people'*:

“Ye know just reading something some scientist has written is not the same. When you see actually what it is like people are more likely to care more. Cos if people just read a list of symptoms that is not really...but if people are actually saying how it effects them and the good parts of it, it really is helpful for people”.

Simon.

Online blogs were also interpreted as spaces for sensitive and personal disclosure. For some participants, engagement in blogging for this purpose was not something they felt comfortable doing. Participants spoke of the need to keep emotion *‘bottled down’*, a strategy perceived at odds with engagement with the online activity understood as being for open personal disclosure. Blogging anonymously was considered by participants. The appeal to blog anonymously appeared to relate to perceptions of masculinity disclosed in other extracts of participant’s narratives. For example, participants conveyed the belief that men should keep emotion bottled in, developed through the behaviour of key figures in their lives such as their fathers. The following extracts from Mohsin’s account portray this view of blogging:

“No I keep stuff bottled down I always have”. Mohsin.

“(pause) I thought about doing like an anonymous thing”. Mohsin.

I don’t know how my Dad sees it. He never really speaks about anything. He’s a typical bloke ye know. He keeps everything bottled in. Mohsin.

For other participants, blogging was an activity incompatible with their ethos and view on life. For example, Mark described an attitude of *‘doing’* as oppose to *‘talking’*, and therefore blogging was viewed as something that *‘I can’t waste my time on’*. It could be interpreted that Mark was expressing an awareness of his own mortality in his use of discourse. The temporality of life was not to be wasted through talking, but needed to be used wisely by *‘doing’* and engaging in experiences beneficial to the self. Furthermore, associations between blogging and personal disclosure were dismissed, and viewed as inappropriate by some participants. The following extracts are examples of this attitude towards blogging:

“No it’s a...I can’t waste my time on it. That’s what I think to be honest. Instead of talking about it I would rather do”. Mark.

“Oh no, it’s like say if someone dies in your family, you don’t post it online. It’s not what it (social media/blogging) is for”. Mark.:

‘No I don’t wanna’ Craig

Blogging, along with other forms of social media were not always accessible to participants. For example, Tom was aware of the opportunities for communication with others through blogging, but had ‘no idea of the first place to start’ to interact with these online spaces:

“But it is just annoying cos like I know that I would get on with a lot of people but it is just I don’t really know what to go on, like to talk to people on blogs and stuff like that I’ve got no idea of the first place to start really so”. Tom

Online blogging offered a myriad of meanings for participants. Unlike closed Facebook groups related to DMD, there was less of a consensus on the meaning of blogging. While some participants described the possibility of blogging in the future, only Zahid detailed his experiences of actively blogging. His narrative of online blogging is discussed within the next sub-theme.

5.6.3 Online blogging as a process towards the acceptance of self

This sub-theme portrays Zahid's journey with online blogging, and the varying meanings he developed towards the activity. Zahid first began to blog after being encouraged by his mother to start *'putting down in writing'* his existential and psychological musings pertaining to his own existence:

"Well initially it was my mum she was saying that you're sitting around a lot you should do something, and I have always liked kind of reading, and language and psychology, so I enjoyed doing that (blogging) because...I think in a way I was taking control of my life. I felt that through writing I was, kind of it helped me to kind of like look at my past and how I used to feel, and I think I have always just connected with...like everything I do even when I read comics and stuff I always like to kind of understand psychological effects, so I thought oh it is best to just kind of put them down in writing and that's how it started". Zahid.

The act of blogging aided a cathartic process of making sense of his past, and the feelings he associated with that time. Doing so, initiated a process of *'taking control'*, fundamental to which was a confronting of self:

"But I think through blogging it helped me to confront my feelings. Cos for me mental health has been very difficult, but I didn't realise at the time that it was kind of anything to do with mental health (blogging). But just writing more and thinking deeply kind of pushed me to look at difficult things. Yeah, rather than thinking of it just as a disability, just also about how my mind coped with the condition really". Zahid.

Zahid reiterated how blogging pushed him to confront *'difficult things'* and focus on how his mind *'coped with the condition'*. In particular, the deteriorative nature of his condition was something his mind struggled to cope with and make sense of at a younger age:

"Well with Duchenne because it is deteriorating disease I think of it like decaying, I am decaying away. So, through that, when I was younger that decaying process it was very difficult to deal with and kind of like accepted it over the years. I seemed to have in a weird way kind of embraced that decay and kind of live with it without too much emotionally grieving process. Because

like, there are certain things that I didn't think I would be able to cope with, so with that it has kind of helped me accept and see that it happens to everyone".

Zahid.

Making sense of his 'decay' was an understandable struggle for Zahid. However, experiencing the 'decay' as it happened progressively over the years, resulted in an awakening that he was able to emotionally cope with it. This resilience came as a surprise to Zahid '*there are certain things that I didn't think I would be able to cope with*'. His awakened resilience appeared to foster a sense of acceptance toward his condition, something that was further supported through an acknowledgement that '*it happens to everyone*', albeit at a later stage in life. Nevertheless, coming to accept the 'decaying' nature of his condition was difficult:

"I think dealing with that acceptance was really really difficult, and half of the time I don't know how I did it...". Zahid

Doing so however, was integral to him accepting his condition as part of his Being. Writing, and in particular the open access nature to online blogging was pivotal to this process, in that Zahid was not only accepting his condition as part of his Being to himself, but also to the wider public who had access to his blogs in which he detailed this journey of acceptance:

"I think in a way I was hiding behind that, so I think that pushing myself to write was quite a stressful and scary thing for me, but I think that was necessary for my growth really and accepting yourself because on the internet anyone can read your blogs so it was a bit of a scary moment but a really good moment".

Zahid.

Zahid described how writing about accepting his condition was necessary for his 'growth'. There was a sense in his discourse that Zahid felt that the 'decaying' he earlier alluded to, was both of the body and of the mind. Whilst ever Zahid was unable to accept his condition, it held a dominance over his Being, weakening both his body and mind. Through the painful and emotionally exhausting experience of coming to accept and recognise his condition, Zahid was able to quieten it's significance to his Being, allowing him to grow and flourish. Zahid detailed this process further in the following quote:

“And there is two choices I can either cry and mope and not do anything or I can use it to be a lot more helpful and kind of be a lot more err, kind of embracing myself. Because if I didn’t embrace my condition, it is like I am rejecting a part of myself (long pause). It is not an important part but it is a small part that is kind of important to embrace in a sense. Cos once I embrace it then I can like ignore it cos it is sitting there happy. Whereas it is not like being annoying, and making noise, and shouting, and trying to be the centre of attention”. Zahid.

Zahid poignantly articulated how he chose an existence in which he embraced all manner of his self, including his condition. Doing so, enabled the condition to sit quietly as part of his Being, satisfied in its acknowledgement that it is recognised and accepted. Zahid’s description illuminates how without acceptance, his condition is wholly encompassing of the self, dominating in its insistence on being heard and recognised. In taking ownership of his condition, Zahid appeared to retake a sense of control over it. It was no longer a foreign force, placing its dominance over him, but one which he had come to confront, grieve, and come to peace with.

Sharing his journey with others through blogging provided a sense of purpose that enabled him to navigate challenging life decisions, and reassess what being at home entailed. Life at home was manageable because through blogging Zahid still maintained a *‘purpose in life’*. Zahid described how his purpose was to illuminate his life in order to inform *‘other boys with Duchenne’* that life still holds possibilities and meaning. Zahid’s confidence to blog was fed by positive and meaningful feedback from those who read the content he posted:

“I was in two minds should I stop uni or not cos I thought oh well if I don’t go to uni, I would be at home and do nothing what was quite scary for me. But kind of with blogging it made me realise, I kind of felt that was my purpose in life, that if I’ve got a disability I feel that I should express my life so people can understand my disability. And even other boys with Duchenne could kind of see that oh there is possibilities, yeah you can get a job, and you can have meaning, and people do want to listen to your perspective”. Zahid.

“And then I got a bit more confident cos that’s when I was thinking oh people actually really like my writing and also I have had a lot of people say that it has

helped their sons, a lot of parents have said that yeah, and even other boys have said to me that it has helped". Zahid.

"...a lot of parents are like oh I've read your blog and my son is struggling and its helped them, and so that kind of helps me in a way because kind of you realise there is a lot more people out there that are silent so I think writing is my duty in a way because if sharing my life is going to help other people you kind of get more motivated." Zahid

Discourse such as 'oh people actually really like my writing' revealed almost an epiphany for Zahid, a sudden awareness that the material he was posting was meaningful and useful to not just himself but others. Zahid disclosed how being aware that he was helping others through his blogging also helped himself, in that it provided motivation and encouragement to continue to write, as a matter of duty to help others. Zahid also described how his blog has led to further opportunities to become 'known' beyond his blog. For example, Zahid described how he writes for a popular video gaming magazine, and has presented on the subject of accessibility at many national and international conferences:

"I just feel that I am putting something meaningful so people can connect to it wherever they are or what time, and it will always be there so in some way I feel like it is my job to do that, to carry on and write about how I live". Zahid

"I think it just helps you with your self-worth because you are kind of doing something meaningful. Cos a lot of my work I have got through people reading my blogs and they've kind of really liked what I have been saying so I've had a lot of opportunities just through that (blogging) really". Zahid.

Zahid described how the opportunities that were presented to him through his blog enabled a positive reflection of his condition and its impact on his life. For Zahid, his condition provided opportunity rather than restricting it. Blogging appeared to sit in the centre of his world, as an entity that he connected to in order to find meaning, purpose, and value:

"I find that with Duchenne without it I wouldn't have got all these kind of opportunities I have now, so I think that has helped me a lot to process how I used to feel a lot as a child. That it is difficult, it is a difficult condition to live with but then there is a lot of positives as well. Which is a bit difficult for a lot of other

boys to kind of see, but I do really believe that kind of it has been a positive thing". Zahid.

'I think everything is tied into my blogging, it is like a tangle of wires really going into places all stemming from blogging with different connections'. Zahid.

Zahid reflected on how his current existence differed greatly from the assumed existence he projected as a younger self. The term 'dream' was reflective of the meaning and significance attributed to the life he lives, and the recognition of how life was projected to be very different. Blogging provided a platform to make his dream a reality. Part of Zahid's purpose was to share his story through his blog to others, based on the acknowledgment that much like his younger self, many boys with Duchenne imagine a limited existence. Zahid documented and shared his journey toward meaning, purpose, and acceptance, in an attempt to enlighten others towards a similar path:

"Yeah I feel like a lot of my friend's aren't kind of, they don't like writing and that it is not their thing but I thought if (blog) they might connect with it, and it is sort of my duty in a way to Champion Duchenne and to show everybody what is possible because when I was growing up I never really thought anything, like half of the stuff I do now I could never imagine myself doing that if you asked me fifteen years ago. And the funny thing is I used to always think oh I would love to work in the gaming industry and you think oh it is a dream, whereas now I am actually doing it". Zahid.

In summary, this sub-theme has presented a unique account of blogging from the perspective of one participant. Zahid's narrative illuminates the potential of blogging as a social media activity that provides meaning, purpose, and value to his everyday life. While Zahid was the only participant who actively engaged with blogging, his account provides evidence of the potential benefits of the activity to young men with DMD.

5.6.4 Seeking a sense of belonging within social media

Achieving a sense of belonging was a challenge for some participants within their offline lifeworlds. Participants described the impact of their prognosis on how they interpreted their presence in the world as adults. In particular, living beyond the life expectancy outlined by healthcare professionals at the point of prognosis left participants 'lost' and required them to change their 'whole world view'. Central to this change, was seeking a sense of belonging in the world:

“Erm no, it has not always been there, it was just when I was at home a lot. I just, because when you are talking about diagnosis they say you kind of die in your teens and afterwards when I was 18 and I was still here I was lost and I was thinking my whole world view has changed and I don't know what to do. Yeah, and like doctors are kind of wrong in a way by saying about your teens, and some do, but not everyone, so I think it makes you confident that I have to...this is my life and I have to do what I want in a way yeah. I require a quality of life”. Zahid.

“I have always wanted to belong somewhere” Zahid

Social media appeared to provide an alternative space to their offline lifeworlds to source belonging. Participants described how they identified others with shared interests through activity such as online video gaming. For example, Lee outlined how he formed friendships with others and developed a 'crew' of people that facilitated a sense of interpersonal and group belonging:

“Just play the game and then end up finding them in the game, their doing something that I liked or something then I say something about whatever, then we end up becoming friends that way. So started off becoming friends with one person then meet all his friends”. Lee

“Yeah I've got like a crew of 4,5,6 people that I go on with. I've known them nearly 2 years so”. Lee.

Belonging was also found in the relationship between participant and avatar. Participants described how in times of offline social isolation, they found friendship and bonds with the computer generated avatars they came to know through video gaming. Role playing games (RPGs) in particular fostered and created an environment to develop friendships with avatars. The dynamic

between participant and avatar was experienced through the temporality of the participant's lifeworld. Some participants described how the meaning of their avatar friendships altered as they formed friendships outside of video gaming. The following extracts illustrate this experience of belonging:

'Cos with a lot of games where you can dress your characters and form friendships with them like the game Mass Effect that is why I like RPG's. But the thing is when I was younger I didn't really realise what I was doing, that it was a way of getting friends and learning how to interact with people So, I just meant it vicariously really. And now when you think back you think 'oh those games really did help you to, kind of not feel as isolated'. Cos the thing is at that time I played Mass Effect, and I felt really kind of good cos I had friends but recently I had gone back to playing it and got a different feeling.' Zahid.

'I don't really feel like I want it for friends, so it is really strange to kind of experience it again. (In response). Yes definitely, it is fulfilled by different means now.' Zahid.

Participants also alluded to the importance of groups and pages hosted on the social networking site Facebook as spaces to interact with others who share similar interests. For example, interests in topics and genres such as animation or video games that participants previously 'had no one to talk to about' were shared with others through Facebook groups. Participants descriptions of being part of Facebook groups associated with their interests where they 'helped each other out' illuminated notions of team-work, companionship, and togetherness, that ultimately may have led to a sense of belonging:

"..So I've joined that Facebook group because like there is all the different things you can do in the game and it's just basically a load of people helping each other out to do this one thing in the game". Lee.

"So then it makes like another community that like I am part of and stuff like that and most of like the big groups of people I know are basically through games and stuff". Lee.

"Ye know with a lot of people it helps their confidence, playing online, talking to likeminded people". Mohsin

“Watching it, reading the mags, watching them on TV mainly, and then when Facebook came out, they’ve got their own page, and you find likeminded people that are into the same stuff as you ye know it’s good cos in the past I wouldn’t have had no one to talk to about it”. Mohsin

The video-sharing site YouTube was highlighted as useful for keeping up to date with developments and changes related to shared interests with peers, such as video game updates or the release of new films or music. In turn, watching videos also viewed by in some instances millions of other people may also have conjured up a sense of belonging:

“Just watching videos and stuff...gaming videos, all sorts of videos”. Craig.

“Oh yeah YouTube I will watch YouTube all the time. Err yeah. Yeah cos I use my Xbox to watch YouTube”. Tom.

“I watch a lot of YouTube channels, like who do loads of updates about new games coming out and stuff like that”. Mohsin.

“I just go on YouTube to find out what is going in games really”. Lee.

Social media also provided ‘something to talk about’ with others that reduced feelings of being alienated from social groups. More so, participants described how video gaming in particular provided a shared identity upon which friendships could be formed with others:

“Yeah but in the game you are all the same, and the same abilities, cos you don’t feel like erm alienated cos you are playing what they are talking about. So I think that has given me something to talk about really. Yeah I think that is why before I was a bit anxious with friends because I didn’t have much to talk about but with gaming you do, so it gives me meaning, identity”. Zahid.

Whilst the majority of participants described social media as a platform for engagement with others. For other participants, intercommunication was less important:

“So I know what is going on basically...having a look yeah...seeing what is going in the world...just seeing what people are up to...not connecting just seeing”. Craig

Social media appeared to be Craig's portal to observe the world rather than connect with it. His use of discourse such as 'having a look' portrayed a self that was cautiously peering into an alternate world whilst not feeling drawn to connecting with it. For Craig, the need to belong may have been met in other contexts outside of his online world, such as through his interaction with close family members and friends. His perspective illustrated the individual differences within the sample and offered an alternate account to how social media is interacted with by participants.

This sub-theme illustrated how participants felt a sense of belonging through social media. Principally, to feel a sense of belonging online was to be provided with the opportunity to share in the interests of others, and have their presence valued and acknowledged within such spaces.

5.6.5 Revealing the self online

Several participants described experiences of being bullied and marginalised with their offline lifeworld. Online, participants described how they had to adopt a cautious approach to who and how they discussed their condition with others, should they wish to do so. Participants spoke of a sense of caution about discussing their condition, owing to a sense that their disability would be 'picked up on' by others. More so, participants relayed how disclosing their disability to others may have limited their opportunities to socialise with groups 'who aren't disabled'. Furthermore, the use of discriminative discourse was also experienced by participants, with terms such as 'spaz' encountered when competing with opponents through online video gaming. The following extracts detail examples of participants' experiences of discriminatory behavior on social media:

"Yeah I would say so. With erm, I can't really, nothing really specific has happened with me but I just think there is a lot of like, if you've got a disability or anything people will sort of pick up on that bit ye know what I mean" Simon.

Yeah but also what's annoying is I can get on with anyone, and sometimes it is nice just to talk to people who aren't disabled. Ye know what it mean it's just like cos you are disabled you can only talk to other people who are disabled. Tom

"Ye know fair enough you do get the odd arsehole online but ye get that anywhere ye go. I mean a while ago I was playing Tekken online and someone messaged me online cos I beat them calling me a spaz or something like that. They didn't know I had a disability, as soon as I told him he actually went off the chat straight away. But then I'm thinking to myself, he called me a Spaz but he lost". Mohsin.

Participants were therefore understandably cautious of the aspects of self, included their disability they shared with others on social media. For some young men, interaction via social media was an opportunity to not reveal their disability to others, and instead highlight other aspects of their identity. Indeed, participants described how withholding their disability from others when interacting on social media enabled them 'to be seen as a person and a gamer'.

“...would probably put gamer and the types of games that I play or whatever but that would be about it really”. Lee.

“Well I think it is easier to kind of not allow them see your disability straight away. To see you as a person and a gamer and so I think that is really what was good. I realised that you formed friendships that is about a lot of other things than just your disability.” Zahid

In instances where participants chose to disclose their disability to others on social media, they largely did so cautiously. Lee in particular provided an account of the process that he went through before telling others that he is in a wheelchair:

“But obviously they do know that I am in a wheelchair and stuff like that. That’s kinda like, I try get to know people for a few weeks before I tell them that I am in...because obviously some people don’t get that and then they kinda make a joke out of it and stuff like that so I just want to make sure that I can kinda tell the type of person that would do that for instance and then when I feel confident that they are not I will tell them”. Lee.

Lee described how he had to make sense of the ‘type’ of person he was interacting with online before feeling confident enough to ‘tell them’ about his disability. This could often take place over a ‘few weeks’. Lee appeared to disclose past experiences whereby others online had ‘not got it’ and ‘made a joke out of it’. As a result, Lee had to remain guarded online and be cautious around who he discussed his disability with.

Social media was described by participants as providing the opportunity to control what aspects of self they disclosed to others. However, their felt sense of need to do so illustrates the prejudice and discrimination against their Being both in offline and online spaces.

5.6.6 Summary of superordinate theme

Social networking platforms, blogs, and spaces hold a range of meaning to participants. Closed groups and pages associated with DMD were described as valuable online spaces to connect with others living with DMD and share/source information relation to the condition. Online blogging held a myriad of meanings across the group. While for some participants blogging was integral to their

sense of purpose, for others it held less value. Social networking spaces and online video games appeared to provide an alternative space to their offline worlds to source belonging by virtue of their capacity to bring likeminded people together. Finally, participants described the requirement for caution in disclosing their disability to others online, grounded in experiences of discrimination towards their condition both online and offline.

5.7 Summary of findings: The intersection and enveloping of two lifeworlds.

The findings of this study have described the lived experience of social media from the perspective of young men with DMD. The essence of their lived experience can perhaps be best summarised as an intersection and enveloping of their two lifeworlds, the offline and the online. Superordinate theme one provided a description of their offline lifeworld and in doing so attended to the background or 'situated perspectives' (Merleau-Ponty, 1945/1962) to which social media appeared. Within the offline lifeworld of young men with DMD participants described the lived experience of Being-with others, and alluded to the factors of their lifeworld that influenced their daily Being in the world.

Entering an alternate online lifeworld accessible through social media was an everyday experience for many participants. Superordinate theme two attended to the transcendental nature of the lived experience of video gaming. For participants, video gaming presented an online lifeworld to become immersed in and leave behind their offline lifeworld. Within their online lifeworld, participants described experiencing an altered sense of Being, whereby they went beyond their 'normal experiencing' of the offline lifeworld. The two lifeworld's continuously intersect and envelope in their experiences of video gaming. Participants described how video gaming stirred reflections of the self that exists within the offline lifeworld. Furthermore, the online lifeworld was described as a fragile space, with the realities of the offline lifeworld continuously making themselves known to the young men through challenges related to accessibility.

The online lifeworld was also represented by the lived experiences of social networking sites, blogs, and online spaces, attended to in superordinate theme three. Participants described the value of closed Facebook groups and pages associated with DMD, as online spaces to connect with others with similar lived experiences, and source/provide information about DMD. The meaning of online blogging to the young men further illuminated the intersection and enveloping of the two lifeworld's. For some participants, its meaning was redundant because of an everyday attitude of 'doing' as opposed to 'talking'. Conversely, for one participant in particular, blogging provided purpose and

fulfilment in his everyday Being in the world. The online lifeworld also appeared to provide a sense of belonging that may otherwise have been absent offline. Connecting with others who shared similar interests in topics such as animation and video gaming via social networking groups and pages were meaningful experiences to participants. More so, the online lifeworld provided opportunity to present the self in line with how participants wished to be viewed, such as a 'person' or 'gamer'. Disclosure of disability was therefore an option as opposed to a requisite of engagement with others.

The next chapter distils the lived experience of social media further, moving from the three superordinate themes outlined to a discussion of what are interpreted to be the essential components of the lived experience of social media to young men with DMD.

Chapter 6 Discussion

The aim of the study was to explore the lived experience of social media from the perspective of young men with DMD. This chapter presents a discussion of the components of social media that were interpreted to be essential to the lived experience of social media, to young men with DMD. Thus illuminating the nature of their lived experience of social media. The chapter will commence with a reflective summary of the processes of meaning making, between participants and myself as researcher. I will then discuss the key study findings with reference to existing literature, theoretical concepts, and the interpretive phenomenological approach that has guided the study.

6.1 Reflections on the ‘meaning-making’ process between participants and myself as researcher

Unlike other phenomenological approaches for example Giorgi's Descriptive Approach (2009), to engage in phenomenology from the perspective of IPA, is also to engage in hermeneutics. As Smith (2018, p.6) postulated '*the thing is ready there to shine forth, but detective work is needed to enable that to happen*'. This section of the discussion reflects on the dynamic between myself and participants, as together we aimed to bring to light and construct the meaning of previously taken-for-granted lived experiences of social media.

Inherent in the relationship between myself and the participant/s was the acknowledgement that we are both 'sense-making agents' (Smith, 2018.p.2) who cannot help but find meaning in our everyday encounters with the world. While inherently the focus in both interview and analysis was on the participant's account, we both brought something to each interaction.

Consequently, each interaction between myself and the participant involved a process whereby I attempted to make sense, of the participant trying to make sense, of the meaning of their lived experiences of social media. This is a process referred to as 'the double hermeneutic' (Smith, Flowers, et al. 2009. p.35). As discussed in Section 3.5 of this thesis, 'meaning' according to IPA, is a layered process that begins in the literal and ends with the existential (Smith,

2018). While the core aim of IPA is to reach the 'experiential significance' (Smith, 2018.p.3) of the phenomena, I reflect on how this point was reached differently for each participant.

The aim of the methods of data collection employed was to create an environment whereby participants felt comfortable in disclosing their lived experiences of social media. I reflect on the different methods of data collection used to do so in Chapter 3. I was aware, particularly within the first interviews with participants, that the questions I was asking about their use of social media appeared 'odd' and out of context. For the most part, the consistent presence of social media in the lives of the young men meant that it existed in their 'taken-for-granted' view of the world. Therefore, questions such as 'Can you describe to me what social media means to you?' (interview guide, appendix 7) were often initially met with long pauses by participants, as if the question was stirring a thought that had previously been hidden. It was necessary to allow the time and space for participants to ponder these questions. Often, opportunities presented to return to these questions and expand on them in later interview.

The relational dynamic of the meaning-making process was revealed in the dialogue used by participants. In the first interviews, terms such as 'do you know what I mean', or 'do you get where I am coming from' were frequently used. I interpreted this form of 'dialogical hermeneutics' (Smith, 2018.p.8) as participants testing the water of our relationship, asking questions through their discourse such as: Does this researcher understand me? Does he understand my perspective? Do we understand each other? I consciously attempted to form shared understandings during these early interview encounters, drawing and sharing my own experiences where appropriate. Nevertheless, I was aware that my position of reference was fundamentally different to participants. Therefore, while I aimed to understand as best as possible the meaning of the lived experiences shared by participants, inevitably, I was reminded by participants that my position rendered me unable to fully understand their experiences. Revealed through discourse such as '*I mean you don't understand*'.

Despite our alternate worlds, the shared engagement between myself and the participants over time fostered a dynamic whereby participants felt able to openly discuss their lived experiences of social media. Nevertheless, the

'experiential significance' (Smith, 2018, p.3) of social media was conveyed differently by each participant. For example, two of the participants had a cognitive impairment that limited their ability to freely use discourse to describe their experiences. Therefore, reaching an understanding of the meaning of social media to their Being was a descriptive exercise focused on the literal meaning of social media. I was initially troubled by these interviews, and grappled with a sense of guilt that I, as the interviewer, was not facilitating the interview in a way that was appropriate to their needs. However, during my time with these participants, over interview I came to learn that they valued being part of the study. Their involvement mattered to them, and conveying their experience, while largely descriptive, enabled them to provide their 'story'. Consequently, the 'experiential significance' of social media to their Being was found in their descriptive accounts of the placement of social media in their daily lives.

Reaching the existential experiential significance of social media to other young men involved in the study occurred via different pathways. For some, video gaming formed the landscape to which meaning could be explored. In these instances, meaning was transferred between the participant and myself both through visual illustration, and verbal dialogue. I came to understand what social media meant through the participant showing me, guiding me through their video gaming lifeworld, accompanied by descriptions and talk of the online world as presented. On occasion I became lost in whose meaning I was encountering. Such was the close intrinsic bond between participant and avatar and the reverie of participants, it was difficult to distinguish at times whose description I was hearing. Meaning reflection was essential to these interviews, moments to revisit the interview either at the end or in subsequent interview provided opportunity to ensure meaning was understood and as intended by the participant.

For other participants, interviews were deeply existential from the start. The tone of the interview was immediately controlled by the participant to one of 'me' and social media. It felt at times as if their dialogue had been set free, I tried to keep the interview as open as possible during these encounters, and allowed

the participant to guide me to their own unique experiential significance of social media.

I struggled with moving the meaning-making process from interpreting the participant's verbal talk, to interpreting their words on a transcript. Eautough, Smith, et al (2008) refer to the process as a 'Distanciation' and that was how I would first describe coming to read the transcripts; distant. The intersubjective meaning that had bonded our interviews and the meanings shared was no longer present. It took time and effort for me to hear the participant's voice again, and begin to understand their meaning. Reflecting on the process of analysis described in section 4.6. of Chapter 4, I recount the importance of my imaginative dwellings noted in my research journal. I found to enter back into the participants lifeworld through their text, I had to freely imagine how the descriptions of their experiences were 'lived'. I frequently asked myself 'what was this experience like for the participant?' Only in doing so, did I feel able to sufficiently connect to their meaning.

The meaning-making process between my myself and participants was an enriching and powerful experience. The next sub-section details the 'product' of this meaning-making process, whereby the essential components of the lived experience of social media, as firstly described by participants, and then analysed and interpreted are detailed.

6.2 The essential components of the lived experience of social media

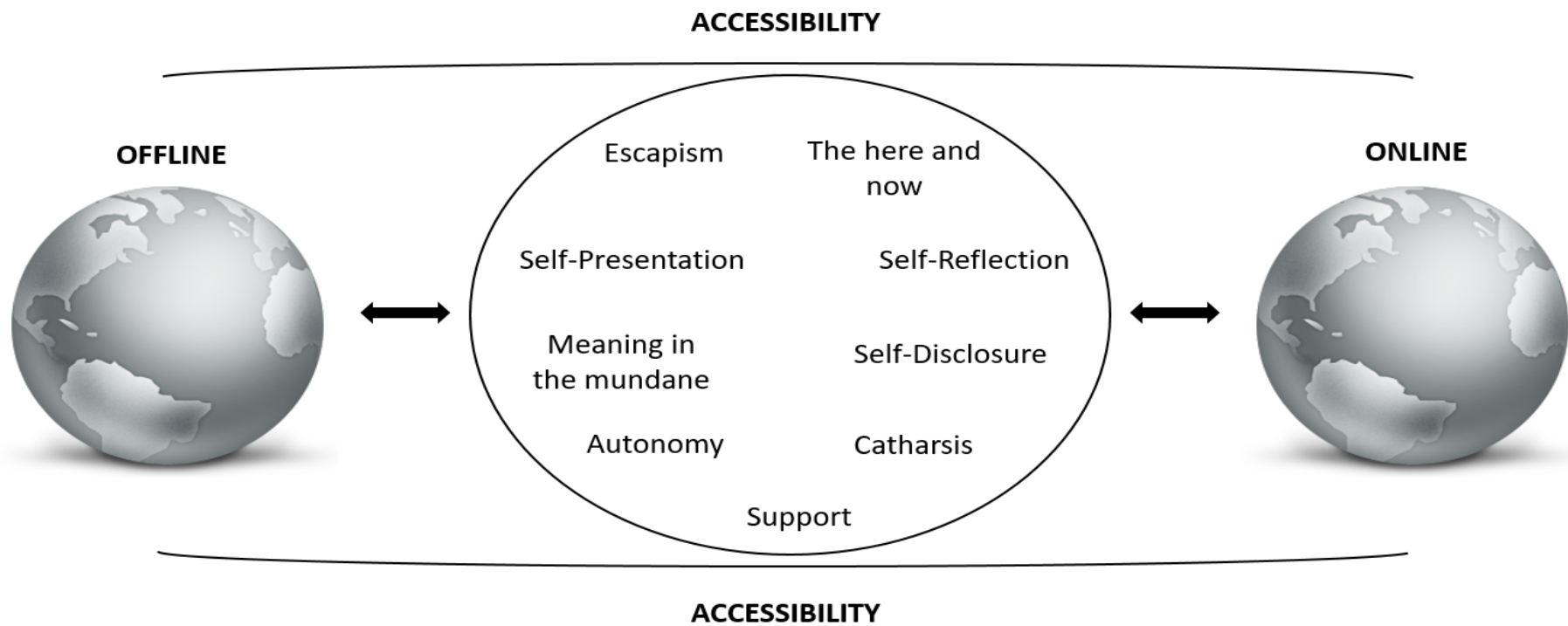
This section features a discussion of what I interpret to be the essential components of the lived experience of social media derived from an iterative process of revisiting the three superordinate themes and their sub-themes outlined in Chapter 5. In identifying the essential components, the purpose is to draw the reader close to the lived experience of social media. Figure 6.1 provides a diagrammatic overview of the essential components of the lived experience of social media situated within the three superordinate theme findings. Figure 6.2 presents a visual representation of the offline and online lifeworld's of young men with DMD, to depict how their interaction forms the

essential components of the lived experience of social media. Each component is discussed in relation to existing theory and evidence.

Figure 6.1: The essential components of the lived experience of social media.



Figure 6.2: The intersection and enveloping of two lifeworlds



6.2.1 Self-Presentation

As outlined in Chapter 2, self-presentation or 'impression management' relates to a person's attempt to convey an image of the self to others (Goffman, 1959). Therefore, the sociality of the lifeworld can be understood as a 'performance', whereby social interactions feature on stages in which actors aim to control the impressions that others, or the 'audience' form of them (Goffman, 1959).

Studies discussed in Chapter 1 and 2 suggest that within the offline lifeworld of people with disabilities, impressions of the self may be formed before any opportunity to influence the impression is offered (Wästerfors and Hansson, 2017. Skyrme, 2017). Invasive gestures such as pointing or staring, accompanied with patronising behaviour or derogatory comments are frequent lived experiences (Wästerfors and Hansson, 2017; Skyrme, 2017). These experiences can suppress the autonomy of people with disabilities to express themselves in line with how they wish to be perceived. The findings of this study revealed that young men with DMD also experience acts of marginalisation such as bullying and teasing that suppressed their ability to have ownership and influence over the impression others created of them offline.

Previous evidence suggests social media offers an alternate 'stage' for people with disabilities to convey their selves to others. Social media platforms provide the opportunity to engage with a selective self-presentation, providing people with disabilities control over the aspects of themselves they reveal or conceal to others (Pempek, Yermolayeva, et al. 2009). For example, online users can decide the profile picture they use, the information they provide in their 'biopic', and who has access to this information (Treem, Leonardi, 2012). Consequently, users of social media can choose to depict aspects of self that create an identity impression in line with how they wish to be perceived by others (Waters and Ackerman, 2011).

A key finding of the study described in this thesis was that young men with DMD were able to post information on social media that led to impressions of the self in line with how they wished to be viewed, such as a 'person' and 'gamer'. In turn, these impressions led to friendships being formed based on shared

interests. A study by Chadwick and Fullwood (2018) on social networking among adults with intellectual disabilities found that being able to post information about their interests and hobbies on their social networking profiles facilitated positive impression management. However, in positioning the lived experience of social media in the broader context of the participant's offline worlds this study has illuminated why the ability to express agency in how the self is presented to others online, holds meaning to young men with DMD. This finding offers a unique contribution to the evidence base on the importance of online self-presentation in relation to young people with disabilities.

6.2.2 Self-Disclosure

As outlined in Chapter 2, self-Disclosure refers to the process of sharing information, experiences, and feelings with others (Liu and Brown. 2014). The findings of this study which revealed that young men with DMD engage with self-disclosure to different degrees dependent on the information or experiences they disclosed. Differences were apparent in how participants disclosed their disability to others, and how they disclosed other aspects of their multi-dimensional selves.

6.2.2.1 Self-Disclosure of Disability

A finding of the study was that participants engaged in different levels of self-disclosure related to their disability that resonate with Furr, Carreiro et al (2016) conceptual framework of online self-disclosure. Developed from a Grounded Theory study, the framework of online self-disclosure illustrates how people with physical disabilities adopt three strategies to self-disclosure; namely, an open, secure, or limited approach (Furr, Carreiro, et al. 2016).

An open approach to self-disclosure is characterised as a full disclosure of disability, including both visual and textual representations, to an audience of both disabled and non-disabled peers. Of the eight participants in the current study, only one described an open-approach to disclosing his disability to others. As detailed in Chapter 5 (section 5.6.3), Zahid openly wrote and posted via his publicly-accessible online blog about his journey to accepting his disability. He spoke of the open-access nature of his blog as 'scary' but a necessary component to 'his growth' and acceptance of his disability.

Significantly, central to Zahid's continuing motivation to blog openly about his condition, was the response he received from users who interacted with his posts. Zahid found purpose and fulfilment in the acknowledgement that his blog was 'helping other boys with Duchenne'. This in turn, motivated him to continue to blog.

It had been suggested that open disclosure on social media is in general associated with gender, with women more openly self-disclosing compared to men (Petronio, 2002. Kleman. 2007). Gender stereotypes and expectations are conveyed and associated with women typically being more open and expressive compared to men in the online world (Petronio, 2002. Love, Thompson, et al. 2014). Studies specifically focussing on open self-disclosure of illness predominately report the experiences of women (Keim-Malpass, Adelstein, et al. 2015; Keim-Malpass, Albrecht, et al. 2013; Nesby and Salamonsen. 2016; Pounders, Stowers. 2017), with few examples of men engaging in open-disclosure about their life-limiting illness (Lowney, O'Brien. 2012). While Zahid open disclosed about his disability, other participants attributed masculine expectations of Being derived from their fathers as a barrier to open self-disclosure. The variance in experiences of illness disclosure within the sample is reflective of the requirement to be open to the multidimensional factors that surround self-disclosure such as culture, motivation, and risk (Waters and Akerman, 2011).

A more common strategy adopted by young men with DMD was a 'secure disclosure' of their disability to others, defined as both disclosure of disability on a platform that featured an audience of disabled peers, and carefully orchestrated disclosure with a purpose to open audiences (Furr, Carreiro, et al. 2016). The majority of participants had posted on closed Facebook groups developed to support people living with DMD. In this context, disclosure involved sharing practical experiences and advice related to medical equipment.

Outside of illness-specific closed online groups and pages, not all participants suggested that they shared their disability to others via social media. However, participants were aware that other users 'may pick up' on their disability. Furthermore, the distinctive properties of social media such as asynchronous communication, and anonymity has given rise to offensive behaviour and

cyberbullying (Davis, Randall et al. 2015). Off-the-cuff derogatory remarks such as the term 'spaz' were described by the young men, suggestive of the potential exposure to abuse for participants in disclosing their disability openly online. In addition, participants described the benefit of withholding their disability, allowing them to be viewed as a 'person' and 'gamer'. Consequently, for young men with DMD, sharing their disability with others risks tainting a projected normalised self, obtainable through the ability to control what information they disclose to others online. The notion that people with disabilities may wish to refrain from sharing their disability openly online, but were happy to do so via closed illness specific groups was also found by Griffiths, Paneli et al (2015) who researched the co-design of a website for adolescents and young adults with cancer.

Personal disclosure online to others through avatar to avatar relationships has previously been associated with a sense of trust among users (Sibilla, Mancini, 2018). A comparable finding in this study was that video games appeared to be the most likely space for young men with DMD to disclose their disability to others, outside of closed illness-specific groups. Nevertheless, disclosure was not a straightforward nor an immediate act. Participants described how the process occurred over a period of time, during which they attempted to 'try to get to know people' to assess 'the type of' people they were interacting with. Only when participants had established a sense of a trust with their video gaming peers did they disclose their disability.

The final strategy of self-disclosure according to Furr, Carreiro, et al (2016) is limited disclosure, characterised as disclosure only through selective channels such as a private chat. Rationale for limited disclosure included fears of being bullied or facing rejection (Furr, Carreiro, et al. 2016). Past experiences of non-response to posts is also associated with limited disclosure (Crook, Glowacki et al. 2015). The findings of this study suggest that participants who chose to not disclose their disability on social media did so because they did not feel a desire to associate themselves to their disability online. Both of the participants who chose not to disclose their disability were dismissive of the use of social media to connect with others with similar lived experience. This finding is comparable with previous research with a sample of young men with DMD that found they

did not wish to interact with their peers because ‘they remind me of things I don’t want to talk about’ (Sanger, 2019, p. 66).

The findings of the study described in this thesis on online disability disclosure align with the conceptual framework of online disability disclosure outlined by Furr, Carreiro, et al (2016). Examples of the three categories of disclosure were evident in the study findings and therefore suggest similarities exist in the lived experience of online disclosure across life-limiting/threatening conditions.

6.2.2.2 Self-Disclosure of the Multi-Dimensional Self

Studies on the use of social media by adolescents and young adults (AYAs) with life-limiting/threatening conditions, or disabilities have largely focused on their use of social media for reasons associated to their conditions. Of the 25 studies included in the integrative review outlined in Chapter 2, only eight offered findings on social media use outside of illness specific contexts. Of those eight, four were focused on video gaming, while the remainder either explored use of a specific platform, e.g. Facebook, or focused on social media broadly without specific reference to platforms/type. Consequently, the multidimensional selves of AYAs with life-limiting/threatening conditions, including DMD were largely underrepresented in the literature on their use of social media.

Studies that offered a more holistic view of social media use found motivations for engagement in the activity were comparable to their non-disabled peers. (Shpigelman and Gill, 2014. Griffiths, Panteli, et al, 2015) For example, Facebook was cited as important to maintain friendships, stay up to date with the activity of peers, and provide updates as to their own activity via status updates (Shpigelman and Gill (2014). The findings of this study revealed that while young men with DMD engage in illness specific groups, and some engage with blogging to discuss their daily life with Duchenne, they also openly shared aspects of their self including their hobbies, interests, and talents on groups and pages hosted on social networking sites, and through video gaming. For example, participants reported the benefits of engaging with likeminded people about a specific hobby or interest. A significant finding of this study was that participants valued expressing their identity as a gamer. Doing so, provided

access to meeting others within social networking groups dedicated to video games. The identity of a gamer is recognised and accepted among peer groups. Young men with DMD commonly face barriers to engagement in traditional social settings (Abbott, Carpenter, 2014). Online, projecting their identity as a gamer can forge new pathways to sociality that may otherwise not exist, and open new ways of connecting with others.

6.2.3 Escapism

Evidence highlights that video games have the capacity to enable the disabled gamer to 'drift away a little' (Wästerfors and Hansson, 2017. p.1151) and 'escape reality' (Beeston, Power, et al. 2018.p.7). However, little was understood about the lived experience of escapism within the literature, with studies largely reporting outcomes from survey data that lacked interpretative insight (Stewart, 2010. Beeston, Power, et al. 2018). This study offers a unique perspective on how young men with DMD experience escapism through video gaming. Experiences of escapism relate to the ability of young men with DMD to disengage from their offline self and transcend into an alternate world to become or 'Be' their avatar. This experienced and embodied transformation altered the potentialities of their lived experience and offered them an alternate way of Being in the world. Within this world, the 'restrictive potentialities' (Merleau-Ponty, 1962) that the young men may have experienced within their offline world are departed and replaced with new horizons of Being unique to each participant (section 5.5.1.).

As outlined in Chapter 3, an artist was asked to visually interpret a sample of extracts. Figure 6.3 depicts the experience of life through video gaming as interpreted by the artist.

Figure 6.3: Illustration by Robert Maida: Life through video gaming



The meaning of escapism for each participant was located in the departure of all that was known offline to them, to the unrestricted potentialities lived through their embodied avatar. Interestingly, the finding that escapism is experienced through the embodiment of avatars is also located in the narratives of non-disabled gamers. For instance, a phenomenological study of 24 adult able bodied video gamers found that gamers embodied characters located in video games to escape *'the mundane familiarity of everyday life'* (Molesworth, 20019. p.381). The lived experience of escapism is not wholly unique to disabled gamers, but reflective of the situated contexts of individuals that serve to

determine what they each define as the 'mundane' or 'familiar' in their lifeworld's and to which they seek escapism from.

The lived experience of escapism for the participants of this study was not always located in the 'here-and-now' (Ashworth, 2006.p.221) but was reflective of episodes in their lives when their requirement to depart and 'shut out' or 'forget' their offline world was most salient, such as periods when they 'were stuck in bed'. This finding is parallel with those from a qualitative study that explored video gaming from the perspective of 15 Swedish adolescents and young adults with disabilities (muscle diseases, cerebral palsy, Asperger's syndrome) (Wästerfors & Hansson 2017). The study found that disabled gamers experienced escapism as a 'situational refuge', or as momentary suspension employed during difficult life events. For example, one participant described a need for video games at a time when he started to use a wheelchair, altering his offline identity among his peers (Wästerfors & Hansson 2017, p.1148).

This prior research also identified that the requirement for escapism within video gaming was less intense among participants who had established meaningful and occupied offline lives (Wästerfors & Hansson 2017). The findings of the current study concur; where participants discussed their offline worlds/experiences as meaningful, the requirement to 'escape' through video gaming was less sought. Conversely, participants whose offline narratives were largely typified by extended periods of time at home unoccupied or feeling unfulfilled, described their video gaming routine as wholly encompassing of their daily lives '*from whatever time I get up till when I go to sleep*'. Nevertheless, video gaming was described as a consistent and reliable haven to escape to as and when they needed it for the majority of participants.

6.2.4 Self-reflection

A novel finding of this study was how avatar engagement stirred young men with DMD to engage in self-reflection. Fundamental to the experience of self-reflection was the belief that the avatars embodied by participants represented more than hollow, software manufactured clusters of pixels, but were perceived to exist as Beings in their own right. Participants spoke of their ability via their avatar to not be *something* else but rather to be *someone* else.

The participants appeared to experience self-motivation via the actions of themselves as avatars, and both comfort and excitement in what they were able to achieve and do during their embodied player-avatar experience. This embodied avatar experience seemingly awoke the young men up to new potentialities of Being otherwise inaccessible to them and especially so in their offline worlds. For example, as an avatar they have the ability to walk or drive. Access to such experiences led participants to an existential musing of how life would appear as a Being in the world who could walk or drive. This finding can be understood in light of existing literature. For instance, one study found that video games represented 'metaphorical sites' (Wästerfors & Hansson 2017.p.1151) for people with disabilities to contemplate and make sense of their everyday lives. Video gaming therefore appears to provide the opportunity for therapeutic self-reflection that may allow young men with DMD to make sense of their offline everyday lives.

Avatars within video gaming enable young men with DMD to become another self, a self with a different outward identity, with different characteristics and abilities that may be nullified or be otherwise inaccessible to the young men. Avatars provide volition to act in ways they are unable to do offline, and provide them with a sense of achievement and skill in being able to accomplish in-game goals and missions. These capacities stir self-reflection for young men with DMD..

As outlined in Chapter 2, Higgins's Self-Discrepancy Theory (1987) posits how people can experience discrepancy between their actual self, and their ideal self. A finding of this study was that young men with DMD may experience a discrepancy between their actual self and ideal self, and perceptions of the self

are foregrounded or entwined in experiences with their avatar self. The wish to 'Be' their avatar self was expressed and grounded in the belief that the avatar self lived a life more exciting than their own.

A previous study has alluded to the notion of 'avatar idealisation', described as the perception that the personality of the avatar is favoured and idealised over the personality of the gamer (Sibilla, Mancini, 2018, p.15). The concept has been associated with feelings of jealousy (Molesworth, 2009). While participants of the study outlined in this thesis did not specifically allude to feelings of jealousy, in describing their lived experience of social media, it was noted that the tone or 'mood-as-atmosphere' (Ashworth, 2006.p.223) appeared to be of longing or jealousy when discussing the characteristics of their avatars. Reflection for participants on this matter was evident in their accounts in how they described how life might appear if they could do all that they can as their avatar and what life would be like if they could 'Be' their avatar.

Whether reflection through player-avatar relationships exists only in the lived experiences of people with disabilities remains unknown. However, the findings of one study reported in Chapter 2 suggests that the desire to find 'insight' through video games, defined as "the feelings associated with contemplating, introspecting, and experiencing greater understanding of essential values, fundamental beliefs, and important life lessons" (Oliver, Bowman, et al, 2015, p9) is less appealing to able-bodied video gamers. The study found that able-bodied video gamers frequently characterised video games as 'fun', they were significantly less likely to report video games as insightful or meaningful (Oliver, Bowman, et al. 2015). Consequently, it could be suggested that young men with DMD are drawn to their avatars as more than figures of 'fun' because they represent what is otherwise absent in their offline worlds and it is this acknowledgement of things missing that motivates them to engage in video gaming, and also stirs them to reflect on their offline Being in the world.

The finding that young men with DMD find reflection in video gaming avatars is novel and has value in understanding why they engage with the activity. Furthermore, the finding that young men with some DMD may find discrepancies in their actual self in comparison to their avatar self is useful to

understanding how young men with DMD interpret their existence and self within their offline worlds.

6.2.5 Meaning in the mundane

Within the world of video gaming it is suggested that multiplayer games (games that involve several players through an online connection) are increasing in popularity, suggestive of a turn from single-player story-modes to multiplayer online gaming (Jones, 2020). However, this trend does not appear to be reflective of the preferred video gaming style of players with disabilities with single player video gaming preferred (Porter, Keinz, 2013. Beeston, Power, et al. 2018). The findings of the current study provide insight into why single player video games hold meaning to young men with DMD. These meanings connect to participants' hopes and dreams but also to being liberated from their limitations. For example, washing and grooming are personal and intimate activities that form part of everyone's everyday taken-for-granted routines. For young men with DMD, the ability to engage with these activities independently is often not possible, with a reliance on carers for assistance (Abbott, Carpenter, 2015). .

Single player role-playing games or 'RPGs' enable players to assume the roles of characters in a game, with autonomy over their narrative and actions (Drachen, Hitchens, et al, 2009). RPGs enabled young men with DMD in the current study to experience activity such as washing and grooming that are otherwise deemed mundane to the able bodied other. Participants found meaning in the mundane activities they could act out in their gaming because as Beings who are dependent on the care of others, having control over these activities was perceived as empowering. Activities such as shaving and grooming their characters beard was experienced as a deeply intimate and meaningful experience between player and avatar. This is possibly because undertaking the grooming is novel and not an everyday experience, coupled with knowing how it feels to be the receiver of those cares and wanting to maintain dignity.

A survey of gamers with disabilities found that the ability to relax was also a motivator for engagement with video gaming (Beeston, Power, et al. 2018). This finding is mirrored in the current study, Participants found reverie in experiences of driving to the speed limit and indicating through single player video games. Given the plethora of video games whereby acts of

flying, driving fast cars, or violence are routine and readily-available, it was noteworthy that participants largely focused on otherwise mundane experiences (to the able bodied) in their descriptions of their video game behaviour. As video-game developers continue to push the industry towards multi-player gaming, the solace, reverie, and meaning players with disabilities appear to find in the immersive and personal journeys of single-player video games should not be under acknowledged.

The finding that young men with DMD find meaning in the mundane illuminates the prejudice inherent in what is understood as 'mundane'. What is 'mundane' to the able bodied Being may be encountered as extra ordinary for young men with DMD and potentially for those with other disabilities or other life limiting /threatening conditions that result in functional decline. The purpose of this finding is not to highlight a divide or difference of Being, but to illustrate the many facets of meaning found within video games amongst young men with DMD.

6.2.6 Catharsis

As outlined in Chapter One, daily life as a young man with DMD can be challenging. The findings of this study revealed how participants regularly experienced feelings of frustration, stress, and anger. Avenues to express and make sense of emotions, can be limited owing to the young men's inner need to protect those closest to them (also reported by Abbott, Carpenter. 2010; Hunt et al. 2016). The current study has found that video gaming offers a cathartic experience for young men with DMD.

The term 'catharsis' relates to an emotional release, and it is acknowledged that physical activity can aid the release of emotions that may be troubling, such as frustration, stress, or anger (Cherry, 2020). In the current study participants engaged in sporting activity through their avatars such as boxing; with the heavy punching bag replicated through the frantic tapping of a button in the search for a cathartic release. It was through this energetic physical activity that video gaming provided a safe space for young men with DMD to vent emotions otherwise contained in their offline lifeworld. The cathartic value of video games is also appealing to able-bodied video gamers. A qualitative study by

Molesworth (2009) found that a sample of 24 video gamers engaged with the activity to release the frustrations that manifested in their daily lives. Violent video games have been associated with catharsis seeking particularly in relation to anger-management (Ferguson, Olson, et al. 2010). A notable finding of this study was that video games that enabled users to engage in extreme violence such as shooting to kill, were associated with periods whereby frustration and anger were most salient. For some participants, the requirement to seek a cathartic release decreased, as they turned 'into a person who is a lot more calmer'. In turn, their preference of video games changed toward cerebral gaming that stimulated thought. Consequently, the findings of this study suggest different video games hold contrasting purposes dependent on the emotional needs of the video gamer. Nevertheless, it is evident that video games offer cathartic value to young men with DMD. This finding is under-represented by intervention studies that seek to highlight the physical benefits of video gaming for rehabilitation or physio (Rowland, Malone, et al, 2016. Rinne, Mace, et al, 2016).

6.2.7 The 'here and now'

An essential component of the lived experience of social media use by young men with DMD appeared to be a focus on the 'here and now'. No participants described using social media platforms to discuss matters related to end-of-life. A qualitative study on end-of-life planning with young men with DMD found a sample wished to talk about matters related to end-of-life, but were rarely asked or involved in discussions with health professionals on the topic (Abbott, Prescott, et al, 2017). Closed illness-specific social media groups on sites such as Facebook may provide a suitable environment to discuss such matters with others who share similar lived experience. However, the findings of this study suggest that while these online spaces are well used, their purpose is to discuss and share experience on matters prominent to the here and now, such as sourcing appropriate equipment.

Online blogs were a prominent social media activity explored by studies included in the integrative review outlined in Chapter 2. Notably, the activity was

associated with end-of-life review, with several studies reporting its use for the purpose of leaving a legacy and narrative of their life (Keim-Malpass, Adelstein, et al, 2015; Nesby, Salamonsen, 2015; and Lowney, O'Brien, 2011). The findings of this study suggest that online blogging held diverse meaning across participant accounts. Some participants did not see value in the activity, whilst others were more open to blogging. One participant regularly blogged to the extent that it had become his 'duty to share' his life. However, the focus of his posts were on 'championing Duchenne' to 'show other boys with Duchenne that there are possibilities, that you can have meaning with Duchenne'. Similarly, other participants who had considered blogging were motivated to do so with the aim of showing others that attending University is a real possibility for young men with DMD. Therefore, young men with DMD were motivated to blog to guide others, based on their own experiences to live a fulfilling life with Duchenne.

The finding that young men with DMD do not engage with social media to discuss matters beyond the here and now is supported by previous study with young men with DMD (Gibson, Young, et al, 2007. Abbott, Carpenter, 2014. Pangalila, Geertrudis, et al, 2015. Finkelstein, Marcus, 2018). The advancing illness trajectory of DMD is likely to be a factor in why young men with DMD focus their social media activity on improving, or remaining in the present. Young men with DMD are also now adjusting to the likelihood of living into their 30's and 40's. Consequently, the focus for participants may well be on achieving their best quality of life as young adults. Nevertheless, the prospect of death and dying may still hold presence in their lives. A previous study found that in times of crisis, such as on hearing the death of a friend, the prospect was at its most salient (Abbott and Carpenter (2014, p.1199). It is essential that young men with DMD are supported to talk about matters related to death and dying should they wish to do so. However, the findings of this study suggest social media is not currently utilised by young men with DMD to engage in such conversation.

6.2.8 Autonomy and support through closed Facebook groups

A plethora of groups, pages, and profiles exist across social media platforms that hold a shared aim of promoting the wellbeing of young men with Duchenne Muscular Dystrophy. However, prior to this study, little was understood about how and why the population interact with these spaces. The findings of this study revealed that young men with DMD valued the privacy, support, and ability to express autonomy over matters related to DMD through closed illness-specific groups and pages on Facebook. Almost all of the young men who took part in the study were members of online groups such as 'DMD Pathfinders' that are hosted on Facebook. These groups were primarily used to post and receive information about Duchenne, such as advice on suitable ventilators. This finding is relatable to previous studies on the use of illness-specific online spaces by adolescents and young adults (AYAs) with life-limiting/threatening conditions, that found informational support is more widely shared on closed groups, discussion boards, and forums, in comparison to emotional support (Donovan, LeFebvre, et al, 2014, Lee, Cho, 2019, Myrick, Holton, et al, 2016) . However, the findings of this study have uncovered the meaning of the lived experience of sharing and receiving informational support for young men with DMD.

Young men with DMD found meaning in the ability to source information about Duchenne themselves, either through interaction with other members of the group, or through reading posts on the group feed. Having the autonomy to find information about their condition through closed online-groups was important for the young men. Doing so, was described as empowering, and helped participants accept and come to terms with their condition. A study on the involvement of young men with DMD in decisions about their care found that healthcare professionals on occasion directed information to parents or carers, as opposed to the young person (Skyrme, 2017). Consequently, away from the gaze of healthcare professionals, parents, and significant others, closed online-groups can be valuable spaces to express autonomy and self-responsibility over their healthcare needs. In turn, receiving and viewing information about DMD within the safety of the closed-group was beneficial in helping young men make sense of their condition.

Online social support has been associated with improving wellbeing through establishing a sense of connectedness and social belonging (Van de Velden, Setti, et al. 2019). The findings of this study have highlighted that closed social media groups can enable a sense of togetherness and belonging that some participants had previously not felt prior to joining the group. Furthermore, the confidence of some participants was attributed by them as been the result of 'feeling part of a group'.

Social networking sites have altered the way social support is offered and received. For example, the ability to engage with a broad audience, and provide/receive varied information from diverse networks has opened up new avenues of social support (Liu, Wright, et al, 2018). While opportunities to meet others with similar lived experiences are available offline such as via respite hospice stays, the findings of the study have revealed closed illness-specific support groups can be a further option for young men with DMD to draw on should they wish to connect with others with similar lived experiences.

Anecdotal evidence on the use of social media by young men with DMD had suggested that closed illness-specific groups hosted on social networking sites such as Facebook were used by the population. However, prior to this study, no empirical evidence existed into the reasons young men with DMD engage with these spaces. This study has provided new insight into the meaning of closed illness-specific groups that can be used to inform future interventions aimed at supporting young men with DMD, and adolescents and young adults with life-limiting/threatening conditions, or disabilities more broadly through social media.

6.2.9 Accessibility.

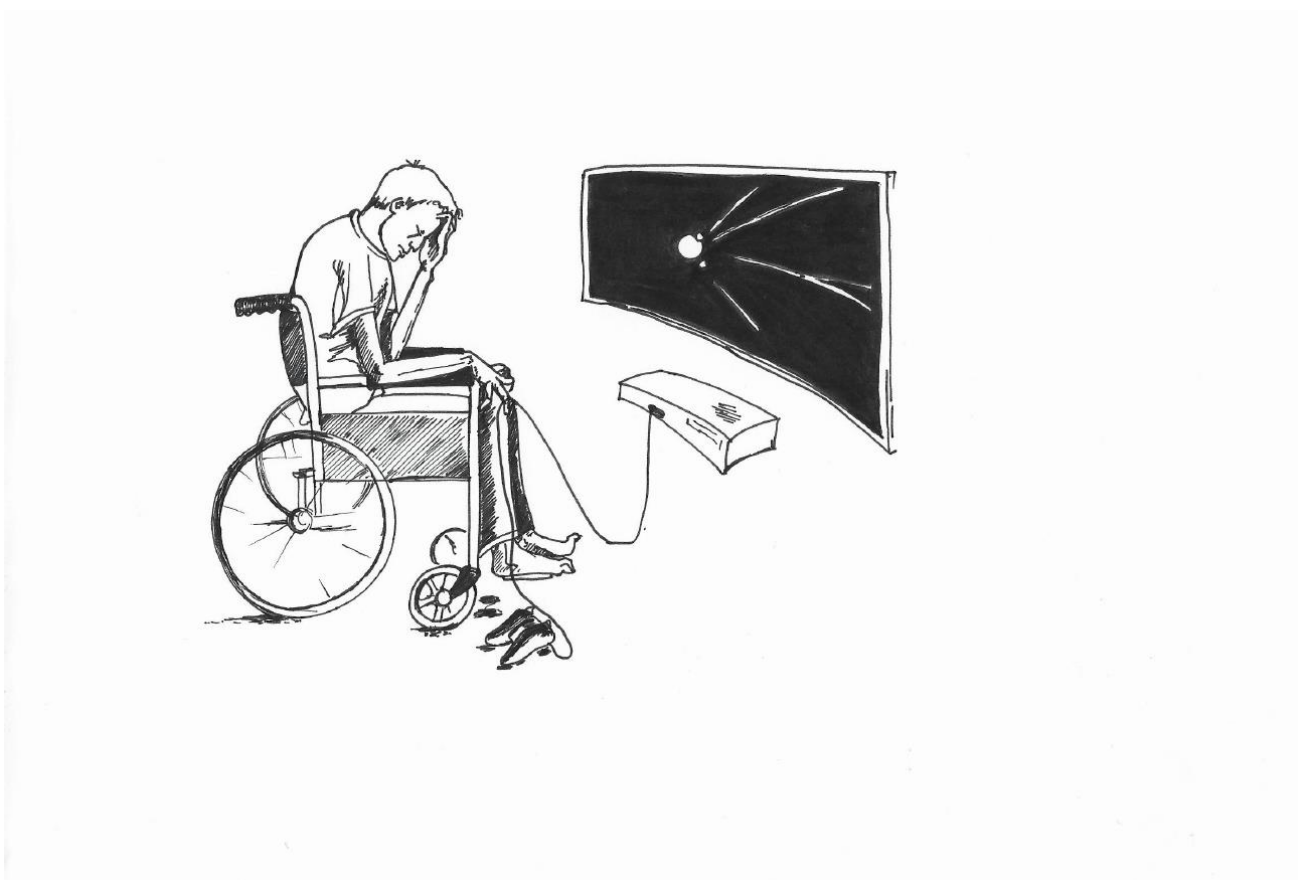
Accessibility can be defined as 'the quality of being able to be reached or entered' (Dictionary.com, 2020). As illustrated in Figure 6.2, accessibility was an essential component to both the online and offline lifeworlds of young men with DMD. Accessibility will first be discussed in relation to its significance to the online lifeworld's of young men with DMD, before a discussion of its presence in their offline lifeworlds.

6.2.10 **Online accessibility**

Video games represent an individual cosmos for young men with DMD to become immersed within. Immersion through video games enabled an escapism or departure from their offline worlds for participants. The lived experience of immersion did not just occur but was dependent on several factors, the most salient appeared to be the ability for the young men to leave their bodies and offline worlds behind to become an embodied avatar, a process that rendered their bodies absent. In Leder's (1990) phenomenological exploration of the 'absent body' (Leder, 1990.p.4) he describes how the body exists in a taken-for-granted state when it is able to function as intended. In this state, it acts as a silent medium into the lifeworld of video gaming. The findings of this study revealed how the accessibility challenges of video gaming foregrounded the lived body, and represented an interference into the online lifeworld that disrupted the immersive experience of video gaming.

As outlined in Chapter 3, extracts of the participants' transcripts were shared with an artist, to add a further interpretative layer to the analysis. Figure 6.4 presents an illustration of the accessibility challenges faced by young men with DMD.

Figure 6.4: Illustration by Robert Maida of the accessibility challenges faced by young men with DMD.



For young men with DMD, accessibility barriers limited the potentialities of their lived experience of video gaming, and derailed the ‘project’ (Ashworth, 2006.p. 222) of their online lifeworld. The lived experience of being unable to press buttons on a controller or fulfil ambitions to play football at an elite level were deeply embodied and focused on the fingers of the young men. The mind and fingers represented an unsynchronised mind-body connection, the fingers unable to perform to the mind’s orders; the mind unable to gratify the fast-action needs of the video game necessary for the immersive experience desired. In similarity with Kathy Charmaz’s (1983) description of serious illness on the body; the body still made noise even when the mind wished it not to. Parallels are also drawn with the lived experiences of video gamers living with motor-

related physical disabilities in Sweden who described the body as present during video gaming through fatigue and breathlessness (Wästerfors & Hansson 2017). In testament to the resilience of the population, the young men with DMD in this study developed innovative and inventive methods to maintain access to the online lifeworld accessible through their video gaming.

The methods deployed by young men with DMD described in section 5.5.5 of this thesis are also voiced within the wider literature (Porter and Keinz. 2013; Wästerfors and Hansson, 2017). For example, participants had to educate themselves to code video gaming software to adjust and remap video controllers to meet their needs, a strategy also reported by young people with motor-related disabilities (Wästerfors and Hansson, 2017). The use of voice control was a further strategy deployed by the young men involved in this study, and is reported elsewhere in the literature on video gaming by disabled gamers (Porter and Keinz. 2013). The charity 'Special Effects' was described as helpful in working with the young men to alter and adapt their video game controllers to suit their needs. Other studies also alluded to the use of charities whose mission was to make video gaming more accessible to gamers living with disabilities (Wästerfors and Hansson. 2017. Porter and Keinz. 2013). The presence of these charities in the lived experiences of gamers with disabilities is representative of their value to the population.

International legislation such as The 21st Century Communications Act (2010) was passed to ensure technology companies delivered software and products that 'increased the access of persons with disabilities to modern communications'. It was therefore surprising to learn that young men with DMD continue to face a battle in trying to obtain video gaming equipment and software inclusive of their needs. The overwhelming narrative from the young men interviewed was that developers 'don't seem to understand' that their needs are unique and are consistently not met by the software available. While software hailed as inclusive to gamers with disabilities in the literature (e.g. 'The Xbox Adaptive Controller'. Bailey, 2019) featured in the narratives of participants, their experience of the controller was that it was difficult to use. This finding is symptomatic of design recommendations for game developers that are often based on laboratory studies that lack ecological validity and

undermine the complexity of the user population (Porter, Kientz, 2013). Perhaps the most damning finding of this study in relation to accessibility was that young men with DMD feared the release of new consoles. What should be a time of excitement for gamers generally, is met with uncertainty and fear of whether the new console controllers will enable interaction. It is clear therefore that the voices and needs of young men with DMD are still not heard within the video gaming industry. The implications for industry of these findings are explored in depth in section 7.3.3.

6.2.11 Offline accessibility

For several participants, reaching an offline lifeworld that was meaningful and fulfilling was a challenge, particularly for those who had finished mainstream education. For these participants, there was little evidence of any provision or service planning to ensure they had access to 'a programme of meaningful daily activities' as adults, outlined by clinical guidelines for the care of young men with DMD (Birnkrant, Bushby, et al, 2018,p. 451). Furthermore, participants expressed an understanding that the social spaces readily available to their able-bodied peers were denied to them. Featured in the interviews of the young men were examples such as them talking about limited or no disabled access to buildings such as clubs, bars, and gyms. Consequently, at the time of interview they were either attending a specialist college that did not meet their educational needs, or spent the majority of their time at home. This finding is shared in the wider literature, with studies also finding that some young men with DMD have few opportunities to engage in meaningful activity (Abbott, Carpenter, 2014; Graham, Rose, 2017; Pangalia, Geertrudis, et al, 2015).

In the face of offline accessibility barriers, participants sought solace in social media, and in particular video gaming despite the barriers to accessibility they also faced online. Time spent video gaming was not quantified by the occasional hour, but by several hours, or in some cases formed their everyday routine 'from whatever time I get up till I go to sleep'. It appeared that the structure and purpose otherwise provided through employment, or an active social life, was met through video gaming and other forms of social media, such as watching videos on YouTube. This is not to say that the young men were content and satisfied with the presence of video gaming in their everyday lives.

As one participant conveyed, 'if I could get out and do all that stuff I would hardly ever go on my Xbox'. Video gaming could therefore be a 'vicious circle', with participants trapped within a world that appeared to offer more than the life that existed outside of it.

For participants whose offline world was largely accessible, in that they were able to engage in daily activity that was meaningful to them, such as playing wheelchair football, shopping, and socialising. The presence of social media held less status and importance. It was a tool that largely facilitated an already rich social life. These participants were motivated to engage in daily living outside of social media because it was viewed meaningful and fulfilling. Consequently, their need for escapism, immersion, and avatar embodiment were reduced by an offline lifeworld that catered to their needs, and therefore the fight for accessibility to the offline lifeworld seemingly mattered less. The finding that the offline lifeworld of participants influenced their experiences of their online lifeworld is novel. Previous study on social media use by adolescents and young adults with life-limiting/threatening conditions, or disabilities has largely focused on the analysis of online content (chapter 2). Consequently, little was known about the context that surrounded motivations for social media use, such as escapism and socialisation. The findings of this study have illuminated why the requirement for escapism or socialisation mattered more to some participants than others.

6.3 Summary

This chapter has discussed the essential components of the lived experience of social media to young men with DMD; self-presentation, self-disclosure, escapism, self-reflection, meaning in the mundane, catharsis, the 'here and now', autonomy and support, and accessibility. Previous literature and theoretical concepts have been drawn on to explore, contextualise, and illuminate each essential component. The next chapter draws the thesis to a close, and outlines the key messages from the study, considers its strengths

and weaknesses and implications and considers avenues for future/further research.

Chapter 7 Conclusion

Young men with DMD are living longer due to advancements in medical technologies and care. However, opportunities for engagement in meaningful activity are not always available, resulting in a significant proportion of young men with DMD being isolated at home with limited social lives. The study has explored the lived experience of social media in young men with DMD, and in doing so has illuminated the meaning of the phenomena to their Being. This chapter will present the key messages from the study findings, before outlining the strengths and limitations of the study. The implications for practice, policy, and developers are then discussed. Recommendations for future research are outlined, followed by a description of the dissemination strategy. The chapter concludes with a reflexive statement on my research journey, before a final summative conclusion to the study .

7.1 Key messages from the study

This IPA study has shed light on the lived experience of social media to young men with DMD, a phenomena acknowledged as present in their lives, but underexplored in terms of utility and value to their Being. Four key messages relevant to healthcare workers, gaming, website, and app developers, academics, and young men with DMD are outlined.

Several participants who took part in the study spent the majority of their time at home, and had limited lives outside of social media. While social media provided meaningful engagement in activity such as video gaming, browsing online videos, and connecting with others online. Participants expressed a wish to live more fulfilling, engaging, and social lives outside of social media. Local authorities and Clinical Commissioning Groups could consider further ways to support young men with DMD to live meaningful and fulfilling adult lives. Although social media is an outlet and provides a source of support,

wellbeing, and identity formation, where young men with DMD had other interests, social media was viewed to be needed less in their lives and was not such a prominent everyday aspect of their lives.

Second, social media offers young men with DMD agency over their self-representation. The relative anonymity of social media provided choice to the participants of what aspects of the self they revealed to others online. Participants were well aware that, offline, other people formed impressions of them before they were granted opportunity to alter those impressions. Further education and the active inclusion of young men with DMD is needed to alter the perception of people with disabilities outside of disabled communities. While ever young men with DMD experience suppression and discrimination of their selves offline, social media provides an alternate space to relinquish control and forge identities in line with how they wish to be viewed. Gaming industries/companies could also include further representation of disabled gamers in their product design and testing to increase accessibility and to find economical ways of inclusion in terms of the practicalities and usability of software and aides.

Third, young men with DMD value the privacy, autonomy, and shared ownership of closed illness-specific groups and pages that are predominately hosted on the social networking site Facebook. These groups and pages offer a private space for young men with DMD to source information about their condition and provide and receive support from others, away from the gaze of healthcare professionals, parents, and significant others. However, not all of the participants were knowledgeable about how to access these online spaces. Healthcare professionals and support workers are ideally placed to signpost and provide support where needed to facilitate social media participation.

Fourth, video games enable young men with DMD to engage in activity that they would be unable to do offline. These activities involved what others may consider mundane, walking, driving, washing, yet they held meaning to participants that should not be ignored. As video games become ever-more complex, it should be acknowledged that for video gamers who live with impairments, meaning often exists in the very fundamentals of avatar movement. Virtual reality is hailed as the new generation of video gaming, it is

critical that in its development, the accessibility needs and desires of young men with DMD are accounted.

Finally, entry into social media is dependent on developers recognising and incorporating the accessibility needs of young men with DMD into their software and equipment. Young men with DMD currently face the very real threat of life without social media, a prospect that is experienced through the daily challenge of attempting to seek harmony with controllers that are rarely designed to their needs. The 21st Century Communications Act (2010) was passed to make technology companies accountable for the inclusivity of the technology they manufactured. The narratives of participants involved in this study suggest significant strides still need to be made to ensure people with physical impairments can continue to access an online world that for many holds significant meaning.

7.2 Strengths and limitations of the study

Several strengths and limitations of the study are worthy of mention. A key strength of the study is that it is the first study to explore the lived experience of social media from the perspective of young men with DMD. It therefore offers a novel and valuable contribution to the empirical evidence base on living with DMD that is still largely in its development.

A further strength of the study is the IPA methodology and methods. Adopting a methodology that values the idiographic meaning of phenomena, and using associated methods has led to study findings that have uncovered the lived experience of social media to young men with DMD. As a result, the study has identified the meaning of social media across a range of platforms from social networking sites to blogging, to video gaming for young men with DMD. Identifying the platforms and qualities of social media that held meaning to young men with DMD offers a valuable and useful contribution towards future studies, interventions, and activities aimed at supporting the population through social media.

The use of video gaming as an interview technique was also a strength of the study. The involvement of game play as an active agent of the interview

technique provided both visual, as well as verbal insight into the lived experience of video gaming, a core social media platform that featured in the daily lives of the majority of participants. Furthermore, video gaming offered a shared space of shared meaning that the participant and I could connect over and establish rapport, a critical step in developing an openness to the existential meaning of phenomena. The technique is not without its limitations, as described in Chapter 3, fast-paced video games were counter-productive to creating an environment whereby participants could share their narrative. Nevertheless, the inclusion of video gaming within interviews was novel, and the experiences of the technique in this study provide grounding to develop the interview approach in future studies.

A limitation of the study was that it did not involve young men with DMD as patient-public involvement representatives. The benefits of actively involving people who have direct lived experience of the topic been explored are well cited (Brett, Staniszewska, et al, 2012; Marks, Mathie, et al, 2018; Tomlinson, Medlinskiene, et al, 2019). They include, ensuring the aims of the study address the needs of the sample, ensuring the patient perspective is salient in the analysis of data, and disseminating the findings of the research through channels that will directly benefit the sample (Brett, Staniszewska, et al, 2012; Marks, Mathie, et al, 2018; Tomlinson, Medlinskiene, et al, 2019). However, the involvement of young men with DMD as direct PPI representatives for the study would not have been without its challenges. For example, funding for transport and training to enable their participation in all aspects of the research process such as data analysis would be needed (Marks, Mathie, et al, 2018). A PPI strategy of involving two PPI representatives, both of whom had extensive experience caring and working with young men with DMD was decided. Involving both representatives from the study inception to the delivery of outcomes helped to maintain a patient/clinician perspective throughout.

A further limitation of the study was the homogeneity of the sample and a focus solely on the singular experience of young men with DMD. The study may have benefitted from a broader sample, drawing on carer, and parent perspectives of social media use. However, the homogeneity of the sample was a necessary

requisite in line with the IPA methodological underpinnings of the study for gaining insight into the lived experience of a phenomena that had previously not been explored. Participants were recruited from a range of ethnicities, including British Asian and White British. Furthermore, a diverse age range also existed in the group, with participants aged between 18 and 28.

7.3 Implications

The findings of the study have possible implications at a practice, policy, and developer level. These are each individually discussed.

7.3.1 Practice implications

The study findings have implications for the delivery of care to young men with DMD:

- Respite care provided by children and young adult hospices is valued by young men with DMD, participants spoke of the benefits of experiencing music festivals, engagement in activity with others with shared experiences, and having the opportunity to develop friendships with others. Few children and young adult hospices offer respite care for young people over the age of 25 (Fraser, Aldridge, et al, 2011) Therefore, there is a clear risk that young men with DMD may fall into the 'respite care gap' (Watson, 2013) whereby they do not have access to developmental and appropriate respite care.
- Health professionals and carers need to be attuned to the social media needs of young men with DMD. The benefits of social media have been demonstrated, however, they can only be realised with the necessary signposting and accessibility to support to enable young men with DMD to effectively engage with social media.
- Video gaming holds cathartic benefits for young men with DMD. Care settings, where appropriate, should aim to ensure young men with DMD have access to video gaming technology. The potential of mobile-gaming carts are described in section 7.5.

7.3.2 Implications for care guidelines

- Recent care guidelines on psychosocial support for young men with DMD (Birnkrant, Bushby, et al, 2018) are dismissive of the potential benefits of social media as a tool to support psychosocial support. The findings of this study have shown that social media can be a vital support for young men with DMD. While the delivery of care that supports young men with DMD to live fulfilling and meaningful lives should be the priority. It is important to acknowledge that social media appears to be well used by young men with DMD, and can benefit their psychosocial wellbeing through experiences of catharsis, escapism, and support.

7.3.3 Developer implications

- The accessibility needs of young men with DMD who video game are still under acknowledged. While it is encouraging that the market for accessibility equipment to support video gaming is growing, the findings of this study suggest they are not always fit for purpose. Young men with DMD need to be active agents in the development of future accessibility software.
- Video gaming offers a world for young men with DMD to enter into to engage in experiences they are otherwise denied offline. Virtual Reality (VR) offers the prospect of improving the immersive qualities of these experiences. As this technology develops, young men with DMD and other physical disabilities should be actively consulted to ensure the software is developed to cater to their needs.

7.4 Recommendations for future research

Research into the use of social media to support people with life limiting/threatening conditions including DMD both in, and outside of the care setting is still relatively in its infancy. Key recommendations for future research include:

- The role of people with neuromuscular conditions such as DMD in the development of accessibility related software and design to enable continued participation in video gaming.

- The value of video gaming as a communicative tool to network young people with life limiting conditions who receive hospice respite care.
- To understand the value of social media as a support network for parents of young people with life limiting conditions.

7.5 Dissemination strategy

Respite care offered by children and young adult hospices was used at least once a year by the young men who took part in the study (Chapter 3) described in this thesis. While it is acknowledged that not all young men with Muscular Dystrophy access respite care provided by a hospice/s. It was appropriate to direct the outputs of the research into the areas of practice that the sample directly engaged with. It is acknowledged that the dissemination of research findings can be better translated into meaningful and impactful outputs through the involvement of Patient Public Involvement (PPI) (Baxter, Muir, et al. 2016). To this end, the two PPI representatives who had supported the research study since its early development (Chapter 3) worked with the researcher to develop and deliver two workshops that formed part of two separate staff training days at a Children and Young Adult hospice.

The aim of the workshops was to raise staff awareness of the benefits of social media to young men with Muscular Dystrophy directly, and also where applicable the wider cohort of young people who receive respite care delivered by the hospice. It was noteworthy that while the hospice had the necessary hardware and appliances to enable young people to access social media freely, the staff who provided care to the young people were largely unaware of the significance of social media to their Being both within, and outside of the hospice setting. Sharing the findings of the study in a deliverable manner to staff was therefore beneficial in illuminating the meaning of social media to young people in receipt of their care.

Several outcomes resulted from the workshops. First, staff were enlightened to how social media can complement existing therapies offered by the hospice such as arts and music. Second, staff were educated on the accessibility challenges faced by young men with DMD, and the charities and support

services available to signpost to support the young men. Third, practical information was fed back to the IT team, such as frustrations voiced by participants regarding WiFi and various locks on sites. Providing insight into why social media held importance to the sample was beneficial in contextualising the necessity to improve these practical barriers. Finally, in an attempt to provide an online space for young people to communicate outside of the hospice setting, staff had established a forum accessed through the hospice website. However, the forum was rarely used. The workshops aided staff to think about alternative ways of supporting young people outside the hospice setting based on the findings of the research. For example, the idea of connecting young people together via online video gaming was discussed. Staff feedback of the workshops was positive, an example of feedback is provided.

Figure 7.1: Email received from the Nurse Consultant of the children and young adult hospice where the workshop was provided.

Thu 22/08/2019 12:16

Hi George,

Quick email to say I've already lost count of the number of people who have spoken to me after your session to say how much they enjoyed it – it really resonated with the team. I think you've created a group of gamers!!

Thanks very much for sharing with us.

Alongside the delivery of staff educational workshops, the researcher also developed a relationship with a local charity. 'The RockinR' was established in 2018 by the parents of Reece Miree, an 11 year old boy who died of an inoperable and incurable brain tumour known as DIPG (Diffuse Intrinsic Pontine Glioma). Reece's parents recognised the impact video gaming had in his short-life, and how particularly towards his end-of-life, it was a crucial to his wellbeing in providing him satisfaction and belonging. In Reece's legacy, his parents founded the 'RockinR' (Reece's Game Tag) with the aim 'to provide fun and

smiles to children and young people spending time in hospitals and hospices throughout the United Kingdom' (TheRockinR.org). The charity meets this aim through the donation of mobile video gaming carts to hospices and hospitals.

A key finding of this research was that video gaming can provide escapism for young men with DMD, particularly during times when their illness was foregrounded, such as periods isolated in bed. While both hospices associated with this study had supply of video gaming equipment. Interaction with the equipment was dependent on having the mobility to access the spaces where the devices were located. One of the advantages of the mobile video gaming carts provided by the RockinR is that they can enable video gaming for patients who are isolated in bed. I worked with the RockinR to arrange the delivery of a mobile video gaming cart to both hospices who took part in the study, and who therefore provided respite care for the young men who were involved in the research.

Figure 7.2: Photos taken of the mobile video gaming carts delivered by the 'RockinR' to two children and young adult hospices.



7.6 Reflexive Statement

Prior to my engagement with this research study, my only experience of young person's palliative care had been as a scared and anxious observer of the palliative care my Godmother's daughter received. Helena was born with a number of severe disabilities limiting her ability to communicate conventionally. As a young shy boy trying to interpret and make sense of my Being in the world in the presence of Helena, I coped by maintaining a safe distance and attempted to communicate and interact with Helena only when prompted to do so. Beginning this PhD study over ten years later, I was acutely aware of my preconceptions and presumptions informed by past experiences, and their potential influence on the study.

As described in Chapter One, acquiring a volunteer care role at a local children and young adult hospice enabled a lived understanding of the role of social media in the hospice setting, that helped to guide and shape the aims of the study. I have since reflected on how important the experience as a carer was in forcing me to confront my presumptions and feelings of fear, anxiety, and awkwardness towards young person's palliative care that I vividly recall prior to my first shift at a children and young adult hospice. In writing this reflective piece, my intention is to demonstrate how Being-with each of the young people I met, including those who took part in the study, moved me towards new ways of thinking and indeed Being.

Volunteering at the hospice forced me to confront the societal teachings and discourses of disability that I had previously unknowingly absorbed, and indeed my anxieties and fears that manifested from such teachings that posit a fixed boundary between the 'disabled' and 'nondisabled'. At times this 'confronting' was experienced in its magnitude. For instance, on one occasion I was left to care for a young woman with severe disabilities who was crying hysterically after her meal time had finished, ending one of the main sensory experiences available to her. My first reaction was to source more food for her, only to be told that this was not an option as she was on a calorie restricted diet due to her weight. Left with few other options, I attempted to play the guitar and sing to her with another carer. Within such moments, the innate human condition to aid

others was at its most salient, pushing away my prior nervousness and awkwardness that I had come to associate with interacting with young people with complex disabilities. This experience undoubtedly shaped me, not as a researcher but as a person, although in doing the latter it inherently provided me with a level of openness, understanding, and confidence towards the young person's palliative care environment that improved the former.

In my time with the young men who took part in the study, I learnt that I shared a lot more in common with them than I had ashamedly presumed.

Conversations on experiences of visiting bars or clubs in our local city, or on the football league standings, or the release of a new video game formed part of the dialogue shared between myself and the young men involved in the study.

Consequently, during each engagement, my preconceptions of what it meant to be a young man with DMD altered and changed.

I entered into this study as someone who had long suffered with anxiety since my teenage years. Spending time with young men of a similar age who, despite their daily challenges do their best to live positive and fulfilling lives has significantly altered my daily outlook. Anxiety still holds presence in my everyday Being in the world, but I am to worry less and live more, a mantra bestowed as a result of this study, and the people I met throughout.

7.7 Final Conclusion

The study presented in this thesis has explored and presented the lived experience of social media from the perspective of young men with Duchenne Muscular Dystrophy. Through an appreciation of both their offline and online lifeworlds the study has revealed my interpretation of the lived experience of social media and its meaning in the lifeworld's of eight young men who live with the condition. The meaning of social media to young men with Duchenne Muscular Dystrophy appears at its most harmonious when it is experienced as an activity for enjoyment, connectivity, discovery, and occasional refuge.

To access this meaningful online world, young men with Duchenne Muscular Dystrophy need to be signposted to it and supported to use it. This is not negating the need to provide young men with DMD with access to other meaningful offline life experiences. Where young men with DMD can be supported to live fulfilling and meaningful lives both in and outside of social media, they are able to shape positive identities. This can be achieved through accessing developmentally appropriate care and recreation provision, and being offered suitable accessibility options.

In presenting this thesis, the mean-making process acknowledged in section 6.1. enters its final phase, whereby a triangulation of meaning or 'triple hermeneutic' occurs. It is now the reader who is making sense, of my own interpretations, of the participant's interpretation of their lived experience of social media. My aim has been in the inevitable distillation of meaning to present the participants account in such a way that has enabled the reader to grasp a sense of lived experience of social media to young men with DMD.

This study has provided the foundation upon which I intend to develop future study aimed at supporting young people with conditions such as Duchenne Muscular Dystrophy to live fulfilling and meaningful lives.

References

- Abbott, D., Carpenter, J. 2010. *Becoming an adult. Transition for young men with Duchenne muscular dystrophy.* (online). Muscular Dystrophy Campaign. 04.06.19. Available from: https://research-information.bris.ac.uk/ws/portalfiles/portal/187889045/Becoming_a_Man_Life_with_Duchenne_muscular_dystrophy_PDF_1_726kB_.pdf
- Abbott, D. 2012. Other voices, other rooms: Reflecting on talking to young men with Duchenne muscular dystrophy and their families and transition to adulthood. *Children and Society.* **26**(1), pp.241-250.
- Abbott, D., Carpenter, J. 2014. 'Wasting precious time': young men with Duchenne muscular dystrophy negotiate the transition to adulthood. *Disability and Society.* **29**(8), pp. 1192-1205.
- Abbott, D., Carpenter, J. 2015. "The things that are inside of you are horrible". Children and young men with Duchenne Muscular Dystrophy talk about the impact of living with a long-term condition. *Child Care in Practice.* **21**(1), pp.67-77.
- Abbott, D., Prescott, H., Forbes, K., et al. 2017. Men with Duchenne muscular dystrophy and end of life planning. *Neuromuscular disorders.* **27**(1), pp. 38-44.
- Action Duchenne, 2020. *Homepage.* (online). (Accessed 10th December, 2020). Available from: <https://www.actionduchenne.org/>
- Anderson, P., Hepworth, M., Kelly, B., et al. 2007. *What is Web 2.0? Ideas, Technologies and Implications for Education.* (online). (Accessed 10th December 2020). Available from: http://www.ictliteracy.info/rf.pdf/Web2.0_research.pdf
- Arksey, H., Knight, P. T. 1999. Approaches to interviewing. In *Interviewing for social scientists.* London: SAGE publications.

- Arksey, H., O'Malley, L. 2005. Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology*. **8**(1), pp.19-32.
- Arribas-Ayllon, M., Walkerdine, V. 2017. *Foucauldian Discourse Analysis*. Chapter in *The SAGE Handbook of Qualitative Research in Psychology*, pp. 110-123. London: SAGE.
- Arundale, R. 2010. Face as emergent in interpersonal communication: An alternative to Goffman. In Bargiela-chiappini, F., Haugh, M. 2010. *Face, communication, and social interaction*. London: Equinox, pp.33-35.
- Ashworth, P.D. 2003. An approach to phenomenological *psychology*: The contingencies of the lifeworld. *Journal of Phenomenological Psychology*. **34**(2), pp. 145-156.
- Ashworth, P.D. 2006. Seeing oneself as a carer in the activity of caring: Attending to the lifeworld of a person with Alzheimer's Disease. *International Journal of Qualitative Studies on Health and Wellbeing*. **1**(4), pp. 212-225.
- Ashworth, P.D. 2015. The lifeworld- enriching qualitative evidence. *Qualitative Research in Psychology*. **13**(1), pp. 1-15.
- Aveyard, H. 2007. *Doing a literature review in health and social care. A practical guide*. Maidenhead: Open University Press.
- Bach, J.R. 2007. Palliative care becomes "uninformed euthanasia" when patients are not offered non-invasive life preserving options. *Journal of Palliative Care*. **23**(1), pp.181-184.
- Bailey, J.M. 2019. *Adaptive video game controllers open worlds for gamers with disabilities*. The New York Times. (online). (Accessed 10th December, 2020). Available from: <https://www.nytimes.com/2019/02/20/business/video-game-controllers-disabilities.html>
- Banks, J., Bowman, N.D. 2013. Close intimate playthings? Understanding player-avatar relationships as a function of attachment, agency, and intimacy. *Selected papers of internet research*. **14**(0), pp. 1-4.

- Baxter, S., Muir, D., Brereton, L., et al. 2016. Evaluating public involvement in research design and grant development: Using a qualitative document analysis method to analyse an award scheme for researchers. *Research Involvement and Engagement*. **2**(13).
- Bazarova, N.N., Choi, Y.H. 2014. Self-disclosure in social media: Extending the functional approach to disclosure motivations and characteristics on social network sites. *Journal of Communication*. **64**(4), pp. 635-657.
- Beck, T. 2013. A phenomenological analysis of anxiety in experienced social situations. *Journal of Phenomenological Psychology*. **44**(2), pp. 179-219.
- Beeston, J., Power, C., Cairns, P., et al. 2018. Characteristics and motivations of players with disabilities in digital games. (online). (Accessed 14th June, 2020). Available from: <https://arxiv.org/abs/1805.11352>
- Bettany-Saltikov, J. 2012. *How to do a Systematic Literature Review in Nursing*. Maidenhead: Open University Press.
- Bers, M.U., Gonzalez-Heydrich, J., Raches, D., et al. 2001. Zora: a pilot virtual community in the paediatric dialysis unit. *Studies in Health Technologies and Informatics*. **84**(1), pp.800-804.
- Birnkrant, D.J., Bushby, K., Bann, C.M., et al. 2018. Diagnosis and management of Duchenne Muscular Dystrophy, part 3: primary care, emergency department, and transitions of care across the lifespan. *Lancet Neurology*. **17**(1), pp.347-361.
- Birnkrant, D.J., Noritz, G.H. 2008. Is there a role for palliative care in progressive pediatric neuromuscular diseases? The answer is "Yes"! *Journal of Palliative Care*. **24**(4), pp.265-269.
- Boyd, D.M., Ellison, N.B. 2007. Social Networking Sites: Definition, History, and Scholarship. *Journal of Computer Mediated Communication*. **13**(1), pp.210-230.
- Brett, J., Staniszewska, S., Mockford, C., et al. 2012. Mapping the impact of patient and public involvement on health and social care research: a systematic review. *Health Expectations*. **17**(1), pp.637-650.
- Brown, J.D. 2009. *The Self*. London: Psychology Press.

- Bullingham, L., Vasconcelos, A.C. 2013. The presentation of self in the online world: Goffman and the study of online identities. *Journal of Information Science*. **39**(1), pp. 1-12.
- Bushby, K., Finkel, R., Birnkrant, D.J., et al. 2010. Diagnosis and management of Duchenne Muscular Dystrophy, part 1: Diagnosis and pharmacological and psychosocial management. *Lancet Neurology*. **9**(1), pp.77-93.
- Chadwick, D.D., Fullwood, C. 2018. An online life like any other: Identity, self-determination, and social networking among adults with intellectual disabilities. *Cyber psychology, behaviour and social networking*. **21**(1), pp. 56-64.
- Chalmers, L., Glasziou, P. 2009. Avoidable waste in the production and reporting of research evidence. *The Lancet*. **374**(1), pp. 86-89.
- Charmaz, K. 1983. Loss of self: a fundamental form of suffering in the chronically ill. *Sociology of Health and Illness*. **5**(2), pp.168-193.
- Cherry, K. 2020. *The role of catharsis in psychology*. Very well mind. Accessed 30th December 2020. Available from: <https://www.verywellmind.com/what-is-catharsis-2794968>
- Clark-Gordon, C.V., Bowman, N.D., Goodboy, A.K., et al. 2019. Anonymity and online self-disclosure: A meta-analysis. *Communication Reports*. **32**(2).
- Cresswell, J.W. (1998). *Qualitative Inquiry and Research Design. Choosing Among Five Traditions*. SAGE Publications: Thousand Oaks, CA.
- Crook, B., Glowacki, M.E., Love, B., et al. 2015. Hanging by a thread: exploring the features of nonresponse in an online young adult cancer survivorship support community. *Journal of Cancer Survivorship*. **10**(1), pp.185-193.
- Crook, B., Love, B. 2016. Examining the light and dark of an online young adult cancer support community. *Qualitative Health Research*. **6**(1), pp.938-948.
- Cross, M. 2013. Demonised, impoverished and now forced into isolation: the fate of disabled people under austerity. *Disability and Society*. **28**(5), pp.719-723.

- Crowe, S., Fenton, M., Hall, M., et al. 2015. Patients', clinicians', and the research communities' priorities for treatment research: there is an important mismatch. *Research Involvement and Engagement*. **23**(1), pp.1-14.
- Daugherty, T., Eastin, M.S., Bright, L. 2008. Exploring Consumer Motivations for Creating User-Generated Content. *Journal of Interactive Advertising*. **8**(2), pp.16-25.
- Davis, J.L., Jurgenson, N. 2014. Context collapse: Theorising context collusions and collisions. *Information, communication, and society*. **17**(4), pp. 476-485.
- Davis, K., Drey, N., Gould, D. 2009. What are scoping studies? A review of the nursing literature. *International Journal of Nursing Studies*. **46**(1), pp.1386-1400.
- Davis, K., Randall, D.P., Ambrose, A., et al. 2015. 'I was bullied too': stories of bullying and coping in an online community. *Information, communication, and society*. **18**(4), pp. 357-375.
- Dengah, H.J., Snodgrass, J.G. 2020. Avatar creation in video gaming: between compensation and constraint. *Games for health journal*. **9**(4), pp. 1-15.
- Denzin, N.K. 1997. *Interpretative ethnography: Ethnographic practices for the 21st century*. Thousand Oaks: SAGE.
- Dictionary.com. 2020. *Accessibility*. (online). (Accessed 21st December, 2020). Available from: <https://www.dictionary.com/browse/accessibility>
- Disability Rights UK, 2020. *Independent Living*. (online). (Accessed 10th December 2020). Available from: <https://www.disabilityrightsuk.org/independent-living-0>
- DMD Pathfinders neuromuscular alliance, 2020. *Homepage*. (online). (Accessed 10th December, 2020). Available from: <https://www.pathfindersalliance.org.uk/>
- Donovan, E.E., LeFebvre, L., Tardiff, S., et al. 2015. Patterns of social support communicated in response to expressions of uncertainty in an online community of young adults with cancer. *Journal of Applied Communications Research*. **42**(1), pp.432-455.

- Drachen, A., Hitchens, M., Eladhari, M.P., et al. 2009. Role playing games: The state of knowledge. Available from: <http://www.digra.org/wp-content/uploads/digital-library/09287.23528.pdf>
- Eatough, V., Smith, J.A., Shaw, R. 2008. Women, anger, and aggression: An Interpretative Phenomenological Analysis. *Journal of interpersonal violence*. **23**(12), pp. 1767-1799.
- Eatough, V., Smith, J.A. 2017. *Chapter 12: Interpretative Phenomenological Analysis: In Willig, C., Rogers, F. (2017) SAGE Handbook of qualitative research in psychology*. Routledge: London.
- Etchells, P. 2019. *Lost in a Good Game*. London: Icon Books Ltd.
- Federal Communications Commission. 2010. *21st Century Communications and video accessibility act*. (online). (Accessed 10th December, 2020). Available from: <https://www.fcc.gov/consumers/guides/21st-century-communications-and-video-accessibility-act-cvaa>
- Ferguson, C.J., Olson, C.K., Kutner, L.A., et al. 2010. Violent video games, catharsis seeking, bullying, and delinquency: A multivariate analysis of effects. *Crime and Delinquency*. **60**(5), pp. 764-784.
- Finkelstein, A., Marcus, E. 2018. Realising autonomy: the phenomenology of independence and interdependence while living with Duchenne muscular dystrophy. *Disability and Society*. **33**(3), pp. 433-453.
- Finley, L. 2017. Championing 'reflexivities'. *Qualitative Psychology*. **4**(2), pp. 120-125.
- Forgie, S.E., Duff, J.P., Ross, S. 2013. Twelve tips for using Twitter as a learning tool in medical education. *Medical Teacher*. **35**(1), pp.8-14.
- Fraser, L. K., Aldridge, J., Manning, S., et al. 2011. Hospice provision and usage amongst young people with neuromuscular disease in the United Kingdom. *European Journal of Paediatric Neurology*. **15**(1), pp.326-330.
- Furr, J.B., Carreiro, A., McArthur, J.A. 2016. Strategic approaches to disability disclosure on social media. *Disability and Society*. **31**(10), pp. 1353-1368.

- Gadamer, H.G. 1998. *Truth and method*. 2nd Edition. New York: Continuum. (Original work published 1960).
- Gibson, B. E., Young, N.L., Upshur, R. E., et al. 2007. Men on the margin: A Bourdieusian examination of living into adulthood with muscular dystrophy. *Social science and medicine*. **65**(1), pp.505-517.
- Gil-Lopez, T., Shen, C., Benefield, G.A., et al. 2018. One size fits all: Context collapse, self-presentation strategies and language styles on Facebook. *Journal of Computer-Mediated Communication*. **23**(1), pp. 127-145.
- Giorgi, A. 2009. *The descriptive phenomenological method in psychology: A modified Husserlian approach*. Duquesne University Press: Pennsylvania
- Glaser, B.G., Strauss, A. L. 1967. *Discovery of Grounded Theory. Strategies for Qualitative Research*. Routledge: New York.
- Goffman, E. 1959. *The presentation of self in everyday life*. New York: Doubleday.
- Goffman, E. 1961. *Encounters: Two studies in the sociology of interaction*. Harmondsworth. Penguin Books.
- Goffman, E. 1964. The neglected situation. *American Anthropologist*. **66**(1), pp.133-136.
- Goldspink, S. 2019. Booming clangs and whispering ghosts: Attending to the reflexive echoes in IPA research. *Qualitative research in psychology*. **16**(2), pp. 291-304.
- Gov. UK, 2020. *The Data Protection Act*. (online). (Accessed 10th December, 2020). Available from: <https://www.gov.uk/data-protection>
- Graham, C.D., Rose, M.R. 2016. What explains high life satisfaction in men living with Duchenne Muscular Dystrophy? A preliminary study to inform a psychological intervention. *Muscle and Nerve*. **56**(1), pp. 163-166.
- Grant, M., Booth, A. 2009. A typology of reviews: an analysis of 14 review types and associated methodologies. *Health Information and Libraries Journal*. **26**(1), pp.91-108.

- Griffiths, F., Cave, J., Boardman, F., et al. 2012. Social networks- The future of healthcare delivery. *Social Science and Medicine*. **75**(12), pp. 2233-2241.
- Griffiths, C., Paneli, N., Brunton, D., et al. 2015. Designing and evaluating the acceptability of Realshare: An online support community for teenagers and young adults with cancer. *Journal of Health Psychology*. **20**(1), pp.1589-1601.
- Gunning, R. 1968. *The Technique of Clear Writing*. McGraw-Hill: Michigan.
- Hacker, K., van Dijk, J. 2003. The digital divide as a complex and dynamic phenomenon. *The information society*. **19**(4), pp. 13-24.
- Hamad, A. A., Wu, X., Rubin, A. 2014. A twitter recruitment intelligent system: association rule mining for smoking cessation. *Social Network Analysis and Mining*. **4**(1), pp. 1-19.
- Heidegger, M. 1927/2011. *Being and Time*. (Macquarrie, J., Robinson, E. Trans). Harper and Row: New York.
- Heilferty, C.M. 2009. Towards a theory of online communication in illness: Concept analysis of illness blogs. *Journal of Advanced Nursing*. **65**(1), pp.1539-1547.
- Hendricks, S., Düking, P., Mellalieu, S.D. 2016. Twitter strategies for web-based surveying: descriptive analysis from the international concussion study. *JMIR Research Protocols*. **5**(3), pp.179-185.
- Higgins, E. T. 1987. Self-discrepancy: A theory relating self and affect. *Psychological Review*. **94**(1), pp. 319-340.
- Hill, M.E., Phillips, M.F. 2005. Service provision for adults with long-term disability: A review of services for adults with chronic neuromuscular conditions in the United Kingdom. *Neuromuscular disorders*. **16**(1), pp.107-112.
- Hogan, B. 2010. The presentation of self in the age of social media: Distinguishing performances and exhibitions online. *Bulletin of science, technology, and society*. **30**(6), pp. 377-386.
- Horrigan-Kelly, M., Millar, M., Dowling, M. 2016. Understanding the key tenets of Heidegger's philosophy for Interpretive Phenomenological Research. *International Journal of Qualitative Methods*. **1**(1), pp.1-8.

Hunt, A., Carter, B., Abbott, J., et al. 2016. Pain experience, expression and coping in boys and young men with Duchenne Muscular Dystrophy- A pilot study using mixed methods. *European journal of paediatric neurology*. **1**(20), pp.630-638.

Husserl, E. (1970) *The Crisis of European Sciences and Transcendental Phenomenology: An Introduction to Phenomenological Philosophy*. Translated by David Carr. Northwestern University Press. Evanston

ID Tech. 2018. *The many different types of video games and their subgenres*. (online) (Accessed 18th December 2019). Available from: <https://www.idtech.com/blog/different-types-of-video-game-genres>

Ihde, D. (1986). *Experimental Phenomenology. An Introduction*. The Putnam Publishing Group. New York.

Internetmatters.org. 2020. *Online gaming: the benefits*. (online) (Accessed 12th December 2020). Available from: <https://www.internetmatters.org/resources/online-gaming-advice/online-gaming-the-benefits/>

Jackson, G.B. 1980. Methods for integrative reviews. *Review of Educational Research*. **50**(3), pp.438-460.

Jones, K. 2020. *Online gaming: The rise of a multi-billion dollar industry*. Technology. (online). (Accessed 30th December, 2020). Available from: <https://www.visualcapitalist.com/online-gaming-the-rise-of-a-multi-billion-dollar-industry/>

Jones, E.E., Pittman, T.S. 1982. Towards a general theory of strategic self-presentation. *Psychological perspectives of self*. **1**(1), pp. 231-262.

Kaplan, A.M., Haenlein, M. 2010. Users of the world, Unite! The challenges and opportunities of social media. *Business Horizons*. **53**(1), pp.59-68.

Keim-Malpass, J., Adelstein, K., Kavalieratos, D. 2015. Legacy making through illness blogs: online spaces for young adults approaching the end of life. *Journal of Adolescent and Young Adult Oncology*. **4**(1), pp.209-212.

- Keim-Malpass, J., Albrecht, T., Steeves, R.H., et al. 2013. Young women's experiences with complementary therapies during cancer described through illness blogs. *Western Journal of Nursing Research*. **35**(1), pp.1309-1324.
- Keim-Malpass, J., Steeves, H.R. 2012. Talking with death at a diner: Young women's online narratives of cancer. *Oncology Nursing Forum*. **39**(1), pp.373-378.
- Kleman, E. 2007. *Journaling for the world to see: A proposed model of self-disclosure intimacy in blogs*. In annual meeting of the National Communication Association. Chicago.
- Knight, S. 2009. *NLP at work: The essence of excellence*. London: WS Bookwell.
- Kozinets, R.V. 2002. The field behind the screen: Using Netnography for Marketing research in online communities. *Journal of Marketing Research*. **39**(1), pp. 61-72.
- Landfeldt, E., Lindgren, P., Bell, C.F., et al. 2015. Compliance to care guidelines for Duchenne muscular dystrophy. *Journal of Neuromuscular diseases*. **2**(1), pp.63-72.
- Landfelt, E., Lindgren, P., Bell, C.F., et al. 2016. Health-related quality of life in patients with Duchenne muscular dystrophy: a multinational cross-sectional study. *Developmental medicine and child neurology*. **58**(5), pp.508-515.
- Laughey, D. 2007. *Key themes in media theory*. Maidenhead: Open University Press.
- Laverty, S.M. 2003. Hermeneutic phenomenology and phenomenology: A comparison of historical and methodological considerations. *International Journal of Qualitative Methods*. **2**(3), pp. 21-35.
- Leder, D. 1990. *The Absent Body*. Chicago: University of Chicago Press.
- Lee, H.E., Cho, J. 2019. Social media use and wellbeing in people with physical disabilities: Influence of SNS and online community uses on social support, depression, and psychological disposition. *Health Communication*. **34**(9), pp.1043-1052.

Lincoln. Y., Guba, E.G. 1985. *Naturalistic Inquiry*. Newbury Park: SAGE.

Live Strong Young Adult Alliance. 2006. *Closing the gap: Research and care imperatives for adolescents and young adults with cancer. Report of the adolescent and young adult oncology progress review group*. (online). US Department of Health and Human Services. 10th December 2020. Available from: https://www.livestrong.org/sites/default/files/what-we-do/reports/ayao_prg_report_2006_final.pdf

Liu, D., Brown, B.B. 2014. Self-disclosure on social networking sites, positive feedback and social capital among Chinese college students. *Computers in Human Behaviour*. **38**(1), pp. 213-219.

Love, B., Thompson, C.M., Knapp, J. 2014. The need to be Superman: the psychosocial support challenges of young men affected by cancer. *Oncology Nursing Forum*. **41**(1), pp.21-27.

Lowney, A.C., O'Brien, T. 2012. The landscape of blogging in palliative care. *Journal of Palliative Medicine*. **26**(1), pp.858-859.

Lue, Y.J., Chen, S., Lu, Y. 2017. Quality of life of patients with Duchenne muscular dystrophy: from adolescence to young men. *Disability and Rehabilitation*. **39**(14), pp. 1408-1413.

Liu, D., Wright, K.B., et al. 2018. A meta-analysis of social network site use and support. *Computers and Education*. **127**(1), pp. 201-213.

Luft, S. Husserl's phenomenological discovery of the natural attitude. *Continental Philosophy Review*. **31**(1), pp. 153-170.

Marks, S., Mathie, E., Smiddy, J., et al. 2018. Reflections and experiences of a co-researcher involved in a renal research study. *Research Involvement and Engagement*. **4**(26), pp. 48-56.

McCay-Peet, L., Quan-Haase, A. 2016. *The SAGE Handbook of Social Media Research Methods*. London: SAGE.

Mendell, J.R., Shilling, C., Leslie, N.D., et al. 2012. Evidence based path to newborn screening for Duchenne muscular dsystrophy. *Annals of Neurology*. **71**(1), pp.304-313.

- Merleau-Ponty, M. 1945/1962. *The Phenomenology of Perception*. (translated by C. Smith). Routledge and Kegan Paul: London.
- Merriam-Webster. 2020. *Blog*. (online) (Accessed 10th December 2020). Available from: <https://www.merriam-webster.com/dictionary/blog>
- Merriam-Webster. 2019. *Definition of video game*. (online). (Accessed 18th December 2020). Available from: <https://www.merriam-webster.com/dictionary/video%20game>.
- Miller, W. 2015. Understanding Grounded Theory. *American Society for Clinical Laboratory Science*. **28**(3), pp. 197-200.
- Miller, H., Arnold, J. 2009. Identity in cyberspace. In Wheeler, S. *Connected minds, emerging culture. Cyber cultures in online learning*. Greenwich: IAP.
- Mohanty, J., McKenna, W.R. 1989. *Husserl's Phenomenology: A textbook*. University Press of America: Washington.
- Molesworth, M. 2009. Adult's consumption of video games as imaginative escape from routine. *Advances in consumer research*. **36**(1), pp. 378-383.
- Moran, D. 2000. *Introduction to Phenomenology*. Routledge: London.
- Morgan, D.L., Guevara, H. 2012. *Rapport*. Cited in The SAGE Encyclopaedia of qualitative research methods. Thousand Oaks: SAGE.
- Morse, J.M. 2015. 'Data were saturated...' *Qualitative Health Research*. **25**(5), pp. 587-588.
- Moser, A., Korstjens, I. 2017. Series: Practical guidance to qualitative research. Part 3: Sampling, data collection and analysis. *The European journal of general practice*. **24**(1), pp. 1-10.
- Muscular Dystrophy UK. 2020. *Duchenne muscular dystrophy (DMD)*. (online) (Accessed 10th December 2020). Available from: <https://www.muscular dystrophyuk.org/about-muscle-wasting-conditions/duchenne-muscular-dystrophy/duchenne-dmd-factsheet>

- Myrick, J.G., Holton, A.E., Himelboim, I., et al. 2016. #Stupid Cancer: Exploring a typology of social support and the role of emotional expression in a social media community. *Journal of Health Communities*. **31**(1), pp.596-605.
- Nakamura, L. 2002. *Cybertypes: Race, ethnicity, and identity on the internet*. New York: Routledge.
- Nesby, L., Salamonsen, A. 2016. Youth blogging and serious illness. *Journal of Medical Humanities*. **42**(1), pp.46-51.
- NIHR Involve, 2020. *People in Research*. (online). (Accessed 10th December 2020). Available from: <https://www.invo.org.uk/>
- Noble, H., Smith, J. 2018. Reviewing the literature: Choosing a review design. *Evidence-Based Nursing*. **21**(1), pp.39-41.
- Ocloo, J., Matthews, R. 2016. From tokenism to empowerment: progressing patient and public involvement in healthcare improvement. *BMJ Quality and Safety*. **25**(1), pp. 626-632.
- Oliver, M., Bowman, B., David, N., et al. 2015. Video games as meaningful entertainment experiences. **145**(1), pp. 1-33.
- Orb, A., Eisenhauer, L., Wynaden, D. 2004. Ethics in qualitative research. *Journal of nursing scholarship*. **33**(1), pp. 93-96.
- Pangalila, R.F., Geertrudis, A.M., Bergen, M.P., et al. 2015. Quality of life of adult men with Duchenne muscular dystrophy in the Netherlands: Implications for care. *Journal of Rehabilitative Medicine*. **47**(1), pp.161-166.
- Peat, G., Rodriguez, A., Smith, J. 2019. Interpretative Phenomenological Analysis applied to healthcare research. *Evidenced-Based Nursing*. **1**(1), pp. 7-9.
- Peat, G., Smith, J., Rodriguez, A. 2018. Mobilising identity through social media: psychosocial support for young people with life-limiting conditions. *Evidence Based Nursing*. **21**(2), pp. 60-62.
- Pempek, T.A., Yermolayeva, Y.A., Calvert, S.L. 2009. College student's social networking experiences on Facebook. *Journal of Applied Developmental Psychology*. **30**(3), pp. 227-238.

- Pennebaker, J.W. 2012. *The psychology of physical symptoms*. New York: Springer
- Petronio, S. 2002. *Boundaries of privacy*. Albany, NY: State University of New York Press.
- Pluye, P., Robert, E., Cargo, M., et al. 2017. A mixed methods appraisal tool for systematic mixed studies reviews. (online). (Accessed 10th November 2017). Available from: <http://mixedmethodsappraisaltoolpublic.pbworks.com>
- Porter, J.R., Keintz, J.A. 2013. An empirical study of issues and barriers to mainstream video game accessibility. *Proceedings of the 15th International Conference on Computers and Accessibility*. **3**(1), pp.1-8.
- Potter, J., Wetherell, M. 1987. *Discourse and social psychology. Beyond attitudes and behaviour*. London: SAGE.
- Pounders, K., Stowers, K., Wilcox G., et al. 20017. Exploring gender and identity issues among female adolescent and young adults who connect in an anonymous platform. *Journal of Health Psychology*. **22**(1), pp.548-560.
- Pringle, J., Drummond, J., McLafferty, E., et al. 2009. Interpretative Phenomenological Analysis: a discussion and critique. *Nurse Researcher*. **18**(3), pp. 20-24.
- Przybylski, A.K., Weinstein, N., Murayama, K., et al. 2012. The ideal self at play: The appeal of video games that let you be all you can be. *Association for Psychological Science*. **23**(1), pp. 69-76.
- Rasid, N., Nonis, K.P. 2015. Exploring communication technology behaviour of adolescents with Cerebral-Palsy in Singapore. *International Journal of Special Education*. **30**(3), pp.17-38.
- Reuter, M. 1999. Merleau-Ponty's notion of pre-reflective intentionality. *Synthese*. **118**(1), pp. 69-88.
- Rigby, S., Ryan, R.M. 2011. *Glued to games: How video games draw us in and hold us spellbound*. California: Praeger

- Rinne, P., Mace, M., Nakornchai, T., et al. 2016. Democratising Neurorehabilitation: How accessible are low-cost mobile-gaming technologies for self-rehabilitation of arm disability in stroke? *PLoS One*. **5**(11), pp. 1-7.
- Robinson, P., Giorgi, B., Ekman, S.L. 2012. The lived experience of early stage Alzheimer's Disease: A three year longitudinal phenomenological case study. *Journal of Phenomenological Psychology*. **43** (2), pp. 216-238.
- Rogers, C.R. 1961. *On becoming a person: A therapists view of psychotherapy*. Boston: Horton Mifflin.
- Royal College of Nursing. 2020. *What are Neuromuscular disorders?* (online). (Accessed 10th December 2020). Available from: <https://www.rcn.org.uk/clinical-topics/neuroscience-nursing/neuromuscular-disorders>
- Rowland, J.L., Malone, L.A., Fidopiastis, C.M., et al. 2016. Perspectives on active video gaming as a new frontier in accessible physical activity for youth with physical disabilities. *Physical Therapy*. **96**(4), pp. 521-532.
- Sanger, K. 2019. *Being a young adult with Duchenne's muscular dystrophy: wellbeing and priorities for adult life*. Ph.D. thesis, Staffordshire University.
- Sartre, J. P. (1956) *Being and Nothingness: A phenomenological essay on Ontology*. Trans. H Barns. New York. Pocket Books
- Saunders, B., Sim, J., Kingstone, T., et al. 2017. Saturation in qualitative research: exploring its conceptualization and operationalization. *Quality & Quantity*. **52**(1), pp. 1893-1907.
- Schaubert, V. 2019. My disabled son's amazing gaming life in the World of Warcraft. *BBC News*. (online). (Accessed 10th December 2020). Available from: <https://www.bbc.co.uk/news/disability-47064773>
- Schlenker, B.R. 1980. *Impression management: The self-concept, social identity, and interpersonal relations*. Monterey, CA: Brooks/Cole.
- Sherman, G.L. Martin Heidegger's concept of authenticity: A philosophical contribution to student affairs theory. *Journal of College and Character*. **10**(7), pp. 1-9.

- Shpigelman, C., Gill, C.J. 2014. Facebook use by persons with disabilities. *Journal of Computer-Mediated Communication*. **19**(1), pp. 610-624.
- Sibilla, F., Mancini, T. 2018. I am (not) my avatar: A review of the user-avatar relationships in massively multiplayer online worlds. *Journal of Psychosocial Research on Cyberspace*. **12**(3), pp. 1-15.
- Skyrme, S. 2017. "I just try to be as independent as possible": Duchenne muscular dystrophy, agency, and contextualised competence. *Global studies of childhood*. **7**(3), pp.278-289.
- Sloan, L., Quan-Haase, A. 2017. *SAGE Handbook of Social Media Research Methods*. London: SAGE.
- Smith, J.A. 2004. Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative research in psychology*. **1**(1), pp. 39-54.
- Smith, J.A., Flowers, P., Larkin, M. 2009. *Interpretative Phenomenological Analysis. Theory, Method, and Research*. Sage: London.
- Smith, J.A. 2011. Evaluating the contribution of interpretative phenomenological analysis. *Health psychology review*. **5**(1), pp. 9-27/
- Smith, J.A. 2018. Participants and researchers searching for meaning: conceptual developments for interpretative phenomenological analysis. *Qualitative Research in Psychology*. **16**(2), pp. 166-181.
- Special Effects. 2020. *Special Effect.Org. The Gamers Charity*. (online) (Accessed 10th December, 2020). Available from: <https://www.specialeffect.org.uk/>
- Spinelli, E. 1989. *The interpreted world: An introduction to phenomenological psychology*. SAGE Publications: London.
- Statista, 2020. *Facebook users by country 2020*. (online) (Accessed 10th December, 2020). Available from: <https://www.statista.com/statistics/268136/top-15-countries-based-on-number-of-facebook-users/>

Statista, 2020. *WhatsApp- Statistics and Facts*. (online) (Accessed 10th December, 2020). Available from:
<https://www.statista.com/topics/2018/whatsapp/>

Stewart, S., Hansen, T.S., Carey, T.A. 2010. Opportunities for people with disabilities in the virtual world of Second Life. *Rehabilitative Nursing*. **35**(6), pp. 254-259.

Streubert, H. J., Carpenter D, R. 2011. *Qualitative Research in Nursing. Advancing the Humanistic Imperative*. Lippincott Williams & Wilkins: Philadelphia.

Tappan, M.B. 2010. Interpretive psychology: stories, circles, and understanding lived experience. *Journal of Social Issues*. **53**(4), pp. 645-656.

Thomas, S.P. 2005. Through the lens of Merleau-Ponty: advancing the phenomenological approach to nursing research. *Nursing Philosophy*. **6**(1), pp.63-76.

Thompson, C.M., Crook, B., Love, B., et al. 2015. Understanding how adolescents and young adults with cancer talk about needs in online and face-to-face support groups. *Journal of Health Psychology*. **21**(1), pp. 2636-2646.

Todres, L., Galvin, K.T., Dahlberg, K. 2007. Lifeworld-led healthcare: Revisiting a humanising philosophy that integrates emerging trends. *Medicine health care and philosophy*. **10**(1), pp. 53-63.

Together for Short Lives. 2020. *Categories of life-limiting conditions*. (online). (Accessed 10th December 2020). Available from:
<https://www.togetherforshortlives.org.uk/changing-lives/supporting-care-professionals/introduction-childrens-palliative-care/categories-of-life-limiting-conditions/>

Tomlinson, J., Medlinskiene, K., Cheong, V., et al. 2019. Patient and public involvement in designing and conducting doctoral research: the whys and the hows. *Research Involvement and Engagement*. **5**(23), pp. 1-12.

Toombs, K. 1995. The lived experience of disability. *Human Studies*. **18**(1), pp. 9-23.

Treem, J.W., Leonardi, P.M. 2012. Social media use in organisations: Exploring the affordances of visibility, editability, persistence, and association. *Annals of the internal communication association*. **36**(1), pp. 143-189.

Twenty-First Century Communications Act. 2010. Washington: Federal Communications Commission.

Van der Velden, P.G., Setti, I., Van der Meulen, E., et al. 2019. Does social networking use predict mental health and sleep problems when prior problems and loneliness are taken into account? A population-based prospective study. *Computers in Human Behaviour*. **93**(1), pp.200-209.

Vitak, J., Kim, J. 2014. You can't block people offline: examining how Facebook's affordances shape the disclosure process. *In proceedings of the 17th ACM conference on computer supported cooperative work and social computing*. 461-474. ACM

Vuillerot, C., Hodgkinson, I., Bissery, A., et al. 2010. Self-perception of quality of life by adolescents with neuromuscular diseases. *Journal of Adolescent Health*. **46**(1), pp. 70-76.

Waters, S., Ackerman, J. 2011. Exploring privacy management on Facebook: Motivations and perceived consequences of voluntary disclosure. *Journal of Computer-Mediated Communication*. **17**(1), pp. 101-115.

Wästerfors, D., Hansson, K. 2017. Taking ownership of gaming and disability. *Journal of youth studies*. **20**(9), pp.1143-1160.

Wasilewski, M, B., Stinson, J. N., Webster, F., Cameron, J. I. 2019. Using Twitter to recruit participants for health research: An example from a caregiving study. *Health Informatics Journal*. **25**(4), pp.1485-1497.

Webwise. 2020. *What is Messenger?* (online) (Accessed 10th December, 2020). Available from: <https://www.webwise.ie/parents/explained-what-is-messenger/>

Whittemore, R., Knafk, K. 2005. The integrative review: Updated methodology. *Journal of Advanced Nursing*. **52**(5), pp.546-553.

Widdas, D., McNamara, K., Edwards, F. 2013. *A core care pathway for children with life limiting conditions*. Third Edition. Bristol. Together for Short Lives.

- Willig, C., Rogers, W.S. 2017. *The SAGE handbook of qualitative research in psychology*. London: SAGE.
- Winterling, J., Wiklander, M., Obol, C., et al. 2016. Development of a self-help web-based intervention targeting young cancer patients with sexual problems and fertility distress in collaboration with patient research partners. *Journal of Medical Internet Research*. **5**(1), pp.1-12.
- Wood, J. T. 2004. *Communication theories in action: An introduction*. 3rd Edition. Belmont CA: Wadsworth.
- World of Warcraft* (standard edition). 2010. Computer (Game). Blizzard Entertainment: California.
- Woodcock, I.R., Fraser, L., Norman, P., et al. 2016. The prevalence of neuromuscular disease in the paediatric population in Yorkshire, UK; variation by ethnicity and deprivation status. *Developmental medicine and child neurology*. **58**(8), pp. 877-883.
- Yancher, S.C. 2015. Truth and disclosure in qualitative research: Implications for hermeneutic realism. *Qualitative research in psychology*. **12**(2), pp. 107-124.
- Yardley, L. 2008. Demonstrating validity in qualitative psychology. In J.A. Smith (Ed.), *Qualitative Psychology*. (2nd Edition), pp. 235-251). London: SAGE.
- Yardley, L. 2017. Demonstrating the validity of qualitative research. *The journal of positive psychology*. **12**(3), pp.295-296.
- YouTube. 2020. (online). (Accessed 10th December, 2020). Available from: <https://www.youtube.com/>
- Zielke, M.A., Roome, T., Krueger, A.B. 2009. A pedagogical model for virtual world residents: A case study of the virtual ability Second Life island. *Journal of Virtual Worlds Research*. **2**(1), pp. 1-9.

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Appendix

7.8 Appendix 1: Hospice letter of agreement to support the study

Dear George,

It was good to meet you a couple of weeks ago and to have the opportunity to discuss your worthwhile and interesting PhD study.

Personal identity and individuality is something that we're very passionate about Martin House. With this in mind, we'd be happy to support your project by enabling you to recruit participants via the hospice, pending ethical approval from the university REC and subsequent agreement by the Martin House research committee.

I look forward to hearing from you following your successful ethics application. Good luck!

Kind regards,

Michael

Dr Michael Tatterton

7.9 Appendix 2: Recruitment cover letter

Dear **name**,

We are writing to invite you to take part in a piece of research that is being led by a PhD student from the University of Leeds, called George Peat. George is interested in exploring how young men with Duchenne Muscular Dystrophy who use Martin House use social media, and would like to chat with you about your experiences. George has written an information leaflet explaining his study, which is enclosed.

George is visiting Martin House regularly, and will be here during your next stay between **date** and **date**. I wonder if you would like to speak to George about your experiences – there is no pressure to do so, but sharing your experiences with him will help him understand how young people who come to Martin House use social media.

George does not know who we have invited to speak with him, and your details have not been shared with him. If you decide to speak to George, everything you talk about will be confidential, and used only for his research.

If you have any questions, you can contact George using the details on the enclosed sheet. If you'd prefer, you can contact me before your stay, or when you next visit Martin House.

Looking forward to seeing you in a few weeks.

Best wishes,

7.10 Appendix 3: Participant Information Sheet



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Me, Myself, and Social Media

Hi, my name is George and I am a PhD student at the University of Leeds. I would like to invite you to take part in a research project that explores how young men who have Duchenne Muscular Dystrophy use gaming and social media. This information sheet has been designed to provide you with information about the study so you can decide whether or not you would like to take part. The research is being conducted as part of my PhD project.



What is the purpose of the project?

The purpose of the project is to explore how and why young men who have Duchenne Muscular Dystrophy (DMD) use gaming and social media. Social media includes any interaction that takes place online, from social media platforms like Facebook, Twitter, and Instagram, to gaming platforms. The project is interested in your experiences of using gaming and social media.

Why have I been asked to participate?

You have been asked to participate because the study is interested in how young men (aged 13 to 35) who have DMD use gaming and social media. The project will include around 10 young men.

What will be involved if I take part in the study?

Taking part in the study would involve interacting with me about your experiences of using gaming and social media. This would involve taking part in an interview face to face at Whitby Lodge. The interview will take place during a time most suitable to you. If it is okay with you I would like to record the interview. The interview is likely to take around one hour. However, if you wish to talk for less time or more time than one hour that is fine.

What are the possible advantages and disadvantages of taking part?

This research will go towards understanding how effective gaming and social media is in providing psychological and social support for young men who visit hospices such as Martin House. Taking part in this research will take approximately one hour of your time. During the interview, it is possible that topics of sensitivity may arise. Should you feel uncomfortable about talking about anything, we can move onto another topic or stop the interview.

Can I withdraw from the study at any time?

You can withdraw from the study at any point during the interview. In addition, after the interview you will have a period of one month to withdraw your data from the study. To do this you would just need to contact me, either of my supervisors, or Dr Clare Harley (details provided below) and you do not have to give a reason. If you withdraw from the study, any data you have provided will be deleted.

Will the information I give be kept confidential?

The conversation we have will be recorded with your permission. The audio recording will then be stored in a password protected file on a University of Leeds computer. Only I (George) will have access to the audio recording. I will then transcribe the audio recording which means writing down what you have said word for word. Once I have done this I will permanently delete the audio recording of the interview. When I transcribe the audio recording I will not write anything down that is personal about you, such as your name or age. That way, it will not be possible to identify you through the data you provide. I will store the transcript file of the interview in a password protected file on a University of Leeds computer. The only time I may need to tell someone else of what we talk about is if you tell me something that would make me think you or someone you know may come to harm. In this instance, I would inform you that I have divulged the relevant information to a member of staff at Martin House hospice.

What will happen to the results of the study?

The conversations we may have will be turned into data and used in a report that the University of Leeds will read. It may also be published in journals and presented at conferences related to the topic area of psychological and social support for young people who visit hospices such as Martin House.

Who has reviewed and approved the study?

The research has been considered by an independent group of people called a Research Ethics Committee. This study was reviewed by the Faculty of Medicine and Health Ethics Committee at the University of Leeds on the 09/03/18 and approved.

Information about the research team

The lead researcher is George Peat, a PhD student at the University of Leeds. His supervisors are Dr Alison Rodriguez and Dr Jo Smith. Their details, as well as the details of Dr Clare Harley who is not directly involved in the study but whom you can contact if you have any concerns about the study are below:

Dr Alison Rodriguez

a.m.rodriguez@leeds.ac.uk

Dr Jo Smith

j.e.smith1@leeds.ac.uk

Dr Clare Harley

c.harley@leeds.ac.uk

What to do next?

If you are interested in taking part in an interview during your stay at Martin House then please contact me by email at hcgwp@leeds.ac.uk. If you do not wish to take part in the study then you do not need to do anything.

Thank you for taking time to read this information sheet

7.11 Appendix 4: Parent/Guardian information sheet

Me, Myself, and Social Media

Information sheet for parents/guardians

(Please keep this copy)

My name is George Peat and I am a School of Healthcare PhD student studying at the University of Leeds. I am conducting a research study and I would like your child to take part.

This information sheet will provide you with information about the study. This sheet has been included as part of an information pack that is designed for your son. I would be grateful if you could take the time to read this sheet and assist your son in reading the information about the study.

What is the study about?

Young men with Duchenne Muscular Dystrophy are a population that have received little attention within research. Social media has been suggested to help provide psychological and social support for young people. This study would like to understand how young men with Duchenne Muscular Dystrophy use social media. It is hoped that as a result of this study hospices such as (hospice removed) will have a better understanding of how young men with Duchenne Muscular Dystrophy use social media for psychological and social support.

Why has your child been chosen?

The study is recruiting young men aged 16-35 with Duchenne Muscular Dystrophy who visit hospices such as Martin House and who use social media.

Does your child have to take part?

No. It is entirely up to your son if he wishes to take part or not. The purpose of the information pack is to provide him with enough information to make an informed decision as to whether or not he would like to take part. If he would like to take part, your son will be asked to give verbal consent. They will be asked on a number of occasions throughout the research process if they are comfortable in taking part. Your son can decide to not take part and they do not have to give a reason and this will not affect their care.

What does the study involve if my child takes part?

If your son is interested in taking part in the study, an email address will be provided in the information booklet that they can use to let the researcher know they are interested in taking part in the study. If your son expresses interest in the study, a date and time will be agreed for the researcher to meet them face to face on a date that they are visiting (hospice). If they are happy to be interviewed, they will be asked questions about their experiences of using social media. Your son's answers will be digitally recorded to allow the researcher to analyse your son's responses. Only the researcher will listen to the recording and it will be deleted at the end of the study.

Will his taking part be kept confidential?

Yes. All the information I receive from your son will be treated as confidential. Any personal information such as his name will be anonymised so their data will not be identifiable. The data your child provides will be stored on a password protected University of Leeds computer.

What are the possible benefits of taking part?

Participating in the study will help hospices like Martin House understand how young men with Duchenne Muscular Dystrophy use social media. By doing so, they will have a greater understanding of what level of psychological and social support social media provides for young people who visit Martin House.

What are the possible disadvantages of taking part?

Participating in the study may be tiring for your son. The interview should take about one hour. However, if your son would like to stop the interview at any time it will be made clear that it is completely okay for them to do so. In addition, it is possible that topics may arise during the interview that are particularly sensitive or upsetting for your son. If this happens, your son will be asked if they are okay to talk about the topic and be reassured that they do not have to do so.

What will happen if my child does not want to carry on in the study?

Your son is free to withdraw from the study at any time. In order to do so they just need to let any member of the research team know, but they do not have to give a reason. If your son decides to withdraw from the study, any data that your son has provided will be destroyed up until one month after the interview.

What if there is a problem?

The interview will take place at Martin House hospice. If anything happens to your son during the interview at the hospice then you will be contacted. If you have a concern about any aspects of the research you can contact George Peat or one of his supervisors via the contact details below. If you would prefer to speak to someone who is not directly involved in the study you can contact Doctor Paul Marshall whose contact details are also below.

What will happen to the study results?

The research is part of a PhD project. The results will be written up and included in a thesis that will be submitted to the University of Leeds. The results may also be published as part of an article in a research journal or presented as a presentation at a conference.

Who is organising and funding the research?

The research is organised and funded by the University of Leeds.

Who has reviewed and approved the study?

The research has been considered by an independent group of people called a Research Ethics Committee. This study was reviewed by the Faculty of Medicine and Health Ethics Committee at the University of Leeds on the 13/02/18 and was approved.

Thank you for taking the time to read this information sheet. Please also take time to read the other information provided in this pack.

This is your copy for you to keep.

I would be extremely grateful for your assistance.

If you have any questions about the study you can contact the researcher George Peat on hcgwp@leeds.ac.uk.

Or you can contact one of George's PhD supervisors

Dr Alison Rodriguez

a.m.rodgriguez@leeds.ac.uk

Dr Joanna Smith

j.e.smith1@leeds.ac.uk

If you would prefer to speak to someone who is not directly involved in the study then you can contact Dr Clare Harley:

Email c.harley@leeds.ac.uk

7.12 Appendix 5: Carer information sheet



UNIVERSITY OF LEEDS

School of Healthcare Studies

Me, myself, and social media

Information sheet for nurses/carers

(Please keep this copy)

My name is George Peat and I am a School of HealthCare PhD student studying at the University of Leeds. I am conducting a research study that may include young men who are under your care.

What is the study about?

Young men with Duchenne Muscular Dystrophy are a population that have received little attention within research. Social media has been suggested as useful the day to day lives of young men with Duchenne Muscular Dystrophy. This study would like to understand how useful social media might be in helping young men with life limiting conditions manage, develop, and support their identity. It is hoped that as a result of this study health care professionals and organisations will have a better understanding of what helps young men with Duchenne Muscular Dystrophy manage, develop, and support their identity.

What would the study involve for the young person?

The young person will be asked to take part in an interview. During the interview, they will be asked questions about their use of social media.

What will happen to the study results?

The research is part of a PhD project. The results will be written up and included in a thesis that will be submitted to the University of Leeds. The results may be published as part of an article in a research journal or presented as a presentation at a conference.

Who is organising and funding the research?

The research is organised and funded by the University of Leeds.

Who has reviewed and approved the study?

The research has been considered by an independent group of people called a Research Ethics Committee. This study was reviewed by the Faculty of Medicine and Health Ethics Committee at the University of Leeds on the () and was given a....

What would your role in the study be?

The young person may need assistance in communicating during the interview. Or, they may just want someone to accompany them during the interview. Your role would therefore be either helping them to communicate with me, or just being with them during the interview to provide care and assistance should they require it.

7.13 Appendix 6: Consent Form



UNIVERSITY OF LEEDS
School of Healthcare Studies

Project Me, Myself, and Social Media

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| <p>Please confirm whether you agree with the statements by putting your initials in the box below or saying yes or no</p> | |
| I have read and understood the information about the study | |
| I have had the opportunity to ask questions and discuss this study | |
| I have received answers to all the questions I have asked | |
| I have received enough information about the study | |
| <p>I understand that I am free to stop being in the study.</p> <ol style="list-style-type: none"> 1. At any time up to one month after the interview prior to data analysis 2. Without having to give a reason for not wanting to be in the study. 3. And any information collected about me will be destroyed | |
| I understand that the interview I take part in will be audio recorded, and that I can ask for the recording to be stopped, or be deleted, at any point up to one month after the interview. | |
| I am willing for photographs to be taken of any drawings or writing that I produce during the interview. | |
| I am happy to be contacted one week after interview by email for the purpose of adding any comments to the one's I gave during the interview. | |
| I understand that any information I provide, such as my name or other personal details, will be kept confidential, stored securely and only accessed by people carrying out the study | |
| I understand that any information I provide, such as what I say during interview and the photos taken of any drawings or writings that I do, may be written in articles, or on presentations, but any details of me will be protected. | |
| I agree to take part in the study | |
| Participant Signature Date | |
| Name of Participant | |
| Researcher Signature Date | |
| Name of Researcher | |

7.14 Appendix 7: Interview Guide

Interview Guide

Introducing the researcher and the interview

- Introduce myself, talk about my hobbies, interests
- Introduce the interview, so basically I am interested in your experiences of gaming and social media and what they both mean to you. Essentially why are they in your life, why do they matter to you?

Understanding the participant

- Can you describe yourself to me?

Social media activity

- What social media platforms do you use? Facebook, Instagram, Twitter etc. Video gaming?
- . Can you tell me about any particular experiences relating to using social media platforms such as Facebook etc.?
- What platforms do you use the most? Why?
- How do you interact online? Just browse, talk to others?

Social media and the self

- Can you describe to me what social media means to you?
- Do you experience differences in the activities you able to engage in offline and on social media?

Social media and self-disclosure

- What aspects of yourself do you like to share with others on social media?

Social media and accessibility

- How easy is social media to engage with?
- Do you face any challenges to using social media?

Closing interview

- Thank the participant for taking part in the interview.
- Enquire about how they are feeling after interview.
- Invite participant to participate in a follow-up interview.
- State rights regarding the withdrawal of their data.

7.15 Appendix 8: Master table of themes

| Superordinate theme one: Existence outside social media: Navigating the offline world | | |
|---|---|---|
| Sub-Theme | Codes | Example Quotes |
| Being-with others | <p>Education pivotal experience to Being, positive and negative experiences, contrasting accounts</p> <p>Positive; friendship, valuing the self, active social existence, belonging.</p> <p>Negative; bullying, isolation, marginalisation, discrimination, lack of opportunity to build friendship.</p> <p>Isolation after education, lack of opportunity, time spent at home, lack of facilities, lack of disabled access, 'no chances'.</p> <p>Hospice environment one of few spaces to connect, dependent on who they are staying with,</p> | <p><i>"Erm, yeah just cos all of my mates are there, it is the only reason I like school to be honest with ye". Kez.</i></p> <p><i>Well secondary school was just awful erm like we were so isolated as well like. Like everyone with either summet wrong with them or anything like that went on a different break always and I think it all stems back to that really". Tom.</i></p> <p><i>"Whereas I know other lads who are in the same situation as me, but they've got no friends because they've had no chances..." Mohsin.</i></p> <p><i>"I don't go to college anymore, I am just at home". Craig</i></p> <p><i>"Social animal". Mark</i></p> |
| Factors that influence perceptions of Being | <p>Differing opportunity, purpose, fulfilment, funding support, belonging, meaning, valued skills, short lived, shut down, lack of funding, facilities,</p> | <p><i>"I used to play for them but they have no ambition and just wanted to play for fun. But this team actually play for winning. So then I moved to them". Mark.</i></p> <p><i>"Ever since I was little I have always really like Martial Arts. And I used to go to a youth club, which was just like to meet other lads with similar conditions, ye know that have got muscular dystrophy. But underneath the youth club was a boxing gym. And I used to sneak off downstairs</i></p> |

| | health, loss of opportunity, contrasting accounts, | <p><i>and watch them train. And a few times they used to, I used to make comments when they were training like ye doing it wrong. Or you've got too much weight on one leg. And on one occasion the trainer actually said to me I know what I am talking about". Mohsin</i></p> <p><i>"It shut down years ago". Mohsin.</i></p> <p><i>"I was going to get into it...that was just before I was ill. So now I don't think I could do it like" Tom.</i></p> |
|--|--|---|
| Superordinate theme two: Transcending into an alternate reality; Life within gaming | | |
| Sub-theme | Codes | Example Quotes |
| An altered sense of Being | An alternative space, immersion, transcendence, beyond normal experiencing, altered Being, expansive spaces, experiencing the previously unexperienced, making salient traits of self otherwise suppressed, purpose, leadership, role responsibilities | <p><i>"And I got so into that world it was amazing". Mohsin.</i></p> <p><i>"Like in games I can do stuff that I wouldn't be able to do in real life and stuff, so it's just a bit escapism I think, from just, life really". Simon.</i></p> <p><i>"I always say to my mum and dad if I was able bodied, I would be an MMA fighter. I would be in martial arts, hence that's why I play a lot of Tekken". Mohsin.</i></p> <p><i>"It's like I just find it amazing that you can go wherever you want...". Lee.</i></p> |
| A questioning of Being through gaming | Questioning of offline Being, how would I be if? Ability to transcend leads to questioning of Being, walking, driving, characters, comparing the self. | <p><i>"Yeah would I drive like I do on GTA and do the stuff I am doing in the game. Ye know what I mean that's the thing. Cos in my case I have never been able to walk. Ye know what I mean I have never had that. So there is always that thing of what would I be like if I could walk?" Mohsin.</i></p> <p><i>"I just think I would love to be some of the characters that I am in the games and stuff. I just think ugh, probably because their life is a bit more exciting than mine ye know what I mean. It's quite hard for me to explain but yeah". Simon.</i></p> |

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| <p>Gaming as cathartic; A welcomed intrusion</p> | <p>Cathartic, coping mechanism, venting frustration, anger. Making sense of emotion, releasing stress, cleansing the self, removal of emotion that is harmful to wellbeing</p> | <p><i>“Yeah so it started from there really, and I kind of used it (gaming) as sort of a coping mechanism as I got older. Mainly because as a kid I was confused, I had a lot of anger, ye know about myself and the position I am in. I just didn’t understand why, so I used Tekken (game) as a way to vent out my frustrations”. Mohsin.</i></p> <p><i>“Well I think like for Xbox it is a way of like sort of taking out my stress and stuff”. Simon.</i></p> <p><i>“Yeah it is (emphasis), cos like, I suppose some games where you can get quite involved, like angry at so it is quite a good way to like get rid of anger as well”. Tom.</i></p> |
| <p>The importance of gaming to Being; an enforced companionship</p> | <p>Consistent presence of gaming, eternal, grown up with gaming, ‘since forever’, companionship, closeness to gaming, occupies daily Being, enforced, lack of opportunity outside of gaming, restricted opportunities, ‘nothing else to do’, evolvment of companionship, less reliance over time, vicious circle.</p> | <p><i>“Well I have been gaming forever really, like as young as I can remember really I have always played it” Tom.</i></p> <p><i>“Mm about 6 (hrs) from whatever time I get up till when I go to sleep. Sometimes it can be like more than 6 but on a regular day, it is normally 6”. Lee.</i></p> <p><i>“I mean you don’t understand if you’ve got a disability, and you’ve got an overprotective family, that don’t let you play out because they are scared that you are going to get hurt, or ye know, or that you are going to get picked on, or ye know, ye not going to fit in, the only thing you can do is gaming”. Mohsin</i></p> <p><i>“If I could, I would not just game, if I could get out and do all that stuff I would hardly ever go on my Xbox”. Tom.</i></p> |

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| <p>Gaming as a fragile reality; A persistent intrusion</p> | <p>Blurred realities, blurred concept, intrusion of body onto online reality, immersion intruded upon, lack of strength impacts game play, experienced through the other, life without gaming, lose the plot, annoyance, frustration, anger, charities, accessible technologies, customisation, aiding ability to remain immersed, resilience, perseverance.</p> | <p><i>Whereas like Red Dead Redemption, and for like when you have to slow time down or like track animals I can't press both analogue sticks in. So I am a bit stuck there so it's sort of hindered me playing a game to like its fullest ability cos I can't do what's quite important in the game".</i> Tom.</p> <p><i>"Honestly it was the best thing ever, he is the best player I have ever seen play. And then recently he lost the ability to use his fingers. And I thought if that happened to me, I would probably lose the plot".</i> Mohsin.</p> <p><i>"Yeah well the company that I know are called Special Effects, they are a charity, and what they do is help people with disabilities, they will talk to ye, ask you what the problem is, ye know and what needs doing, and they will take the controller, and they will try and customize it for you. To help you out".</i> Mohsin.</p> <p><i>"Well I can't do it anymore".</i> Craig.</p> <p><i>"No, well I struggle to use the controller so".</i> Mark.</p> |
| <p>Superordinate theme three: The meaning of social networking platforms, blogs, and spaces</p> | | |
| <p>#DMD; group identity, autonomy, and making the other aware</p> | <p>Group identity, belonging, ownership, sense of togetherness, assistance others, aiding others, autonomy over health decisions, making the other aware, lack of accessibility, importance of signposting online groups/pages.</p> | <p><i>"Well I'm on a DMD...my disability we've us own pathfinders group. Yeah so we chat to one another ye know if people have problems like ye know to do with ventilators or....they will put it on (the group) and everybody will comment on it and yeah we just discuss whatever".</i> Mark</p> <p><i>"Yeah connecting to other people. Actually (emphasis) interacting with another person, that you can feel helpful towards that other person..."</i> Mohsin.</p> <p><i>"And yeah if there is anything I feel strongly about I will talk about it (online) ye know what I mean if it is something about my life like with my disability and stuff I do often voice stuff".</i> Simon.</p> <p><i>"I mean I don't know I've tried to like research other people with disabilities but it comes up with nothing really" Tom.</i></p> |

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| <p>Online blogging; A variation of meaning</p> | <p>Varying meanings, individual differences, raising awareness, conveying to the other the experience of living with a NMC, personal disclosure, emotion bottled down, masculine expectations, anonymous, prioritisation, lack of time, blogging lacks purpose, inaccessible space.</p> | <p><i>"I have been thinking about maybe doing that. To just talk about my life, and for awareness, I definitely am thinking about doing that. And I might do a bit about university cos I know there is people that might be scared to because of their disabilities and stuff and I just want people to know what it is like". Simon.</i></p> <p><i>"No I keep stuff bottled down I always have". Mohsin.</i> <i>"(pause) I thought about doing like an anonymous thing". Mohsin.</i></p> <p><i>"No it's a...I can't waste my time on it. That's what I think to be honest. Instead of talking about it I would rather do". Mark.</i></p> <p><i>'No I don't wanna' Craig</i></p> <p><i>"But it is just annoying cos like I know that I would get on with a lot of people but it is just I don't really know what to go on, like to talk to people on blogs and stuff like that I've got no idea of the first place to start really so". Tom</i></p> |
| <p>Online blogging as a process towards the acceptance of self</p> | <p>Purpose, championing Duchenne, making sense of condition, helping others, opportunity, writing as duty, sharing life</p> | <p><i>"I think in a way I was hiding behind that, so I think that pushing myself to write was quite a stressful and scary thing for me, but I think that was necessary for my growth really and accepting yourself because on the internet anyone can read your blogs so it was a bit of a scary moment but a really good moment". Zahid.</i></p> <p><i>"...a lot of parents are like oh I've read your blog and my son is struggling and its helped them, and so that kind of helps me in a way because kind of you realise there is a lot more people out there that are silent so I think writing is my duty in a way because if sharing my life is going to help other people you kind of get more motivated." Zahid</i></p> |
| <p>Seeking a sense of belonging within online spaces</p> | <p>Fitting in, being part of something, finding others through gaming, friendship,</p> | <p><i>"Just play the game and then end up finding them in the game, their doing something that I liked or something then I say something about whatever, then we end up becoming friends that way. So started off becoming friends with one person then meet all his friends". Lee</i></p> |

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| | <p>community, belonging, shared interests, changing narrative, finding likeminded people, connecting with others over interests, YouTube, attend to interests, staying up to date, belonging online less important to others, observing preferred to connecting.</p> | <p><i>“Watching it, reading the mags, watching them on TV mainly, and then when Facebook came out, they’ve got their own page, and you find likeminded people that are into the same stuff as you ye know it’s good cos in the past I wouldn’t have had no one to talk to about it”.</i> Mohsin</p> <p><i>“I watch a lot of YouTube channels, like who do loads of updates about new games coming out and stuff like that”.</i> Mohsin.</p> <p><i>“So I know what is going on basically...having a look yeah...seeing what is going in the world...just seeing what people are up to...not connecting just seeing”.</i> Craig</p> |
| <p>Revealing the self online</p> | <p>Disability ‘picked up’ by others, restricts online Being, discriminative discourse, treading carefully, disclose disability to only those they trust.</p> | <p><i>“Yeah I would say so. With erm, I can’t really, nothing really specific has happened with me but I just think there is a lot of like, if you’ve got a disability or anything people will sort of pick it up on that bit ye know what I mean”</i> Simon.</p> <p><i>Yeah but also what’s annoying is I can get on with anyone, and sometimes it is nice just to talk to people who aren’t disabled. Ye know what it mean it’s just like cos you are disabled you can only talk to other people who are disabled.</i> Tom</p> <p><i>“But obviously they do know that I am in a wheelchair and stuff like that. That’s kinda like, I try get to know people for a few weeks before I tell them that I am in...because obviously some people don’t get that and then they kinda make a joke out of it and stuff like that so I just want to make sure that I can kinda tell the type of person that would do that for instance and then when I feel confident that they are not I will tell them”.</i> Lee.</p> |

