

**The experience of caregivers supporting adults with intellectual disabilities during
hospitalisation: a qualitative study**

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Psychology and Neuroscience

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ATTESTATION OF AUTHORSHIP

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

Emma Fuller

10th November 2022

DEDICATION

I dedicate this dissertation to my wonderful mother, gone too soon.

Linda Nolene Fuller

1964-2021

A lover of life, and generous woman, with a positive attitude, who believed anything was possible.

So much of who I was, who I am, and who I will be, both personally and professionally, is because of you.

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ABSTRACT

This study aimed to explore the lived experiences of caregivers supporting adults with intellectual disabilities (ID) during hospitalisation within Aotearoa.

Whilst there has been research that has examined the hospitalisation experiences of caregivers supporting adults with ID internationally, there has been little research undertaken in Aotearoa within this context. Identifying caregivers' experiences of whether caregivers have been adequately supported during hospital stays supporting their adult with ID, and establishing what worked well and what did not work well, is a crucial element to understanding whether the caregivers were overwhelmed or had insufficient support at any point of the hospital stay with their adult with ID in Aotearoa.

This study utilises a qualitative methodology as it enabled lived experiences to be shared, which will help to determine what services within the Aotearoa hospital system are necessary to better support this population in the future. Caregivers of six adults with intellectual disabilities were interviewed using semi-structured interviews. Transcripts from these interviews and thematic analysis have been used to identify key themes.

The findings discovered the increasing reliance placed on caregivers of adults with ID whilst in hospital. These were highlighted through the interdependence within the themes developed in this research; advocacy, environment, lack of support, lack of awareness, interpersonal care, informed consent, communication, health experience and sense of abandonment.

This study broadens the body of knowledge through understanding the challenges caregivers face. Caregivers involved in this study were predominately family caregivers, therefore non-qualified, supporting findings that they are involved in processes beyond their personal competencies. The findings highlight that caregivers experienced insufficient support whilst supporting their adult with ID when in hospital in Aotearoa. This study can be

used to show awareness of the challenges that caregivers face in Aotearoa, with further research looking into how these challenges can be addressed. Future research needs to consider the use of artificial intelligence and technology advances that provide assistance with advocating, communication, and supporting ID adults, thus relieving their caregivers of some of these burdens. This is expected to provide positive outcomes.

CHAPTER ONE: INTRODUCTION

Intellectual Disability (ID) is presently one of the common developmental conditions affecting many people in different parts of the world (IHC New Zealand, 2017). Intellectual Disability (also known as intellectual developmental disorder) is a significant impairment in general cognitive functioning, social skills, and adaptive behaviour of a person; resulting in significantly sub-average general intelligence consisting of an intelligence quotient of 70 or less (American Psychiatric Association, 2013). Intelligence scores are commonly used to determine the severity of ID and have life-long implications for a person's development in all areas of functioning (Patel et al., 2018). It may be challenging for people with intellectual disabilities to tackle new problems or make practical judgements. Additionally, they can be unable to learn or think clearly and be lacking in the necessary skills to support their adaptive behaviours (Koenderink, 2018).

Maulik and colleagues (2011), discussed the prevalence of intellectual disability across the world as being around 1%. In comparison, in Aotearoa, 2% of the total population have an intellectual disability (96,800 people) (Statistics New Zealand, 2013). Adults with intellectual disabilities aged 15 – 44 make up 3% and those over the age of 45 with intellectual disabilities making up 1% of the adult population (Ministry of Health, 2011).

Demographic Trends

As with the general population (Brown, 2015), the life expectancy of people with ID has increased substantially during the last century (Ministry of Health, 2012). Indeed, the gains in life expectancy for people living with ID has been greater, and has occurred more recently and even more rapidly than the non-ID population (Patja et al., 2000). People with ID are now surviving longer than previously anticipated, and the population's ageing appears to be comparable to that of people without ID (Patja, et al., 2000).

The most common causes of ID are genetic conditions (Keskinova & Ajdinski, 2018). As an ethnic group, Māori and Pacific people make up 8% of the Aotearoa population (New Zealand Foreign Affairs and Trade, n.d.) and are known to have higher than average disability rates in comparison to other ethnic groups in Aotearoa (Statistics New Zealand, 2013). In Aotearoa there is access to free healthcare in public hospitals, making it more likely and easier to seek a diagnosis of ID. The fact that those with lower socio-economic status's are more likely to receive the diagnosis of 'intellectual disability' has drawn greater criticism, as well as ethnic, and racial, cultural minority groups (Bray, 2003), contributing to the variability in prevalence estimates (Larson et al., 2001).

Who are the caregivers?

The majority of people with an intellectual disability live satisfying and happy lives. However, those adults with severe intellectual disability, may need caregiver support to develop new skills of communication and ability to understand complex information. A dyadic process, or an interdependent interaction between caregivers and care-receivers, is the foundation of caregiving. The intricate exchanges that make up the dyadic connection can be demanding and unpleasant for both the caregiver and care-receiver (Lyons & Lee, 2018). Those adults with higher disability levels, who require caregiver assistance, have both unrecognised and unmet needs, requiring the vital help of caregivers. It can be stated that the Aotearoa health system depends heavily on caregivers to provide appropriate support for adults with ID (Ministry of Social Development, 2018).

Within Aotearoa it is estimated that one in ten people provide care for adults with ill health or intellectual disability (Ministry of Health, 2022). These caregivers are most likely to be between the ages of 50 and 54 years, providing an average of 30 hours or more per week of care (Ministry of Social Development, 2018). Caregivers provide a critical role in enabling

people with ID to live and participate within their communities (Ministry of Social Development, 2018).

Role of caregivers

Caregivers are crucial to a functional society. They enable those who have additional needs to develop, live and participate within their communities with greater independence, autonomy, quality of life and social inclusion (Lyons & Lee, 2018). Caregivers enable the caring of the day-to-day needs of adults with intellectual disabilities, such as bathing, feeding, and interacting with the patients (Moghimi, 2007). However, in practise, caregivers are also expected to perform more challenging duties including housework, laundry, exercising patients, shopping, and entertaining adults (Ravenswood et al., 2014). However, a caregiver's main responsibility is to help those in need, giving caregivers a sense of satisfaction and reward (Chen et al., 2013).

Role of parents as caregivers

Within the population of intellectually disabled adults, reliance on family to be their advocates and communicators, and look after their daily needs is imperative for their day to day living (Charles, 2020). Parents with intellectually disabled adult children carry the weight of care that has been put in place as their role as parents (McCormick et al., 2020). Few studies have indicated that parental roles of adults with ID within healthcare settings are used to enhance healthcare professionals response to the patients' health, and as a result, the experiences of stress and burden that had been put on these caregivers of adults with ID are evident (Rapanaro et al., 2007).

While the role of professional caregivers (palliative care, aged care, disabled care) and family caregivers can have different titles, these differences will be discussed in more detail later in the report. However this study mainly focuses on experiences of family as caregivers,

with further research of professional caregivers within Aotearoa to be addressed in future research.

As children with intellectual disabilities reach adulthood, they face unique challenges navigating the healthcare system. One overseas study, conducted in Switzerland, shows that health professionals are not yet trained in how to manage and identify the specific health needs of this population (Raimy & Paignon, 2019), and medical schools are just initiating the training of physicians now in the management and treatment of patients with ID and their caregivers (Raimy & Paignon, 2019).

Thus the need for a better understanding of the lived experiences of caregivers supporting adults with intellectual disabilities when in hospital and the issues they encounter during hospital stays is of high importance. This understanding therefore will be able to determine what services hospital systems in Aotearoa need to provide for caregivers of adults with ID in the future. The limited published research in Aotearoa does not address the experiences of caregivers supporting ID adults, specifically in hospital or as outpatients. Traditionally, research within Aotearoa has concentrated on the experiences of children or adults with ID, with little consideration of the effects on the caregivers and their perspectives, highlighting the relevance and importance of this research study.

Given this, the objective of this study aims to explore the lived experiences of caregiver's supporting intellectually disabled adults. A qualitative methodology was selected as it is the most suitable approach to attain a thorough interpretation and understanding of the experiences of caregivers when supporting their adult with ID whilst in hospital within the Aotearoa context. Particularly, this study design has utilised thematic analysis, a qualitative data analysis framework, developed by Braun & Clarke (2006), to analyse the interview transcripts to identify themes and patterns within the qualitative data.

Semi-structured interviews have been used for interviews with family caregivers supporting adults with intellectual disabilities. The format of semi-structured interviews allows open ended responses from participants and provides more in-depth information than a structured interview format. Recruitment has involved between 6-10 participants, over a 3-month period until theoretical saturation was reached.

Researcher's Interest in the topic

I have developed an interest in caregiving as a result of professional and personal life experiences. I grew up with a terminally ill mother who required full time care during her treatment, of which I was the sole caregiver for her while also completing my studies. I came to learn of the hard and busy nature of work as a caregiver, however I thoroughly enjoyed being able to be with her and provide the support that she constantly required. I then got a position working with intellectually disabled adults by running a community group for a group of them to come together and interact. While the job was stressful at times, it provided me with happiness and I felt like I was doing something worthwhile, building life-long rapports and friendships with many of the adults that I cared for. Throughout this period of my life, I came to realise just how overlooked caregivers are. If I didn't provide the daily support for my mum or weekly community groups for ID adults to gather together, they would not be able to function appropriately. I found that the lack of recognition and respect for caregivers was wide and disturbing. It was then that I began researching the issue and realised that while literature has examined caregivers' experiences overseas, there is little research on how caregivers feel and the experiences they face in Aotearoa. This made me realise that this required further research.

Researcher's Presumptions

As mentioned, I have previously worked with adults with ID for some time and therefore I have an understanding of the issues caregivers face. Firstly, I am aware that the role

of a caregiver can be frustrating and often stressful. Secondly, I am also very aware that the role of a caregiver can be a very busy one, and that because of this, caregivers are often left feeling exhausted. Finally, I am very aware that all caregivers take on these roles because they enjoy it, with family caregivers providing care for a lack of financial reward. For the purpose of the interviews in this study, it was decided that I would not disclose my previous experience in this field in order to ensure reliability and remove bias, allowing participants to explain things in their own detailed way.

This introduction has outlined the purpose of this study with a brief introduction to the methodology and the study's context. Additionally, it emphasises the researcher's interest in the subject and analyses any presumptions the researcher may have made. A literature review will follow, presenting a thorough background summary of overseas experiences of caregivers of intellectually disabled adults which will provide a larger overview of the topic internationally, and allow comparisons to be made within the Aotearoa setting.

The following chapter provides a comprehensive description of the methodological approach of thematic analysis, data collection processes, and ethical considerations within this study. The results section will provide an in depth description of the themes identified through thematic analysis with supporting quotations from the interview transcripts. Concluding with, a discussion of these results is conveyed in the context of the literature, and within the field of caregivers supporting ID adults in Aotearoa. This will identify potential limitations, future recommendations for researchers, clinicians and the wider hospital systems within Aotearoa.

CHAPTER 2: LITERATURE REVIEW

Intellectual Disability is a significant impairment in general cognitive functioning, social skills, and adaptive behaviour of a person, limiting them with significantly sub-average general intelligence, and an intelligence quotient of 70 or less (American Psychiatric Association, 2013). Most epidemiological surveys generally categorize the severity of intellectual disability as mild ($IQ \geq 50$) or severe ($IQ \leq 50$) (Patel et al., 2018), with people who have severe intellectual disability usually requiring life-long intensive supports. Every intellectually disabled adult is affected in a different way through not being able to communicate their needs and wants, not being able to describe their experiences, symptoms or what they are feeling, or use behaviour to communicate their distress.

There are two forms of caregiving, known as family caregivers who take on the role of caregivers for family members who have become ill, including tasks such as advocacy, decision making and emotional support (Hudson et al., 2010). The other, is non-family caregivers who are often known as professional caregivers who work in residential care or in health and disability sector. Both caregiver roles have stressful aspects, but it also has positive aspects such as the caregiver feeling useful and appreciated in knowing they are making a difference to the well-being of their patients (Pinquart & Sorensen, 2003).

A caregiver's key role is to help to make a difference in the patient's care by being reliable, supportive, and sensitive to the patient's physical and emotional well-being. Studies have shown that working conditions of caregivers are characterised by long hours, heavy work demands and low pay (Badkar et al., 2009), while also being impacted by communication issues between patient and hospital staff (Walsh et al., 2011), advocating for the patient (Charles, 2020), and the economic impact (Schultz & Eden, 2016). All of which have shown to impact the physical and mental health of caregivers (Schulz & Sherwood, 2008).

Whilst there is limited research addressing the caregiving arrangements and caregiver's views on hospital care of intellectually disabled adults in Aotearoa, there are some international studies which have explored different aspects of this topic. The purpose of this chapter is to examine how the current overseas literature views caregiver experiences, as well as identifying any gaps in the research. This chapter discusses the lack of communication and advocacy that caregivers overseas are experiencing. Followed by the lack of support and economic impacts which appears to result in physical and emotional distress of caregivers, from past overseas literature. Included in this review is the reliability of these international studies, leaving a summary of the research gaps that have been identified in the process, and why this study is important for future literature.

Communication

Charles (2020), which was a study on the communication experiences of family caregivers of hospitalised adults with intellectual and developmental disabilities, identified four main overarching themes related to family members when their loved ones with ID were hospitalised; the need for advocacy, the need for better communication, sense of abandonment, and lack of confidence. The lack of communication between health professionals, ID adults, and caregivers, was evident through health professionals not asking questions about the patient's level of communication or functioning (Charles, 2020), leading to reported miscommunications and instances of mistrust with hospital professionals' competence to deliver quality patient care (Charles, 2020). The result of this lack of communication between health professionals and ID adults was highlighted by Walsh et al., (2011); discussing the negative impacts that this had on patients with ID and caregiving participants in their study. Caregivers in this study were asked about the methods that they had seen health professionals use to determine the extent of the patients' pain, with results concluding that the majority of health professionals based and relied their assessment of pain of the patient on what the

caregiver told them (47.3%) (Walsh et al., 2011), which Charles (2020) associated with poorer patient outcomes and an increased likelihood of rehospitalisation.

Caregivers talked openly about always having to be vigilant and constantly at the bedside of the adult with ID (Charles, 2020). Caregiver participants reported that staff made assumptions about the patient's with ID; presuming that they were more limited than they were (Charles, 2020). Comments were made from caregivers about health professionals not addressing the appropriate needs of adults with ID, such as not administering medication on time, and assessments being inadequately performed, as well as misinterpreting patient cues, leading to distress for the patient with ID and the caregiver (Charles, 2020). Depending on the severity of ID of the patient, Patel et al., (2021) reports how patients could not understand the term 'Covid-19' which with the lack of communication as discussed by Charles (2020) and Walsh et al., (2011), led to instances of poor social isolation, lack of distancing, poor hygiene and not understanding how to wear masks and conduct appropriate handwashing. This identified the potential lack of specific training on how to communicate with and support patients with ID (Doherty et al.,2020) and led to caregivers having to inform hospital staff about medical conditions of people with ID; implying the significance that appropriate communication with caregivers is crucial (Larkin et al., 2018) in improving patient safety and satisfaction and ensuring that adults with ID are not negatively impacted (Patel, et al., 2021). Consequently, the potential higher risk of infection for caregivers during Covid-19 with a lack of understanding from adults with ID and potential non-compliance of social distancing and hygiene, resulted in heightened anxiety for some of the caregivers during this time (Chadda, 2014).

Lack of support

The lack of support of caregivers was a common thread highlighted by Charles (2020). Similarly, from Patel et al., (2021) caregivers identified having a lack of support and communication from stator services, often resulting in being left to cope alone.

In the absence of an adequate mental health infrastructure, the caregivers take multiple roles in providing care for persons with mental illnesses, incorporated within other regular family responsibilities (Chadda, 2014). Mothers caring for a child with ID similarly reported feeling abandoned by professional services during the first lockdown restrictions (Rogers et al., 2021). Nonetheless, some caregivers made special mention of their appreciation they had received from other sources such as friends and family (Patel, et al., 2021).

Charles (2020) recorded delays in the emergency departments and inattention to patient and caregiver needs. This compounded the patients' anxiety and behavioural problems, leaving them with a sense of abandonment and lack of support. Extended periods of waiting led caregivers to believe that staff were not tailoring patient care for adults with ID; interpreting delays as neglect, and being taken advantage of as they were compelled to stay at the bedside, even though the caregivers reported feelings of exhaustion. A lack of confidence in medical professionals' abilities for caring for adults with ID was expressed by caregivers due to a lack of communication during hospital stays. There were complaints relating to medications, assessments and nursing care and issues of compromised patient safety, with the consequence of caregivers having the view that the inadequate experience of hospital staff was a lacking of care and knowledge, which Patel et al., (2021) discussed whether other people were fully aware of or appreciated the challenges that caregivers of adults with ID confronted.

Furthermore, caregivers were often left feeling isolated and afraid for their adult with ID as the care received was not equitable compared to the care that other patients were perceived to be receiving. This resulted in the perception that some hospital staff were biased and uncaring. It is observed from Charles (2020) that there was frustration and role confusion

for the caregivers where nurses had the expectation for them to perform nursing duties such as providing direct patient care, toileting, feeding and close observation to prevent them from pulling out medical devices. Clearly, caregivers are untrained to perform these tasks. Their interventions could have led to negative outcomes, although some were expected to provide care, others were completely disregarded, resulting in a negative emotional and physical impact on caregivers.

Economic impacts

National surveys show that many family caregivers reported financial strain associated with their roles as caregivers and their families (Spillman et al., 2014), suggesting that there are important economic effects of taking on the caregiving role (Schulz & Eden, 2016).

Caregivers of ID adults can suffer significant financial consequences with respect to both direct out-of-pocket costs and long-term economic and retirement security (Schulz & Eden, 2016). This often means that due to the demands of caregiving required, there are fewer opportunities for caregivers to be in paid work (Ministry of Health, 2022), other than those who are professional caregivers, where caregiving is seen as a low-skilled and undervalued job (Martin, 2007) resulting in a substantial number of people not being able to stay in the work force and jeopardising their income (Schulz & Eden, 2016). Literature identifies that work involving caring pays less than any other kinds of work (England & Folbre, 1999). This is thought to be related to the gender gap in pay (England & Folbre, 1999) where there are more women than men that do caring work (Ravenswood & Markey, 2017). In Aotearoa 92% of the caregiving workforce is female (Ravenswood et al., 2014).

Extra costs associated with caregiving, such as special foods, medications, incontinence products (not always funded), extra heating, petrol and hot water have also been discussed as an extra financial burden for family caregivers with an adult with ID living at home (Jorgensen et al., 2010). The importance of this and the need for greater resources to adequately support

this group of caregivers is vital (Jorgensen et al., 2010) as it is evident that family caregivers are undervalued and under provided for in this way.

Professional and family caregivers

Frustrations from family caregivers were emphasised about the caregivers themselves not being heard or included in information sharing and decision making as caregiver's felt they had a wealth of information to share. Family caregivers are considered experts on their family members, having an in-depth knowledge of patient needs; therefore, they have the ability to advise and support hospital personnel (Tuffrey-Wijne et al., 2014) however caregivers felt that this was not facilitated (Charles, 2020). For patients with ID, who generally have communication challenges, communicating with their caregivers is crucial (Tuffrey-Wijne et al., 2014) and improves patient safety and satisfaction. However, as Walsh et al., (2011) emphasised, caregivers perspectives should not be relied on solely.

Contrastingly, professional caregivers discuss their experiences within the medical system when supporting an adult with ID (Mastebroek et al., 2016). Professional caregivers saw that by combining their own observations of behaviour and mood of an adult with ID, as an important strategy for recognising the health needs of the adult with ID. In addition, caregivers mentioned that by having built a trusting relationship with the adult with ID, the retrieval of information from the adult with ID about their health needs was more forthcoming than it was with an unfamiliar health professional that the adult with ID did not know, increasing the need for the caregivers constant attendance (Mastebroek et al., 2016).

Professional caregivers discussed their supporting role in helping to mediate conversations by comforting their adult with ID, initiating conversations, giving communication advice and by coaching the adult with ID when information was withheld (Mastebroek et al., 2016). The professional caregivers were able to create a space for the patient

to be heard, redirecting the conversation back to them to check that they understood what was being said by the health professional and interpreting the information as required.

This research focusses mainly on experiences of family as caregivers through the participants recruited, however further research could be conducted in the future of external professional caregivers in Aotearoa.

Validity and Reliability of past literature

The research for the study (Charles, 2020) was completed in an accurate way with bias being minimised through an ordered and scientific methodology completed, which allows false conclusions and potentially misleading statements to be prevented (Simundic, 2013). It is key to note that the literature discussed had some restrictions such as the participants involved in the studies were primarily caregivers experiences within the United States and overseas, not including Aotearoa. Therefore these results may not align with caregiver's experiences within the Aotearoa hospital systems. The previous literature reports discussed were not global studies, therefore climate or environment factors may also have had an impact on the results. For example, the Charles (2020) study was completed in the United States where their healthcare system is known to be the most expensive in the world (Kashef, 2016). Therefore, the participants in this study could have had more of an economical advantage in comparison to other countries around the world, and therefore gaining insight into whether this research data aligns with caregivers experiences in other countries, including Aotearoa, would need to be explored.

Specifically, there was very strict criteria that all participants had to fit within all literature discussed, creating a smaller sample size, which reduces the validity of the study (Faber & Fonseca, 2014) as it may not be as accurate to the wider population outside of their respective countries.

There is some Aotearoa literature explaining the economical strain that is evident in the population of caregivers of adults with ID (Jorgensen et al., 2010), as previously discussed, however it will be interesting to determine whether there is an economic impact on the experiences of caregivers of adults with ID within this research.

Rationale for study

The experiences of caregivers in general and caregivers of ID adults are frequently unnoticed in research to date. As models of caregiving through current literature experience tend to be of family acting as caregivers have identified negative experiences that caregivers have had with their intellectually disabled adult (Gibbs et al., 2008). External caregivers have discussed similar challenges (Mastebroek et al., 2016).

The limitations of different health services, economic differences and inequalities amongst different populations (Schutte,2018), of applying worldwide literature to the Aotearoa context clearly identifies the rationale for further research of these issues.

Hence through this study, it is proposed to explore the experiences of caregivers of intellectually disabled adults during hospitalisation in more detail within the Aotearoa context, and further determine whether the reported international experiences and barriers align with experiences from caregivers of ID adults in Aotearoa so that adequate support can be provided for this population if needed in the future.

CHAPTER 3: METHODOLOGY

The qualitative approach for this study used semi-structured interviews, focusing on the lived experiences of caregivers of adults with ID when in a hospital environment. It attempts to understand and have some perception on the experiences of caring for adults with ID during their hospitalisation in Aotearoa. A qualitative research model is more suited for this study with the process of gathering, analysing, and interpreting non-numerical information (Silverman 2021). This allows the real life encounters of the Aotearoa hospital system to be explained through the lens of a caregiver supporting an adult with ID. This chapter will discuss this research methodology, data collection and analysis methods in more detail. It will evaluate the reliability and validity of this research.

Participants

To have been considered for inclusion into this study, participants must have been a support person or caregiver for someone diagnosed with an intellectual disability (defined as having a Full Scale IQ (FSIQ) score that is below 80), that had been hospitalised in the last twelve months.

The participant must also have had the access to the appropriate computer, tablet or phone to be able to participate in an online interview.

People who were invited to participate in this study must have also had to fulfil the following criteria:

1. Being able to read and write English sufficient to understand the Informed Consent process (Appendix A, B) and complete the Participant Information Sheet (PIS) (Appendix C).
2. Being able to engage in conversational English to participate in an interview.

Sampling Method

Participants were recruited into this study through social media advertising, snowballing recruitment, researcher's networks, and community groups that support people with intellectual disabilities. The snowballing sampling method involves research participants recruiting other participants for the study (Kirchherr, 2018). This is helpful in a qualitative study, due to caregivers of ID having involvement with other such caregivers (Crouse & Lowe, 2018) enhancing the qualitative research and the population of caregivers which in turn broadens the overview of experiences of caregivers supporting adults with ID.

Ethical Considerations

The ethical application for this study was approved by the AUT University Ethics Committee on 4th July 2022 (Appendix D).

The study structure identified that confidentiality and autonomy could not be certain at all times due to the nature of online interviews, nonetheless, confidentiality was maintained throughout. When specific quotes are used in the report, the participants are given numbers instead of names to also maintain confidentiality. This was supported by deleting any data/information that could identify the participants from the transcripts. It was also emphasised in the consent process at the beginning of the interview, that participants had the choice of having any identifiable data being removed or allowing it to be continued to be used.

The aspect of participant safety, prevention of harm, and respect of privacy underlies all research. Smith et al., (2009) emphasised the significance of acknowledging that discussing sensitive information might make participants feel ashamed, emotionally uncomfortable, and potentially angry, through qualitative research, despite it being unusual in quantitative research,. Participants shared their perspectives on how taking care of an adult with ID puts them at risk for vulnerability. Particularly when they are discussing difficult or private issues. By controlling how much information they share, participants can reduce the chance that they

will feel exposed as a result of over-disclosure when using a qualitative methodology (Simundic, 2013).

Informed Consent

Informed consent was provided by each participant who participated in the study using an online platform Qualtrics. This was reconfirmed at the time of contacting participants and at the start of each interview. Information about the study was provided to each participant in both written and electronic format, through a Participant Information Sheet (PIS) (Appendix C), and discussed at the beginning of each interview to confirm that the participant understood the study. Each participant was made aware and had agreed to their consent being recorded (Appendix A and B) at the beginning of every interview.

Participant safety was achieved by reassuring participants in the PIS and at the beginning of the interview that they were able to withdraw or pause the interview at any time. This would not be a disadvantage in any way, and their information shared would be removed.

Recruitment Process

Recruitment of potential participants was completed through approaching networks and support agencies, using email advertisement and social media links. Participants have not been contacted by the researcher directly. Participants having accessed the PIS, appropriately consented to participate and provided their contact details for contact.

The email invitation sent to potential participants (Appendix E) contained the participant information sheet (PIS) as an attachment and link to the study survey site. Access via the website link in the email, led to a digital PIS, and a consent form where they were able to consent to participate in the study if they wished too. Participants who were comfortable with an interview process, interview dates and times were scheduled to best suit them.

Interviews

Interviews were conducted over Zoom. Semi-structured interviews were conducted with caregivers supporting adults with ID during which time theoretical saturation was reached with six participants. Interviews lasted between 30 to 40 minutes. The use of semi-structured interviews allowed flexibility between researcher and participants with questioning and the direction of the interview through participant responses. This resulted in more in-depth information than a structured interview format would provide (Cohen & Crabtree, 2006). The research questions were open-ended to encourage participants to express their experiences. The interviews were recorded and transcribed by the researcher through the Welder Transcription software programme.

The interview consisted of four initial written questions (Appendix F), however were adjusted depending on the participants' responses. The interview protocol was constructed to produce caregivers of ID adults' perspectives for example, their feelings, thoughts, and experiences when supporting their ID adult when in hospital. Direct questions were not always asked, with discussion based around what the participant felt comfortable sharing.

In-depth interviews require developing rapport, which is a crucial step. Gaining the participants' trust creates a relaxed, safe environment in which they can freely discuss their experiences and attitudes during the interview (DiCicco-Bloom, & Crabtree, 2006). This is why at the beginning of the interview the researcher spent time focusing on the participant, by smiling and allowing a personal connection to develop. General questions like 'how have you been?', and 'how was your day?', as well as the researcher having a soft, approachable and professional demeanour allowed the interaction between the participant and researcher to develop. The researcher also thanked the participant for their time up front so that the participant could feel appreciated. Questions were used as a guideline and were not necessarily asked word for word.

Recorded interview transcription process

On completion of interviews, the interviewer transcribed audio files and transcriptions were corrected. For reliability, interview transcripts were analysed and coded as soon as possible after each interview. Handwritten field notes and interview impressions were also employed in the study. Recordings and transcripts were only viewed by the researcher. These were made available to participants if requested.

*Method of Data Analysis**Thematic analysis process*

Thematic analysis, according to Braun & Clarke (2006), is a technique for analysing qualitative data that comprises looking through a dataset to find, examine, and report recurring patterns. It is a technique for summarising data, but when choosing codes and creating themes, it also involves interpretation.

Thematic analysis is a good fit for the purpose of this study as it allowed the researcher to draw patterns across the research and allowed themes to be constructed easily across the data set. The theoretical flexibility of thematic analysis enabled the approach to be most suitable for this qualitative research (Nowell, 2017). An advantage of thematic analysis, is that it is a method rather than a methodology (Clarke & Braun, 2017). This means that unlike many qualitative methodologies, it is not tied to a particular epistemological or theoretical perspective, allowing a very flexible methodology (Nowell, 2017).

The goal of a thematic analysis is to identify themes and patterns in the dataset that are important or interesting, and use these themes to address the research or say something about an issue (Maguire & Delahunt, 2017). A six step process for using thematic analysis, drawing on Braun and Clarke's (2006) framework, has been used to analyse the data in this dissertation;

familiarisation, coding, generating themes, reviewing themes, defining and naming themes and writing up.

1. **Step One: The first step is becoming familiar with the data.** The researcher became familiar with the entire body of data by reading and re-reading the transcribed interviews. At this stage the researcher made notes and jotted down any early impressions.
2. **Step Two: Initial codes** were then generated to reduce large amounts of the data into smaller segments by organising it in a meaningful and systematic way. The researcher coded each segment of data that was relevant to or captured something interesting about the research question, but not coding every piece of text. Open coding was used for these as pre-set codes were not made. Instead this evolved and modified as the researcher worked through the coding process. The researcher used a qualitative data analytic software called Miro to do this.
3. **Step Three: Searching for themes.** A theme is a pattern that highlights a key or intriguing aspect of the data or research project (Braun & Clarke, 2006). Initial themes were identified, allowing broader themes to emerge from the data.
4. **Step Four: Reviewing themes.** The researcher then re-read the data to ensure that the themes were supported in the context of the entire data set.
5. **Step Five: Defining themes.** This involved identifying what each theme is about overall. Braun and Clarke (2006) explain that this step is about identifying the 'essence' of what each theme is about. Essentially, the researcher must find out what the theme is saying and how they relate to each other.
6. **Step Six: Write up.** Lastly, the researcher writes up the analysis and findings from the emerged themes.

Quality and Credibility

When conducting a qualitative study it is important that the research process is validated through the use of control measures such as reliability, utilising credibility, and confirmability (Morrow 2005). The use of constant persistent engagement with the participants by prolonged observation in the field with peer researchers, allowed credibility to be accomplished (Morrow 2005). Credibility is shown when the data gathered by the researcher is represented reliably, through consideration of the data's internal consistency along with accurate interpretation and analysis (Morrow 2005). For this research it is important to make sure that research bias has been removed through ensuring that the interpretations of the findings are not based on personal viewpoints and preferences by being reflexive and acknowledging the role as a researcher (Korstjens & Moser, 2018).

Since the discussions and interviews are conducted by researchers, any information gathered during a qualitative study may possibly be influenced by the researchers' underlying beliefs (Korstjens & Moser, 2018). Therefore, as a psychology student, when conducting qualitative research, it is essential to acknowledge the role as a researcher in this research and to examine one's own beliefs, assumptions, and practices, during the process of collecting, analysing, and interpreting the data (Korstjens & Moser, 2018). To ensure the participants autonomy, participants were not identified in their interview transcriptions.

CHAPTER 4: FINDINGS

The objective of this study is to explore the experiences of caregivers supporting adults with ID when in hospital in Aotearoa. This chapter presents the discoveries of their experiences from the interview transcripts, followed by a summary of the themes with established quotes and descriptions to support, from the six interviews that took place with caregivers of adults with ID. The findings are analysed, organised and categorised into the themes. Theoretical

saturation was reached after six interviews, at which time themes became repetitive. Some specific comments from participants are addressed in Table 2 with a selection of further comments discussed afterwards.

Participants

The participant demographic and characteristic details of the six caregivers who took part in this study are conveyed in the table below (Table 1). All caregiver participants in this research were a caregiver of an adult (over the age of 18) with an intellectual disability. The caregiver ages ranged from 27 to 69, whilst the adult with ID that the caregiver was caring for ranged from 20 to 33. From the six caregiving participants that participated in the study, the mean age was 50.5 years, with considerable variation. The adults with ID that they cared for had a mean age of 25 years. All met the criteria of having a full Scale IQ (FSIQ) score of below 80 and had been hospitalised in the last twelve months. All six caregiving participants were of New Zealand European ethnicity with one participant also sharing a Māori ethnicity.

Table 1

Table 1. Table of Participant Demographic Information

Caregiver Participant Pseudonym	Age of Caregiver	Age of adult with ID	Ethnicity of Caregiver
Participant 1 (P1)	27	24	NZ European & Māori
Participant 2 (P2)	57	24	NZ European
Participant 3 (P3)	69	24	NZ European
Participant 4 (P4)	49	24	NZ European
Participant 5 (P5)	56	33	NZ European
Participant 6 (P6)	46	20	NZ European

Table 2*Table 2. Table of Superordinate and Subordinate Themes*

Superordinate Themes	Subordinate Themes	Selected Illustrative Quotes
Advocating	<i>Speaking up</i>	"If I hadn't been so vocal and pushy, she might not be here today" - P4 "As a caregiver, you have to be very strong and say that the person with ID has had enough or he's going to have a meltdown." - P2 "I personally feel like it's really important to have someone there to advocate for him and just to make sure that he's comfortable, kind of knows what's going on, and kind of ease those anxieties that naturally come with being in the hospital setting" - P1
	<i>Translating</i>	"When the doctor explained the procedure to her, she just said no, he wasn't explaining it in a way she could understand, instead left it up to me as caregiver to interpret what he said and tell her in a more understanding way." – P3
	<i>Navigating</i>	"For people with intellectual disabilities, navigating systems and getting to appointments are quite difficult" – P1 "We are quite lucky in that I am a nurse, so we have quite good health literacy and are very comfortable navigating the health system". – P2
Environment	<i>Location</i>	"Some places are a lot more approachable and have a lot more care and compassion." – P6 "Some places feel a lot more clinical and don't have a bedside manner." – P6 "When she moved from the children's wing to adults care, we noticed a huge difference in what she was expected to do herself, even though she has a disability." – P6
Lack of Support	<i>Caregiver</i>	"It's exhausting having to be vocal and fight with the system, especially when you are caring for someone with an intellectual disability too." – P4
	<i>Wider family</i>	"There have been times where I have definitely seen Mum and Dad burnt out, tired and they get frustrated as well." – P1
	<i>Financial</i>	"It's quite challenging because we have two other children to look after as well, so there was care for them to be organised while I was at the hospital." – P2

		“There were times the parking bills mounted up.” – P6
Lack of Awareness	<i>Time Experience</i>	<p>“Maybe trying to understand the patient a bit more and giving them more time.” – P1</p> <p>“If they haven’t had experience with ID adults its difficult, it has been our world for so long now so we know how to engage with it, but for those who don’t, it can be quite tricky.” – P3</p> <p>“They did it three times, and they weren’t able to read the signs that he had had enough.” – P2</p> <p>“People don’t have an understanding of ID across the board.” – P5</p>
	<i>Confidence</i>	<p>“There are some people that are better than others, but training would definitely help.” – P2</p> <p>“A little bit more awareness around those needs of the patient with ID.” – P1</p> <p>“It’s just more awareness and more confidence in working with people with intellectual disabilities.” – P1</p> <p>“Making sure that they knew how she would be after her surgery was a big concern for me.” – P6</p>
Interpersonal Care	<i>Support</i>	<p>“Nurses and doctors aren’t able to care for her needs in that way.” – P3</p> <p>“Everybody has been accommodating.” – P4</p> <p>“If we weren’t there, he would have sat in bed all day and no one would have showered him or done anything.” – P5</p> <p>“Sometimes there are cold responses and feels like they are there just to get paid.” – P6</p>
	<i>Acknowledgment</i>	<p>“A little bit more respect and acknowledgement for him as a person might be useful.” – P1</p> <p>“When she was there, she didn’t really interact with him. It was more just shove on the blood pressure cuff and then leave.” – P1</p> <p>“Even eye contact with him, making sure he is part of it would go a long way.” – P1</p>
Informed Consent	<i>ID Adult</i>	<p>“Hospital systems aren’t trained with people who understand cognitive problems, you can get the answer you want out of someone with ID.” – P5</p>
	<i>Caregiver</i>	<p>“Even something as simple as getting consent, was not as simple with ID adult.” – P2</p> <p>“They put him on a research trial with his consent but without talking to me about it first as caregiver.” – P5</p>
	<i>Legal standings</i>	<p>“We can’t give consent. We’ve been in a couple of tricky situations where the doctor asked for consent and she said no as didn’t understand.” – P3</p>

	<p>“Mum has a technical legal standing, so health professionals are respectful of her role.” – P1 Because I am his welfare guardian, the hospital staff tend to talk to me, they don’t talk with him a lot.” – P2</p>
<p>Communication</p> <p><i>Health professionals</i></p> <p><i>ID adults</i></p>	<p>“They mainly just speak with the caregiver, they don’t try and make much of an effort, instead of relying on caregiver.” – P1 “When they interact with him at his level its really amazing, but they are also respectful that he has this disability.” – P1 “They sat him down, they explained the whole procedure to him and it was his choice whether he wanted it or not.” – P2 “He wasn’t explaining it to her in a way she could understand, instead left it up to me as caregiver.” – P3 “Sometimes the words are too big, they don’t make it easy for them to understand.” – P3 “Some of them are quite good and would acknowledge that she has a soft toy or something and incorporate that into conversation with her.” – P6 “It falls on the caregivers.” – P4 “They can’t read his signals, and if he had a meltdown health professionals would struggle to manage that.” – P2 “We have to dumb it down for her and talk to her in a way that she understands.” – P4 “When processes aren’t explained to her, she doesn’t understand and its quite terrifying for her.” – P4 “He can’t say I’ve had enough and I need to leave now.” – P2 “When she’s put under pressure, I think she finds it difficult to express herself.” – P3</p>
<p>Health Experience</p> <p><i>Caregivers</i></p>	<p>“It certainly helps from my perspective.” – P2 “I think if there was someone that had more understanding of how the hospital system worked, they could ask better questions on her behalf.” – P3 “When you disclose that you’re a nurse, things start to change.” – P5 “He’s fortunate that I know the process, other families don’t.” – P5 “You have to be very pushy and so if you don’t have any health literacy, that’s very difficult.” – P2</p>
<p>Reliance/Abandonment</p> <p><i>Undervalued</i></p>	<p>“Perhaps just a little bit more respect or acknowledgement of what we might have said would be good.” – P1 “Sometimes you feel frustrated because you feel like you’re not being heard or listened to.” – P1</p>

<i>Responsibility</i>	<p>“It’s a big responsibility that we take really seriously, because we know that it’s difficult for her to function out there on her own.” – P3</p> <p>“I feel like they could make more of an effort to interact with him on his level rather than relying on me as the caregiver a little bit too much.” – P1</p>
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Participants discussed having to fulfil many roles as a caregiver when supporting their adult with ID in hospital. Throughout the interviews they discussed many of these roles and issues, which have been identified as themes from the data analysis (Table 2).

Theme One: Advocacy

This theme consisted of participant discussions of caregivers being left to advocate for the adult with ID, translating/explaining important medical terminology, and having to navigate the hospital system themselves.

Participants discussed the need to be “*pushy and vocal in order to make sure that the adult with ID felt comfortable and knew what was going on*” (P1), easing anxieties that they had, which came naturally with being in the hospital setting.

Participant 4 made a direct statement saying “*if I hadn’t been so vocal and pushy, she might not be here today*”. Participant 4 had attempted to alert hospital professionals of her daughters significant visual deterioration. However despite her repeated concerns, she felt ignored, ultimately tests confirmed visual and hearing loss. Participant 4’s account was not unique, with these findings inferring that the hospital environment increases vulnerability in those with ID, in the absence of an appropriate caregiver advocate.

One situation that left a caregiver playing the role of translator, was discussed from Participant 3, which involved “*a doctor not explaining a medical procedure in a way that the adult with ID could understand, resulting in the adult with ID saying ‘no’ to an important medical procedure*”. In order for the procedure to go ahead it became the caregiver’s

responsibility to discuss the procedure with the adult as the doctor could not explain it in a way that the adult with ID could understand. Is this an appropriate responsibility for a caregiver?

Participant 1 mentioned the difficulty that her adult with ID had navigating the hospital system, mentioning that if they *“did not have a health background to understand these systems, it would become quite difficult to find their way around the hospital and get to appointments”*. Without a knowledge of health experience, caregivers explained that it would be quite easy to become lost and therefore the potential to miss appointments as well as the stress of the adult with ID would make it overwhelming. Participant 3 mentioned that appointments are very difficult to get, and would sometimes be cancelled at the last minute, which she said her adult with ID *“becomes distressed very easily as she is used to routine”*. Therefore, getting to appointments on time is imperative, and *“consistency across the hospital system would be good.”*

Theme Two: Lack of support

A common theme that was evident across all participant interviews was the lack of support provided to them personally within the hospital system. The participants interviewed discussed the need for more support for them as caregivers when they are supporting their ID adult when in hospital. This identified that appropriate services were not readily available for this cohort.

Discussions around *“nothing catered for families if they want to stay; like a lazy boy chair (P5),”* as caregivers felt they had an obligation to be with the patient constantly. For these caregivers, there was *“a lack of food provided” (P5)* as well as *“no facility or support for the caregiver to have a break or shower” (P5)*, which resulted in *“frustration, tiredness and times of burnout (P1)”* of the caregiver, as they were expected to be an unpaid, unrecognized member of the team with no consideration for what they needed as caregivers.

This led caregivers to discuss how they had financial difficulties due to the ongoing out of pocket spending, such as food and parking that were not provided, where Participant 6 explained how her and husband struggled to pay the parking bills that they had to over a course of a 4 week stay in hospital with their ID adult, mentioning *“there were times the parking bills mounted up”* (P6). The hospital would not subsidize any of it. Is this a fair and equitable process?

Caregivers mentioned that more support is needed not only for them as caregivers but also for their wider families. Participant 2 raised the challenges she had faced having other children to look after as well, *“It’s quite challenging because we have two other children to look after as well, so there was care for them to be organised while I was at the hospital.”*

Theme Three: Environment

A concern across participant discussions often involved how patients were treated differently across various hospitals as well as between wards. Participant 6 voiced her concerns around the changes that occurred *“When she moved from the children’s wing to adults care, we noticed a huge difference in what she was expected to do herself, even though she has a disability.”* It is important to note that whilst it was appropriate due to her physical age to be moved to the adult medical ward, however there was an inappropriate expectation that she would have an adult understanding. The caregiver discussed that her mental age was not considered which left the caregiver feeling like the *“medical staff did not adapt the care they provided to suit her needs (P6)”* and mental age of the adult with ID.

It was also discussed that the care and the way hospital staff interacted with the adult with ID varied across different hospitals. Participant 6 stated that *“Some places are a lot more approachable and have a lot more care and compassion for people with disabilities.”* This participant continued to discuss the *“lack of bedside manner that some hospitals had (P6)”* which she discussed as *“important when dealing with an adult with ID (P6)”*.

Theme Four: Lack of awareness of ID

Lack of awareness of ID was a strong focal point of discussion during the interviews. ID was described by family caregivers as an ‘invisible disability’ in that the absence of physical signs of disability meant that others would expect those with ID to function as ‘normal’ in social circumstances.

When caregivers spoke of lack of awareness with patients with ID, they were talking about examples of hospital staff where *“they weren’t able to read the signs that the patient had had enough”* (P2), *trying to understand the patient a bit more and giving them more time”* (P1), and having *“more awareness around the needs of the patient with ID”* (P1).

Participants stated both positive and negative experiences of awareness saying that *“there are some people that are better than others”*. Participant 2 iterating that *“training would definitely help”* improve the awareness of the needs of people with intellectual disabilities. Overall though, caregivers felt that this was another reason that their presence was necessary in hospital in order for their adult with ID to receive optimal care, for example, *“making sure that they knew how she would be after her surgery was a big concern for me”*(P6).

Theme Five: Interpersonal Care

Discussions from caregivers included the ‘value of care’ that their adult with ID received while in hospital. Participant 4 mentioned a positive experience where *“everybody had been accommodating”* however, this appeared to be a rare experience as more commonly caregiver participants discussed *“nurses and doctors not able to care for patient needs”* (P3) and interactions they had with health care professionals as complex, difficult and frustrating.

The caregivers felt this put more pressure on them, one acknowledging that *“if we weren’t there, he would have sat in bed all day and no one would have showered him or done anything”* (P5). Another example was when the caregiver observed that *“the nurse didn’t really interact with him. It was more just shove on the blood pressure cuff and then leave,”*

leaving the caregiver to feel that had they not been there, their adult with ID would have become quite distressed, *“even eye contact with him, making sure he is part of it would go a long way”* (P1).

Theme Six: Communication

Communication within hospital stays provided varying responses, both positive and negative from the caregivers. Each participant spoke of this at length. Eighty percent of the caregiver statements in this research were portrayed as negative experiences for the caregiver and their adult with ID. For example, participant 3 stated *“sometimes the words are too big, they don’t make it easy for them to understand”*, which left it up to the caregiver to decipher and *“relay specific information to the adult with ID in a way that could understand,”* (P3) as health professionals were *“not making much of an effort”* (P1). Participant 4 supports this by stating that *“it falls on the caregivers”* and that they as caregivers *“have to dumb it down for her and talk to her in a way that she understands”*. Caregivers noticed that health professionals *“can’t read his signals and if he had a meltdown, they would struggle to manage that”*, thus, again leaving it up to the caregivers to manage.

In contrast, participant 6 discussed a positive experience, where *“some of them (health professionals) are quite good and would acknowledge that she has a soft toy or something and incorporate that into conversation with her.”* The caregiver mentioned that this situation was non-stressful and took the pressure off her, allowing the caregiver to be there for support. Similarly, participant 2 also said *“they explained the whole procedure to him and it was his choice whether he wanted it or not.”*

Theme Seven: Informed Consent

Negative experiences originated from multiple experiences; from health care professionals excluding the family member with ID in conversation; poor communication on the part of the health care professionals; and health literacy issues for caregivers and their

family member. When signing documents requesting legal and informed consent, this was typical. These tense and frequently complicated medical meetings highlight the dependence that caregivers face and the necessity for them to serve as the patients eyes and ears while balancing privacy concerns with the possibility of overlooking crucial medical information.

“Even something as simple as getting consent, is not as simple with ID adult” (P2). Participant 3 spoke at length about a particular situation involving a consent process that she had experienced, where *“the doctor had asked for consent and the adult with ID immediately said no as she didn’t understand and the doctor asked me as caregiver what to do next”*. The caregiver mentioned that had she not been there, the procedure would not have gone ahead as her adult with ID had not been spoken to and told about the procedure in a way that she could understand. *“The responsibility fell to me but we got through it”* (P3).

Caregivers spoke about the reliance they felt of being present with their ID adult when consent is spoken about. This is due to *“hospital systems not trained with people who understand cognitive problems, and being able to get the answer you want out of someone with ID”* (P5). Participant 5 found that *“They put him on a research trial with his consent but without talking to me about it first as caregiver”* and she explained that he didn’t even know what the trial was about.

Theme Eight: Health Experience

A number of participants discussed how having a prior health background *“certainly helps from my perspective”* (P2), when supporting an adult with ID in hospital. When one participant revealed to hospital staff that she was a nurse, she stated that *“things started to change”* (P5). She discussed that the level of care improved as a result, which took a significant amount of pressure off her.

Health literacy was also mentioned as an important factor, with this, caregivers who had health knowledge, knew the right questions to ask. Without this, and without being pushy,

caregivers noted that it would be difficult to understand and know what to ask health professionals, as health staff were not always forthcoming with all the information and options available, which adults with ID were not able to ask.

Theme Nine: Sense of abandonment

Overall, the underlying theme for this research is the heavy reliance on caregivers to constantly be at the bedside to provide extra care, as they felt like they needed to be there due to observations where *“they (medical professionals) could have made more of an effort to interact with him on his level”* (P1). The participants felt that there was a heavy reliance on them and they didn’t feel valued from the medical professionals.

CHAPTER 5: DISCUSSION

This study has used a qualitative approach to explore the experiences of caregivers supporting adults with ID during hospitalisation in Aotearoa. Given the very limited research on caregiver experiences supporting adults with ID in Aotearoa, this study has provided some insight on their experiences, and as a result may help to determine what services within the New Zealand hospital system are necessary to better support these healthcare providers. Applying thematic analysis to this research has allowed the researcher to investigate these experiences within the hospital system in Aotearoa. Nine themes were identified (Table 2). This chapter will provide an examination of the themes that are categorised as they relate to earlier literature and recognising research limitations. The investigation identifies some suggestions for future improvements for hospitals within Aotearoa.

Our findings highlight the increasing reliance placed on caregivers of adults with ID whilst in hospital. There are consequences highlighted through the interdependence within the themes developed in this research; advocacy, location, lack of support, lack of awareness, interpersonal care, informed consent, communication, health experience and sense of abandonment. This is consistent with Charles (2020) who associated these with poorer patient outcomes and probability of rehospitalisation of such patients.

Whilst some comparisons can be drawn with previous literature that address these themes, and their inter-relationships, we have considered these within the Aotearoa context. The data suggests that caregivers are being left to advocate, translate and navigate the hospital system themselves. It is evident that advocacy within the hospital environment was considered hostile by participants, particularly in the view of the perceived poor communication skills of many health care professionals, with the potential for misinterpretation, for both caregivers and those with ID. This recognised the need for caregivers to *“be pushy and vocal”* in order to know what was going on.

As well as caregiver participants sharing their frustrations of having to interpret/translate medical jargon to the adult with ID, and in turn expressing the adult with ID's views and wishes. Health professionals were not giving adequate time to talk and provide explanation of procedures in an acceptable way for the adult with ID to comprehend. Charles (2020) supports these experiences where he discusses caregivers talking openly about always having to be vigilant and constantly at the bedside of the adult with ID to ensure that the patient had some understanding, as well as provide an explanation of what doctors were saying.

These results identified that there was a lack of awareness of these issues from health professionals. The resulting communication barrier being an issue and making it was evident that it was often necessary for the caregiver to be present. Doherty et al., (2020) mentions that this could be a result of the potential lack of specific training on how to communicate with and support patients with ID.

Several caregivers in this study commented on the lack of asking and understanding of health professionals had regarding the patient's level of communication or functioning. This is consistent with the Charles, (2020) where nurses did not ask questions about the patient's level of communication or functioning and which Walsh et al., (2011) noted that a 47.3% of health professionals were reported to base and rely their assessment of pain of the patient on what the caregiver told them.

These themes highlight that without the caregiver present, the adult with ID would most probably not receive the adequate treatment required. Furthermore other participants identified that the health professional may not have received or understood patient cues, particularly relevant to issues, for example, that of obtaining appropriate informed consent. Being involved in the process of appropriate informed consent is integral to improving the adult with ID's sense of abandonment and the level of care required of the caregiver. Within this study caregivers appeared to recognise these behaviours were dependent on an individual health

professional, their level of understanding, as well as well as the different health facilities/environments within which they worked.

Caregivers repeatedly emphasised that both the hospital staff and the adults with ID increasingly relied upon the caregivers to ensure that there were no gaps in the care of their patient. It highlighted that they were required to be very proactive, to be a driving force for the care of their adult with ID, ensuring that there was focus and perseverance towards better care. This continual reliance can contribute to caregivers feelings over being overwhelmed, frustration, anxiety, anger, helplessness and invisibility. This requires stamina for the continual need to act as a strong advocate for their adult with ID's , to work through the barriers of poor communication and support, consistency, and collaboration between the adult with ID and hospital staff. The caregivers felt that numerous situations may have been avoided had they been listened to and their opinions valued. The concern around whether other people were fully aware of or appreciated such challenges that caregivers face is highlighted by past literature, (Patel et al., 2021), justifying the importance of this research.

The stressors, and situational fatigue affect caregivers own health and mental wellbeing. The impact that these themes of non-supportive interactions with health professionals had on caregivers should act as a catalyst for the development of individual-level initiatives to be introduced.

The interdependency of themes learned in this research are also important to enhance an adult with ID experiences. Lack of support as a theme could be due to the lack of poor communication processes, as discussed. There appears to be strong interdependency across the themes, whereby significantly improving one theme will also have positive flow on effect to other themes.

Limitations

Throughout this research, numerous limitations have been identified. All participants being female identifies probable gender bias and could have impacts on the outcome of the study. The experiences of caregivers may not have been conveyed as accurately because of self-reporting and the potential loss of recall of important details. The level of severity of the adult with ID was also undetermined ranging mild to severe, which would have had an impact on the experiences of caregivers provided.

This research was conducted using a self-selection process, supported in past literature by Smith et al., (2009), suggesting that self-selected participants potentially increase the risk of bias for those sharing experiences. Consequently, this research could have caught the interest of those caregivers with negative views towards the health system because of their frustration of not being heard, and participating in this research, addressing those needs and providing a platform to be heard.

Consistent with research reflexivity, it is critical to reflect on how the characteristics of the researcher potentially may influence the data and analysis. As a female researcher with previous caregiving experience, and working with intellectually disabled adults, may have an influence on the interviews if this was disclosed to participants. However, for the purpose of the interviews in this study, it was decided that I would not disclose my previous experience in order to ensure reliability and remove bias. This allowed participants to explain things in their own detailed way. Although there was a rapport between the interviewer and participants, the participants had a clear level of awareness and attentiveness of the research purpose by being part of the research procedure. Although international studies were available, the absence of any previous research within Aotearoa has made any relevant comparison impossible.

Future Research

Given their poor health, the absence of accessible and attractive health advocacy tools for this population of adults with ID and their caregivers is surprising (Lennox et al., 2004).

The need for information regarding health records and how to work with the needs of an adult with ID while also being able to understand the level of their disability, through the role of technology could be explored. For example, one central/national integrated health record database for all health services to access health records and appropriate ways of caring for a person would provide continuity of care and a better health experience for health professionals, patients and caregivers.

The potential for a software application (app) to be developed to help a person with ID communicate easier with health professionals, and vice versa, easing the burden for the caregiver to advocate, increasing informed patient care and improving doctor-patient communication (Malik et al., 2019). The development of an app for this circumstance is not necessarily new technology as there is already existing artificial intelligence (AI) being used within the health sector (Malik et al., 2019). Sinsky et al., (2016) found that use of AI in this way not only reduced manual labour and frees up the primary care physicians time, but also increase productivity, precision and efficacy (Malik et al., 2019). Which, if utilised, would therefore allow more tailored and personal care to be available to these patients with ID.

Conclusion

This research has explored the experiences of caregivers supporting adults with ID when in hospital in Aotearoa. It has provided various insights into the negative and positive experiences of caregivers. Although a limited study, the findings are consistent with previous overseas literature. Participants expressed positive and negative perspectives about their experiences of hospital care in Aotearoa which are explained through interdependent themes

of advocacy, lack of support, location, lack of awareness of ID, interpersonal care, communication, informed consent, health experience and a sense of abandonment and reliance. Results have validated previous literature. The stressful experiences in overseas health care facilities, align with results from this study. This has shown the need for improvements to be made for the continuity of care for adults with ID in order to relieve the pressure and stress felt by caregivers in Aotearoa. Caregivers are mainly voluntary, without funding, and are an unrecognised, but essential provider of care for adults with ID.

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APPENDIX A: PARTICIPANT CONSENT FORM

Consent Form

Project title: The Experience of Hospitalisation of People with Intellectual Disabilities; a Mixed-Methods Study of the experiences of people with intellectual disabilities, their caregivers and support people, and stakeholders

Project Supervisor: **Dr Liesje Donkin**

Researchers: **Dr Marleen Verhoeven, Dr Helen Buckland-Wright, Carrie McColl & Emma Fuller**

- I have read and understood the information provided about this research project in the Information Sheet dated 4th May 2022.
- I have had an opportunity to ask questions and to have them answered.
- I understand that notes will be taken during the interviews and that they will also be audio-taped and transcribed.
- I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without being disadvantaged in any way.
- I understand that if I withdraw from the study then I will be offered the choice between having any data that is identifiable as belonging to me removed or allowing it to continue to be used. However, once the findings have been produced, removal of my data may not be possible.
- I agree to take part in this research.
- I wish to receive a summary of the research findings (please tick one): Yes No

Participant’s signature:

Participant’s name:

Participant’s Contact Details (if appropriate):
.....
.....
.....
.....

Date:

Approved by the Auckland University of Technology Ethics Committee on *type the date on which the final approval was granted* AUTEK Reference number *type the AUTEK reference number*

Note: The Participant should retain a copy of this form.

APPENDIX B: ORAL CONSENT FORM

Oral Consent Protocol

For use when interviews are being conducted by videoconference.

Project title: The Experience of Hospitalisation of People with Intellectual Disabilities; a Mixed-Methods Study of the experiences of people with intellectual disabilities, their caregivers and support people, and stakeholders

Project Supervisor: **Dr Liesje Donkin**

Researcher: **Carrie McColl & Emma Fuller**

The participant joins the videoconference

Do you agree to my recording your consent to participate?

If they agree, then the record function will be activated and they will be asked the following:

- Have you read and understood the information provided about this research project in the Information Sheet dated dd mmmm yyyy?
- Do you have any questions about the research?
- Do you understand that notes will be taken during the interviews and that the interview will also be audio-recorded and transcribed?
- Do you understand that taking part in this study is voluntary (your choice) and that you may withdraw from the study at any time without being disadvantaged in any way.?
- Do you understand that if you withdraw from the study then you will be offered the choice between having any data that is identifiable as belonging to you removed or allowing it to continue to be used? However, once the findings have been produced, removal of your data may not be possible.
- Do you agree to take part in this research?
- Do you wish to receive a summary of the research findings? (please tick one): Yes No
- Do you want me to send you a copy of the audio recording for this consent? Yes No
- Please confirm you name and contact details

Participant's name:

Participant's Contact Details (if appropriate):
.....
.....
.....
.....

I will now turn off the recording of the Consent and then will start a separate recording for the interview.

Approved by the Auckland University of Technology Ethics Committee on *type the date on which the final approval was granted* AUTEK Reference number *type the AUTEK reference number*

Note: The Participant should retain a copy of this form.

APPENDIX C: PARTICIPANT INFORMATION SHEET

Participant Information Sheet

Date Information Sheet Produced:

30th April 2022

Project Title

The Experience of Hospitalisation of People with Intellectual Disabilities; a mixed-methods study of the experiences of people with intellectual disabilities, their caregivers and support people, and stakeholders

An Invitation

Kia ora, we are a team of researchers and psychologists working together to better understand the experience of hospitalisation of people with intellectual disabilities in Aotearoa. As a caregiver or support person of someone with an intellectual disability, or as a community stakeholder, you are invited to take part in our study. Taking part in this research study may help to improve support for people with intellectual disabilities when receiving hospital care.

What is the purpose of this research?

The purpose of this research is to try to better understand how adults with intellectual disabilities experience being in the hospital, to find out what things make the hospital experience easier, and to discover the things that might make hospital experiences more difficult. We are interested in hearing your perspective of hospitalisation as someone who supports someone with intellectual disability, or a stakeholder that is involved with providing services to some-one with intellectual disabilities. It is hoped that by having a good understanding of these challenges, new resources can be developed that will assist people with intellectual disabilities who are hospitalised in future.

The findings of this research may be used for academic publications and presentations, will be feedback to interested organisations, and will contribute towards my qualification in a Bachelor of Health Science (Honours) degree.

How was I identified and why am I being invited to participate in this research?

You may have heard about the study through an email advertisement that was sent to community agencies that support people with intellectual disabilities, through social media advertising this study on Facebook or through your networks.

To be considered for inclusion in this study, you will need to meet all the following criteria:

- You are a support person or caregiver for someone with an intellectual disability that has been hospitalised in the last 12-months OR are involved in an organisation (such as an NGO, charity of medical service) that provides services to people with an intellectual disability.
- You have access to the technology required to complete the online survey or for an online (teleconference) interview if I decide to participate in the interview

How do I agree to participate in this research?

Your participation in this research is voluntary (it is your choice) and whether you do or do not choose to participate will not advantage or disadvantage you. You are able to withdraw from the study at any time. If you choose to withdraw from the study, then you will be offered the choice between having any data that is identifiable as belonging to you removed or allowing it to continue to be used. However, once the data has been de-identified, removal of your data may not be possible.

If you wish to participate in the study, click on the link at the end of this information sheet indicating that you consent to participate.

What will happen in this research?

There are two ways that you can participate in this study. You can complete an online survey where you are asked to share your views on hospitalisation, or in an interview with one of the members of the research team. If you are interested and you agree to be interviewed, once you provide your contact details online, a researcher

will contact you within 48 hours to book a time to be interviewed. The interview will involve talking to the researcher by video conference call (eg Zoom or Teams Meetings) about your past experiences of supporting or providing services to someone with intellectually disabilities who was hospitalised.

The researcher will ask you questions about things that made hospitalisation easier, and about things that that may have made your experience more difficult. With your consent, the interview will be recorded and accessed by the researcher (the person that interviewed you), so that they can transcribe the data for further analysis. Transcriptions of interviews will be analysed to determine the main themes and findings of the interview. It is hoped that the research findings will inform recommendations about how to better support people with intellectual disabilities during hospitalisation.

What are the discomforts and risks?

We don't expect the interview or online survey to cause any harm to you; however, you could become upset when reflecting on your experiences of supporting or treating someone when they were hospital.

How will these discomforts and risks be alleviated?

If you do feel distressed by the interview process, Dr Liesje Donkin (the principal researcher for this study) will contact you to facilitate appropriate support for you. Please let your interviewer know if you would like to be contacted.

AUT Student Counselling and Mental Health is able to offer three free sessions of confidential counselling support for adult participants in an AUT research project. These sessions are only available for issues that have arisen directly as a result of participation in the research and are not for other general counselling needs. To access these services, you will need to:

- drop into our centre at WB203 City Campus, email counselling@aut.ac.nz or call 921 9998.
- let the receptionist know that you are a research participant, and provide the title of my research and my name and contact details as given in this Information Sheet.

You can find out more information about AUT counsellors and counselling on <https://www.aut.ac.nz/student-life/student-support/counselling-and-mental-health>

What are the benefits?

If you agree to participate in this research, your insight and experiences may influence the support offered to people with intellectual disabilities who are hospitalised in the future. Finds from the study will also be used to generate new resources that will better support adults with intellectual disabilities during periods of hospitalisation.

A benefit to the researchers is that the research findings will be used in academic publications and presentations and will count towards the students' qualification in a Bachelor of Health Science (Honours) degree.

How will my privacy be protected?

To protect your privacy, data from the online survey and/or recorded interview will be stored in a digital file folder protected by password on a secure server at AUT.

The privacy of you as a participant will be protected by coding all data and removing all identifiable information to ensure that any data published or otherwise disseminated can in no way identify you. Although identifiable data will be collected (eg., name and contact details), only the primary researchers will have access to the raw data files and following transcription, original recordings will be deleted.

What are the costs of participating in this research?

There will be a cost of your time if you choose to participate in the study. The online survey is expected to take about 10 - 15 minutes to complete. If you choose to be interviewed by a researcher, this could take a further 30 – 60 minutes of your time.

What opportunity do I have to consider this invitation?

You will be able to consider the invitation for 6-8 weeks while recruitment is open. You are able to directly contact the research team to discuss the study before deciding to participate or to arrange for a pen-and-paper survey if you wish to do so. Your participation in this study is completely voluntary (meaning you can choose if you want to be involved). You can withdraw from the study at any point and for any reason, with no explanation needed. If you wish to withdraw from the study and to have your information removed, please let one of the researchers know.

Will I receive feedback on the results of this research?

A summary of the findings of the research will be sent to you if you wish to receive them. When you complete the consent form, you have the option to indicate if you would like to receive a copy of the findings.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Dr Liesje Donkin, liesje.donkin@aut.ac.nz, 021 847 886.

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTECH, ethics@aut.ac.nz, (+649) 921 9999 ext 6038.

Whom do I contact for further information about this research?

Please keep this Information Sheet and a copy of the Consent Form for your future reference. You are also able to contact the research team as follows:

Researcher Contact details:

Dr Liesje Donkin (BSc, MSc(Hons), PGDipHlthPsych, PGDipArts(Dist), PGDipClinPsych, PhD)
liesje.donkin@aut.ac.nz
(021) 847 886

Emma Fuller (BSHc)
Vpc0907@autuni.ac.nz
02102976683

APPENDIX D: ETHICS APPROVAL



Auckland University of Technology Ethics Committee (AUTEC)

Auckland University of Technology
D-88, Private Bag 92006, Auckland 1142, NZ
T: +64 9 921 9999 ext. 8316
E: ethics@aut.ac.nz
www.aut.ac.nz/researchethics

21 July 2022

Liesje Donkin
Faculty of Health and Environmental Sciences

Dear Liesje

Re Ethics Application: **22/131 The experience of hospitalisation for people with intellectual disabilities; a qualitative study of tangata whaiora, their caregivers, and stakeholders.**

Thank you for providing evidence as requested, which satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTEC).

Your ethics application has been approved for three years until 21 July 2025.

Non-Standard Conditions of Approval

1. Re word the statement at the end of the survey to say ' We anticipate that we will have the study completed and the results available by March 2023, a summary can be found <https://academics.aut.ac.nz/liesjedonkin>. Perhaps suggest they make a note of it, as once the survey has been submitted they will not have access to the details.
2. Please review and edit 'The Support Person and Caregiver Participant Information Sheet ' as it makes reference to 'stake holder' involved in providing services'.

Non-standard conditions must be completed before commencing your study. Non-standard conditions do not need to be submitted to or reviewed by AUTEC before commencing your study.

Standard Conditions of Approval

1. The research is to be undertaken in accordance with the [Auckland University of Technology Code of Conduct for Research](#) and as approved by AUTEC in this application.
2. A progress report is due annually on the anniversary of the approval date, using the EA2 form.
3. A final report is due at the expiration of the approval period, or, upon completion of project, using the EA3 form.
4. Any amendments to the project must be approved by AUTEC prior to being implemented. Amendments can be requested using the EA2 form.
5. Any serious or unexpected adverse events must be reported to AUTEC Secretariat as a matter of priority.
6. Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the AUTEC Secretariat as a matter of priority.
7. It is your responsibility to ensure that the spelling and grammar of documents being provided to participants or external organisations is of a high standard and that all the dates on the documents are updated.
8. AUTEC grants ethical approval only. You are responsible for obtaining management approval for access for your research from any institution or organisation at which your research is being conducted and you need to meet all ethical, legal, public health, and locality obligations or requirements for the jurisdictions in which the research is being undertaken.

Please quote the application number and title on all future correspondence related to this project.

For any enquiries please contact ethics@aut.ac.nz. The forms mentioned above are available online through <http://www.aut.ac.nz/research/researchethics>

(This is a computer-generated letter for which no signature is required)

The AUTEC Secretariat
Auckland University of Technology Ethics Committee

APPENDIX E: EMAIL INVITATION

Kia ora,

We are writing to you to tell you about a research project that we are currently undertaking where we are seeking to understand the experience of hospitalisation for people with intellectual disabilities, their support people and caregivers, and community stakeholders.

We are interested in hearing about your views and experiences of being hospitalised or supporting someone while they are in hospital and how this could be improved.

There are two ways that people can participate in the study – by an interview or by doing an online, anonymous survey.

If you would like to participate in an interview or would like to know more about the study, please contact Dr Liesje Donkin (Lead Researcher) on liesje.donkin@aut.ac.nz or (021) 847 886.

If you would like to do the online survey, please click on the link below that best describes you.

For the study for **people with intellectual disabilities**

[ADULTS WITH AN INTELLECTUAL DISABILITY STUDY LINK](#)

For the study for **caregivers or support people of people with intellectual disabilities**

[CAREGIVERS STUDY LINK](#)

For the study for **community stakeholders who support people with intellectual disabilities**

[STAKEHOLDERS STUDY LINK](#)

Please feel free to forward this invitation to anyone that may be interested in participating so that they can read about the study and make a decision about participating. Please do not forward their contact details to us directly as we require them to make contact with us themselves.

Ngā mihi,

Dr Liesje Donkin, Dr Marleen Verhoeven, Emma Fuller, & Carrie McColl

APPENDIX F: INTERVIEW QUESTIONS

Project Title: A study of caregivers supporting adults with intellectual disabilities during hospitalisation: a qualitative study of adults and their caregivers.

Researcher: Emma Fuller

Project Supervisor: Dr Liesje Donkin (BSc, MSc(Hons), PGDipHlthPsych, PGDipArts(Dist), PGDipClinPsych, PhD)

Participant Interview Questions: Adults with Intellectual Disability Experiences of Hospitalisation

Participant Interview Questions: Caregivers of Adults with Intellectual Disability Experiences of Hospitalisation

1. What were your experiences, as a caregiver, of supporting an intellectually disabled adult during hospitalisation?
2. What things worked well for you as a caregiver of an intellectually disabled adult during a hospital stay?
3. What things would you like to see improved to help other caregivers of intellectually disabled adults during a hospital stay?
4. Did you feel overwhelmed being a caregiver of an intellectually disabled adult whilst they were in hospital?

