Goal setting for people with mild cognitive impairment or dementia participating in rehabilitation programs

by

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Table of Contents

ABSTRACT

Globally, unmet rehabilitation needs are increasing (Gimigliano & Negrini, 2017). Rehabilitation can reduce the impact of disability and improve participation in daily tasks (World Health Organisation, 2021b). Goal setting is a crucial component of the rehabilitation process; it supports the implementation of appropriate interventions (Wade, 2020b), and is typically conducted in collaboration with the patient, family and/or caregiver (Levack, Dean, Siegert, & McPherson, 2006; National Stroke Foundation, 2010; Wade, 2009). Effective goal setting between patients and health professionals can improve motivation to participate (Leach, Cornwell, Fleming, & Haines, 2010). Patients are more engaged in therapy if they are involved in their own health care decision making and have a shared understanding of reasons for rehabilitation (Leach et al., 2010; Wade, 2009).

Over the years, a considerable amount of research has been conducted on how rehabilitation services are delivered, with a strong emphasis towards adopting a person-centred approach (Santana et al., 2018). Goal setting is a means to enable person-centred care in rehabilitation and whilst a person-centred approach is viewed as essential, barriers do exist (Sugavanam, Mead, Bulley, Donaghy, & van Wijck, 2013). Cognitive and communication difficulties have been identified as key barriers to goal setting in rehabilitation (Rosewilliam, Roskell, & Pandyan, 2011; Sugavanam et al., 2013). People with mild cognitive impairment or dementia will experience changes in cognition and communication. A person-centred approach for this population may prove to be challenging. Regardless, people with mild cognitive impairment or dementia require access to rehabilitation to maintain their functional abilities and participate in daily activities (World Health Organisation, 2017). Dementia is a leading cause of disability burden in older people in Australia and is a health priority worldwide (World Health Organisation, 2017, 2021a). This thesis therefore aims to examine the scope and validity of goal setting

for people with mild cognitive impairment or dementia participating in rehabilitation programs.

The first study, described in Chapter three of this thesis, is a scoping review of goal setting for people with mild cognitive impairment or dementia participating in rehabilitation programs. The purpose was to identify existing approaches to goal setting including barriers and enablers for people with mild cognitive impairment or dementia participating in rehabilitation programs. It was found that both structured and unstructured methods of goal setting are used, and that strategies to overcome cognitive and communication barriers can be used to maximise participation.

Chapter four presents findings from a quantitative study that examined whether people with mild cognitive impairment or mild severity dementia can accurately measure progress towards goals and/or report outcomes, using goal attainment scaling. A key finding was that goal attainment scaling can be used for this population.

Results of the two studies suggest that regardless of cognitive and communication difficulties, people with mild cognitive impairment or dementia can engage in goal setting using a structured approach. These findings should prompt health professionals and rehabilitation programs to adapt clinical practice. This will enable people with mild cognitive impairment or dementia to gain greater access to rehabilitation.

DECLARATION

I certify that this thesis:

1. Does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university; and

2. the research within will not be submitted for any other future degree or diploma without the permission of Flinders University; and

3. to the best of my knowledge and belief, does not contain any material previously published or written by another person except where due reference is made in the text.

Signed.....

Date.....

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To my family and friends, thank you for providing a safety net. Your ongoing support provided comfort during the most challenging periods.

Lastly, I am so thankful for the personal and professional growth that accompanies this research degree. I value the knowledge and skills that I have gained and look forward to future research endeavours.

LIST OF TABLES

LIST OF FIGURES

LIST OF PUBLICATIONS

Jogie, P., Rahja, M., van den Berg, M., Cations, M., Brown, S., & Laver, K. (2021). Goal setting for people with mild cognitive impairment or dementia in rehabilitation: A scoping review. Australian Occupational Therapy Journal, 1–30. https://doi.org/10.1111/1440-1630.12758

CHAPTER ONE: INTRODUCTION AND RATIONALE FOR THESIS

Dementia is a global health challenge with significant impact for the individual, their family, community and society (Bernstein Sideman et al., 2022; World Health Organisation, 2017). In 2017, following substantial advocacy from dementia associations around the world, the World Health Organisation (WHO) global action plan on the public health response to dementia was adopted by Member States (World Health Organisation, 2017). The overall vision of the action plan is “a world in which dementia is prevented and people with dementia and their carers live well and receive the care and support they need to fulfil their potential with dignity, respect, autonomy and equality” (World Health Organisation, 2017, p. 4). Seven key action areas are outlined in the action plan with targets to be achieved by countries in 2017 – 2025.

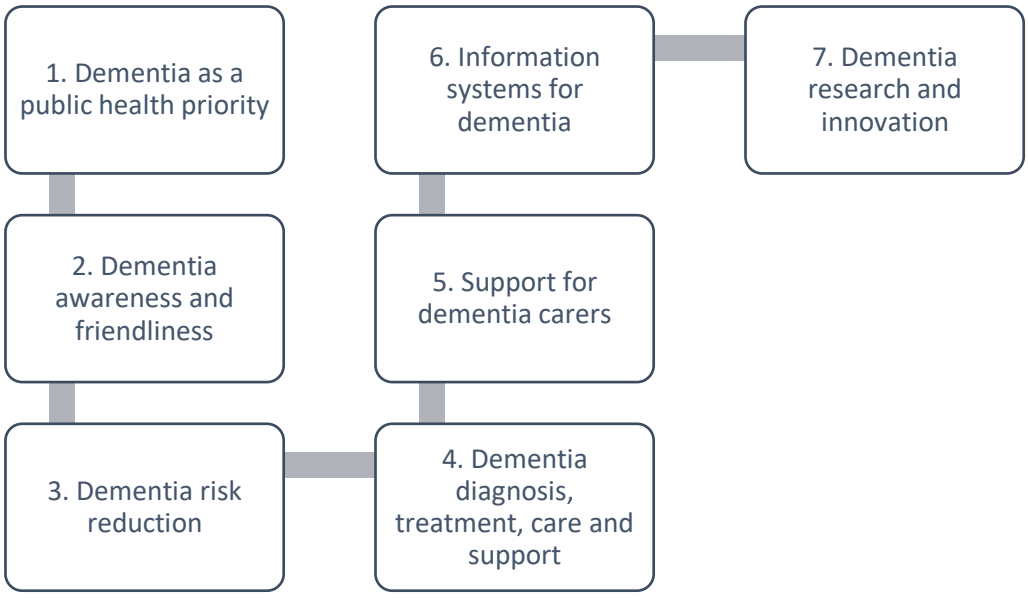

Figure 1-1: Key action areas (World Health Organisation, 2017)

Priority action area 4 is about dementia diagnosis, treatment, care and support. Within this action area, the World Health Organisation global action plan states that people with dementia require person centred health and social care, including access to rehabilitation programs to ensure maintenance of functional abilities (World Health Organisation, 2017). Dementia Clinical Practice Guidelines further emphasise this and recommend that people with dementia are supported to maintain independence by engaging in exercise, activities of daily of living and activities deemed to be important for the person with dementia (Laver et al., 2017). The challenge exists in that rehabilitation and therapeutic interventions specifically addressing the symptoms of dementia are not widely recognised nor routinely available (Cations et al., 2020). In addition, rehabilitation pathways specifically for people with dementia are not well established in comparison to other conditions, for example. neurological conditions such as stroke and acquired brain injury (Cations et al., 2020).

Goal setting is considered a fundamental aspect of rehabilitation (National Stroke Foundation, 2010; Wade, 2009) and has been identified as a means of enabling person centred health care (Levack & Siegert, 2014; Steele Gray et al., 2020; Turner-Stokes, 2009). The literature suggests however, that in people with dementia, due to changes in cognition and communication difficulties, goal setting is considered challenging (Thorpe, Forchhammer, & Maier, 2019), and that there are preconceptions about whether or not people with dementia can successfully engage in goal setting and successfully participate in rehabilitation programs (Cations et al., 2020; Mitchell, Harvey, Brodaty, Draper, & Close, 2016).

1.1 Research aim and study objectives

This thesis aims to examine the scope and validity of goal setting for people with mild cognitive impairment or dementia participating in rehabilitation programs. In order to do so the following two objectives were identified.

1) To describe existing approaches to goal setting for people with mild cognitive impairment or dementia participating in rehabilitation programs.
2) To examine whether people with mild cognitive impairment or mild severity dementia can measure progress towards goals and accurately report outcomes.

Two separate studies were completed to address the research aim and objectives. The first study involved conducting a scoping review to identify the extent and nature of available research pertaining to goal setting for people with mild cognitive impairment or dementia participating in rehabilitation programs. The second study is a quantitative research study examining the validity and responsiveness of goal attainment scaling when used with people with mild cognitive impairment or mild severity dementia.

These studies were completed to increase knowledge and awareness of goal setting for people with mild cognitive impairment or dementia participating in rehabilitation programs.

CHAPTER TWO: LITERATURE REVIEW

This chapter provides further background pertaining to the research completed in this thesis. As the research relates to mild cognitive impairment and dementia, an overview of population ageing, dementia and mild cognitive impairment is provided, including symptoms and recommendations for management. Understanding rehabilitation and goal setting is key in addressing the research aim. The chapter therefore discusses rehabilitation, providing a definition, explanation of the rehabilitation process and highlights its importance and relevance to person centred goal setting. The theoretical background of goal setting is discussed to enhance understanding of and implications of goal setting for people with mild cognitive impairment or dementia. Finally, the chapter explains the current pathway to access rehabilitation for hospitalised persons with dementia in Australia and a summary of identified gaps in the literature is provided.

2.1 Introduction

2.1.1 An ageing population

Population ageing is a global phenomenon and has implications for all sectors of society (Land & Lamb, 2008). It refers to a shift in the age structure of the population, whereby an increase in the number of older people compared to the younger population exists. Key reasons include a decline in fertility rates and improving life expectancy (Bloom & Luca, 2016). Whilst the proportion of older people is growing worldwide, population ageing is most prominent in Europe and Northern America with more than one in five persons aged 60 years or over in 2017 (United Nations, 2017). In Australia, 15% of Australians (3.8 million) were aged 65 years and over in 2017 and the number of older people is expected to more than double by the year 2057 (Australian Institute of Health and Welfare, 2021).

The ageing population presents several challenges for the health and welfare sectors as chronic diseases and disability are more common in older people (Australian

Institute of Health &Welfare, 2014). As people continue to live longer, the prevalence of disability increases, and several health concerns associated with ageing results in an increased demand for healthcare services such as hospital care. Dementia is one health condition associated with increasing age and age is one of the greatest known risk factors for dementia (World Health Organisation, 2021a).

2.1.2 An overview of dementia

Dementia is described as a progressive cognitive impairment that impacts on a person's ability to independently engage in everyday activities (American Psychiatric Association, 2013). Whilst dementia mainly affects older people, the cognitive decline associated with dementia exceeds that which is expected as part of the usual ageing process (World Health Organisation, 2021a). Worldwide there are currently more than 55 million people living with dementia. More specifically, in Australia there is an estimated 459,000 people living with dementia in 2020 (World Health Organisation, 2021a).

The presentation of symptoms in people with dementia varies amongst individuals however most common cognitive symptoms include memory loss, impaired communication, increased difficulty recognising objects or familiar people, impaired executive functions such as the ability to plan and manage daily tasks, and disorientation to place and time (Duong, Patel, & Chang, 2017). Typically the symptoms of dementia progress gradually through three stages which are classified as mild (early), moderate (middle), or severe (late) (Australian Institute of Health and Welfare, 2021). These stages further assist in understanding the signs and symptoms of the disease and are illustrated in Table 2.1.

Mild dementia	Moderate dementia	Severe dementia
• Mostly able to function independently • Occasional forgetfulness • Become easily confused • Poor judgement with planning and decision making • Loss of interest in previously enjoyed activities	• May require assistance in daily tasks • Greater memory loss • Increased confusion while at home • Behavioural changes including agitation, suspicious, change in sleeping pattern • Worsening of symptoms in the late afternoon (sun downing)	• 24/7 care and support with daily tasks • Extensive memory loss • Unaware of time and place • Difficulty recognising people • Difficulty walking • Behavioural changes including aggression

Table 2-1 Three stages of dementia: Signs and symptoms
(Australian Institute of Health and Welfare, 2021; World Health Organisation, 2021a)

Dementia is a leading cause of disability and dependency among older people and has significant social and economic implications (Rakesh, Szabo, Alexopoulos, & Zannas, 2017). There is currently no cure for dementia and research on the most effective ways to prevent dementia is building but still emerging (Livingston et al., 2020). According to the Lancet Commission 2020 report on dementia, risk factors for dementia include: less education (lower cognitive reserve), hypertension, hearing impairment, smoking, obesity, depression, physical inactivity, diabetes, low social contact, excessive alcohol consumption, traumatic brain injury and air pollution (Livingston et al., 2020). Some of these identified risk factors are modifiable, such as smoking, obesity, physical inactivity, less education, diabetes, hypertension, alcohol consumption and depression. Actions to address these may prevent or delay up to 40% of dementias worldwide (Livingston et al.,

2020) and positively impact social and economic sectors (Rakesh et al., 2017). A recent review of existing evidence on dementia prevention suggests that dementia prevention requires a multifactorial approach (Rakesh et al., 2017). Regular physical exercise, a healthy diet, reduced stress and improving vascular risk factors are suggested interventions to prevent cognitive decline (Rakesh et al., 2017).

For those living with dementia, the impact on individuals and society is widely acknowledged. In the absence of curative drugs, non-pharmacological approaches are recommended as best practice in managing symptoms of dementia and have shown improved outcomes (Laver et al., 2017). Currently, several non-pharmacological approaches exist. The Clinical Practice Guidelines for Dementia in Australia (Laver et al., 2017) recommends the following as best practice in managing symptoms of dementia:

1) Engaging the person with dementia in meaningful activities
2) Collaboration with the caregiver and family
3) Caregiver education
4) Capacity building in managing symptoms of dementia

In addition, the Lancet Commissions 2020 report recommends a holistic and individualised approach due to the complexity of care needs associated with dementia (Livingston et al., 2020). Most people will live for many years after a diagnosis of dementia (Brodaty, Seeher, & Gibson, 2012) highlighting the importance of embedding non-pharmacological approaches as standard practice and management for those living with dementia.

2.1.3 Mild cognitive impairment

Mild cognitive impairment is described as a decline in cognition (beyond age related expected decline) (Gauthier et al., 2006; Petersen, 2011). It is detected when someone performs outside of normal scoring range on a screening test but does not impact on a person's ability to engage in everyday tasks (Langa & Levine, 2014). Worldwide, approximately 12-18% of people aged 60 years or older are estimated to be currently living

with mild cognitive impairment (Alzheimer's Association, 2021) and there is a high risk for people living with mild cognitive impairment progressing to dementia (Petersen, 2016; Petersen et al., 2018). Approximately 8 -15% of people diagnosed with mild cognitive impairment will develop a diagnosis of dementia within a year highlighting the importance of early detection and management (Petersen, 2016).

Symptoms of mild cognitive impairment include changes in memory and thinking such as forgetting important dates, misplacing items and losing track of conversations (Petersen, 2011, 2016). However, mild cognitive impairment differs in presentation from dementia as people with mild cognitive impairment maintain the capacity to engage in everyday tasks independently and do not demonstrate other cognitive signs of dementia such as impaired judgement or reasoning (American Psychiatric Association, 2013). Due to the high risk of mild cognitive impairment progressing to dementia and known impact of dementia on an individual and society, early detection of mild cognitive impairment is deemed important (Petersen, 2016). According to the American Academy of Neurology Practice Guidelines on Mild Cognitive Impairment (Petersen et al., 2018), clinicians should use validated tools to assess for mild cognitive impairment and monitor cognition over time. Furthermore, clinicians should support patients and families in understanding their diagnosis, management strategies and possible prognosis (Petersen et al., 2018).

Whilst there is currently no specific pharmacological and non-pharmacological treatment for mild cognitive impairment supported by research evidence, the American Academy of Neurology guidelines recommend regular exercise (twice per week) and further state that cognitive interventions may support cognitive function (Petersen et al., 2018).

2.2 Rehabilitation

2.2.1 Defining rehabilitation

Literature suggests that there are varying opinions and understanding about rehabilitation (Wade, 2020b). For the purpose of this research study, the rehabilitation definition provided by the World Health Organisation (2011) will be used.

The World Health Organisation (2011) defines rehabilitation as *"a set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments"* (World Health Organisation, 2011, p. 96).

Rehabilitation can be provided in any setting and is a vital service for any individual with an acute or chronic illness (World Health Organisation, 2021b). Traditionally, rehabilitation was presumed to be an intervention targeted only towards people with certain conditions (such as spinal injury), however this notion is changing and globally the need for rehabilitation is increasing with growing evidence supporting the benefits of rehabilitation for both the individual and society (World Health Organisation, 2021b). The influential World Health Organisation Rehabilitation Plan (2030) was announced by the World Health Organisation in 2017 in response to increasing rehabilitation needs worldwide (Gimigliano & Negrini, 2017). The World Health Organisation Rehabilitation Plan (2030) presents a number of recommendations to strengthen rehabilitation services and encourages health systems to consider the way in which rehabilitation services are delivered across the continuum of care. Moreover, it aims to increase awareness of the unmet rehabilitation needs worldwide (Gimigliano & Negrini, 2017).

Rehabilitation has been described as a set of interventions that are tailored to an individual's priorities or goals (Wade, 2020b). It involves a comprehensive assessment and collaboration with the individual (and their significant others) in which goals are identified

specific to their needs, wishes and situation. These individualised goals form the basis for ongoing interventions.

Much research has been conducted to establish the core aspects of rehabilitation. According to Wade (2020b), involving an expert multidisciplinary team in the rehabilitation process is a key component for effective rehabilitation. Additionally, use of a biopsychosocial framework is strongly suggested and further compliments multidisciplinary teamwork (Wade, 2020a). The biopsychosocial model is an interdisciplinary model that examines the interplay between biological (genetics, physical health), psychological (mood, behaviour) and social factors (family, cultural, socioeconomic) in relation to health and illness (Borell-Carrió, Suchman, & Epstein, 2004). It was developed by Dr. George Engel and Dr. John Romana in 1977 who argued that a complex interaction exists between biological, psychological and social systems impacting on a person's health, illness and health care delivery (Engel, 1981). Engel proposed that whilst a person may have a predisposition for a medical illness, social and/or psychological factors may in fact contribute to and trigger the illness (Engel, 1981). The biopsychosocial model of illness was thus put forth in opposition to the traditional biomedical model approach to health and reflects a more holistic approach. This approach has been embedded in clinical practice (specifically in rehabilitation settings) and in 2002 was adopted by the World Health Organisation in developing the International Classification of Functioning framework (ICF) (Wade & Halligan, 2017). Evidence further suggests that the model has been widely used to support assessment and goal setting in rehabilitation; and promotes a person-centred approach to rehabilitation (Smith, Fortin, Dwamena, & Frankel, 2013; Wade & Halligan, 2017).

2.2.2 Process of rehabilitation

The rehabilitation process is best described in a recent review by Wade (2020a). It is a problem-solving process which can be defined in three steps, illustrated in Figure 2.1. In most settings, the first step in the rehabilitation process involves an initial assessment. The purpose of the initial assessment is to gain an understanding of the individual's situation, establish their usual level of function, and determine factors currently influencing their participation in everyday activities. The initial assessment is typically framed within the biopsychosocial model of illness as the framework enables information to be collected across all domains (biological, psychological and social). It provides a deeper understanding of the complexity of factors that may influence rehabilitation, which is pivotal in the assessment phase as they can greatly influence an individual's situation, may guide goal setting, and influence chosen interventions (Engel, 1981; Wade, 2020a).

After undertaking a comprehensive initial assessment, in the second step of the rehabilitation process, goals for rehabilitation are identified by the multidisciplinary team in collaboration with the individual receiving rehabilitation services. Goals are chosen based on the individual's wishes, needs and priorities. Once goals are agreed upon (in consultation with the individual), it is then necessary to plan the steps or actions required to achieve these identified goals. This is referred to as a goal planning (Levack & Siegert, 2014). The third step in the rehabilitation process involves implementation of interventions (tailored to the individual's specific needs and goals) in collaboration with the multidisciplinary team. A range of interventions have been identified in the literature including 1) task specific practice relating to functional activities, 2) exercise, 3) patient and family education on self-management, and 4) psycho-social support (Wade, 2020a, 2020b).

Finally, an important step in the rehabilitation process involves monitoring and/or revision. According to Wade (2020a) rehabilitation programs should be monitored regularly

to establish benefits of the intervention and to ensure that the intervention is not causing any harm to the individual. By regularly monitoring the intervention, one will be better able to determine progress towards goals and establish whether or not specific interventions should be adapted or ceased (Wade, 2020a).

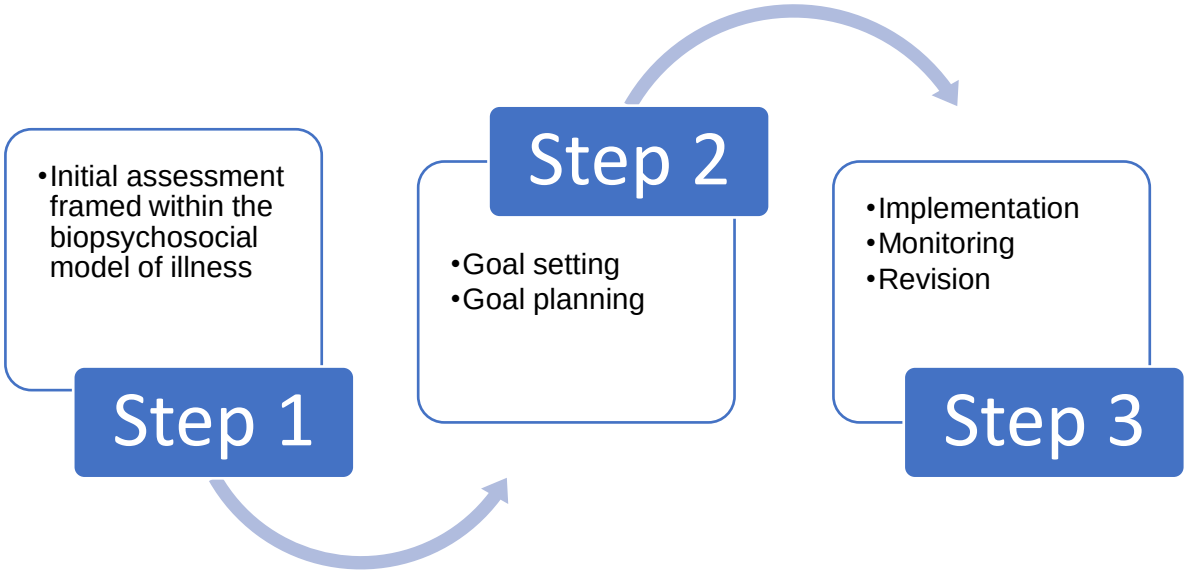

Figure 2-1 Illustration of the rehabilitation process as described by Wade (2020a)

2.2.3 Importance of rehabilitation

Rehabilitation aims to a) reduce the impact of disability, b) optimise participation in daily tasks c) reduce the need for hospitalisation, d) reduce the length of stay in hospitals and e) reduce the need for financial or caregiver support (World Health Organisation, 2021b). Several systematic reviews have reported on the effectiveness of rehabilitation for patients with multiple sclerosis (Amatya, Khan, & Galea, 2019), hip or joint replacements (Khan, Ng, Gonzalez, Hale, & Turner-Stokes, 2008), following surgery for lumbar spine stenosis (McGregor et al., 2013) and following exacerbation of chronic obstructive pulmonary disease (Puhan, Gimeno-Santos, Cates, & Troosters, 2016). In addition, a Cochrane systematic review assessing the effects of multidisciplinary rehabilitation for people with acquired brain injuries found that the process of rehabilitation (involving a multidisciplinary

team with skill and knowledge in neurological rehabilitation) improves outcomes for this population group (Turner-Stokes, Pick, Nair, Disler, & Wade, 2015).

Globally, universal access to rehabilitation has been recognised as a health priority (Heinemann et al., 2020; United Nations, 2015), and the World Health Organization is committed to increasing awareness of unmet rehabilitation needs worldwide as well as strengthening rehabilitation services (Gimigliano & Negrini, 2017). One of the proposed actions in raising awareness amongst policy makers is the need to demonstrate the efficacy of rehabilitation as a health intervention thereby advocating for ongoing research in this area. With regards to strengthening rehabilitation services, the World Health Organisation presents a number of recommendations such as a) a recommendation for rehabilitation systems to be included in all levels of health systems (primary, secondary and tertiary), b) a recommendation that hospitals have specialised rehabilitation units for inpatients with complex needs and c) that rehabilitation interventions must be based on an assessment of the patient's needs by a skilled multidisciplinary workforce (Gimigliano & Negrini, 2017). These recommendations encourage health systems to consider the way in which rehabilitation services are delivered across the continuum of care and to further consider how and where rehabilitation services are delivered to people with complex needs, including older people.

In summary, the importance and role of rehabilitation is well recognised. Global action is required to achieve rehabilitation aims, i.e. to reduce the impact of disability, reduce the need for hospitalisations, reduce the impact of burden on carers and to address unmet rehabilitation needs as highlighted by the United Nations and World Health Organisation (Gimigliano & Negrini, 2017).

2.2.4 Person-centred approach to rehabilitation

The terms patient-centred care and person-centred care are commonly used in health care settings and research into these concepts is widespread (Feldthusen et al., 2022). Patient-centred care is an approach in which the patient (recipient of medical care) is actively involved in decisions regarding their health and care is tailored to the individual's needs, preferences and values (Kuipers, Cramm, & Nieboer, 2019). This concept was further developed in recent years and the term person-centred care is currently used and encouraged (Ekman et al., 2011). Person-centred care is an approach whereby the person is viewed as a unique being and the focus of this approach is on the person and not their disability or condition (Santana et al., 2018). Person-centred care promotes a more holistic approach in which aspects such as a person's life experience, language, culture, beliefs and identity are considered (Håkansson Eklund et al., 2019). Within this approach there is a shift towards individualised care, empowering people to take control of their own health and supporting people to acquire the knowledge and skills to manage their own health. Additionally, adopting a person-centred approach in health care delivery has been recognised as a high priority (Santana et al., 2018).

According to the World Health Organisation (2022), a person-centred approach is key in achieving universal healthcare and health systems are urged to shift the focus of service delivery from a disease model to one in which the person is placed at the core. In 2007, Member States of the World Health Organisation endorsed a framework for person-centred health care to support governments in initiating action towards a person-centred approach. This shift in focus aims to enable a) equitable and quality care, b) individualised care, c) cost effective care and d) improve resilience and self-management of health care needs (World Health Organisation, 2022). Within this framework, the World Health Organisation highlights that action is required by all parties (individuals, families and

communities; health practitioners, health organisations and health systems) to achieve person-centred care in health care (World Health Organisation, 2022).

Most recently, Feldthusen et al. (2022) conducted a systematic overview of reviews relating to centredness in health care. The review describes a number of prerequisites to facilitate person-centred care including time (to build rapport with patients and/or significant others) and staff education/training (on empathy, communication skills, cultural sensitivity and shared decision making). Use of a care plan is further discussed as positively influencing person-centred care as care plans increase awareness of patients' preferences and goals (Feldthusen et al., 2022). Lastly, the Canadian Occupational Performance Measure (COPM), which is a standardised goal setting tool, is also described as facilitating person-centredness in healthcare as it enables collaboration between the patient and health professional when setting goals and increases awareness of the patient's values and preferences (Feldthusen et al., 2022).

2.3 Goal setting

2.3.1 An overview of goal setting

Goal setting has been defined as *"the establishment or negotiation of rehabilitation goals"* (Levack & Siegert, 2014, p 11) and is considered a key element of rehabilitation. It is the process of identifying something that a person wants to accomplish and establishing measurable actions and timeframes towards this (Wade, 2009). There is growing awareness and recognition of goal setting or goal planning methods in clinical practice with an emphasis on goal orientated interventions (Levack et al., 2015). For many health professionals, goal setting is considered standard practice in rehabilitation settings with national guidelines, such as the Clinical Practice Guidelines for Stroke, recommending goal orientated interventions (National Stroke Foundation, 2010).

Research into goal setting is believed to have commenced in the 1960's and goal setting became more prominent in rehabilitation in the 1980's (Levack & Siegert, 2014).

Several theories underpinning goal setting can be found in the literature, each playing a key role in supporting the development of goal setting.

2.3.2 Theoretical background

A summary of fundamental goal setting theories are presented below. The theoretical background of goal setting is key to improving our understanding of the mechanisms behind goal setting. In addition, an improved understanding enables us to better consider the implications of goal setting for people with mild cognitive impairment or dementia

2.3.2.1 Neuropsychology perspectives

Considerable research has been conducted in the neurosciences field to support goal setting. Neuropsychologists have played a significant role in identifying areas of the brain that are associated with goal directed behaviour and share the belief that goals are embedded in human behaviour. In reviewing the literature it is evident that executive functions, specifically the prefrontal cortex is critical in goal directed behaviour (Berkman, 2018). Executive functions are a set of cognitive skills that help to manage life tasks and allow us to a) stop and think before acting (self-control), b) monitor our thoughts, emotions and behaviour (self-monitor), c) initiate and plan tasks (task initiation and organisation), d) hold key information in our memory to complete a task (working memory), e) problem solve new complex situations (flexibility), f) regulate emotions (emotional control) and g) create steps to reach a goal (planning and time management) (Cristofori, Cohen-Zimerman, & Grafman, 2019). For example, executive functions enable us to plan and organise a holiday, arrive at work on time, get dressed in the morning and control our reactions to emotional situations. Deficits in executive functions impact on goal directed behaviour as goal directed behaviour requires the integration of skills across these cognitive domains.

Goal directed behaviour is described as a complex process in which we firstly identify and then work towards achieving a desired action or state (Duncan, Emslie,

Williams, Johnson, & Freer, 1996). For example, when preparing a dessert for a dinner party. The process of identifying a list of ingredients required and going to the grocery store with the view of obtaining the ingredients to prepare the dessert is considered goal directed behaviour.

Goal management training (Levine et al., 2000) is one approach to goal directed behaviour that is grounded in neuroscientific principles. It was developed by Ian Robertson in 1996 for patients with a traumatic brain injury, and is a structured standardised process aimed at training individuals to monitor and guide goal directed behaviour (Levine & Stamenova, 2018). Goal management training has five stages, and each stage relates to goal orientated behaviour. The overall aim is to train individuals to (1) *stop* and think about what they are doing, (2) *define* the goal of the task, (3) *list* and focus on the steps involved in achieving their goal, (4) *learn* and carry out each step. In stage five the individual is required to (5) evaluate that the outcome of their performance aligns with the identified goal *(check).* In the event of any inconsistency, the five steps are repeated. This strategy encourages you to stop and think during the steps of a task and to maintain the goal in memory whilst performing the task. It encourages you to break down the goal into manageable steps and to prioritise steps required to achieve the goal (Siegert, 2014).

Whilst in neuropsychology goal setting has mainly focussed on identifying the cognitive aspects of goal setting, as opposed to the establishment of goals (Siegert, 2014), it has played an important role in enhancing our understanding of goal setting in rehabilitation contexts. Neurocognitive perspectives highlight the importance and relevance of the frontal lobe in goal directed behaviour and there is validated evidence showing that incorporating goal management training into rehabilitation programs has been effective in individuals who have suffered traumatic brain injuries (Spikman, Boelen, Lamberts, Brouwer, & Fasotti, 2010; Tornås et al., 2016) and older adults experiencing cognitive changes (Levine et al., 2007; van Hooren et al., 2007).

2.3.2.2 Self-regulatory perspective

Self-regulation is a complex concept with a range of definitions (Mol et al., 2021). It has been described as self-management, self-monitoring and self-determination i.e. an active process which involves monitoring and guiding one's own behaviours, emotions, and thoughts (Levack & Siegert, 2014). Self-control and the ability to regulate one's behaviours is a cognitive process (executive function) which as described prior is required for directing goal directed behaviour. Self-regulation as a theory is grounded in applied psychology and considers how individuals decide to work towards their goals (Markus & Wurf, 1987). Self-regulation models indicate that three core components are involved within the self-regulation process. These include (1) *selecting the goal* (a decision needs to be made about what the person wants to do prior to self-regulation behaviour occurring), (2) *preparation of action* (this step involves planning the actions that need to be implemented to achieve the selected goal) and a (3) *cybernetic cycle of behaviour* (Markus & Wurf, 1987). The term cybernetic is used to describe behaviours of dynamic systems (Zhi, 2018). A cybernetic model or system consists of inputs, outputs and feedback loops. Within these systems, there is a monitor which compares what is happening within the system with what should be happening. If a discrepancy is picked up, a controller then adjusts the behaviour towards the desired outcome (Encyclopaedia Britannica, 2021).

One method of applying this theory to goal setting and rehabilitation is a model that was developed by Carver and Scheier (1998). Carver and Scheier's model of self-regulation is framed within the concept of a feedback loop.

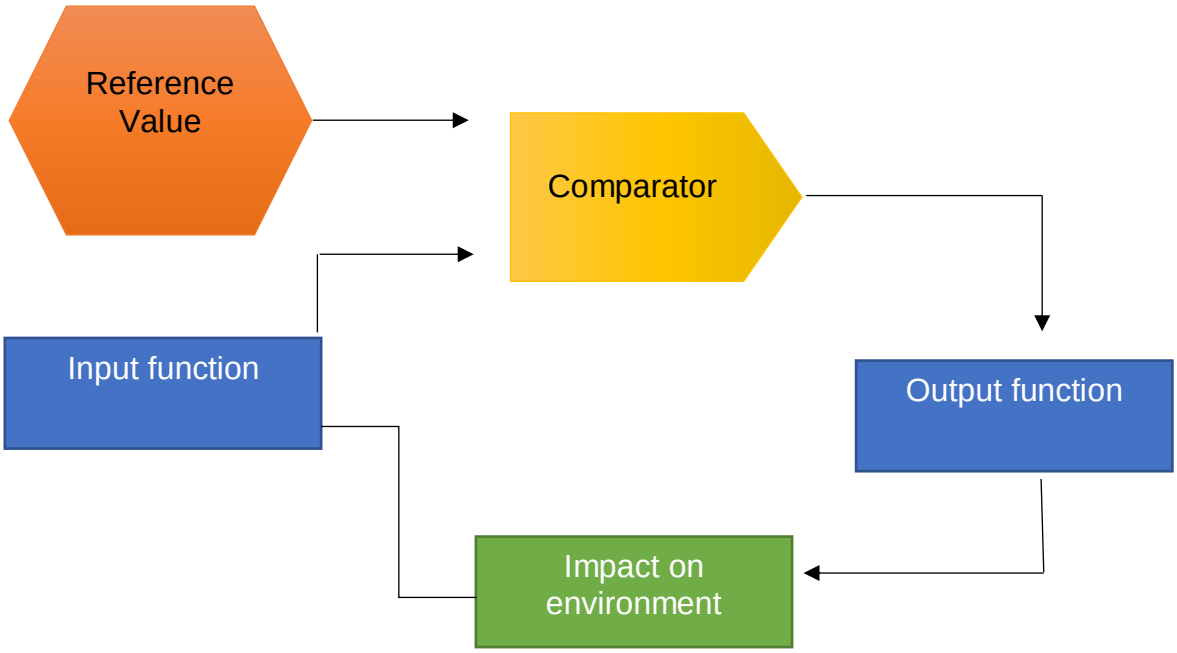

Figure 2-2 Self-regulation process based on Carver and Scheier's control theory (1998)

Within this model the goal is referred to as the *reference value* as all the action is directed towards this point (Levack & Siegert, 2014). According to Carver and Scheier (1998), one aspect of goal achievement is the need to evaluate one's current situation against the desired state (goal). Perception of current situation is referred to as an *input function*. Behaviour should then be modified to overcome this discrepancy *(output function).* Carver and Scheier (1998) explain that cognitive systems *(comparator)* enable one to compare the input (perception of current situation) with the reference value (end goal) and the system is then reliant on the output function to correct the discrepancy by adjusting one's behaviour.

Carver and Scheier (1998) further argue that individuals are working towards more than one goal at a time and a hierarchy of goals therefore exists which further impact on behaviour. Goals may range from abstract (higher grade) goals, such as goals related to systems, values and principles, to concrete (lower grade) goals, such as activities or tasks. This is an important consideration for clinicians in rehabilitation settings as whilst patients

may identify concrete rehabilitation goals (e.g. ‘to be able to walk to the toilet on my own’) they may also have more abstract goals (e.g. ‘I want to be healthy’) which they are evaluating themselves on, thereby modifying their behaviour (Levack & Siegert, 2014).

2.3.2.3 Self-efficacy and social cognitive theory

Self-efficacy and social cognitive theory are frequently used in rehabilitation and more specifically goal setting research (Levack & Siegert, 2014). Self-efficacy as proposed by Albert Bandura (1977) refers to an individual’s perception of their own capabilities to succeed at and/or accomplish a task. Self-efficacy is believed to be a motivator for goal setting. People are more likely to work towards their goals when they believe that they can achieve them and likewise are less likely to work towards goals if they do not believe that they can succeed (Locke & Latham, 2006). Self-efficacy is a key component in Bandura’s social cognitive theory which emphasises that behaviour is influenced by cognitive factors (Bandura, 1977).

Bandura’s social cognitive theory provides a framework for understanding human behaviour, factors that influence human behaviour and the process in which learning transpires (Bandura, 1977). It considers the unique ways that individuals acquire and maintain behaviour, while considering the social environment in which the behaviour occurs. Bandura (1977) argues that an individual’s behaviour is learned through observation of others and through this process individual’s start to take control of their behaviour. The social cognitive theory emphasises the importance of internal and external social influences and states that a reciprocal relationship exists between personal, environmental and behavioural factors (Bandura, 1977). It considers the interaction between person factors, such as a persons’ thoughts, emotions and cognition; and the environment that the person is in (physical or social), and how these interactions influence behaviour which in turn influences the environment. For example, when cooking personal factors influencing this behaviour may include previous experience in cooking, confidence

or self-efficacy in cooking and/or cooking skills. Environmental factors may include having a suitable kitchen to cook in and/or having someone to cook with, which may make the task more enjoyable. These personal and environmental factors influence behaviour as cooking may not be an enjoyable task if the physical environment is inappropriate to complete the task therefore resulting in the person not engaging in the task.

According to Bandura (1977), self-efficacy is one of the three factors influencing the relationship between behaviour and environment and self-efficacy is developed from four main sources of influence. These include 1) mastery experience (the experience that a person gains when they have been successful at a new challenge), 2) vicarious experience (experience gained from observing others successfully completing a task), 3) verbal persuasion (the reinforcement one gets when positive feedback is provided during a challenging task) and 4) physiological feedback (impact of one's emotional, physical and psychological well-being).

Bandura's social cognitive theory and findings in relation to self-efficacy provide insights into goal directed behaviour and given that goal directed behaviour is a large component of rehabilitation, it is no surprise that theories of behaviour play a role in goal setting and rehabilitation.

2.3.2.4 Organisational psychology perspectives

Organisational psychologists contributed significantly to understanding the impact of goal setting on human behaviour (Levack & Siegert, 2014). Whilst many of the research studies are based in work settings, they provide a sound theoretical background for goal setting in rehabilitation settings (Locke & Latham, 2002). Organisational psychologists Edwin Locke and Gary Latham conducted many studies looking at goal setting and its influence on human behaviour (Locke & Latham, 1990). Locke and Latham's goal setting theory was developed in 1960 and found that employees were more motivated when they were given goals that were clearly defined and challenging, and when provided with appropriate and

constructive feedback (Locke & Latham, 2002). Locke further found that challenging goals lead to higher performance as achieving a more challenging goal led to a greater sense of accomplishment (Locke & Latham, 1990, 2002). In 1990, Dr. Gary Latham conducted research into goal setting in the workplace and his findings supported those of Locke's. Locke and Latham then went on to outline the five principles for goal setting known as the goal setting theory.

According to Locke and Latham (1990), goal setting theory incorporates five principles for goal setting. Each principle is aimed at improving an individual's chance of success in achieving the goal.

Figure 2-3 Principles of Goal setting as proposed by Locke and Latham (1990)

The first step is 'clarity', referring to the importance of setting clear and specific goals. This step is built on the notion that setting clear goals assists in understanding what you are trying to achieve. Setting clear goals further allows you to measure your progress towards the intended outcome and has been deemed to be an important component in goal setting approaches such as goal attainment scaling and the SMART approach to goal setting (Doran, 1981; Turner-Stokes, 2009). The second principle is 'challenge'. Locke and Latham found that if a goal is too easy to achieve there is a lack of motivation towards this

goal. In addition to this, goals that are too easy do not encourage people to increase their performance. Similarly if goals are perceived as too challenging it may discourage participation (Locke & Latham, 1990). The third principle is 'commitment'. Commitment is an important aspect of working towards a goal and according to Locke and Latham, performance is at its peak when people are committed (Locke & Latham, 1990). The fourth principle discusses the importance of 'feedback'. Feedback is important to continue to motivate someone to work towards their goal. Locke and Latham argue that if a person does not know how they are doing, it is difficult to adjust or modify the effort/strategies towards the goal (Locke & Latham, 2002). Lastly, the final principle is 'complexity'. For a task to be motivating it must not be too complex, indicating that the goal should be achievable. If goals are too complex it might be overwhelming. For example, one approach is to break down complicated tasks into sub-tasks thereby making it more achievable.

In summary, Locke and Latham's goal setting theory implies that goal setting, when completed appropriately, can be an important means of improving motivation and productivity (Locke & Latham, 1990). It focusses on the fundamental principles (i.e. clarity, challenge, commitment, feedback and complexity) required for setting an effective goal and how these principles impact on motivation and goal directed behaviour. This is different from other presented theories, such as the social cognitive theory for example, focusing on the impact of human behaviour on goal directed behaviour. Both theories however note the importance of self-efficacy and the role it has as a motivator for goal directed behaviour and goal commitment (Locke & Latham, 2002).

2.3.2.5 Summary

The theories discussed were specifically chosen as they provide a more in depth understanding of the various mechanisms behind goal directed behaviour and also provide strategies and/or principles which may be useful to consider for people with mild cognitive impairment or dementia in rehabilitation settings.

2.3.3 Known effects of goal setting

Literature suggests that patients, families, and carers became actively involved in goal setting around 1999 and several benefits to goal setting are reported (Levack & Siegert, 2014). Research by organisational psychologist's Edwin Locke and Gary Latham described the impact of goal setting on human behaviour (Locke & Latham, 1990). Locke and Latham (1990) found that goal setting improves task performance by positively influencing motivation (Levack et al., 2006). Goal setting has also been found to improve communication and collaboration in teams, assist in setting expectations, evaluate progress and support patients to adapt to their new disability (Levack et al., 2015; Plant, Tyson, Kirk, & Parsons, 2016; Sugavanam et al., 2013).

2.3.4 Goal setting approaches

In 2006, Levack et al. (2006) conducted a review of existing literature on goal planning in rehabilitation. The identified literature was qualitatively synthesised and it was suggested that goal setting in rehabilitation is commonly undertaken to (1) improve patient outcomes (with use of standardised outcome measures), (2) improve patient autonomy, (3) evaluate outcomes and to (4) uphold contractual, legislative or professional requirements (Levack et al., 2006).To date, a broad range of approaches to goal setting in rehabilitation have been identified in the literature, providing clinicians with an opportunity to carefully consider which approach may be most suitable for their specific client population or purpose. Some examples of goal setting approaches include Goal Attainment Scaling (GAS) (Kiresuk & Sherman, 1968), the Canadian Occupational Performance Measure (COPM) (Law et al., 1990), the Self- Identified Goal Assessment (SIGA) (Melville, Baltic, Bettcher, & Nelson, 2002), SMART goal planning (Doran, 1981), and Goal Management Training (GMT) (Levine et al., 2000).

In reviewing goal setting methods, Levack and Siegert (2014) highlighted a number of differences in goal setting approaches. One example is the fact that goal attainment

scaling and SMART goal planning can be used across a number of professional groups, whereas the COPM and SIGA are discipline specific and intended for use by occupational therapists only (Law et al., 1990; Melville et al., 2002; Turner-Stokes, 2009). Also, goal attainment scaling requires goals set to be objective, to measure goal attainment, whereas when using the COPM goals are set within occupational domains and are self-rated by patients (Law et al., 1990; Turner-Stokes, 2009). When selecting a goal setting approach it is therefore necessary to consider factors such as a) the purpose of goal setting, b) the patient population engaging in goal setting and c) the professional person/group using the goal setting approach (Levack & Siegert, 2014).

2.3.4.1 Goal attainment scaling

Goal attainment scaling is one approach to goal setting that has been well-researched and applied in several areas of rehabilitation (Ashford & Turner-Stokes, 2014; Rockwood, Stolee, & Fox, 1993; Rushton & Miller, 2002; Stolee, Stadnyk, Myers, & Rockwood, 1999; Williams & Stieg, 1986). Goal attainment scaling is unique in its approach as it offers a means of quantifying goal achievement as opposed to measuring improvements in function only, as per standardised outcome measures, such as the Functional Independence Measure (FIM)(Turner-Stokes, 2009). Goal attainment scaling is thus a useful measure in certain clinical populations whereby expected improvements in overall function may be limited due to the nature of the disease or injury i.e. people with dementia and was therefore examined further.

Goal attainment scaling was first introduced in the 1960s by Kirusek and Sherman and provides a structured method of goal setting and measurement (Kiresuk & Sherman, 1968). Literature indicates that the application of goal attainment scaling has transformed since it was first introduced. The approach described by Ashford and Turner-Stokes (2006) will be used for the purpose of this research study. It outlines five components to goal attainment scaling:

1. The first step *(identification of goals)* is about establishing goals for rehabilitation with the patient and/or carer and is a key feature of this method. Goals should follow the SMART goal planning principle i.e. they should be specific, measurable, achievable, realistic and timed (Turner-Stokes, 2009). There is no restriction on the goals being set and the therapist uses clinical reasoning and evidence-based knowledge to predict the expected outcome.

2. Possible outcomes *(defining expected outcomes)* for each goal are then objectively defined on a 5-point scale as illustrated in Figure 2.4 and a baseline score is established.

-2	-1	0	+1	+2
Much worse	Somewhat worse	Expected outcome	Somewhat better	Much better

Figure 2-4 Goal attainment scaling 5-point scale (Turner-Stokes, 2009)

A score of 0 indicates that the goal has been achieved at the expected level. If a better-than-expected outcome is achieved, this is scored +1 (somewhat better) or +2 (much better). A score of -1 (somewhat worse) or -2 (much worse) indicates that the person has achieved a worse than expected outcome.

3. *Baseline scoring:* Identified goals are objectively defined on the 5-point scale prior to intervention and according to Turner-Stokes (2009) the therapist must discuss the goals with the patient and/or family prior to the intervention to ensure understanding, mutual agreement and to set realistic expectations. When defining the baseline score, Turner-Stokes (2009) report that this score should be rated as -1 (somewhat worse) unless the patient is at the lowest possible level, indicating a baseline rating of -2 (much worse).

4. *Weighting of goals:* An additional aspect of the goal attainment scaling approach is the ability to assign a weight to goals. Patients may identify some goals as more important than others and some goals may also be identified as more difficult than others to achieve, leading to weighting of goals. Goals can be weighted to take account of the importance of the goal to the patient and or difficulty that the team anticipates in achieving it (Turner-Stokes, 2009). Goals are weighted on a 4-point scale outlined in Figure 2.5.

Importance	Difficulty
0 = not at all important	**0 = not at all difficult**
1 = a little important	**1 = a little difficult**
2 = moderately important	**2 = moderately difficult**
3 = very important	**3 = very difficult**

Figure 2-5 Importance and difficulty 4-point scale (Turner-Stokes, 2009)

5. The final step of the goal attainment approach involves reviewing patients at the end of the intervention, using the scale of possible outcomes (Figure 2.4), to establish an achieved score *(goal attainment).* An overall goal attainment score can then be determined by applying a formula (Kiresuk & Sander, 1978) or by using a published goal attainment scaling calculation sheet (Appendix G) (Turner-Stokes, 2009). A mean goal attainment score of 50 indicates overall goal attainment at the expected outcome level. Scores greater than 50 (with a standard deviation of 10) indicate a better-than-expected outcome and scores less than 50 indicate a less than expected outcome (Chew, Chong, Fong, & Tay, 2015; Turner-Stokes, 2009).

One benefit of this approach to goal setting is that goal attainment scaling enables goals to be tailored to an individual's ability (within a structured format) and measures goals that are important to the patient and/or carer, which aligns with person-centred practice Turner-Stokes (2009) further argue that this method of goal setting, i.e. clearly defining goals prior to intervention, ensures that everyone involved has realistic expectations of what is likely to be achieved and provides the multidisciplinary team an opportunity to negotiate what can realistically be achieved (if the identified areas for treatment are unrealistic). It promotes sharing of information, collaboration and communication which are key factors in goal setting and rehabilitation.

2.4 Rehabilitation and goal setting for people with mild cognitive impairment or dementia

2.4.1 Access to rehabilitation

There is a growing body of literature supporting access to rehabilitation programs for people with dementia (World Health Organisation, 2017). According to a summary report on dementia in Australia, older people with dementia are frequent users of health services (Australian Institute of Health and Welfare, 2021). Reports indicate that in 2018-2019, dementia was listed as influencing a person's care in 78 500 hospitalisations in Australia. People with dementia were found to require hospital services for a diverse range of reasons. When examining why people with dementia required a hospital admission, it was found that common principal diagnoses included fractures (femur, lumbar, spine and pelvis), delirium, urinary disorders, respiratory and cardiovascular diseases, signs and symptoms involving the nervous and musculoskeletal systems, and sepsis. Where fractures were listed as the principal diagnosis (and dementia listed as an additional diagnosis), 97% of these hospitalisations were reported to be due to falls (Australian Institute of Health and Welfare, 2021). For those requiring rehabilitation, findings show that many older persons are admitted to Geriatric Evaluation Management (GEM) settings and

are categorised as having complex care needs due to multiple comorbidities (Dutzi, Schwenk, Kirchner, Bauer, & Hauer, 2019).

2.4.2 What is geriatric rehabilitation?

According to the American Psychology Association (2022), geriatric rehabilitation is defined as: *"The process of using somatic therapies (e.g., occupational therapy, physical therapy) to restore to the fullest extent possible the functional abilities of older adults following an illness or injury that resulted in lost or diminished independence* (American Psychological Association, 2022, p. para 1)". Literature suggests that older persons in geriatric rehabilitation settings have specific needs due to ageing and present with specific characteristics such as pre-existing comorbidities and cognitive impairment. Furthermore older persons are admitted to geriatric rehabilitation settings with a range of reasons for admission and require varying interventions (Achterberg, Cameron, Bauer, & Schols, 2019). One person may be admitted with a hip fracture following a fall and require intervention such as physiotherapy before returning home, whilst someone else may present with pre-existing Parkinson's disease and a fall resulting in a fracture, thereby requiring a varying pathway and approach to rehabilitation (Achterberg et al., 2019).

In most subacute geriatric rehabilitation settings, common practice involves the multidisciplinary team working together to firstly establish a person's usual level of function and care priorities. Given the high risk of secondary complications such as delirium, pressure ulcers and falls following a hospital admission for this clinical population, initial care priorities are aimed at preventative strategies including delirium and pressure care management (Achterberg et al., 2019). Goals for rehabilitation are then identified with the overall aim of optimising functional independence and quality of life. It is well known that goal setting is a key aspect of rehabilitation, however for people with dementia, findings suggest that individualised and collaborative goal setting is deemed challenging (Dutzi et al., 2019). In addition to this, rehabilitation for persons with dementia experiencing acute

injuries may not be routinely provided, or viewed as relevant by health professionals, due to preconceptions about the person with dementia's ability to participate (Cations et al., 2020).

2.4.3 Barriers to rehabilitation for people with dementia

When interviewing health professionals to ascertain their views on rehabilitation for people with dementia, Cations et al. (2020) found that allied health professionals had difficulty defining rehabilitation goals for this clinical population due to the progressive nature of the condition and perceived barriers to participation. Many allied health professionals identified impaired cognition as a significant barrier to people with dementia participating in rehabilitation programs, specifically the inability to carry over information learnt from one session to another and impaired insight into one's capabilities. Cations et al. (2020) reported that allied health professionals feel a sense of professional accomplishment when patients achieve positive and measurable outcomes. Yet, given the progressive nature of dementia, similar outcomes were not perceived to be achievable by this population. People with dementia were therefore viewed as a lower priority for therapeutic intervention (Cations et al., 2020). Other barriers to rehabilitation for people with dementia have been reported in the literature including lack of resources such as skilled staff, lack of time to manage the symptoms of people with dementia and lack of understanding about dementia (Hall, Burrows, Lang, Endacott, & Goodwin, 2018).

In spite of known and/or perceived barriers to people with dementia or mild cognitive impairment participating in rehabilitation programs, dementia remains a National health priority in Australia (World Health Organisation, 2017).

2.4.4 Examining the way forward

Evidence suggests that people with dementia can benefit from rehabilitation programs following acute injuries (Resnick et al., 2016; Seitz et al., 2016) and non-pharmacological approaches are recommended as best practice to support with managing symptoms of

dementia (Laver et al., 2017). Most recently, Ries (2022) introduced a framework for rehabilitation for older adults living with dementia. The framework provides practical and evidence-based suggestions for working with people who have dementia and is tailored towards physiotherapists. It is a dynamic framework in which the specific and unique needs of people with dementia are considered and provides evidence based recommendations to achieve therapeutic success (Ries, 2022). Within this framework, strategies such as building a relationship through person centredness, communicating purposefully both verbal and non-verbal, setting goals and prioritising a therapeutic environment are highlighted as key in supporting rehabilitation for people with dementia (Ries, 2022). Without a doubt these strategies align with the overarching call for an individualised approach to rehabilitation and goal setting for people with dementia.

2.5 Summary

This chapter has provided further background supporting the rationale behind this thesis and outlines goal setting as an important aspect of rehabilitation. The chapter illustrates that people with dementia or mild cognitive impairment require an individualised approach to rehabilitation due to the intricacies of the disease and further demonstrates that the extent to which people with dementia are engaged in setting goals for their rehabilitation is unknown. Current literature indicates that people with mild cognitive impairment or dementia can engage in goal setting, however further information is required to establish goal setting methods used. The next chapter presents a scoping review of goal setting for people with mild cognitive impairment or dementia participating in rehabilitation programs.

CHAPTER THREE: GOAL SETTING FOR PEOPLE WITH MILD COGNITIVE IMPAIRMENT OR DEMENTIA IN REHABILITATION: A SCOPING REVIEW

This chapter addresses the first research objective of the thesis which is to describe approaches to goal setting for people with mild cognitive impairment or dementia participating in rehabilitation programs. The findings of a scoping review which was conducted and published in the Australian Occupational Therapy Journal is presented (Refer to Appendix C).

As the primary review author, the candidate contributed to 80% of the paper with support from co-authors and supervisors MR, KL and MB to develop the scoping review protocol and establish the methodological framework. The search strategy was developed with support from supervisor (MR) and translated to the other search engines by the candidate in consultation with a medical research librarian. The candidate and supervisor (MR) completed screening of abstracts and all three supervisors (MR, KL & MB) contributed to screening of full text articles. The candidate completed data extraction with supervisor (MR) checking extracted data to ensure accuracy. All supervisors and co-authors contributed to writing, editing and reviewing the final paper.

Minor changes were made from the published article to ensure consistency within the thesis.

3.1 Introduction

People with mild cognitive impairment and dementia have not traditionally been offered rehabilitation programs to address their symptoms and associated impairments (Cations et al., 2020). In addition, people with dementia have often been excluded from rehabilitation programs for comorbidities, such as a hip fracture (Mitchell et al., 2016). However, there is increasing recognition of the importance and relevance of rehabilitation for this population. The World Health Organisation (WHO) global action plan for dementia states that people with dementia require access to rehabilitation to ensure maintenance of functional abilities (World Health Organisation, 2017). It further emphasises the need for person-centred healthcare, suggesting that care and rehabilitation programs should address goals which are important to the person with dementia.

Goal setting is a critical step for someone commencing a rehabilitation program (Wade, 2009). Setting goals facilitates collaboration between the person receiving rehabilitation services, family and occupational therapist and ensures that therapy is focussed towards a desired and meaningful outcome (Burton, O'Connell, & Morgan, 2016). Research suggests that participation in rehabilitation is enhanced if the goals set are meaningful (Rose, Ashford, Singer, & Turner-Stokes, 2015). Importantly, goal setting increases motivation to participate, allows for a shared and explicit understanding of rehabilitation between key stakeholders (Wade, 2009) and is considered best practice (National Stroke Foundation, 2010).

Australian occupational therapy competency standards (Occupational Therapy Board, 2019) outline an expectation that the therapist collaborates with the client and relevant others to identify enablers and barriers to engagement, establish priorities and develop client centred goals (Occupational Therapy Board, 2019). This competency applies to all population groups including those with mild cognitive impairment or dementia and all settings including community based or inpatient rehabilitation services.

Although goal setting is considered an integral part of rehabilitation, the process is complex and several barriers to goal setting have been identified. A systematic review of goal setting for people with stroke and acquired brain injury showed that patient-level, staff-level and organisational-level barriers exist (Plant et al., 2016). Patient-level barriers included cognitive impairment, communication impairment, mood disorder, reduced insight into capabilities and deficits, presence of comorbidities and lack of knowledge about the condition. Staff and organisational-level barriers included insufficient time, lack of confidence in managing patient's expectations and difference in opinion between patient and staff's perspectives. People with mild cognitive impairment or dementia may experience many or all of these issues which could contribute to further complexity in goal setting. However, barriers can be overcome and despite common preconceptions that people with dementia cannot set rehabilitation goals, a recent study (Dutzi et al., 2019) shows that goal setting for people with dementia is feasible and that people with dementia or mild cognitive impairment are able to identify goals with the assistance of a structured approach. Furthermore, individualised, goal-orientated rehabilitation programs for this population offer the potential to assist in reducing functional disability and maintaining well-being (Clare, Evans, Parkinson, Woods, & Linden, 2011).

Whilst there is accumulating evidence regarding the use and importance of goal setting in dementia, the breadth and extent of literature has not yet been synthesised. As such there is limited awareness of how best to facilitate goal setting in this clinical population. The aim of this scoping review was to identify the extent and nature of available research pertaining to goal setting for people with mild cognitive impairment or dementia participating in rehabilitation programs. The specific questions posed for this review were:

For people with mild cognitive impairment or dementia:

- Which goal setting approaches are used to facilitate goal setting in rehabilitation programs and in what context does this occur?
- What are common rehabilitation goals identified in rehabilitation research studies?
- What are the enablers and barriers to goal setting that have been reported in the literature?
- What are the outcomes of goal setting for people with mild cognitive impairment or dementia participating in specific rehabilitation programs?

3.2 Methods

We used the Arksey and O'Malley (2005) methodological framework as a guide to undertaking the scoping review. A protocol for this scoping review was developed 'a priori' following the template developed by PROSPERO International Prospective Register of Systematic Reviews (National Institute for Health Research, 2020)(Appendix B). No changes were made to the protocol during the review. The review is reported according to the PRISMA extension for scoping reviews (Tricco et al., 2018).

3.2.1 Eligibility criteria

Population

Studies including people with mild cognitive impairment or dementia were included if they were participating in an intervention which had a rehabilitation focus. This may have been called reablement or restorative care in the original paper. Studies including people with cognitive impairment related to stroke or other conditions that may elicit sudden onset of cognitive impairment were excluded from this review. No age limit was imposed on the study population.

Intervention

Studies describing goal setting processes as a formal or informal part of a rehabilitation program or process were included. Rehabilitation in the context of this review was conceptualised as *"a set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments"* (World Health Organisation, 2011, p. 96).

No restrictions were placed on region or country, and no restrictions were placed on care provision setting (i.e. community or care facility) or care professional (i.e. occupational therapy or physiotherapy or multidisciplinary) to broaden the scope of the identified literature.

Study design

Studies of any design were included if they presented original data related to goal setting for people with mild cognitive impairment or dementia. Systematic reviews, study protocols, conference proceedings, editorials and commentary papers were excluded.

Outcome

We included studies which reported on all outcomes of goal setting. As per the review questions, we examined the context in which goal setting is occurring, approaches to goal setting; and which professionals are involved. We aimed to identify common goals identified by people with mild cognitive impairment or dementia as well as the enablers and barriers to goal settings. And finally, we examined the outcome of goal setting for people with mild cognitive impairment or dementia.

3.2.2 Search strategy and selection process

Searches of CINAHL, MEDLINE, Embase and PsycINFO were conducted on 23rd April 2020, with restriction to English articles published in the last 10 years to reflect contemporary literature. The search strategy was developed in MEDLINE prior to being translated for the other search engines. Search terms included words associated with goal

setting approaches and people with mild cognitive impairment participating in rehabilitation programs. The MEDLINE search strategy can be found in Appendix A.

The first two authors independently screened titles and abstracts of studies retrieved from the searches. Full text copies of studies identified as potentially eligible were obtained and imported into an online tool, Covidence (2020). Covidence allowed all authors to easily contribute to the full-text screen whereby each article only required review by two authors to be included in the review. Conflicts were resolved by discussion and/ or engaging with a third review author. Reasons for excluding studies were documented. Furthermore, hand searching of reference lists was used to identify potential additional studies.

3.2.3 Data charting and risk of bias assessment

The first review author (PJ) extracted data independently using a data extraction tool developed in Microsoft Excel with the second review author (MR) checking extracted data for accuracy. Any discrepancies identified were resolved through discussion, or consultation with a third review author when necessary. The data extracted included descriptive data about the study methodology, study design, participants, intervention, and outcomes relating to the review questions. A narrative synthesis of the results is presented.

Risk of Bias and Quality of individual studies was independently assessed by two authors (PJ and MR) using the Mixed Methods Appraisal Tool (MMAT) (The University of Sheffield, 2018). The MMAT allowed for appraisal of the methodological quality of several study types (qualitative research, randomized controlled trials, non-randomized studies, quantitative descriptive studies, and mixed methods studies) and focussed on the core quality criteria for each type. Each included study was principally appraised according to the study design used. If mixed evaluation methods were used within the study, then the study was also appraised according to those criteria using three items of the MMAT (The University of Sheffield, 2018). For example, the study by Clare et al. (2019b) was a

randomised controlled trial incorporating mixed evaluation methods. As such, the study was appraised according to the criteria for randomised controlled trials, qualitative and mixed methods studies. Given the heterogeneity expected in the included studies, we considered this the most efficient appraisal tool.

3.3 Results

As outlined in Figure 3.1, the search identified 11546 references, of which 2970 duplicates were removed. Of the remaining 8576 titles that were screened by title and abstract, 8503 were excluded. Seventy-three full text reviews were completed, and 26 studies met the inclusion criteria. We identified an additional study through searching reference lists and therefore a total of 27 studies were included in the review.

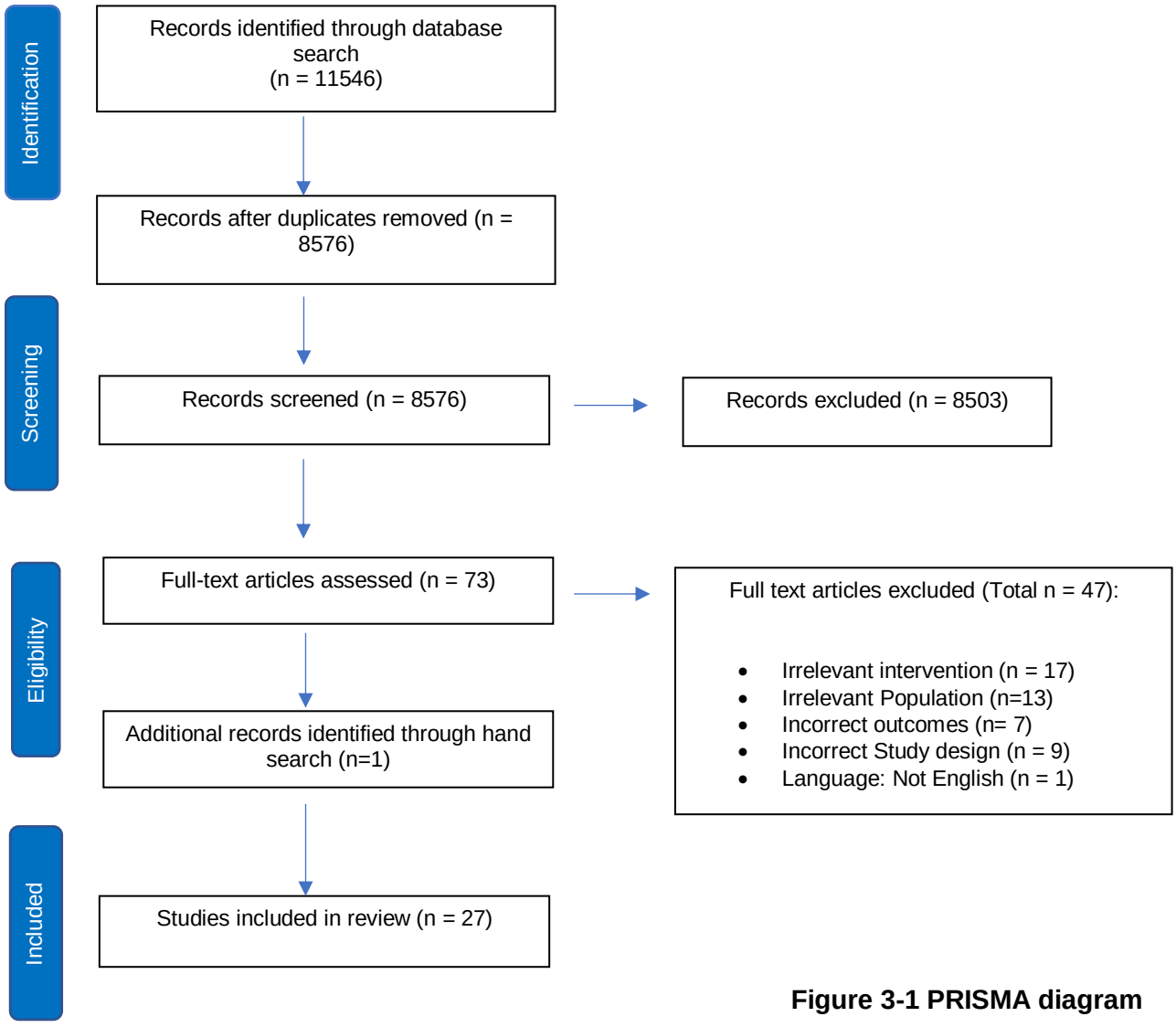

Figure 3-1 PRISMA diagram

3.3.1 Overview of included studies

We identified seven randomised control trials incorporating goal setting for people with mild cognitive impairment or dementia participating in rehabilitation programs (Burton & O'Connell, 2018; Clare et al., 2019a; Clare et al., 2019b; Clare et al., 2010; Hindle et al., 2018; Lu et al., 2016; Regan, Wells, Farrow, O'Halloran, & Workman, 2017). The remaining studies were predominantly pre-post evaluations, or observational studies. Nine studies used mixed methods evaluation methods (Allan et al., 2019; Berwig, Dinand, Becker, & Halek, 2020; Chenoweth et al., 2016; Clare et al., 2019a; Clare et al., 2019b; Jennings, Ramirez, Hays, Wenger, & Reuben, 2018; Lu et al., 2016; O'Sullivan, Coen, O'Hora, & Shiel, 2015; Oksnebjerg et al., 2019) and four studies used qualitative methods (Hall et al., 2018; Khayum & Wynn, 2015; Regan, Wells, & O'Halloran, 2019; Rodakowski et al., 2018b) of which two described case studies (Khayum & Wynn, 2015; Rodakowski et al., 2018b).

Much of the research was conducted in high income countries with eight studies in the United Kingdom (30%), six in the United States of America (22%), four in Australia (15%), two in Denmark (7%), two in Germany (7%), two in Ireland (7%) and one each in Canada (4%), New Zealand (4%) and Singapore (4%). Table 3.1 presents the study characteristics including participant demographics and where the research was conducted. Studies included people with dementia (n=16), mild cognitive impairment (n=8) or a combination of people with mild cognitive impairment and dementia (n=3). Few studies reported dementia severity however those with mild dementia (Clare et al., 2019a; Clare et al., 2019b) to more severe dementia (Chenoweth et al., 2016) were included. The study sample ranged from one to 475 and more than half of the studies (55%) included people with dementia without direct involvement of the family or caregivers specified. Of the 27 studies, 10 (37%) included participants with mild cognitive impairment or dementia and their caregivers and only two (7%) studies included caregivers only.

Table 3-1 Study characteristics

Author, year and country	Study design and participants	Context for goal setting	Goal setting approaches used	Common goals identified	Enablers and barriers to goal setting	Outcomes related to goal setting
Allan (2019), United Kingdom	Mixed methods evaluation including testing of feasibility 11 PwD living at home	Developing an Intervention for Fall Related Injuries in Dementia (DIFRID): A tailored program of activities centred on goals identified with the PwD and their carer over a 12-week period (up to 22 sessions). The purpose is to improve fall-related injuries in PwD living in their own homes.	Goals were identified by PwD and carers (refined by the MDT if needed). Goals were agreed on at the first intervention session, including completion of the GAS and introduction of project diary. If PwD struggled to identify goals, the MDT would insert default goals which were not identified by the PwD.	Participation in outdoors activities (n=12), completing self-care (n=7), undertaking indoor household tasks (n=5), doing indoor leisure activities (n=3).	Enablers: The GAS format allowed breaking down one's goals and enabled participants to document goal attainment progress. Barriers: PwD with more severe impairment had difficulty understanding the goal-setting purpose or retaining goals, resulting in poor success. Lack of skill or experience of staff led to difficulty setting SMART goals.	While goal performance was achieved by participants (as measured on GAS), the importance and difficulty ratings of goal achievement was poorly completed.
Berwig (2020), Germany	Mixed methods evaluation of pre-post study	Participation in MM counselling provided by a certified therapist experienced in using MM	GAS was completed together with carer, person with bvFTD and the MM therapist. It was used to set objectives for the counselling and to	Reducing carer stress, improving mood during interactions and ability to relax for person with bvFTD, improving carer insight and confidence.	Enablers: Carer's acceptance of their relative's dementia. Barriers: Not discussed.	Carers were able to achieve their goals as expected, or better than expected (as

Author, year and country	Study design and participants	Context for goal setting	Goal setting approaches used	Common goals identified	Enablers and barriers to goal setting	Outcomes related to goal setting
	5 Persons with bvFTD and their carers	technique. The MM approach uses video feedback to strengthen the intuitive capability of the carer to communicate with the person in their care. Counselling was provided face to face in the participant's home weekly over 5 weeks. No time-limit imposed on sessions, they lasted until content was complete.	assess the extent to which the primary carer of the person with bvFTD was able to reach these objectives.			measured on GAS).
Burton (2018), Canada	RCT 4 Participants with AD, MCI and	Goal-oriented CR using telehealth videoconferencing compared with in-person CR. Both	Participants were asked to identify 2 CR goals, and these were collaboratively set during their initial assessment.	Keeping track of date and time, remembering names of close family and friends, as well as day-to-day events (such as what was	Enablers: Not discussed. Barriers: Setting several goals may have meant that there was	While goal performance improved across both treatment delivery

Author, year and country	Study design and participants	Context for goal setting	Goal setting approaches used	Common goals identified	Enablers and barriers to goal setting	Outcomes related to goal setting
	subjective cognitive impairment (self-reported)	were provided for 1 hour, once a week, for 8 weeks. Initial assessment in both groups was conducted in-person.	Their baseline performance and satisfaction related to these goals were measured using the COPM.	said in a book or newspaper, or what had done earlier in the day).	contamination between these goals when the purpose was only to work on one goal at a time.	modalities, of the total of 15 goals set, performance on only two goals did not improve by 2 or more points on the COPM. These were with participants in the telehealth group.
Chenoweth (2016), Australia	Mixed methods evaluation of a pre-post study 91 family carers of people with a moderate to severe dementia	Evaluation of a Carer Self Efficacy (SE) Coaching Program delivered through either individual or group coaching. The coaching program consisted of 8 modules, including developing and practicing self-	The SE program included learning activities which were tailored to carers' self-identified needs and abilities. Semi-structured diaries were used by carers to record short- and long-term goals with assistance from their coach.	Understanding reasons for and being able to better manage behavioural changes, seeking support from others, improving confidence in carer role, engaging in health maintenance.	Enablers: Carers in the group coaching found sharing ideas with other carers and developing goals during group learning enabled goal achievement and satisfaction. Barriers: Carers in the individual coaching group found it difficult to decide on short-term goals (and how they could be achieved) as there was	Goal attainment was reported to be more positive for the group coaching group who achieved many of their short- and long-term goals.

Author, year and country	Study design and participants	Context for goal setting	Goal setting approaches used	Common goals identified	Enablers and barriers to goal setting	Outcomes related to goal setting
		determined goals. One-on-one coaching was delivered at the carer's home by trained community carer support nurses about 1 h per week for 20 weeks. Group coaching was offered in 10 2-hour sessions in a respite facility for the PwD and was delivered by 6 different carer support nurses and 4 social workers working in pairs.	Carer coaching addressed skill development and resource acquisition to achieve identified goals. Carer goal-related behaviour was assessed in a one-on-one semi-structured interview during study follow-up, as well as review of carer diaries.		no opportunity to discuss desirable goals with family and friends, or other carers.	
Chew (2015), Singapore	Non-randomized pre-post study	Multidisciplinary rehabilitation program (MINDVital) which consisted of 3-hour weekly group	Participants and caregivers set individual treatment goals at baseline using GAS; GAS scores were	Remaining oriented to time and place (cognition related), improving engagement and social participation, reducing carer stress, improving physical	Enablers: GAS enabled an individualised approach to setting goals (and measuring outcomes) even though the program was delivered primarily in a group.	More than half (62%) of the participants met or exceeded their goals (as

Author, year and country	Study design and participants	Context for goal setting	Goal setting approaches used	Common goals identified	Enablers and barriers to goal setting	Outcomes related to goal setting
	55 persons with mild dementia	therapy sessions over 8 weeks. Groups had 10 participants and were facilitated by physiotherapists, occupational therapists and psychologists. Each session included a 45minute physical exercise program; 1 hour of cognitive stimulation and rehabilitation with social and mental activities and 30minutes of tailored individualised activities.	reviewed at the end of the program.	function, behaviour, mood and sleep.	Caregiver involvement assisted in identifying personally meaningful goals. Barriers: Not discussed.	measured by GAS).
Clare (2010, 2011), United Kingdom	RCT and a non-randomized	A comparison of a CR program with relaxation therapy or no-	The COPM was used with all participants during an initial assessment to enable	Addressing aspects of everyday memory functioning, practical skills and activities, naming or	Enablers: The Goal setting process (use of COPM) covered areas of self-care, leisure and productivity and	Participants in the CR group showed improvements in

Author, year and country	Study design and participants	Context for goal setting	Goal setting approaches used	Common goals identified	Enablers and barriers to goal setting	Outcomes related to goal setting
	sub-group analysis 69 participants with AD or mixed AD and vascular dementia	treatment. The CR program was delivered by an OT and consisted of personalised interventions to address individually relevant goals over 8 weekly 1-hour sessions. Intervention included addressing practical strategies and aides, techniques for learning new information, practice in maintaining attention and concentration, and stress management techniques. Participants were encouraged to work	them to identify up to five personally relevant goals including their performance and satisfaction with these goals. For the CR group, one or two of the identified goals formed the focus of therapy. All participants re-rated their performance and satisfaction with their goals post intervention. Goal attainment was rated as fully achieved, partially achieved or not achieved according to pre-determined criteria.	word finding, concentration, organisation and social interaction.	enabled participants to identify goals that reflected a range of impairments. Barriers: Goal setting was completed by a researcher who was not involved in clinical care making it more difficult to select and operationalise therapy goals.	perceived performance and satisfaction. Carer involvement led to an even larger increase in COPM mean scores for performance. 12 goals (46%) were rated as fully achieved, 13 (50%) as partially achieved and 1 (4%) as not achieved.

Author, year and country	Study design and participants	Context for goal setting	Goal setting approaches used	Common goals identified	Enablers and barriers to goal setting	Outcomes related to goal setting
		on goals and practice strategies between sessions. Carers could join the last 15minutes of the session to support between session application.				
Clare (2019a, b), United Kingdom	RCT 475 participants with AD, vascular or mixed dementia and mild to moderate cognitive impairment (MMSE ≥18)	The study compared goal-based CR with usual care. CR consisted of 10 weekly therapy sessions over 3 months, followed by four 1-hour maintenance sessions over 6 months, delivered in participants' homes by OT and nurse (but could be delivered by other professionals too).	Goals were identified collaboratively through semi-structured interviews using the BGSI. This was done in the beginning of the intervention with a study researcher.	Engaging in activities and personal projects; using appliances, devices and the internet; managing everyday activities, tasks and situations (such as shopping and cooking); remaining oriented to time and space (i.e. knowing what is happening).	Enablers: Participants who were functioning better were more likely to engage well in goal setting. Participants who had been diagnosed more recently, and their carers, tended to be motivated to engage in goals setting. Barriers: Participants with more difficulty in function had more difficulty setting relevant goals or remembering the goal ratings. The goal-setting interview was conducted by the researchers and	Participants showed goal attainment at 3months which was further maintained at 9months. Readiness to change in relation to the goal was significantly associated with goal attainment.

Author, year and country	Study design and participants	Context for goal setting	Goal setting approaches used	Common goals identified	Enablers and barriers to goal setting	Outcomes related to goal setting
		Usual care consisted of medication, monitoring and general psychosocial support.			may have been more efficient if conducted by the therapists.	
Dutzi (2019), Germany	Observational study 101 participants with mild to moderate dementia (MMSE mean 21.9 ± 2.6)	To investigate the feasibility of a semi-structured and structured goal setting with people with mild to moderate dementia. Semi-structured and ICF-based structured interviews were applied to explore patient's rehabilitation goals.	Semi structured interviews were first conducted where participants were encouraged to report important and individually relevant rehabilitation goals (related to their health condition and hospitalization). Next, a structured interview with pre-prepared questions (based on the ICF) and examples of potential rehabilitation goals was completed.	Mobility (most importantly walking), being able to return to or be at home, domestic life (such as doing housework), managing sensory functions such as pain, and self-care.	Enablers: The structured goal-setting approach which was tailored to the person and use of pre-prepared questions and selected categories of the ICF facilitated better identification of rehabilitation goals. Barriers: The unstructured approach to goal setting made it more difficult to set any goals.	A structured approach to goal setting provided a broader, more holistic view of patient's rehabilitation needs compared to an unstructured approach in which 18% of participants were unable to identify goals.

Author, year and country	Study design and participants	Context for goal setting	Goal setting approaches used	Common goals identified	Enablers and barriers to goal setting	Outcomes related to goal setting
			Participants were asked to weigh the goal categories in relation to relevance for their daily life (from not relevant to very relevant).			
Hall (2018), United Kingdom	Qualitative study 11 participants including 6 persons with dementia (AD, VD, LBD, unspecified dementia) and 5 carers of people with dementia	Engaging with a physiotherapist as part of a rehabilitation program. To explore experiences of PwD, and their carers engaging with a physiotherapist as part of a rehabilitation program.	Any type of program that had engaged a person with dementia in physiotherapy sessions.	All participants reported that no specific goals were set before or during treatment.	Enablers: Not discussed. Barriers: Therapist's limited understanding of dementia (could not "see beyond" dementia) meant that no specific goals were set for rehab. Participant's fear of stigma led to them not disclosing dementia and asking for treatment for goals that related to the disease. Poor communication in relation to goal setting led to unclear expectations.	Lack of goal setting led to frustration and confusion regarding therapy received.
Hindle (2018), United Kingdom	RCT 25 participants	CR consisting of 8 weekly 1-hour session that focussed on	Researchers completed a goal setting interview with all participants at baseline using the BGSI	Medication and disease management, planning and doing complex tasks (e.g. cooking), learning new	Not discussed.	Significant improvements in goal attainment were found in the

Author, year and country	Study design and participants	Context for goal setting	Goal setting approaches used	Common goals identified	Enablers and barriers to goal setting	Outcomes related to goal setting
	with dementia associated with PD and 4 participants with Lewy body dementia 26 carers	encouraging participants to pursue their agreed goals using compensatory strategies and/or restorative approaches. Participants were encouraged to practice their strategies between sessions with assistance from a carer if available. CR was compared with RT sessions and TAU group.	(including goal attainment and satisfaction).	skills (e.g. using email), and engaging in leisure activities.		CR group compared to the RT and TAU groups.
Jennings (2018), United States	Mixed methods evaluation including observational study	DCMs assisted 101 dyads in goal setting and evaluating of goal attainment as part of a dementia care management	Following initial goal identification, the DCMs reviewed the top 3 goals for participants using a goal inventory and completed GAS for the	Common goals identified were to improve QoL for the person with dementia (such as ensuring physical safety and continuing to live at home) and caregiver	Enablers: DCM's reported that the GAS process helped set expectations about disease progression and care needs, as well as empowered caregivers who did	74% of participants met or exceeded their goals (as measured by GAS).

Author, year and country	Study design and participants	Context for goal setting	Goal setting approaches used	Common goals identified	Enablers and barriers to goal setting	Outcomes related to goal setting
	101 participants with unspecified dementia and their caregivers in phase 2.	program using GAS. Goals were reviewed at 6 and 12 months.	most important goal the participant wanted to attain. After completing GAS, DCMs were encouraged to add an action plan to assist participants in identifying the steps needed to achieve the goal. These were provided to participants at the conclusion of the initial visit.	support (such as managing own health and stress management).	not feel confident in their decision making. Barriers: Agreeing on goals when they differed between the person with dementia and the caregiver.	DCM's reported an improved understanding of what was most important to patients through the goal setting process.
Judge (2011), United States	Quantitative descriptive study 93 veterans with dementia (Unspecified) and their caregivers	A telephone-based coaching program, Partners in dementia care (PDC) for PwD and their families providing education and information, emotional support, linking families to medical and non-medical services	Goals were developed together with care coordinators and dyads following a multi-dimensional assessment addressing various domains for the person and their caregivers to identify care needs. No formal tools were described, but a consumer driven	Initial goals identified by participants were addressing sensory issues (seeing or hearing), preventing falls, personal care, legal and financial planning and home safety. Initial goals identified by caregivers were accessing formal services, emotional support, and improving capacity to provide care.	Not discussed.	About half (59%) of action steps towards goal achievement were successfully accomplished. Others were either not accomplished, still in progress, or became irrelevant after

Author, year and country	Study design and participants	Context for goal setting	Goal setting approaches used	Common goals identified	Enablers and barriers to goal setting	Outcomes related to goal setting
		and resources; and organising the informal care network.	approach was used with care coordinators to ensure the goals matched the participants (and caregiver) priorities. Action steps were then prepared by the PDC care coordinator and used to help families move toward goal achievement. Following initial completion of the action steps, the coordinator mailed a written Individual Action Plan to families.	Common goals developed jointly with care coordinator were focussed on getting or providing educational information, accessing non-VA and non-Alzheimer's Association services, as well as related VA and Alzheimer's specific services.		being established.
Kelly (2019), Ireland	Quantitative descriptive pre-post study 3 participants with early-stage AD	CR program delivered once a week for 8 weeks, 60-90minutes in duration. CR delivered in participant's homes to facilitate learning	Following initial assessment, the BGSI was used to set 3-4 personal rehabilitative goals with each participant (and caregiver) and rate their performance and	Face-name recall, using phone and relaxation.	Not discussed.	Self-rated goal performance and satisfaction improved for all participants with only 1 out of the 12 goals scoring the same at

Author, year and country	Study design and participants	Context for goal setting	Goal setting approaches used	Common goals identified	Enablers and barriers to goal setting	Outcomes related to goal setting
		in the everyday setting.	satisfaction with these goals.			baseline and post-test.
Khayam (2015), United States	Qualitative Case study 1 participant with Alzheimer's dementia	Provision of SLP to a person with Alzheimer's dementia using a "habilitation" approach which focuses on an individual preserved strength; and developing patient centred goals that focus on the integration of personally relevant stimuli into the care plan. E. g's of stimuli include: Environmental modification, the use of visual memory aids,	No formal tool used for goal setting. Completed by the SLP through discussion with participant and husband regarding functional difficulties at home.	Identified goals related to memory loss and aphasia.	Enabler: Structured conversation regarding former occupation, family and interests allowed the participant to identify her current challenges which could translate into goals. Barriers: Due to decreased insight into deficits, the participant disagreed with goals identified by her husband.	Improvement across all 7 goals were reported at the end of intervention.

Author, year and country	Study design and participants	Context for goal setting	Goal setting approaches used	Common goals identified	Enablers and barriers to goal setting	Outcomes related to goal setting
		counselling and ongoing family education. SLP intervention was provided 45mins a day for 4 weeks.				
Lu (2016), United States	RCT with mixed methods evaluation 36 PwMCI-caregiver dyads.	The study compared satisfaction of using the DEMA (Daily enhancement of meaningful activity) program to an information support control group. DEMA is a tailored program designed to help couples facing MCI to work together to meet goals, remain engaged in meaningful activities and adapt to	No formal tool used for goal setting. Goal setting was completed by a nurse through discussion with the dyad in session 1 after which a plan was developed for self-selected activities that the dyad considered important and meaningful.	Not discussed.	Enabler Use of an activity log helped dyads monitor and measure goal progress. The initial face to face session (during which goals were set) aided with rapport building and helped participants feel more comfortable in continuing with the program (i.e. working towards achieving their goals). Barriers Not discussed.	Prioritizing tasks and engaging in meaningful activities aided goal achievement.

Author, year and country	Study design and participants	Context for goal setting	Goal setting approaches used	Common goals identified	Enablers and barriers to goal setting	Outcomes related to goal setting
		change. The program runs over 6 bi-weekly face to face sessions, 1 hour in duration and is delivered by nurses.				
Meyer (2019), Australia	Non-randomized study 25 dyads (people with unspecified dementia and their caregivers)	Implementation of a falls prevention program for people with dementia living in the community, 12 months in total; incorporating goal setting and development of action plans.	No formal tool was used for goal setting. Action plans or goals were set according to participant's choice, based on the variety of falls prevention strategies presented to them by the lead researcher who was an experienced physiotherapist.	Not discussed.	Not discussed.	PwD could participate in decision making and implementation of falls prevention strategies through meaningful engagement in goal setting.
Øksnebjerg (2019), Denmark	Mixed methods evaluation involving pre-post study	To explore the feasibility and applicability of cognitive rehabilitation and self-management	The Danish version of the BGSI was used to define and assess individual goals (min 1 and max 3 goals set) in collaboration with the	Not discussed.	Enablers: Use of a structured goal setting process (BGSI) allowed identification of individual goals in collaboration with caregivers and professionals.	Higher goal attainment was achieved for participants who continued to use the ReACT app

Author, year and country	Study design and participants	Context for goal setting	Goal setting approaches used	Common goals identified	Enablers and barriers to goal setting	Outcomes related to goal setting
	19 participants with early-stage Alzheimer's disease and their caregivers	groups addressing individual goals over a period of 13 weeks, delivered by a neuropsychologist. Individual sessions included goal setting and introduction to the ReACT (Rehabilitation in Alzheimer's disease using Cognitive support Technology) app; a tailor-made app that combines a range of functionalities to support various aspects of prospective and retrospective memory. Self-management group sessions	participant, caregiver and rehabilitation staff.		Barriers: Not discussed.	post intervention compared to those who did not. Participant and caregiver's evaluation of goal attainment varied which may have been due to carer's being more optimistic about the participant's level of function when they were newly diagnosed.

Author, year and country	Study design and participants	Context for goal setting	Goal setting approaches used	Common goals identified	Enablers and barriers to goal setting	Outcomes related to goal setting
		included psychoeducation and solution focused approaches to challenges in everyday life.				
O'Sullivan (2015), Ireland	Mixed methods evaluation including pre-post study 5 participants with a diagnosis of MCI and their carers.	CR consisting of 6 to 8 individual sessions with a focus on personalized interventions to address individually relevant goals. The sessions included identifying and working on personal rehabilitation goals relevant to everyday life; psychoeducation on MCI; encouraging habits and routines; teaching relaxation;	GAS was used to set goals at baseline and measure the effectiveness of the intervention.	Remembering names (e.g., neighbours or acquaintances), reducing misplaced items, remembering appointments, and relying less on carers to provide information about dates, appointments etc.	Not discussed.	All participants achieved all or some of their goals post-intervention and maintained at least two goals at a 3-month follow-up.

Author, year and country	Study design and participants	Context for goal setting	Goal setting approaches used	Common goals identified	Enablers and barriers to goal setting	Outcomes related to goal setting
		encouraging the use of external aids to compensate for memory difficulties; and teaching memory strategies for learning new information.				
Parsons (2012), New Zealand	Quantitative descriptive study 360 older people with unspecified dementia receiving services from a designated home-care service provider	Use of a designated goal facilitation tool "Towards Achieving Realistic Goal in Elders Tool" (TARGET) to identify client directed goals in older people receiving services from a designated home care service provided.	Before the implementation of TARGET, no formal goal setting tool/process was used. Following the implementation of TARGET, goal setting was completed with all clients by the co-ordinator. The goal identification used two outcome tools. The tools were used as a framework for discussion with the client to identify	Mobility (n= 101), looking after health (n= 99), housework (n= 95), transport (n= 64), recreation and leisure (n = 54).	Enablers: Breaking down activities that were identified as areas of importance enabled formulation of a series of goals. Barrier: Level of cognitive impairment (goal setting less effective with moderate to severe cognitive impairment).	The use of TARGET led to higher levels of goal identification and attainment. 94.2% of cases had a goal recorded for their home care episode post implementation compared to 8.6% of cases prior.

Author, year and country	Study design and participants	Context for goal setting	Goal setting approaches used	Common goals identified	Enablers and barriers to goal setting	Outcomes related to goal setting
			areas of deficits which were listed as areas of importance and areas for change; scored on a scale of 1-3. Long term goals were set using the SMART approach.			172 participants (47.8%) achieved their goals.
Regan (2017, 2019), Australia	RCT and a Qualitative study 40 people with MCI or early dementia and their close supporters participated in the RCT and 15 people with MCI, 14 supporters,	The study compared a cognitive rehabilitation intervention (MAXCOG) to treatment as usual. MAXCOG consisted of 4 weekly 1-hour sessions that focused on personalized interventions to address relevant goals. Delivered by experienced	The COPM was used for goal setting and initially completed by a research assistant. Up to 5 personally relevant goals were identified in areas relating to self-care, leisure and productivity. Levels of performance and satisfaction were elicited on a 10-point scale.	Memory, socialization, improvement in using technology, managing finances and bookwork.	Enablers: Increased insight and confidence allowed participants to generalize skills used to achieve one specific goal to other areas of importance. Barriers: Goal setting was not completed by a clinical treating team which may have impacted willingness to encourage clients to identify goals and continue to participate.	Higher levels of goal performance and satisfaction was reported in the MAXCOG group compared to the control group which highlights the use of personalized interventions to achieve relevant goals.

Author, year and country	Study design and participants	Context for goal setting	Goal setting approaches used	Common goals identified	Enablers and barriers to goal setting	Outcomes related to goal setting
	and 3 counsellors participated in the qualitative study	counsellors including staff from the Alzheimer's Australia Victoria Early Intervention Team and a neuropsychologist to client supporter-dyads in their own homes.				
Rodakowski (2018a), United States	Quantitative descriptive study 13 older adults with MCI	Examining a collaborative goal setting process (Activity Card Sort) between a licensed occupational therapist and a community dwelling older adult with MCI.	Initial goal setting was completed using the Activity Card Sort, which incorporates a semi-structured interview and sorting of photographs of older adults performing activities in the community that were most important to them to improve their performance. Therapists guided participants to identify	Most common goals (n=39) were related to IADLs (such as exercise, grocery shopping, and organising bills) followed by leisure (n=8) goals such as gardening and completing brain activities.	Enablers: The client centred process enabled goal generation related to the participants' interest. Barriers: Not discussed.	All the participants were able to identify activity-based goals through the activity card sort process.

Author, year and country	Study design and participants	Context for goal setting	Goal setting approaches used	Common goals identified	Enablers and barriers to goal setting	Outcomes related to goal setting
			objective goals based on their chosen activities.			
Rodakowski (2018b), United States	Qualitative Case study 1 Participant with MCI	A global strategy training (goal – plan – do check) consisting of 12 1-hour sessions over a 6week period addressing barriers to daily activities as identified by goal setting. Sessions engaged frequent repetition of the strategy and were delivered by an OT in the participant's home.	The COPM was used to generate self-selected goals, rate their importance and estimate current performance on 1–10 scales. The therapist guided the participant to select one goal and develop a plan to address the goal using the global strategy approach.	Increase community involvement, developing an exercise routine, improve physical activity and health, enhance motivation and completion of tasks, increase memory and attention, and enhance sleep hygiene.	Enablers: The participant's motivation to change, as well as awareness of the level of cognitive decline and ability to compensate for this. Barriers: Not discussed.	With support from the OT, the participant was able to evaluate the steps taken to achieve his goal. This led to the participant feeling they could think about activities to do and get involved in activities.
Thorpe (2019), Denmark	Quantitative descriptive study 6 Participants with mild-to-	Use of smart devices to support rehabilitation among people with dementia guided by individually	No formal tool used for goal setting. Goal setting was completed with a researcher trained in psychology.	Getting out of the house each day (n=2) and maintaining an existing activity schedule (n=2).	Enablers: Not discussed. Barriers: Participants found maintenance goals difficult to conceptualise and	Of the 6 participants, none were able to achieve their goal despite goals being identified

Author, year and country	Study design and participants	Context for goal setting	Goal setting approaches used	Common goals identified	Enablers and barriers to goal setting	Outcomes related to goal setting
	moderate cognitive impairment	identified goals. The goals followed themes of mobility and activity and according to participants' own views of what was important to their lifestyle. The study occurred over a period of 8 weeks.	Goals were identified through participants own views of what was important to them and matched to themes of mobility and activity. Participants were asked to evaluate their own goal attainment in weekly phone calls and goal attainment was scored using the ranges described in GAS (-2 to +2).		were less motivated by a goal to maintain rather than improve. Participants had difficulty recalling their goal over the duration of the study.	based on what was important to them. However, it was found that sensory based measures may provide insight into goal attainment for a range of mobility or activity related goals.
Zarit (2020), United Kingdom	Non-randomized, controlled study 96 older adults with unspecified dementia	Comparison of the iN2L technology system with TAU in rehabilitation programs at two separate sites. Rehabilitation services at both sites included daily occupational and	Goals were identified through discussions with patients based on baseline assessments (FIM and BI) which were completed by an OT and PT. For each goal, an expected level of functioning to be obtained by the end of	Not discussed.	Not discussed.	Goal attainment was reached across both groups, although the iN2L group had significantly higher goal attainment than TAU. The treatment effects

Author, year and country	Study design and participants	Context for goal setting	Goal setting approaches used	Common goals identified	Enablers and barriers to goal setting	Outcomes related to goal setting
		physical therapy for PwD. The iN2L is a client-centred system which designs interventions to aid the achievement of OT and PT goals based on the patient's identified interests.	treatment was set. The FIM and BI assessments were completed at end of treatment and goal attainment was scored by comparing the initial and final functioning on each item that had been identified as a goal.			on goal attainment appeared to be significantly mediated by increases in engagement.

Abbreviations used: PwD, persons with dementia; OT, occupational therapist; PT, physiotherapist; MDT, multidisciplinary team; GAS, Goal Attainment Scaling; SMART, Specific-Measurable-Attainable-Realistic-Timely; bvFTD, behavioural variant frontotemporal dementia; MM, Marte Meo; RCT, Randomised controlled trial; AD, Alzheimer's dementia; MCI. Mild Cognitive Impairment; CR, cognitive rehabilitation; COPM, Canadian Occupational Performance Measure; TAU, treatment as usual; MMSE, Mini Mental Status Examination; BGSI, Bangor Goal Setting Interview; ICF, International Classification of Functioning, Disability and Health; VD, Vascular Dementia; LBD, Lewy body dementia; PD; Parkinson's dementia; RT, relaxation therapy; DCM; Dementia care manager; QoL. Quality of life; SLP, Speech language pathology; IADL, Instrumental Activities of Daily Living; iN2L, it's never 2 late; FIM, Functional Independence Measure; BI, Barthel Index;

3.3.2 Quality appraisal of the included studies

Table 3.2 summarises the methodological quality of the included studies using the MMAT (The University of Sheffield, 2018). Nine studies used mixed methods evaluation methods (Allan et al., 2019; Berwig et al., 2020; Chenoweth et al., 2016; Clare et al., 2019a; Clare et al., 2019b; Jennings et al., 2018; Lu et al., 2016; O'Sullivan et al., 2015; Oksnebjerg et al., 2019). Of these, three (Allan et al., 2019; Clare et al., 2019a; Clare et al., 2019b) showed highest level of methodological quality (each scoring 100% for quality on the MMAT) by describing and synthesising all detail and findings from the qualitative and quantitative components in a manner that added value of conducting a mixed methods study. Of the qualitative studies (n=4), two (Hall et al., 2018; Regan et al., 2019) provided comprehensive detail of the study methods. The data collection methods and data synthesis were described in lesser detail in the study by Khayum and Wynn (2015) and also difficult to ascertain from the case study by Rodakowski et al. (2018b). Eight (Clare et al., 2010; Hindle et al., 2018; Judge et al., 2011; Kelly, Lawlor, Coen, Robertson, & Brennan, 2019; Meyer, Hill, Hill, & Dow, 2019; Parsons & Parsons, 2012; Thorpe et al., 2019; Zarit et al., 2020) of the quantitative studies were of higher methodological quality, each scoring 100% for quality on the MMAT. Three non-randomised studies (Chew et al., 2015; Clare et al., 2011; Dutzi et al., 2019) were primarily limited in the detail that was provided in relation to confounding variables. Two (out of seven) of the randomised controlled studies (Burton & O'Connell, 2018; Regan et al., 2017) did not ensure that the outcome assessors were blinded to the intervention provided and in the descriptive study by Rodakowski, Becker, and Golias (2018a) the sampling strategy was not relevant to address the research question thereby impacting the methodological quality of the study.

Table 3-2 Methodological quality of studies

	1. QUALITATIVE STUDIES					QUANTITATIVE														5. MIXED METHODS STUDIES				
						2. RANDOMISED CONTROLLED TRIALS					3. NON-RANDOMISED STUDIES					4. DESCRIPTIVE STUDIES									
	1.1	1.2	1.3	1.4	1.5	2.1	2.2	2.3	2.4	2.5	3.1	3.2	3.3	3.4	3.5	4.1	4.2	4.3	4.4	4.5	5.1	5.2	5.3	5.4	5.5
Allan (2019)	Y	Y	Y	Y	Y						Y	Y	Y	Y	Y						Y	Y	Y	Y	Y
Berwig (2020)	Y	Y	?	Y	Y						Y	Y	Y	?	Y						Y	N	Y	Y	N
Burton (2018)						Y	N	N	N	Y															
Chenoweth (2016)	Y	Y	Y	Y	Y						Y	Y	Y	Y	Y						Y	Y	Y	Y	N
Chew (2015)											?	Y	Y	?	Y										
Clare (2010)						Y	Y	Y	Y	Y															
Clare (2011)											Y	Y	Y	?	Y										
Clare (2019 (a)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y											Y	Y	Y	Y	Y
Clare (2019 (b)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y											Y	Y	Y	Y	Y
Dutzi (2019)											Y	Y	Y	?	Y										
Hall (2018)	Y	Y	Y	Y	Y																				
Hindle (2018)						Y	Y	Y	Y	Y															
Jennings (2018)	Y	Y	Y	Y	Y						?	Y	Y	Y	Y						Y	Y	Y	Y	Y

	QUANTITATIVE																					
	1. QUALITATIVE STUDIES					2. RANDOMISED CONTROLLED TRIALS					3. NON-RANDOMISED STUDIES					4. DESCRIPTIVE STUDIES					5. MIXED METHODS STUDIES				
Judge (2011)																Y	Y	Y	Y	Y					
Kelly (2019)																Y	Y	Y	NA	Y					
Khayam (2015)	Y	?	?	Y	Y																				
Lu (2016)	Y	Y	Y	Y	Y	Y	Y	Y	?	Y											Y	Y	Y	Y	Y
Meyer (2019)											Y	Y	Y	Y	Y										
Øksnebjerg (2019)	Y	Y	Y	Y	Y						Y	Y	Y	Y	Y						Y	Y	Y	Y	Y
O'Sullivan (2015)	Y	Y	?	Y	?						Y	Y	Y	NA	Y						Y	Y	Y	Y	Y
Parsons (2012)																Y	Y	Y	Y	Y					
Regan (2017)						Y	Y	Y	N	Y															
Regan (2019)	Y	Y	Y	Y	Y																				
Rodakowski (2018a)																?	Y	Y	NA	Y					
Rodakowski (2018b)	Y	?	?	?	?																				
Thorpe (2019)																Y	Y	Y	NA	Y					

	1. QUALITATIVE STUDIES	QUANTITATIVE			5. MIXED METHODS STUDIES
		2. RANDOMISED CONTROLLED TRIALS	3. NON-RANDOMISED STUDIES	4. DESCRIPTIVE STUDIES	
Zarit (2020)			Y Y Y Y Y		

Notes Responses: Y, Yes; N, No;?, Cannot tell; NA, Not Applicable.	
Methodological quality criteria	
1. Qualitative studies	1.1. Is the qualitative approach appropriate to answer the research question?
	1.2. Are the qualitative data collection methods adequate to address the research question?
	1.3. Are the findings adequately derived from the data?
	1.4. Is the interpretation of results sufficiently substantiated by data?
	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?
2. Quantitative randomized controlled studies	2.1. Is randomization appropriately performed?
	2.2. Are the groups comparable at baseline?
	2.3. Are there complete outcome data?
	2.4. Are outcome assessors blinded to the intervention provided?
	2.5 Did the participants adhere to the assigned intervention?
3. Quantitative nonrandomized studies	3.1. Are the participant's representative of the target population?
	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?
	3.3. Are there complete outcome data?
	3.4. Are the confounders accounted for in the design and analysis?
	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the research question?

	4.2. Is the sample representative of the target population?
	4.3. Are the measurements appropriate?
	4.4. Is the risk of nonresponse bias low?
5. Mixed methods	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?
	5.2. Are the different components of the study effectively integrated to answer the research question?
	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?
	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?
	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?

3.3.3 Goal setting approaches used

A range of different approaches to goal setting were described including both structured and non-structured methods. The most common structured approaches were standardised methods such as use of the Canadian occupational performance measure (n=6), Bangor goal setting interview (n=5), goal attainment scaling (n=5) and the activity card sort (n=1). One study (Judge et al., 2011) described a structured consumer driven approach whereby goals were matched to the priorities of persons with dementia and their caregivers instead of all areas that may have been identified in the initial assessment as requiring attention. Another study (Parsons & Parsons, 2012) described use of a SMART (Specific, Measurable, Attainable, Realistic, Timely) structured approach to goal setting for persons with mild cognitive impairment and dementia.

Non-structured approaches were described in eight studies with informal discussions being the most common method used (Khayum & Wynn, 2015; Lu et al., 2016; Meyer et al., 2019; Zarit et al., 2020). One study (Chenoweth et al., 2016) discussed use of a semi-structured diary to record short- and long-term goals identified for a coaching program and another study (Thorpe et al., 2019) described matching goals that were identified through persons with mild to moderate cognitive impairment's own views of what was important to them to themes of mobility and activity. Moreover, only one study (Dutzi et al., 2019) described a combination of both structured and non-structured methods; incorporating both semi-structured and structured interviews in the goal setting process. Lastly, one study (Hall et al., 2018) did not specify which approach was used.

Regarding the context in which goal setting occurred. It was found that goal setting occurred mostly in the community (n= 17). Other settings included clinical centres (n= 7), rehabilitation centres (n=2) or the hospital setting (n=1).

3.3.4 Common goals identified

A large variety of goals were identified in the included studies. Self-identified goals for persons with mild cognitive impairment or dementia and caregivers were commonly related to areas of impairment and/or activity and participation (World Health Organisation, 2001). Of the 27 studies, 12 described a combination of goals relating to impairment and activity and participation (Chew et al., 2015; Clare et al., 2011; Clare et al., 2019a; Clare et al., 2019b; Clare et al., 2010; Dutzi et al., 2019; Judge et al., 2011; Kelly et al., 2019; Parsons & Parsons, 2012; Regan et al., 2017; Regan et al., 2019; Rodakowski et al., 2018b), seven studies described activity and participation goals only (Allan et al., 2019; Berwig et al., 2020; Chenoweth et al., 2016; Hindle et al., 2018; Jennings et al., 2018; Rodakowski et al., 2018a; Thorpe et al., 2019) and three studies identified impairment-based goals only (Burton & O'Connell, 2018; Khayum & Wynn, 2015; O'Sullivan et al., 2015). Five studies did not discuss goals set (Hall et al., 2018; Lu et al., 2016; Meyer et al., 2019; Oksnebjerg et al., 2019; Zarit et al., 2020). Activity and participation goals were most commonly identified in the community and social participation domain and impairment-based goals were most commonly related to mental, physical or sensory function. Also, impairment-based goals were typically within the scope of the rehabilitation program of interest. For example, goals set within cognitive rehabilitation programs focussed on cognitive functioning (Burton & O'Connell, 2018; Clare et al., 2011; Clare et al., 2019a; Clare et al., 2019b; Clare et al., 2010; Kelly et al., 2019; O'Sullivan et al., 2015; Regan et al., 2017; Regan et al., 2019).

Where caregivers were involved in goal setting (n=10), only four studies reported goals relating to caregivers (Chew et al., 2015; Jennings et al., 2018; Judge et al., 2011; O'Sullivan et al., 2015). Examples of goals identified included managing stress (n=2), maintaining own health (n=1), and improving carer insight and confidence (n=1) in managing symptoms of the person with mild cognitive impairment or dementia.

3.3.5 Enablers and barriers to goal setting

Several factors facilitating effective goal setting were highlighted in the studies. Eight studies found applying a structured approach to goal setting as a key facilitator. A structured approach enabled individualised goal setting and the ability to document attainment, measure progress and outcomes (Chew et al., 2015; Dutzi et al., 2019; Oksnebjerg et al., 2019). It enabled identification of goals that reflected a range of impairments (Clare et al., 2011; Clare et al., 2010) and were related to the participants' interests (Rodakowski et al., 2018a) A structured process was further found to assist in setting expectations about disease progression and care needs by objectively defining goals (Jennings et al., 2018).

For persons with dementia, those with higher levels of function and lower levels of disability were more likely to engage in goal setting (Clare et al., 2019a; Clare et al., 2019b). Motivation to change, awareness of level of cognitive decline (Rodakowski et al., 2018b) and timing of diagnosis further played a role in effective goal setting as those who were diagnosed more recently were more motivated to participate in goal setting (Clare et al., 2019a; Clare et al., 2019b). In addition to this, a study by Regan et al. (2017) found that increased insight and confidence allowed persons with mild cognitive impairment to generalise skills used to achieve one goal to other areas of importance.

Caregivers' acceptance of their relative's dementia, family support and being involved in the goal setting process were also described as enabling goal setting (Berwig et al., 2020; Chew et al., 2015). Caregivers who were involved in programs that facilitated group discussion reported sharing ideas with others had helped them in the goal setting process (Chenoweth et al., 2016).

Lastly, discussion regarding former occupations, family and interests enabled goal identification (Khayum & Wynn, 2015), and breaking down activities that were identified as important for the person (Parsons & Parsons, 2012) were found to enable goal formulation.

A study by Lu et al. (2016) found that an initial face to face session helped persons with dementia and their caregivers feel more comfortable in continuing to work towards achieving their goals and the use of an activity log assisted persons with dementia and their caregivers to monitor and measure goal progress.

Several barriers were reported to impact goal setting. Severity of cognitive impairment was reported to impact on goal setting ability (with people with more severe symptoms experiencing more difficulty setting goals) (Allan et al., 2019; Clare et al., 2019a; Clare et al., 2019b; Parsons & Parsons, 2012), though few studies (n=2) included participants who had moderate to severe stage dementia. It was also suggested that goal setting was less successful when staff involved lacked knowledge or experience about dementia and rehabilitation (Allan et al., 2019; Hall et al., 2018) or were not involved in the direct clinical care provision (where goal setting was completed by researchers) (Clare et al., 2011; Clare et al., 2019a; Clare et al., 2019b; Clare et al., 2010; Regan et al., 2017). One study (Hall et al., 2018) reported that persons with dementia chose to not disclose their diagnosis of dementia as they were fearful of the associated stigma. Due to this, the goals identified were not related to the disease itself. Poor communication about goal setting also resulted in persons with dementia feeling confused when their therapy ceased.

An unstructured approach to goal setting (Dutzi et al., 2019) and limited opportunity to discuss desirable goals with other caregivers (Chenoweth et al., 2016) were found to increase challenges caregivers experienced with setting goals. Setting goals was also difficult when the person with dementia and caregiver had different priorities and insight or expectations regarding prognosis (Jennings et al., 2018; Khayum & Wynn, 2015). From a practical perspective, one study (Thorpe et al., 2019) reported that people with dementia had difficulty recalling their goals over time, presenting challenges in working towards specific goals. In particular, people with dementia also struggled to conceptualise goals that were related to maintenance of function rather than making improvements.

Beyond that, it was also suggested that setting too many goals can result in contamination between goals which may have a negative impact if the purpose of the intervention is to work on one goal at a time (Burton & O'Connell, 2018).

3.3.6 Outcomes related to goal setting

None of the studies tested the efficacy of goal setting alone in rehabilitation programs for people with mild cognitive impairment or dementia. Moreover, majority of the studies were evaluations of multi-component interventions and therefore we were not able to evaluate the impact of goal setting alone for persons with dementia. Twelve of the studies showed that persons with mild cognitive impairment or dementia and caregivers were able to achieve their goals by engaging in a rehabilitation program of interest (Allan et al., 2019; Berwig et al., 2020; Chenoweth et al., 2016; Chew et al., 2015; Clare et al., 2011; Clare et al., 2019a; Clare et al., 2019b; Clare et al., 2010; Jennings et al., 2018; Judge et al., 2011; O'Sullivan et al., 2015). Seven studies reported improved overall goal performance, satisfaction and attainment (Burton & O'Connell, 2018; Hindle et al., 2018; Kelly et al., 2019; Khayum & Wynn, 2015; Oksnebjerg et al., 2019; Regan et al., 2017; Regan et al., 2019) and two studies found that persons with mild cognitive impairment or dementia and caregivers demonstrated higher levels of goal identification through the goal setting process (Parsons & Parsons, 2012; Rodakowski et al., 2018a).

3.4 Discussion

The aim of this review was to identify the extent and nature of available research pertaining to goal setting with people with mild cognitive impairment or dementia participating in rehabilitation programs. The findings show that goal setting is feasible and there is less evidence available regarding goal setting for people with more severe symptoms of dementia; this is an area that requires further research attention. Although some scepticism about the ability of persons with dementia to engage in rehabilitation and goal setting exists (Isbel & Jamieson, 2016), the results of this review show that several strategies can be used to enhance goal setting in this population. These include use of a structured approach (such as the Canadian occupational performance measure), involvement of caregivers, and individualisation of goals. Additionally, clear communication and documentation of goals can help the person recall specified goals. Similar strategies have also been highlighted in goal setting for people with acquired brain injuries and a study by Prescott, Fleming, and Doig (2019) further suggests using scaffolding to support structured communication and improve participation in goal setting.

Multiple studies suggested that goal setting was difficult when staff had limited knowledge, skills or experience working with people with dementia in rehabilitation settings or when there was a difference of opinion between the person with dementia and their carer regarding goals set. Consequently, rehabilitation services should consider how best to incorporate training for staff and adopt tools to guide goal setting. The World Health Organisation global action plan for dementia states the importance of staff training (World Health Organisation, 2017) aimed at improving knowledge regarding dementia, management of symptoms, and methods to integrate an individualised approach to rehabilitation for this population who experience changes in cognitive and communicative abilities.

These challenges in goal setting are not unique to the field of geriatrics and dementia care. Barriers and enablers identified in this review are similar to those identified in goal setting for people with stroke or acquired brain injuries (Plant et al., 2016). Similar to our findings, barriers in the acquired brain injury population relate to the therapist (lack of goal setting skills, limited knowledge of diagnosis, poor documentation and communication of goals) and the environment (resources, perception of goal setting for people with cognitive impairment, organisational barriers). A point of difference in dementia care stems from the degenerative nature of the condition. Goal attainment may result in the person maintaining independence rather than making improvements per se.

The World Health Organisation describes how rehabilitation should be part of the usual pathway for people with dementia (World Health Organisation, 2017). The emphasis on individualised goal setting found in the studies within this review aligns with patient-centred goal setting which is core to the rehabilitation process (Smit, Bouwstra, van der Wouden, Wattel, & Hertogh, 2018; Wade, 2009) and the fact that activity and participation goals were a feature of many studies is an important finding for occupational therapists. Rehabilitation can and should commence with goal setting which is the foundation for therapy and is considered best practice (National Stroke Foundation, 2010). The results of the current review suggest that skill development to enable staff to support persons with dementia or mild cognitive impairment and their caregivers in the goal setting process plays an important role in effective and individualised goal setting (Allan et al., 2019). Rehabilitation services should consider how best to incorporate individualised goals into care plans to optimise rehabilitation and goal attainment. This may include documentation of goals in the care plan, patient's communication or bedside boards and routine discussion at team meetings.

While goal setting is considered an essential step in the establishment of rehabilitation it has been challenging to illustrate the benefits in randomised controlled

trials. We were unable to identify any randomised trials which tested the efficacy of goal setting alone in this population. A Cochrane Review (Levack et al., 2015) found low quality evidence for the effect of goal setting to improve outcomes for persons with acquired disabilities. However, the evidence suggests there may be some positive psychosocial outcomes such as improved self-efficacy (Levack et al., 2015). Nonetheless, most people acknowledge that goal setting is beneficial and therefore conducting a randomised controlled trial where some participants are unable to set goals for their rehabilitation presents ethical challenges.

3.5 Strengths and limitations

Strengths of this review include a thorough search of all types of studies using a validated approach (Arksey & O'Malley, 2005). The studies identified are a representation of the population of interest. Through the use of a scoping review approach, we have further been able to synthesise existing evidence on an emerging topic to inform clinical practice. A key limitation is that only studies published in the English language were included, which may have resulted in the omission of other relevant studies. We were also unable to consider any form of meta-analysis due to the broad scope and heterogeneity of the studies included.

3.6 Clinical implications

Engaging persons with mild cognitive impairment or dementia in goal setting should be considered as part of usual care in rehabilitation settings. Staff education and training regarding how best to engage persons with dementia is recommended to further enhance goal setting and rehabilitation in this clinical population. Clinicians are encouraged to explore use of structured goal setting processes (such as use of the Canadian occupational performance measure) to optimise goal setting and incorporate strategies to overcome communication and cognitive difficulties experienced by persons with mild

cognitive impairment or dementia. Strategies may include use of existing goal banks or pictures to assist with communication of ideas. Other strategies may include clear verbal and written communication to enable the person to better understand the goal setting process and to better recall goals during the rehabilitation process.

3.7 Conclusion

Despite preconceptions that people with dementia cannot set goals, the findings of this scoping review show that goal setting for people with dementia is feasible, when supported by a structured approach. We synthesised data from 27 studies and found that a range of goal setting approaches were used to enable goal setting for this population, of which a structured and individualised approach was found more favourable. We were unable to evaluate the efficacy of goal setting alone in this clinical population due to the absence of randomised controlled trials assessing efficacy. It is recommended that further research is conducted to explore the validity and responsiveness of standardised goal setting tools (when used with people with dementia) that are commonly used in rehabilitation programs. Based on this review, goal setting for persons with dementia is recommended as best practice and clinicians are encouraged to explore strategies to optimise the goal setting process.

3.8 Examining the next steps

Drawing attention to goal setting approaches and factors that facilitate effective goal setting for people with mild cognitive impairment or dementia is a crucial step forward. Sharing this knowledge can commence a shift in health professional's perceptions and behaviours when engaging people with dementia in rehabilitation and goal setting and further inform the rehabilitation pathway for this population. It is recommended that health professionals actively engage people with dementia and/or their carers in goal setting in rehabilitation settings.

The review identified standardised methods of goal setting as a key facilitator for people with mild cognitive impairment or dementia participating in rehabilitation programs and further reported that a standardised approach enabled goals to be individualised and related to the person's interests. Goal attainment scaling is a standardised, valid and reliable method of person-centred goal setting, as described in chapter two. Literature suggests that health professionals are sceptical about whether or not people with dementia can identify rehabilitation goals or fully participate in rehabilitation programs (Cations et al., 2020) and the next chapter continues to examine this notion.

CHAPTER FOUR: VALIDITY AND RESPONSIVENESS OF GOAL ATTAINMENT SCALING WHEN USED WITH PEOPLE WITH MILD COGNITIVE IMPAIRMENT OR DEMENTIA

In the previous chapter, the extent and nature of available research pertaining to goal setting for people with mild cognitive impairment or dementia participating in rehabilitation programs was synthesised. Goal attainment scaling was identified as a standardised approach facilitating effective goal setting, however there is currently insufficient evidence regarding its applicability as an outcome measure for older people with cognitive disorders.

This chapter addresses the second research objective which is to examine whether or not people with mild cognitive impairment or mild severity dementia can measure progress towards goals and/or accurately report outcomes when participating in rehabilitation programs. The second research objective is addressed by examining the validity and responsiveness of goal attainment scaling when used with people with mild cognitive impairment of dementia. It is hypothesised that goal attainment scaling is a valid tool for people with mild cognitive impairment or mild severity dementia.

This chapter presents a quantitative research study that was conducted at a subacute rehabilitation hospital in Australia following ethics approval from the Monash Health Human Research and Ethics Committee. Approval number: HREC/69866/MonH-2020-241361.

The study has not yet been submitted for consideration of publication.

4.1 Introduction

People with dementia are frequently admitted to acute hospital services as a result of falls, fractures and other medical conditions or co-morbidities (Australian Institute of Health and Welfare, 2021). Access to rehabilitation for people with dementia is an international priority area (World Health Organisation, 2017) and studies have shown that physical function (following hip fractures) of older adults with cognitive impairment can improve if they are granted access to inpatient rehabilitation programs (Muir & Yohannes, 2009; Resnick et al., 2016).

As already described in this thesis, goal setting is a core aspect of rehabilitation (Wade, 2009). Literature suggests that goal setting is feasible for people with mild cognitive impairment or dementia (Dutzi et al., 2019), however health professionals remain sceptical about whether or not people with dementia can identify rehabilitation goals or fully participate in rehabilitation programs (Cations et al., 2020). People with dementia are therefore not always referred for ongoing rehabilitation services following injury/illness as they are considered to have reduced rehabilitation potential (Goodwin & Allan, 2019; Mitchell et al., 2021). Symptoms of dementia including reduced memory, lack of insight and loss of purposeful movement have been reported to interfere with participation in rehabilitation programs (McGilton et al., 2007). Additionally, health professionals have reported that it can be difficult to define meaningful rehabilitation outcomes for people with dementia as a result of the progressive nature of the disease (Cations et al., 2020).

Goal attainment scaling is one approach to goal setting that offers a means of quantifying goal achievement as opposed to measuring improvements in function only (Turner-Stokes, 2009). It is a valid and reliable tool for setting quantifiable person-centred goals, as well as measuring progress towards these goals (Turner-Stokes, 2009). By clearly identifying goals prior to the intervention, goal attainment scaling facilitates communication of shared priorities between health professionals and patients. It also

provides the opportunity to set realistic expectations of what can be achieved (Turner-Stokes, 2009). Goal attainment scaling has been applied in several areas of rehabilitation (Ashford & Turner-Stokes, 2014; Rockwood et al., 1993; Rushton & Miller, 2002; Stolee et al., 1999; Williams & Stieg, 1986) and is deemed feasible for use with older adults in geriatric settings (Toto, Skidmore, Terhorst, Rosen, & Weiner, 2014).

A systematic review by Bouwens, van Heugten, and Verhey (2008), examining the clinimetric aspects of goal attainment scaling when used as an outcome measure for older people with cognitive impairment, identified a small number of relevant studies only (n = 10). Mixed results were found for responsiveness and construct or convergent validity due to the heterogenous samples (Bouwens et al., 2008) and the authors concluded that there is currently insufficient evidence to state that goal attainment scaling is an applicable outcome measure for older people with cognitive disorders.

The aim of this study is to explore if people with mild cognitive impairment or mild severity dementia can accurately measure progress towards goals and/or report outcomes using goal attainment scaling. The secondary aim is to explore the responsiveness of goal attainment scaling in comparison to the Functional Independence Measure (FIM) which is a health-related outcome measure.

4.2 Method

4.2.1 Design

A quantitative, cross-sectional, single site study was conducted. The study evaluated the ability of people with mild cognitive impairment or mild severity dementia to measure progress and/or outcomes when participating in rehabilitation programs using goal attainment scaling.

4.2.2 Participant recruitment and setting

The study site, a metropolitan Australian subacute rehabilitation hospital, provides both fast and slow stream rehabilitation following an injury and/or disease. The hospital has four

Geriatric Evaluation and Management (GEM) wards which are typically for patients over the age of 65 who are admitted with chronic or complex conditions associated with ageing. These patients are admitted to the GEM wards as they are deemed to be inappropriate for fast stream rehabilitation due to a number of factors including, but not limited to, cognition and comorbidities. The multidisciplinary team provides rehabilitation for patients within this service and sets goals for discharge with patients and/or carers/family members. For this study, participant inclusion criteria were (1) admission to the GEM or rehabilitation wards, 65 years of age or older, (2) a diagnosis of cognitive impairment or dementia listed in the medical history, and confirmed with a score of 26 or less on the Montreal Cognitive Assessment (MoCA) indicating the presence of cognitive impairment (Nasreddine et al., 2005), and (3) ability to communicate in English. Participants were excluded if they obtained a score of four or less on the comprehension and/or expression items of the FIM which indicated that they did not have sufficient communication ability to participate in the research. According to the FIM, a score of four for comprehension is applicable when the person *"understands directions and conversations about basic daily needs 75 – 90% of the time, without prompting"* and a score of four for expression is applicable when the person "*expresses basic daily needs and ideas 75% to 90% of the time, without prompting.*"(Uniform Data System for Medical Rehabilitation, 1996, pp. 46-48).

4.2.3 Outcome measures

The goal attainment scaling approach described by Ashford and Turner-Stokes (2006) was used as the primary outcome measure for this research study and has been outlined in detail in chapter two. Goal attainment scaling is a valid and reliable goal setting tool (Kiresuk & Sander, 1978). It enables individualised goals to be set using a quantifiable method and offers an objective means of measuring progress towards goals (Turner-Stokes, 2009).

The secondary outcome measure of interest was the Functional Independence Measure (FIM) which is a health-related outcome measure (depicted in Table 4.2) that is used to measure the changes in disability/functional ability of a person during a hospital rehabilitation admission (Uniform Data System for Medical Rehabilitation, 1996). Comparison of goal attainment change scores to the FIM change scores will provide information about the responsiveness of the tool to change.

The FIM consists of 18 items which are divided into two subgroups of motor and cognition. Each item is scored according to the levels outlined in Table 4.1 and a total FIM score is obtained by calculating the sum of each item. For example, if a person is able to feed independently, they will achieve a score of 7 on admission for eating.

Levels of scoring
Independence:
7 – Complete independence
6 – Modified independence
Modified Dependence
5- Supervision
4- Minimal assistance (Client does 75% or more)
3- Moderate assistance (Client does 50% or more)
Complete dependence
2- Maximal assistance (Client does 25% or more)
1-Total assistance

Table 4-1 FIM levels of scoring (Uniform Data System for Medical Rehabilitation, 1996)

Category	Task Type	No:	Task
Motor	Self-care	1	Eating
		2	Grooming
		3	Bathing
		4	Upper body dressing
		5	Lower body dressing
		6	Toileting
	Sphincter control	7	Bladder management
		8	Bowel management
	Transfers	9	Bed to chair transfer
		10	Toilet transfer
		11	Tub/Shower transfer
	Locomotion	12	Walk/Wheelchair
		13	Stairs
Cognitive	Communication	14	Comprehension
		15	Expression
	Social cognition	16	Social interaction
		17	Problem solving
		18	Memory

Table 4-2 Functional Independence Measure (Uniform Data System for Medical Rehabilitation, 1996)

It is currently a requirement that all person's admitted to rehabilitation and geriatric evaluation management settings are assessed using the FIM at the start and end of their episode of care. The FIM provides a basic indicator of disability/functional ability and is used to measure the efficiency of a rehabilitation program.

4.2.4 Procedures

4.2.4.1 Screening for eligibility

As outlined in Figure 4.1 below, the first step involved screening for potentially eligible participants. This was completed by the higher degree research candidate (PJ) or research colleague (JS) within one to four days of patients being admitted to the rehabilitation and GEM wards. Electronic medical records (EMR) were screened against the inclusion criteria and once the initial criteria were met i.e. admitted to the GEM or rehabilitation wards, 65 years of age or older, able to communicate in English, have a diagnosis of mild cognitive impairment or dementia listed in medical history and do not have a score of four or less on the FIM comprehension and expression items; potentially eligible participants were then approached by PJ or JS for initial contact.

4.2.4.2 Initial contact

PJ or JS met with potentially eligible participants on the ward and obtained verbal consent to complete the MoCA to further determine level of cognitive impairment and eligibility for study participation. A score of 26 or less is indicative of cognitive impairment or dementia and further demonstrated eligibility for study participation (Nasreddine et al., 2005). Once the inclusion criteria were met in full, PJ or JS met with the potentially eligible participant on the ward to obtain written consent for study enrolment.

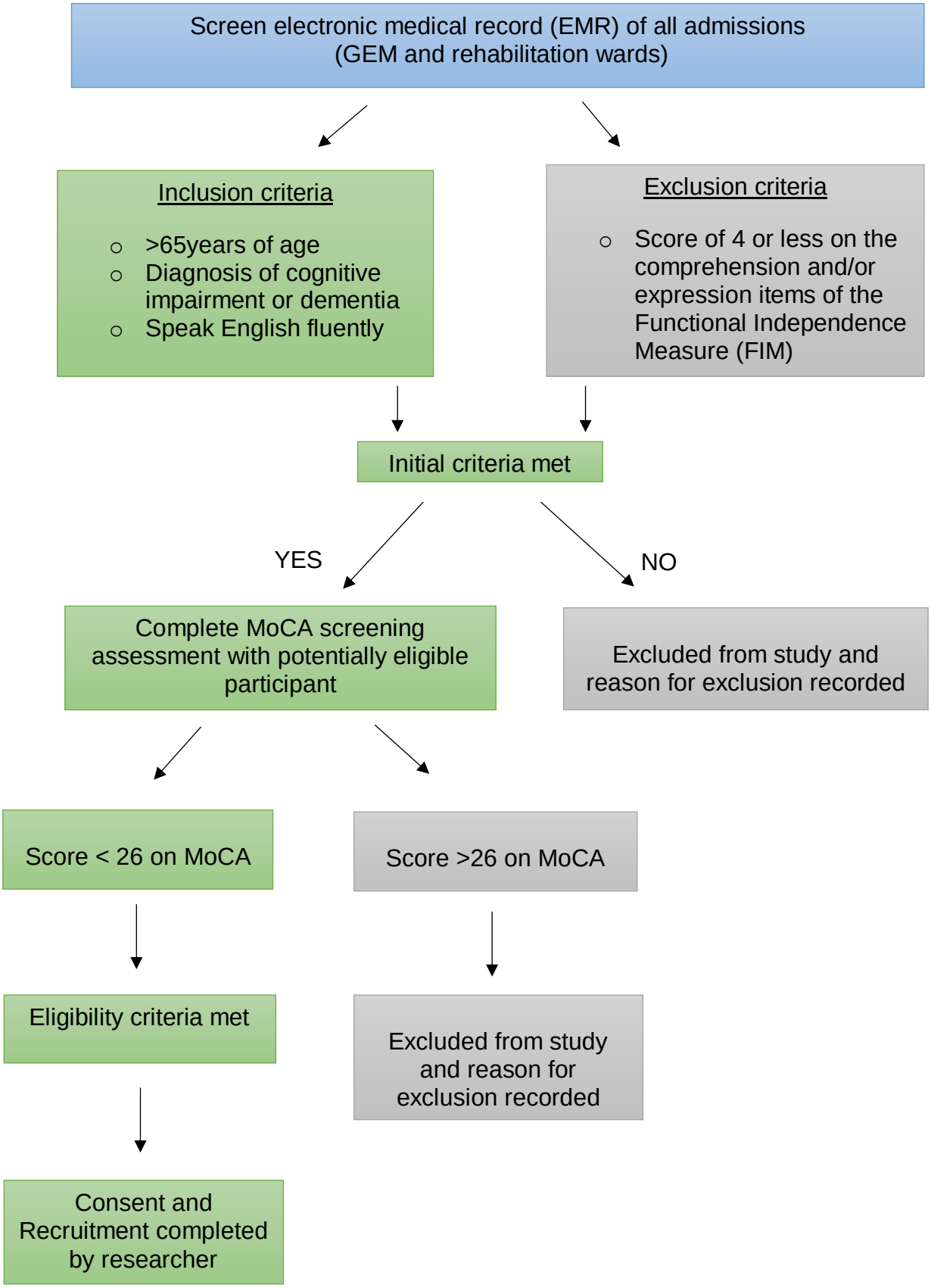

Figure 4-1 Flowchart outlining screening procedure

4.2.4.3 Consent

Consent was obtained with use of a Participant Information Consent Form (PICF). The process involved PJ or JS firstly describing the study to participants and providing written information in the form of a PICF (Appendix E). This was either completed at the bedside or in a private room on the ward.

Provision was made for proxy consent in the form of a person responsible PICF (Appendix F); however this was not required for all participants who enrolled in the study. Given that the eligibility criteria only included persons with mild cognitive impairment or mild severity dementia, participants were able to maintain reasonable ability to make decisions about study participation.

4.2.4.4 Participant commitment

Taking part in the study required the participant to be involved in two consultations during their episode of rehabilitation. In the first session PJ or JS met with the participant to complete goal setting using the goal attainment scaling approach (Turner-Stokes, 2009). Three to four goals for rehabilitation were identified, agreed upon and recorded. The session took approximately 45 to 60 minutes depending on the number of goals set.

Prior to discharge, PJ or JS met again with participants who were asked to evaluate their performance in relation to their goals using the 5-point scale or levels of goal attainment established at baseline. This session took on average 30 to 45 minutes.

Participant ID: *XXX*	Participant stated goals	-2 Much worse	-1 Somewhat worse	0 Expected outcome	1 Better than expected	2 Much better than expected
Goal 1	"Walk better"	Requiring assistance to move from bed to chair with a 4WF	Requiring supervision to move from bed to chair with 4WF	To be able to walk independently with a 4WF household distances	To be able to walk independently with a 4WF >50m	To be able to walk independently with a 4WF in the community

Figure 4-2 Example of goal set (GAS follow up guide)

According to the goal attainment scaling approach described by Ashford and Turner-Stokes (2006), participants were scored at -1 (to allow for possibility of deterioration) or -2 (if no worse condition is clinically plausible) on the 5-point scale at baseline. For example in Figure 4.2 we can see that at baseline, the participant required supervision to move from bed to chair with 4-wheeled frame (4WF).

4.2.5 Data collection

A goal attainment record sheet was used to record identified goals and this was stored in the participant's medical history (Appendix G). Each goal was objectively defined according to the 5-point scale, and this was documented electronically using Microsoft Word and referred to as the goal attainment scaling follow up guide. Baseline goal attainment T-scores were calculated for each participant using the goal attainment scaling calculation sheet provided by Turner-Stokes (2009) (Appendix H) and recorded using an excel spreadsheet.

At the end of the rehabilitation episode, the participant's level of goal achievement was rated separately by the participant and health professional and recorded on the goal attainment record sheet. Achieved goal attainment T-scores were calculated using the excel calculation sheet. Demographic information such as age, gender, reason for admission, and FIM admission and discharge scores were also collected. The FIM was routinely completed by ward staff at admission and discharge as per standard hospital requirement.

4.3 Data analysis

4.3.1 Descriptive statistics

The Statistical Package for the Social Sciences (SPSS) version 27 (IBM Corporation, 2020) was used for quantitative data analysis. Descriptive statistics were used to summarise participant demographics including gender, age, level of cognitive impairment and diagnosis.

4.3.2 Evaluation of validity

Construct validity is understood to be an umbrella term to describe the process researchers use to assess the validity of a measurement procedure that is used to measure a given construct (Laerd dissertation, 2012a). Construct validity consists of

a number of forms of validity. Convergent validity is one way of examining construct validity and involves the use of two measurement procedures and methods (Laerd dissertation, 2012b). We examined convergent validity of goal attainment scaling when used with people with mild cognitive impairment or dementia by testing whether the health professionals rating of goal attainment correlated with the participants. Stata Statistical Software Release Version 16.1 (StataCorp, 2021) was used to ascertain the relationship between participant's rating of goal attainment and health professional's rating using the Bland-Altman plot (Watson & Petrie, 2010). A second statistical package was used as Stata was deemed to be more suitable for the Bland Altman method.

The Bland-Altman plot is a method for comparing two measurements of the same variable and illustrates the agreement between two quantitative measurements (Watson & Petrie, 2010). It does this by plotting the difference in scores of two measurements against the mean for each subject. For e.g. in Figure 4.3, the X-axis shows the mean score for participant and health professional goal attainment ratings, and the Y-axis shows the difference between the two measurements.

The Bland-Altman method further establishes limits of agreement which are defined as the mean difference ± 1.96 SD of differences. If these limits do not exceed the maximum allowed difference between methods, the two methods are considered to be in agreement (Watson & Petrie, 2010).

According to Turner-Stokes (2009), an overall score of goal attainment is determined by using a published goal attainment scaling calculation sheet (Turner-Stokes, 2009). A mean goal attainment score of 50 indicates that the goals were achieved as expected, a score of 50-60 indicates goals were achieved better than expected and a score of >60 indicates goals were achieved much better than

expected. On the contrary, a score of less than 50 indicates a less than expected outcome and a score of <40 indicates a much less than expected outcome (Turner-Stokes, 2009). As a result, the research team agreed that the maximum allowed difference between methods should be within +10 and -10 respectively.

4.3.3 Evaluation of responsiveness

Responsiveness is defined as *"an instrument's ability to detect change over time"* (Lohr, 2002, p. 196). As per the COnsesus-based Standards for the selection of health status Measurement INstruments (COSMIN) guidelines, we used the construct validity approach to examine responsiveness (Mokkink et al., 2010). This approach includes *a priori* hypothesis of expected associations between goal attainment change scores and change scores of the reference tool, the FIM. There is no gold standard measurement tool in this context, and we were therefore unable to apply area under the curve methodology. We examined the strength and direction of change, calculating the Pearson's correlation coefficient for goal attainment and FIM change scores. The strength of the positive or negative correlation coefficient was interpreted according to Cohen (1988) where the closer the correlation coefficient is to +1 or -1, the stronger the association and where $p<.05$ indicates a statistically significant Pearson's correlation. We used criteria described by De Boer et al. (2004) which rates responsiveness as high if less than 25% of the hypotheses are refuted, moderate if 25–50% are refuted and poor if more than 50% are refuted. The hypotheses tested are explained and presented in Table 4.3.

No.	Hypotheses
1	The correlation between goal attainment change scores and FIM change scores is positive and statistically significant i.e. an increase in goal attainment will result in an increase in FIM score or a decrease in goal attainment will result in a decrease in FIM score and $p < .05$
2	The correlation between goal attainment change scores and FIM change scores is moderate ($0.3 < r < 0.5$).

Table 4-3 A priori hypothesis that were examined

4.4 Results

4.4.1 Demographic data

A total of 1012 patient files were screened of which 21 participants met the initial screening criteria. Of the 28, six potentially eligible participants were unwilling to engage in the MoCA assessment as part of the initial criteria screening and one was unable to participate due to being medically unwell and therefore transferred back to the acute hospital. 21(75%) of the 28 potentially eligible participants met the final inclusion criteria and consented to participate. No participants withdrew. Table 4.4 presents participant demographics including primary diagnosis or reason for admission. More than half of the participants (n=16) were female, and participants' age ranged from 65 – 75 years (n= 3), 76 – 85 years (n=10) and 86 - 95 years (n=8). Of the 21 participants, 12 scored between 18 to 25 on the MoCA suggestive of mild cognitive impairment, 9 scored between 10 to 17 suggestive of moderate cognitive impairment and none of the participants scored less than 10 suggesting that no participants had severe cognitive impairment. Falls and fractures was listed as the primary reason for admission for 18 (86%) of the participants and each of the

remaining participants were admitted due to respiratory related issues (n=1), cardiac issues (n=1) or other medical conditions (n=1).

	Number of participants (N=21), %	
Gender		
Female	16	(76%)
Male	5	(24%)
Age, years		
65 – 75	3	(14%)
76 – 85	10	(48%)
86 – 95	8	(38%)
MoCA score		
18 -25 (Mild cognitive impairment)	12	(57%)
10 -17 (Moderate cognitive impairment)	9	(43%)
< 10 (Severe cognitive impairment)	0	(0%)
Primary diagnosis		
Falls and fractures	18	(85%)
Respiratory	1	(5%)
Cardiac	1	(5%)
Other medical	1	(5%)

Table 4-4 Participant demographics

4.4.2 Descriptive analysis: Baseline and achieved scores of outcome measures

Overall, there was an improvement from baseline goal attainment scores to achieved goal attainment scores for all but two participants who showed no change from baseline to achieved ratings (participant 2 and 20 as illustrated in Table 4.5). A similar pattern was seen for FIM baseline and achieved scores, where again improvement was observed in all but one participant, whose overall FIM score was lower at discharge compared to admission (participant 20). Participants were encouraged to set three to four goals for rehabilitation and the mean number of goals set using goal attainment scaling was three.

Participant no.	MoCA score	GAS baseline	GAS achieved (health professional rating)	GAS achieved (participant rating)	GAS change	FIM total (Baseline)	FIM total (Discharge)	FIM change score
1	16	38	62	62	24	70	79	9
2	10	37	37	47	0	64	87	23
3	25	31	62	50	31	72	75	3
4	11	36	68	57	32	71	99	28
5	15	37	70	73	33	70	103	33
6	18	32	50	45	18	91	93	2
7	16	36	64	60	28	78	98	20
8	17	32	55	50	23	68	86	18
9	16	36	50	50	14	67	95	28
10	20	32	55	50	23	61	76	15
11	24	34	61	61	27	83	107	24
12	23	34	50	50	16	78	105	27
13	24	23	56	62	33	49	103	54
14	23	30	50	50	20	82	93	11
15	21	37	50	58	13	84	95	11
16	10	40	50	50	10	87	88	1
17	24	27	50	50	23	58	99	41
18	10	38	50	56	12	58	64	6
19	18	34	47	50	13	68	108	40
20	18	38	38	50	0	85	75	-10
21	21	25	50	50	25	43	98	55

Abbreviations used: MoCA, Montreal Cognitive Assessment; GAS, goal attainment scaling.

Table 4-5 Comparison of change in goal attainment score to change in FIM score

4.4.3 Validity

When examining the Bland-Altman graph in Figure 4.3, it is evident that the points are scattered above and below zero, suggesting that there is no bias of one approach versus the other (Bland & Altman, 1999). Horizontal lines are drawn at the mean difference, i.e. mean score of participant goal attainment score subtracted by the mean score of the health professionals goal attainment score (.328) and at the limits of agreement (LoA). The LoA are wide and there is a high standard deviation (*d*= 6.174) resulting in broader confidence intervals. The 95% upper LoA ranged from 7.561 to 17.297 (width of the interval: 9.736). Similarly, the lower LoA ranged from -16.64037 to -6.904718 (width of the interval: - 9.735). The maximum allowed differences between methods was within +10 and -10 respectively, in line with the levels of goal attainment as outlined by Ashford and Turner-Stokes (2006), therefore suggesting an acceptable agreement.

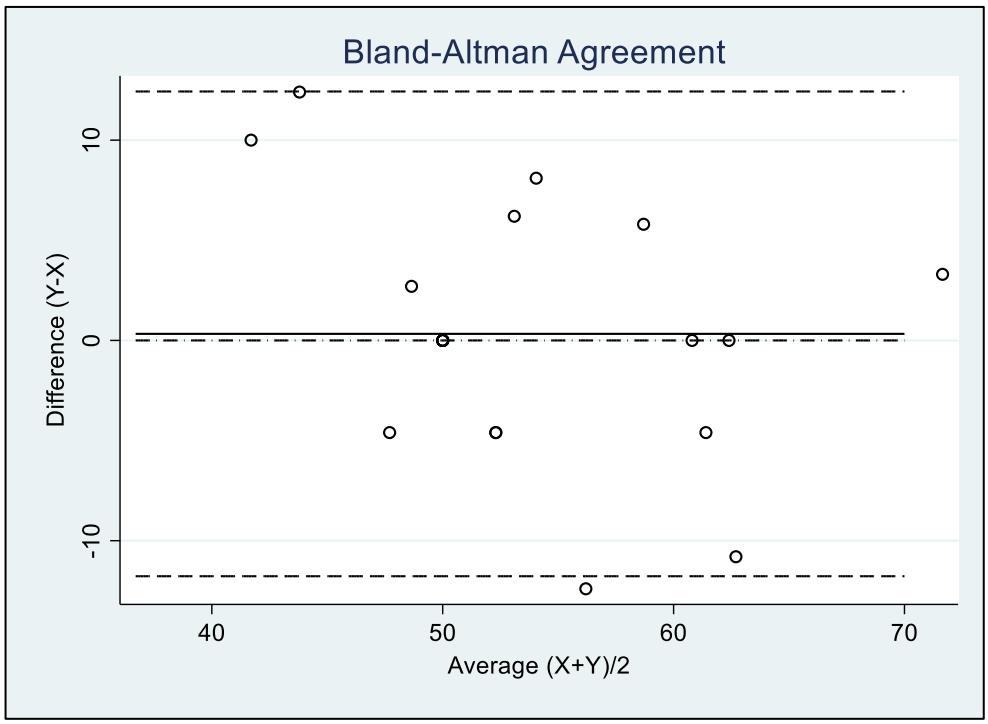

Figure 4-3 Bland-Altman plot

Whilst there was agreement between the health professional and participants in majority of the cases, there were 2 outliers as depicted below (participant 4 and participant 20).

Participant number	MoCA score	GAS achieved (participant rating)	GAS achieved (health professional rating)
2	10	47	37
4	11	57	68
16	10	50	50
18	10	56	50
6	18	45	50
19	18	50	47
20	18	50	38
Abbreviations used: MoCA, Montreal Cognitive Assessment; GAS, goal attainment scaling.			

Table 4-6 Comparison of outliers with participants with similar MoCA scores

The lack of agreement between health professional and participants was initially thought to be due to cognition, however we did not see this level of disagreement for participants with the same or similar level of cognitive impairment. For example, participant 2, 4, 16 and 18's MoCA scores indicate the presence of a moderate cognitive impairment (n= 10 -17); however only participant 4 showed a discrepancy >10 in goal attainment achieved scores. Similarly, participants 6, 19 and 20 have MoCA scores of 18 (indicating mild cognitive impairment) and only participant 20 showed a discrepancy >10 in goal attainment achieved scores between the participant and health professional. While the research team completed goal setting with the participants, the expected outcome level was objectively defined in collaboration with the treating health professional due to their direct involvement with the participant. The study site has a minimum of five to six health professionals per rehabilitation or geriatric evaluation management ward with varying levels of experience in goal setting and measurement which may have contributed to the discrepancies seen for participant 4 and 20. Turner-Stokes (2009) reports that a

mean goal attainment score around 50 indicates accuracy in goal setting (as this depicts that participants achieved their goals as expected). Participant 4 has an achieved score of 68 and participant 20's achieved score is 38 further confirming that the expected outcome levels predicted for these participants may have not been achievable.

Lastly, barriers to using goal attainment scaling for this population was not the focus of this research study, however when meeting with participants at the end of their rehabilitation episode (to measure participants rating of goal achievement), researchers observed that participants did not always recall their goals. Visually presenting goals on the goal attainment 5-point scale assisted in overcoming this barrier.

4.4.4 Responsiveness

Pearson's correlation was run to assess the relationship between goal attainment change scores and FIM change scores in adults aged 65 years or older with mild cognitive impairment or dementia. Preliminary analysis shows the relationship to be linear with both variables normally distributed, as assessed by Shapiro-Wilk's test ($p > .05$). There were two outliers, however researchers made the decision to include these in the overall analysis as these points were valid representations of the data collected. There was no statistically significant correlation between goal attainment scaling and the Functional Independence Measure (FIM), $p = .054$. No correlation meant a priori hypothesis was not accepted and that changes in the FIM were not aligned with changes in goal attainment.

No.	Hypotheses	Result
1	The correlation between goal attainment change scores and FIM change scores is positive i.e. an increase in goal attainment will result in an increase in FIM score or a decrease in goal attainment will result in a decrease in FIM score.	Not accepted
2	The correlation between goal attainment change scores and FIM change scores is moderate (0.3 < r < .5).	Not accepted

Table 4-7 A priori hypothesis outcome

Although the correlation between the two measures was not statistically significant, overall there was an increase in goal attainment scores from baseline to achieved, and an increase in FIM scores from admission to the end of the rehabilitation episode of care (discharge). This was the case for all but two participants (participant 2 and 20). As depicted in Table 4.8, participant 2 showed no change in goal attainment score from baseline to discharge but an increase in FIM score and participant 20 showed no change in goal attainment score but a decrease in the FIM score.

Participant number	GAS baseline	GAS achieved (health professional rating	FIM Total (admission)	FIM total (discharge)
2	37	37	64	87
20	38	38	85	75
Abbreviations used: GAS, goal attainment scaling; FIM, Funtional Independence Measure				

Table 4-8 Depiction of the differences between GAS and FIM as outcome measures

Total FIM scores are made up of 18 items comprised of two domains; motor and cognition (Table 4.2)(Uniform Data System for Medical Rehabilitation, 1996). We therefore examined the specific goals set for these two participants (participant 2 and

20). Both participants set functional goals relating to mobility, toileting and dressing, and both participants did not reach their expected level of outcome (measured using goal attainment scaling). Goal attainment baseline and achieved scores therefore did not change. Despite this, participant 2 may have shown some improvement in their functional ability (in motor and/or cognitive subgroups) resulting in an increase in FIM score and participant 20 may have shown some deterioration in function (in motor and/or cognitive subgroups) resulting in a decrease in FIM score.

These findings highlight the lack of sensitivity of the FIM as an outcome measure and more importantly, highlights the differences between the two outcome measures (GAS and FIM). Goal attainment scaling measures achievement of expectation (what we hoped to achieve) and not physical function (Turner-Stokes, 2009). FIM measures level of disability/functional ability only (Uniform Data System for Medical Rehabilitation, 1996). It does not measure the aims of treatment.

4.5 Discussion

This study examined the validity and responsiveness of goal attainment scaling when used with people with mild cognitive impairment or dementia participating in rehabilitation programs. The study findings suggest that people with mild cognitive impairment or dementia participating in rehabilitation programs can engage in goal setting using goal attainment scaling, regardless of mild to moderately impaired cognition. Cognition is frequently reported to be a barrier to goal setting and rehabilitation for people with mild cognitive impairment or dementia (Allan et al., 2019; Clare et al., 2019a; Clare et al., 2019b; Parsons & Parsons, 2012). However, we found that strategies such as using the goal attainment 5-point scale as a visual representation assisted participant's to recall their goals over time. Similar strategies

were reported in a study by Clair et al. (2022) in which older adults (with complex needs) were provided with a physical copy of their scaled goal. Participants reported this to be beneficial as seeing their goal assisted with focussing on what they were trying to achieve (Clair et al., 2022). Cognitive deficits, including impaired memory recall, is a key symptom of mild cognitive impairment or dementia (Duong et al., 2017; Petersen, 2016). Building awareness into strategies to overcome challenges associated with impaired memory during rehabilitation is therefore important.

Goal setting can be used to evaluate patient outcomes (Levack et al., 2006) and is often used to measure the success of a rehabilitation program in achieving the intended outcomes (Clare et al., 2010). Our study findings were unable to demonstrate statistically significant correlation between goal attainment scaling and the functional independence measure (currently used to measure the changes in disability/functional ability of a person during a hospital rehabilitation admission). Differences in the nature of the two outcome measures have been highlighted and it was noted that while the FIM measures level of disability/functional ability (Uniform Data System for Medical Rehabilitation, 1996), goal attainment scaling measures achievement of expectation (what we hoped to achieve) (Turner-Stokes, 2009). Given that dementia is a progressive condition associated with a gradual decline in function, goal attainment scaling may therefore prove to be a more effective means of evaluating rehabilitation outcomes for this population. Unlike our findings, a study conducted in an inpatient rehabilitation setting in 2020 concluded that goal attainment scaling was associated with changes in functional outcomes (measured by the FIM) and accurately described the patient's rehabilitation progress (Churilov et al., 2020). However, none of the participants in the study were reported to have mild cognitive impairment or dementia. Participant diagnoses included amputee,

musculoskeletal, neurological conditions, spinal conditions and other/deconditioning (Churilov et al., 2020).

Establishing rehabilitation pathways for people with dementia is a known health priority (World Health Organisation, 2017). The 2030 World Health Organisation rehabilitation plan further recommends that rehabilitation interventions should be based on an assessment of the patient's needs by a skilled multidisciplinary workforce (Gimigliano & Negrini, 2017). Collaborative goal setting is one way of assessing/identifying an individual's wishes, needs and priorities for rehabilitation (Wade, 2020b), and goal attainment scaling is one method of goal setting that promotes shared decision making and collaboration in goal setting (Clair et al., 2022; Turner-Stokes, 2009; van Blijswijk et al., 2021). Our study shows that goal attainment scaling can be used for people with mild cognitive impairment or dementia and goal attainment scaling is thus a useful tool to consider in rehabilitation programs for this population.

The National Safety and Quality Health Service (NSQHS) standards in Australia (Australian Commission on Safety and Quality in Health Care, 2019) recommends that clinicians should incorporate goal setting as a person-centred approach towards providing comprehensive care. It further states that organisations should provide access to staff training and education in support of this. Staff training and education is of particular importance with the goal attainment scaling method as the ability to objectively define a patient's expected level of outcome is influenced by the health professionals expertise to predict outcome (Turner-Stokes, 2009). According to Turner-Stokes (2009), multidisciplinary teams can get feedback about the accuracy of their goal setting by reviewing the mean goal attainment scores at the end of the rehabilitation episode. A mean goal attainment achieved score around

50 indicates that goals were achieved at the expected level of outcome (Turner-Stokes, 2009). In our study, it can be noted that a mean goal attainment score of around 50 was not achieved for all participants suggesting reduced accuracy of goal setting and further highlighting the need for staff training in this area.

Finally, this thesis has already discussed the benefits of goal attainment scaling including how well it aligns with person-centred care. Person-centred care is a fundamental principle of the 2018 Alzheimer's Association Dementia Care Practice Recommendations (Fazio, Pace, Maslow, Zimmerman, & Kallmyer, 2018) and is key in achieving universal healthcare (World Health Organisation, 2022). The fact that our study findings support the use of goal attainment scaling (which is a person-centred approach) for people with dementia is therefore key.

4.6 Strengths and limitations

One strength of the study is its uniqueness. Whilst goal attainment scaling has been examined for older people, it's validity for people with dementia has not previously been established. The findings of this research therefore represent an important step forward in goal setting and rehabilitation for people with mild cognitive impairment or dementia. Symptoms of dementia, including decreased memory is known to impact on goal setting (Allan et al., 2019; Clare et al., 2019a; Clare et al., 2019b; Parsons & Parsons, 2012) however this challenge was overcome by using visual prompts such as having the goals displayed on the 5-point goal attainment scale when asking participants to rate their achievement, which is a second strength of the study.

A key limitation of the study includes the small sample size. We screened a total of 1012 patient records against our inclusion criteria however only 21 patients met study eligibility. Although study sample size presents as a limitation, the COSMIN guidelines do not provide a recommendation for sample size when

examining responsiveness (Mokkink et al., 2010). Of the 1012 patient records screened, only 202 patients had a diagnosis of cognitive impairment or dementia listed in their medical history. Given that the patient cohort spanned across four geriatric evaluation management and rehabilitation wards and data collection occurred for nine months, it is likely that a larger number of patients admitted during this timeframe may have had symptoms of mild cognitive impairment or dementia however not formally diagnosed. According to a literature review by Ng and Ward (2019), timely diagnosis of dementia in Australia is not occurring. Time constraints and being acutely unwell were two barriers identified for effective dementia screening and diagnosis in hospital settings (Ng & Ward, 2019). It has been suggested that memory clinics are the most suitable avenue for formal diagnosis of dementia, however currently within the Australian health care system there are long waitlists to access memory clinics (Ng & Ward, 2019).

A second limitation in our study was one of our exclusion criteria, the FIM comprehension score. Potentially eligible participants did not meet study eligibility if they had a FIM comprehension score of less than four (<4) as this indicates insufficient understanding and communication to be able to engage in the study (Uniform Data System for Medical Rehabilitation, 1996). We found that patients admitted had a FIM score of less than four in more than half (n=542) of the patient records screened. Of these, 160 had a diagnosis of cognitive impairment or dementia listed. These 160 patients may therefore have presented with severe cognitive impairment or dementia resulting in not meeting study eligibility criteria. The remaining 382 patient records (with a FIM comprehension score of less than four) did not have a diagnosis of cognitive impairment or dementia listed. A less than

four comprehension score on the FIM for these patients may have been because of other diagnoses impacting speech such as a stroke for example.

A third limitation was the varying time frame between completion of the FIM and goal attainment scaling. The FIM and goal attainment scaling change scores were used to establish responsiveness. Upon admission to the ward, the FIM was routinely completed by ward staff, however goal attainment scaling was only completed by the researcher following study enrolment which may have occurred a few days following admission. At discharge, goal attainment scaling was completed prior to the participant's final day of rehabilitation and the FIM was completed on the day of discharge. This may have impacted overall change scores.

A fourth limitation was due to the Covid-19 pandemic. During waves of the pandemic or when there were Covid-19 outbreaks on the wards, there was a significant drive for patient's to be discharged home sooner, prior to achieving their goals. This impacted on overall goal achievement and goals set as both participants and health professional's had to focus on short term/immediate goals aligned more with "What do I need to achieve to leave hospital" as opposed to more meaningful or personally relevant goals. In addition, as a result of Covid-19, there were many staffing shortages and some participants had multiple health professionals involved in their care who may not have been aware of their goals. This also meant that multiple health professionals were involved in the overall rating of goal achievement for participants.

Finally, the scoping review in chapter 3 identified that goal setting was less successful when completed by a researcher. This may therefore be a fifth limitation in the current study.

4.7 Conclusion

This study found that goal attainment scaling can be used for people with mild cognitive impairment or mild severity dementia. The study further demonstrates that people with mild cognitive impairment or mild severity dementia can set goals for rehabilitation and measure outcomes regardless of impaired cognition. It is recommended that further research is conducted to explore the use of goal attainment scaling for people with mild cognitive impairment or mild severity dementia in a different setting whereby the length of time on the rehabilitation program is longer.

CHAPTER FIVE: DISCUSSION

5.1 Introduction

Goal setting in rehabilitation is commonly undertaken to improve and evaluate patient outcomes (Levack et al., 2006; Levack & Siegert, 2014). People with mild cognitive impairment or dementia may experience difficulties engaging in goal setting due to cognitive and communication difficulties (Allan et al., 2019; Parsons & Parsons, 2012; Thorpe et al., 2019). Understanding approaches to goal setting for this population is therefore required.

Standardised tools or methods of assessment are considered to be gold standard in rehabilitation settings, whereby an expectation to demonstrate the effectiveness of the service or intervention exists (Hurn, Kneebone, & Cropley, 2006). In addition, health professionals are required to apply the best available evidence in their professional practice (Occupational Therapy Board, 2019). While there are an increasing number of studies pertaining to rehabilitation and goal setting for people with mild cognitive impairment or dementia, clinical awareness and application is lacking.

In an effort to increase knowledge and awareness of goal setting for people with mild cognitive impairment or dementia, as well as improve clinical application in rehabilitation settings, the following research questions were addressed:

1) What are the existing approaches to goal setting for people with mild cognitive impairment or dementia participating in rehabilitation programs?
2) Can people with mild cognitive impairment or mild severity dementia measure progress towards goals and accurately report outcomes?

This thesis has presented the findings of two studies which addressed these research questions. Each study has already included discussion about the study findings alongside existing literature. This chapter will present a summary of the key findings, strengths and limitations, and will also discuss the clinical implications for future practice. Lastly, a discussion about future research is presented.

5.2 Summary of findings

Overall, this thesis has demonstrated that despite common preconceptions, people with mild cognitive impairment or dementia can engage in goal setting to support the rehabilitation process. A summary of the key findings is presented below:

5.2.1 Goal setting is feasible, supported by a structured approach

The scoping review synthesised data from 27 studies and found that people with mild cognitive impairment or dementia can participate in goal setting. A number of strategies and approaches were identified, including use of both structured and non-structured goal setting methods. Participant characteristics included people with dementia, mild cognitive impairment or a combination of both. Although, few studies reported on the severity of dementia demonstrating the need for further investigation.

An additional finding of the scoping review was that a structured approach (such as goal attainment scaling) can facilitate effective goal setting for people with mild cognitive impairment or dementia. The review demonstrated that a structured approach enables individualisation of goals, aligned with the person's interests, and enables measurement of progress and outcomes. A structured approach also assists in setting clear expectations about disease progression.

In the included studies, the context for goal setting was predominantly in the community (17 studies). Five studies reported on use of goal attainment scaling of

which only one study described goal attainment scaling in a multidisciplinary rehabilitation setting. Given the reported benefits of this standardised approach, examining its validity when used with people with mild cognitive impairment or dementia, was considered important and useful in supporting goal setting in rehabilitation settings. This work was presented in chapter 4 of this thesis.

5.2.2 Strategies to enhance goal setting for people with mild cognitive impairment or dementia do exist.

The scoping review identified several barriers to goal setting for people with mild cognitive impairment or dementia. It was found that persons with more severe levels of cognitive and functional impairment demonstrated greater difficulty in goal setting as they had difficulty recalling their goals. In addition, goal setting was challenging when carers or persons with mild cognitive impairment or dementia lacked insight into impairments and disease progression. Nonetheless, the review found that strategies to enhance goal setting for this population do exist. A structured approach such as use of goal attainment scaling was found to facilitate effective goal setting. A structured approach enables clear communication and documentation of goals which can overcome concerns about the person with dementia's reduced insight and difficulties in recalling rehabilitation goals.

Staff education and training was also identified as a useful strategy to facilitate goal setting for people with mild cognitive impairment or dementia. The scoping review found that if therapists had a limited understanding of dementia, no specific goals for rehabilitation were set. This also resulted in people with dementia not having a clear understanding of or expectation of therapy.

Finally, the scoping review highlighted that family or caregiver involvement is a valuable strategy to support the goal setting process.

5.2.3 People with mild cognitive impairment or mild severity dementia can set goals for rehabilitation and measure outcomes

The second study in this thesis examined the validity and responsiveness of goal attainment scaling when used with people with mild cognitive impairment or dementia. Goal attainment scaling has been described in detail in chapter 2 of this thesis. By examining the construct validity of goal attainment scaling (using the Bland-Altman method) for this population, the study established that goal attainment scaling can be used for people with mild cognitive impairment or mild severity dementia. Furthermore, this indicates that people with mild cognitive impairment or mild severity dementia can set goals for rehabilitation and measure outcomes. Participants in the study ranged from those with mild cognitive symptoms to those with moderate cognitive symptoms and of the 21 participants, 6 had a formal diagnosis of dementia. Based on participant's MoCA scores, none of the participants presented with severe dementia and the study findings can therefore not be generalised to this population. This is similar to the findings of the scoping review in where there was less evidence for goal setting for people in the later stage of dementia.

The goal attainment scaling method quantifies goals that are tailored to the individual's abilities and measures the aims of treatment (what we hoped to achieve). The findings of the second study in this thesis show that people with mild cognitive impairment or dementia can measure outcomes using goal attainment scaling. It is however important to note that outcomes in the context of goal attainment scaling may not necessarily be related to improvements in function only. Interestingly, whilst the second study did not aim to examine the specific goals set by people with mild cognitive impairment or dementia, even though goal attainment scaling enables choice and control in goals set, all participants identified goals relating to body

functions and/or activity as outlined in the International Classification of Functioning, disability and health framework (ICF)(World Health Organisation, 2001).

5.2.4 Do use of standardised approaches to goal setting improve motivation to participate?

According to Locke and Latham's goal setting theory, setting clear, specific and challenging goals can assist in improving motivation to participate in rehabilitation settings (Locke & Latham, 1990). Motivation is an important aspect of rehabilitation (Levack & Siegert, 2014), and for people with dementia, apathy is one symptom that can impact motivation (Sondell et al., 2018). Considering strategies to improve motivation to participate in rehabilitation programs is therefore valuable for people with dementia. Whilst the second study in this thesis did not measure or explore motivation per se, it is important to note that goal attainment scaling aligns with Locke and Latham's goal setting theory as it provides an approach to goal setting that allows for clear, specific and challenging goals to be set. Goal attainment scaling may therefore further play a role in improving motivation to participation in rehabilitation programs.

5.3 Strengths and limitations

This thesis is comprised of two studies and detailed explanations of strengths and limitations are provided within the individual studies.

A strength of the scoping review is that the inclusion criteria were designed in order to capture data from a large number of studies. Data from 27 studies were synthesised, providing a wealth of information and reflecting a wide population of interest (from those with mild to severe dementia and from a range of settings). The scoping review provided clear recommendations to inform the clinical practice of goal

setting for people with mild cognitive impairment or dementia participating in rehabilitation programs.

The second study examined the validity and responsiveness of goal attainment scaling for people with mild cognitive impairment or dementia participating in rehabilitation programs. This study is unique and is the first of its kind. Whilst goal attainment scaling has been examined for older people, it's validity for people with dementia has not previously been established. The findings of this research represent an important step forward in goal setting and rehabilitation for people with mild cognitive impairment or dementia. The second study also used the COSMIN (COnsesus-based Standards for the selection of health status Measurement Instruments) checklist for responsiveness which is a strength towards the methodological quality of the study.

Key limitations of the second study include the small sample size. Recruitment was slow due to the unexpected number of people who were ineligible. The research setting admits a large number of older people and many participants were screened. A key reason for ineligibility was that a diagnosis of dementia or cognitive impairment was not recorded in the person's medical notes. Furthermore, the impact of Covid-19 in hospital settings was and still is immense. Due to bed pressures, participant goals were considered to be more immediate or short-term goals aligned with "What do I need to achieve to leave hospital?" rather than more meaningful or personally relevant goals. Given the nature of rehabilitation described in the second study (shorter length of hospital stay as a result of Covid-19 bed pressures), it is recommended that the use of goal attainment scaling for people with mild cognitive impairment or dementia is further examined with a larger sample size

and in a setting where the period of rehabilitation is longer. This may be in a community setting.

5.4 Clinical implications for future practice

Despite the growing body of literature pertaining to goal setting for people with mild cognitive impairment or dementia, translation of practice does not appear to have occurred in inpatient rehabilitation settings. As already discussed in this thesis, patient-level, staff-level and organisation-level barriers exist.

Health professionals need to firstly overcome their perceptions of people with dementia's ability to engage in goal setting and rehabilitation (Cations et al., 2020). There is a crucial need to improve knowledge and skills in how best to engage people with mild cognitive impairment or dementia in goal setting and rehabilitation (World Health Organisation, 2017). More widespread staff education and training is required (Australian Commission on Safety and Quality in Health Care, 2019). In line with this, health professionals are encouraged to explore strategies to overcome patient-level barriers (cognitive and communication problems) such as use of visual aids or goal banks.

Secondly, it is known that goal setting is a means of measuring and reporting outcomes (Levack et al., 2006). Health professionals are therefore encouraged to vigorously advocate for integration of standardised goal setting methods for people with mild cognitive impairment or dementia into their practise within rehabilitation settings. Due to known organisation-level barriers such as time and resources (Plant et al., 2016), education of the importance and value of a structured approach to goal setting for people with mild cognitive impairment or dementia is required. Inpatient multidisciplinary teams may need to implement changes to their team processes to incorporate effective goal setting for this population into daily practice. These

changes may include regular staff training and education and clear communication and documentation of goals into care plans. Moreover, a multidisciplinary approach and family or caregiver involvement may be required to regularly orientate patients to their goals.

The finding that goal attainment was not correlated with changes in function (measured by the Functional Independence Measure) shows that different constructs are being measured. Use of the goal attainment scale demonstrates a more person-centred approach to rehabilitation and measurement of outcome (Turner-Stokes, 2009).

5.5 Future research

There is ongoing advocacy for people with dementia to be granted access to rehabilitation programs (World Health Organisation, 2017). Whilst the studies in this thesis concluded that people with mild cognitive impairment or dementia can engage in goal setting in rehabilitation programs, strategies to support cognitive and communication difficulties were only briefly touched on as it was not the focus of this thesis. Further research of these strategies will enhance clinical practice and further support in implementation of standardised goal setting methods for people with mild cognitive impairment or dementia in rehabilitation programs. Future research examining the specific types of goals that people with mild cognitive impairment or dementia choose to pursue in inpatient rehabilitation settings (following an acute injury) might also be worthwhile. This may assist in creating goal banks with visual cues such as pictures to support with goal setting and rehabilitation.

Although 27 studies were included in the scoping review, we were unable to complete any meta-analysis due to the broad scope and heterogeneity of the

included studies and were therefore unable to examine the specific goals set in further detail.

5.6 Conclusion

Goal setting for people with mild cognitive impairment or dementia participating in rehabilitation programs is feasible. People with mild cognitive impairment or dementia can engage in goal setting using a structured approach such as goal attainment scaling.

These findings should prompt health professionals and rehabilitation programs to adapt clinical practice thereby enabling people with mild cognitive impairment or dementia to gain greater access to rehabilitation. Greater access to rehabilitation as outlined by the World Health Organisation (2017) will optimise participation in daily life for this population who are at a high risk of functional decline due to the progressive nature of the disease.

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APPENDICES

APPENDIX A Scoping review; Search strategy used

Includes: Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Daily and Versions(R) 1946 to April 20, 2020

1	**Motivation/ or Goals/ or Intention/**	**90148**
2	(goal* or goal setting* or motivation* or intention or goal attainment).mp.	512271
3	1 or 2	512271
4	Dementia/ or Aids dementia complex/ or Alzheimers Disease/ or Aphasia, primary progressive nonfluent aphasia/ or Creutzfeldt-jakob syndrome/ or Dementia, vascular/ or Cadasil/ or Dementia, multi-infarct/ or Diffuse neurofibrillary tangles with calcification/ or Frontotemporal lobar degeneration/ or Frontotemporal dementia/ or “pick disease” or Kluver-bucy or lewy body disease/ or “diffuse cerebral sclerosis of schilder:/	74568
5	Neurocognitive disorders/ or Cognition disorders/ or Mild cognitive impairment/	88024
6	(dementia or Alzheimer* or progressive aphasia or progressive nonfluent aphasia or creutzfedt-jakob or cadasil or frontotemporal lobar	366397

	degeneration or “pick disease of the brain”/ or Kluver-bucy or lewy bod* or Parkinson* or delirious or delirium*).mp	
7	((cogniti* or neurocognitiv* or neurodegenerat* or degenerate* or function*) adj2 (condition* or disease* or disorder* or declin* or impair*)).mp.	346053
8	4 or 5 or 6 or 7	624350
9	Rehabilitation or Home Care Services/ or Independent Living/ or “Activities of Daily Living”/	116328
10	(reablement or “activities of daily living” or ADL or ADLs or IADL or IADLs or self care or selfcare or daily living activit* or rehabilitat* or neurorehabilitat* or telerehabilitat* or intervention*).mp.	1365828
11	9 or 10	1394834
12	3 and 8 and 11	4121
13	Limit 12 to yr=”2010-Current”	2767

APPENDIX B Scoping review; Study protocol

<table>
<tr><td colspan="2">Review title and timescale</td></tr>
<tr><td>1</td><td>Review title
Goal setting for people with mild cognitive impairment or dementia participating in rehabilitation programs: A scoping review</td></tr>
<tr><td>2</td><td>Anticipated or actual start date: 23.04.2020</td></tr>
<tr><td>3</td><td>Anticipated completion date:30.10.2020</td></tr>
<tr><td>4</td><td>Review team members and their organisational affiliations
Give the title, first name and last name of all members of the team working directly on the review. Give the organisational affiliations of each member of the review team.

<table>
<tr><td>Title</td><td>First name</td><td>Last name</td><td>Affiliation</td></tr>
<tr><td>Mrs</td><td>Praneeta</td><td>Jogie</td><td>Flinders University</td></tr>
<tr><td>Dr.</td><td>Miia</td><td>Rahja</td><td>Flinders University</td></tr>
<tr><td>A/Prof</td><td>Kate</td><td>Laver</td><td>Flinders University</td></tr>
<tr><td>Dr.</td><td>Maayken</td><td>Van den berg</td><td>Flinders University</td></tr>
</table>
</td></tr>
<tr><td>5</td><td>Funding sources/sponsors
Give details of the individuals, organizations, groups or other legal entities who take responsibility for initiating, managing, sponsoring and/or financing the review. Any unique identification numbers assigned to the review by the individuals or bodies listed should be included.
No funding has been allocated for the conduct of this review</td></tr>
<tr><td>6</td><td>Conflicts of interest
List any conditions that could lead to actual or perceived undue influence on judgements concerning the main topic investigated in the review. Are there any actual or potential conflicts of interest?
None Known</td></tr>
</table>

7	Collaborators Give the name, affiliation and role of any individuals or organisations who are working on the review but who are not listed as review team members. Not applicable
Review methods	
8	Review question(s) State the question(s) to be addressed / review objectives. Please complete a separate box for each question. The purpose of this scoping review is to describe approaches to goal setting for people with mild cognitive impairment or dementia participating in rehabilitation programs. The primary review questions are: What goal setting approaches are used for people with mild cognitive impairment or dementia participating in rehabilitation programs? Where is goal setting applied? When? And with which professionals? What are common goals identified? What are the barriers and enablers to goal setting? The secondary aim of this review is to Identify outcomes of goal setting for people with mild cognitive impairment or dementia participating in rehabilitation programs. Identify preferences to goal setting approaches for people with dementia or cognitive impairment participating in rehabilitation focussed programs? Identify the impact of caregiver involvement in goal setting?
9	Searches Give details of the sources to be searched, and any restrictions (e.g. language or publication period). The full search strategy is not required but may be supplied as a link or attachment. We will use the following electronic databases: CINAHL (EBSCO interface);

	MEDLINE (OVID interface); Embase (OVID interface) PsycINFO (OVID interface) The search strategy was developed for Medline using medical subject headings (MeSH) and text words, and then adapted for use with the other bibliographic databases. The strategy combined terms relating to goals and goal setting; dementia and cognitive impairment and; rehabilitation and independent living. We searched the last 10 years (to reflect contemporary literature) and studies published in English language only. The reference lists of included studies will also be hand searched.
10	Condition or domain being studied Give a short description of the disease, condition or healthcare domain being studied. This could include health and wellbeing outcomes. Goal setting during rehabilitation for people with dementia or mild cognitive impairment.
11	Participants/population Give summary criteria for the participants or populations being studied by the review. The preferred format includes details of both inclusion and exclusion criteria. Inclusion criteria: People with dementia or mild cognitive impairment (not cognitive impairment related to stroke). Participating in an intervention which has a rehabilitation focus. Exclusion criteria: We will exclude mild cognitive impairment related to stroke, acquired brain injury and Parkinson's disease.

	We will further exclude systematic reviews, study protocols, conference proceedings, editorials and commentary papers. Studies which do not relate to humans, or which do not report goal setting processes will also be excluded.
12	Intervention(s), exposure(s) Give full and clear descriptions of the nature of the interventions or the exposures to be reviewed We will include studies that describe goals identified during interview or survey either informally or formally as part of a rehabilitation program or process. Rehabilitation in the context of this review is conceptualised as “measures that help individuals with a disability or a disabling health condition achieve and maintain optimum functioning in interaction with their environments” (World Health Organization [WHO], 2011).
13	Comparator(s)/control Where relevant, give details of the alternatives against which the main subject/topic of the review will be compared (e.g. another intervention or a non-exposed control group). Not applicable
14	Types of study to be included Give details of the study designs to be included in the review. If there are no restrictions on the types of study design eligible for inclusion, this should be stated. We will include original research articles in this review. No limits will be imposed on study design.
15	Context Give summary details of the setting and other relevant characteristics which help define the inclusion or exclusion criteria.

Studies will be selected for inclusion only if people living with dementia or (mild) cognitive decline are engaged in goal setting as part of their rehabilitation process. There will be no restrictions by region or country. There will be no restriction on care provision setting (i.e. Community or care facility) or care professional (i.e. occupational therapy or physiotherapy).

16 Primary outcome(s)

Give the most important outcomes. Give information on timing and effect measures, as appropriate.

We will explore approaches to goal setting, types of goals being set as well as factors that influence goal setting within this population.

RESEARCH AIM/PURPOSE	RESEARCH QUESTIONS	OUTCOMES
To describe approaches to goal setting for people with mild cognitive impairment or dementia participating in rehabilitation programs.	What goal setting methods are used?	Methods – options may include Goal attainment scaling, other tools, standardised approaches, and informal methods such as interview or SMART goal setting.
	Where is goal setting applied? When? And with which professionals?	Approach to goal setting. Frequency of goal setting.
	What are common goals?	Types of goals- may relate to desired outcomes (e.g.

			ADL's, participation, community, roles)
		What are the outcomes of goal setting?	Psychosocial (self-efficacy, mood) Function/impairment related
		What are the barriers and enablers to goal setting?	Communication, insight, familiarity with goal orientated thinking, terminology, caregiver involvement

17	Secondary outcomes List any additional outcomes that will be addressed. If there are no secondary outcomes enter None.
	Give information on timing and effect measures, as appropriate. None. We will also explore measures of activity and participation, as well as conduct a narrative synthesis of the countries involved in the studies in the review.
18	Data extraction (selection and coding) Give the procedure for selecting studies for the review and extracting data, including the number of researchers involved and how discrepancies will be resolved. List the data to be extracted. Data is extracted as follow: Two reviewers (PJ and MR) first independently screen titles and/or abstracts based on the inclusion criteria detailed in this

protocol. Differences between reviewers' results will be resolved by discussion and when necessary, in consultation with a third reviewer, KL. If, after discussion, there is still doubt about the relevance of a study or relevance to the review it will be kept.

Full copies will be obtained for all studies identified by the title/abstract screening. We will use Covidence to screen full text based on the inclusion/exclusion criteria as defined in the review protocol. Two reviewers (PJ and MR/KL/MV) will independently conduct the full text review. Any differences of opinion about inclusion/ exclusion will be resolved by discussion between the two reviewers or by consultation with a third reviewer (MR/KL/MV). Reasons for excluding studies will be documented.

We will use the Preferred Reporting Items for Systematic Reviews and Meta-Analyses chart (PRISMA) to summarise the number of papers included/excluded at each stage of the process including the reason for exclusion. The flow chart will clearly outline the review processes.

A data extraction tool will be developed using Microsoft excel to chart results. The following will be included:

Author(s)
Year of publication
Origin/country of origin
Aims/purpose of study
Study population/Participants
Study method
Study setting
Intervention/s used
Outcomes
Key findings that relate to the scoping review question/s.
Authors conclusion

	The primary review author (PJ) will extract data independently. The second review author (MR) will check the included articles. Any discrepancies will be identified and resolved through discussion, or consultation with a third review author when necessary. We will present findings using narratives and tables.
19	Risk of bias (quality) assessment State whether and how risk of bias will be assessed, how the quality of individual studies will be assessed, and whether and how this will influence the planned synthesis. The appraisal will be conducted independently by two review authors. Any disagreements that arise will be discussed, and a third review author will be consulted if necessary. Risk of Bias and Quality of individual studies will be assessed using the Mixed Methods Appraisal tool (MMAT)
20	Strategy for data synthesis Give the planned general approach to be used, for example whether the data to be used will be aggregate or at the level of individual participants, and whether a quantitative or narrative (descriptive) synthesis is planned. Where appropriate a brief outline of analytic approach should be given. A quantitative data synthesis is planned. Data extracted from included studies will be analysed and summarized to answer the stated review objectives using summary tables. No meta-analysis is planned as it is anticipated that there will be significant heterogeneity of service configurations in the included studies.
21	Analysis of subgroups or subsets Give any planned exploration of subgroups or subsets within the review. 'None planned' is a valid response if no subgroup analyses are planned. None planned
22	Dissemination plans

	Give brief details of plans for communicating essential messages from the review to the appropriate audiences. Do you intend to publish the review on completion? The review is intended to be published in a Journal of relevance.
23	Keywords Give words or phrases that best describe the review. (One word per box, create a new box for each term) Goals Goal setting approaches Dementia Mild cognitive impairment Participation in rehabilitation programs

APPENDIX C Scoping review, Published paper (removed due to copyright restriction)

APPENDIX D Quantitative study; HREC approval

Monash Health

Research Support Services
Monash Health
Level 2, I Block
Monash Medical Centre
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6 April 2021

Mrs Praneeta Jogie
Monash Health
Department of Occupational Therapy
400 Warrigal Rd
Cheltenham Vic 3192

Dear Researcher

Study Title: To explore the validity and responsiveness of the goal attainment scale when used with people with mild cognitive impairment or mild severity dementia

ERM Reference Number: HREC/69866/MonH-2020-241361(v1)
Monash Health Reference: RES-20-0000-874A

The Monash Health HREC reviewed the above application at the meeting held on 3 December 2020. In addition, the HREC is satisfied that the responses to our correspondence of 8 December 2020 have been sufficiently addressed.

The HREC approved the above application on the basis of the information provided in the application form, protocol and supporting documentation.

This reviewing HREC is accredited by the Victorian Department of Health and Human Services under the National Mutual Acceptance, single ethical review system.

Approval

The HREC approval is from 6 April 2021.

Approval is given in accordance with the research conforming to the *National Health and Medical Research Council Act 1992* and the *National Statement on Ethical Conduct in Human Research (2018)*. The HREC has ethically approved this research according to the Memorandum of Understanding between the Victorian Department of Health and Human Services and the participating organisations conducting the research.

Approval is given for this research project to be conducted at the following sites and campuses:

You must comply with the following conditions:

The Chief Principal Investigator is required to notify the Manager, Human Research Ethics Committee, Monash Health of:

1. Any change in protocol and the reason for that change together with an indication of ethical implications (if any)
2. Suspected Unexpected Serious Adverse Reactions (SUSARs), Serious Adverse Events (SAEs) or Significant Safety Issues (SSIs) in accordance with the NHMRC safety guidelines as adopted by Monash Health that occur with a Monash Health participant or with a participant from a site that Monash Health has provided HREC review.
3. Any unforeseen events that might affect continued ethical acceptability of the project.
4. Any expiry of the insurance coverage provided in respect of sponsored trials.
5. Discontinuation of the project before the expected date of completion, giving reasons.
6. Any change in personnel involved in the research project including any study member resigning from Monash Health &/or the study team.

At the conclusion of the project or every twelve months if the project continues, the Principal Investigator is required to complete and forward an annual progress report to the Committee.

Reminders to submit annual progress report forms will be forwarded to the researcher.

The Coordinating Principal Investigator is responsible for notifying Principal Investigators. The Coordinating Principal Investigator and Principal Investigators should forward a copy of this letter to their site's Research Governance Officer.

Approved documents

Documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Human Research Ethics Application	HREC/69866/MonH-2021-257249(v3)	31/3/2021
Study Protocol	1.1	7/3/2021
Victorian Specific Module		2/11/2020
Participant Information and Consent Form_Patient	1.2	24/3/2021
Participant Information and Consent Form_Person Responsible	1.2	24/3/2021
Montreal Cognitive Assessment (MOCA)		7/11/2004
Communication & Expression of Interest	-	-
Goal Attainment Scaling (GAS) Record Sheet	1.0	18/11/2020

Site-Specific Assessment (SSA)

SSA authorisation is required at all sites participating in the study. SSA must be authorised at a site before the research project can commence.

The completed Site-Specific Assessment Form and a copy of this ethics approval letter must be submitted to the Research Governance Officer for authorisation by the Chief Executive or delegate. This applies to each site participating in the research.

If you should have any queries about your project please contact the Research Support Services team via email research@monashhealth.org in the first instance.

The HREC wishes you and your colleagues every success in your research.

Yours sincerely

DEBORAH DELL
Manager, Human Research Ethics Committee
& Research Support Services

Participant Information Sheet/Consent Form

Health/Social Science Research - *Adult providing own consent*

Monash Health: Kingston Centre

Title	To explore the validity and responsiveness of the goal attainment scale when used with people with mild cognitive impairment or mild severity dementia.
Protocol Number	Project ID 69866
Project Sponsor	Monash Health
Principal Investigator(s)	Mrs. Praneeta Jogie Ms. Jacqui Salway
Associate Investigator	Associate Professor. Kate Laver Dr. Miia Rahja Dr. Maayken van den Berg
Location	Kingston Centre

Part 1 What does my participation involve?

1. Introduction

You are invited to take part in this research project. You have been invited to participate in this project because you have difficulty with your memory and thinking and are an inpatient at Kingston Centre.

This Participant Information Sheet tells you about the research project and what is involved. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether to take part, you might want to talk about it with a relative, friend or health worker.

Participation in this research is voluntary. If you don't wish to take part, you don't have to. If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:

- Understand what you have read
- Consent to take part in the research project
- Consent to the use of your personal and health information as described

You will be given a copy of this Participant Information and Consent Form to keep.

2. What is the purpose of this research?

Problems with memory and thinking is common in older Australians. Older people admitted to hospital often lose some of their physical fitness and take time to recover. Setting goals for recovery can be a good first step and helps ward staff understand what is important for you. One of the tools that we can use to set clear goals is the Goal Attainment Scale.

The Goal Attainment Scale has not been used as much in older people who might have trouble with their memory and thinking. This study aims to determine whether or not the Goal Attainment Scale can be used with people admitted to hospital who have problems with their memory and thinking difficulties.

This research has been initiated by the researcher, Mrs Praneeta Jogie (Senior Occupational Therapists) and is being conducted towards a Master of Science by Research degree through Flinders University.

3. What does participation in this research involve?

If you are interested in participating in this study the researchers will first confirm you meet the inclusion criteria. If you are eligible for participation you will be asked to provide the researchers with written consent.

Taking part in this study will require your participation in two conversations with a health professional. In the first session you will be asked some questions about what you would like to achieve before going home. You and the health professional will agree on 3-4 key items that are important for you. This session will take approximately 20-30minutes. The goals will be recorded in your medical record and communicated to your team. This is a usual process for most people who are admitted to the ward.

In the second conversation, the health professionals will meet with you before you are discharged home and you will look at your written goals together and discuss if you have met them or not. The health professional will also ask your treating therapists' if they believe that you have met your goals.

All of the project activities will be done while you are in hospital

4. Other relevant information about the research project

This research project will involve up to 50 patients on the rehabilitation and aged care wards at Kingston Centre.

5. Do I have to take part in this research project?

Participation in any research project is entirely voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

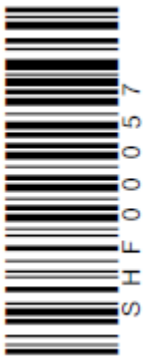
If you do decide to take part, you will be given this Participant Information and Consent Form to sign and you will be given a copy to keep.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your relationship with Monash Health. You will still be able to take part in goal setting at Monash Health if you don't participate in this project.

6. What are the possible benefits of taking part?

There will be no immediate benefit to you from your participation in this research project. However, your involvement will help to provide information about whether or not this goal setting tool can be used for people with dementia and mild cognitive impairment to set measurable and meaningful goals to assist with their recovery.

7. What are the possible risks and disadvantages of taking part?



If you become upset or distressed as a result of your participation in this research, a member of the research team will be able to arrange for counselling or other appropriate support. Any counselling or support will be provided by qualified staff who are not members of the research project team. This counselling will be provided free of charge.

8. What if I withdraw from this research project?

If you decide to withdraw from this research project, please notify a member of the research team. If you do withdraw your consent during the research project, the research team will not collect additional personal information from you, although personal information already collected will be retained to ensure that the results of the research project can be measured properly and to comply with law. If you do withdraw, you will be asked to complete and sign a withdrawal of consent form; this will be provided to you by the research team.

9. Could this research project be stopped unexpectedly?

We do not anticipate that this project would be unexpectedly stopped.

10. What happens when the research project ends?

The results will be reported in academic publications and presented at conferences. Only group summary data will be presented and it will not be possible to identify any individual from the results. If you would like to receive a copy of the research report please let a member of the research team know and one will be provided to you in the form of a one page summary.

Part 2 How is the research project being conducted?

11. What will happen to information about me?

By signing the consent form you consent to the research team collecting personal information such as your age, gender and reason for admission for the research project. All information collected will be stored for a period of 7 years on a password protected computer system at Kingston Centre. Only the research team based at Kingston Centre will have access to the personal data.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified.

The data collected could be used in a future research project, however at this stage there are no such plans. If the data were to be used approval from the Human Research Ethics Committee (HREC) will be required.

12. What if I get injured in the research?

If you suffer any injuries or complications as a result of this research project, you should contact the research team as soon as possible and you will be assisted with arranging appropriate medical treatment. As you are eligible for Medicare, you can receive any medical treatment required to treat the injury or complication, free of charge, as a public patient in any Australian public hospital.

13. Who is organising and funding the research?

This research project is being conducted at Kingston Centre by Occupational Therapists, Mrs. Praneeta Jogie. No external funding has been sought to conduct this study.

No member of the research team will receive a personal financial benefit from your involvement in this research project (other than their ordinary wages).

14. Who has reviewed the research project?

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee. The ethical aspects of this research project have been approved by the Monash Health Ethics Committee.

This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (2018)*. This statement has been developed to protect the interests of people who agree to participate in human research studies.

15. Further information and who to contact

If you want any further information concerning this research project you can contact:

Name	Praneeta Jogie
Position	Senior Occupational Therapist
Telephone	03 9265 1405
Email	Praneeta.Jogie@Monashhealth.org

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact:

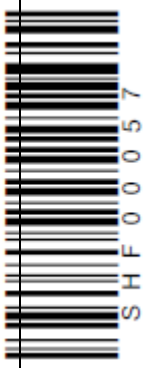
Monash Health HREC Office / Complaints Contact Person

Name	Ms Deborah Dell
Position	Manager Research Support Services and Human Research Ethics Committee
Telephone	(03) 9594 4611
Email	research@monashhealth.org.au

Please quote the following project number: 69866

Consent Form - *Adult providing own consent*

Title	To explore the validity and responsiveness of the Goal Attainment Scale when used with people with Mild Cognitive Impairment or mild symptoms of Dementia
Project Number	69866
Project Sponsor	Monash Health
Principal Investigator(s)	Mrs. Praneeta Jogie Ms Jacqui Salway
Associate Investigator(s)	A/Prof. Kate Laver. Miia Rahja Dr. Maayken van den Berg
Location	Kingston Centre, Monash Health



Declaration by Participant

I have read the Participant Information Sheet, or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project without affecting my future health care.

I understand that I will be given a signed copy of this document to keep.

I understand that my hospital medical records will be accessed.

Name of Participant (please print) _____

Signature Date _____

Declaration by Researcher

I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Name of Researcher† please print)

Signature Date _____

† An appropriately qualified member of the research team must provide the explanation of, and information concerning, the research project.

Note: All parties signing the consent section must date their own signature.

Form for Withdrawal of Participation - *Adult providing own consent*

Title	To explore the validity and responsiveness of the Goal Attainment Scale when used with people with Mild Cognitive Impairment or mild symptoms of Dementia
Protocol Number	69866
Project Sponsor	Monash Health
Principal Investigator(s)	Mrs. Praneeta Jogie Ms. Jacqui Salway
Associate Investigator (s)	A/Prof. Kate Laver Dr. Miia Rahja Dr. Maayken van den Berg
Location	Kingston Centre, Monash Health

Declaration by Participant

I wish to withdraw from participation in the above research project and understand that such withdrawal will not affect my routine treatment, my relationship with those treating me or my relationship with Monash Health.

Name of Participant (please print) _____

Signature Date _____

In the event that the participant's decision to withdraw is communicated verbally, the Researcher will need to provide a description of the circumstances below.

Declaration by Researcher†

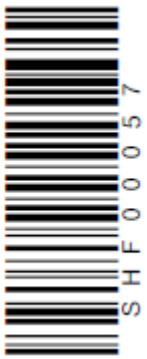
I have given a verbal explanation of the implications of withdrawal from the research project and I believe that the participant has understood that explanation.

Name of Researcher† (please print)

Signature Date

† A member of the research team must provide the explanation of and information concerning withdrawal from the research project.

Note: All parties signing the consent section must date their own signature.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Participant Information Sheet/Consent Form

Health/Social Science Research – *Person responsible/Medical treatment decision maker consenting on behalf of participant*

Monash Health: Kingston Centre

Title	To explore the validity and responsiveness of the goal attainment scale when used with people with mild cognitive impairment or mild severity dementia.
Protocol Number	Project ID 69866
Project Sponsor	Monash Health
Principal Investigator(s)	Mrs. Praneeta Jogie Ms. Jacqui Salway
Associate Investigator	Associate Professor. Kate Laver Dr. Miia Rahja Dr. Maayken van den Berg
Location	Kingston Centre

Part 1 What does participation involve?

1. Introduction

The participant is invited to take part in this research project. This is because they have difficulty with their memory and thinking and are an inpatient at Kingston Centre.

This Participant Information Sheet tells you about the research project and what is involved. Knowing what is involved will help you decide if you want the participant to take part in the research.

Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether or not the participant can take part, you might want to talk about it with a relative, friend or health worker.

Participation in this research is voluntary. If you don't wish for the participant to take part, they do not have to. They will receive the best possible care whether or not they take part.

If you decide you want the participant to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:
- Understand what you have read
- Consent to the participant taking part in the research project
- Consent to the use of the participant's personal and health information as described

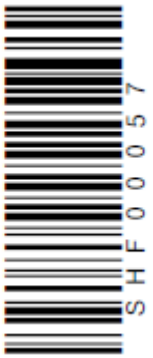
You will be given a copy of this Participant Information and Consent Form to keep.

2. What is the purpose of this research?

Problems with memory and thinking is common in older Australians. Older people admitted to hospital often lose some of their physical fitness and take time to recover. Setting goals for recovery can be a good first step and helps ward staff understand what is important for the participant. One of the tools that we can use to set clear goals in the Goal Attainment Scale.

The Goal Attainment Scale has not been used as much in older people who might have trouble with their memory and thinking. This study aims to determine whether or not the Goal Attainment Scale can be used with people admitted to hospital who have problems with their memory and thinking difficulties.

This research has been initiated by the researcher, Mrs Praneeta Jogie (Senior Occupational Therapists) and is being conducted towards a Master of Science by Research degree through Flinders University.



3. What does participation in this research involve?

If you decide that the participant can take part in this research project, you will be asked to sign the consent form before any study assessments are performed.

Taking part in this study will require the participant to take part in two conversations with a health professional. In the first session they will be asked some questions about what they would like to achieve before going home. The participant and the health professional will agree on 3-4 key items that are important for them. This session will take approximately 20-30minues. The goals will be recorded in their medical record and communicated to their team. This is a usual process for most people who are admitted to the ward.

In the second conversation, the health professional will meet with the participant before they are discharged home and they will look at their written goals together and decide if they have met them or not. The health professional will also ask their treating therapists' if they believe that they have met their goals.

All of the project activities will be done while the participant is in hospital

4. Other relevant information about the research project

This research project will involve up to 50 patients on the rehabilitation and aged care wards at Kingston Centre.

5. Do I have to take part in this research project?

Participation in any research project is entirely voluntary. If you do not wish for the participant to take part, they do not have to. If you decide that the participant can take part and later change your mind, you are free to withdraw them from the project at any stage.

If you do decide that the participant can take part, you will be given this Participant Information and Consent Form to sign and you will be given a copy to keep.

Your decision whether the participant can take part or not to take part, or to take part and then withdraw, will not affect their routine treatment, your or the participant's relationship with those treating them, or their relationship with Monash Health. The participant will still be able to take part in goal setting at Monash Health if they don't participate in this project.

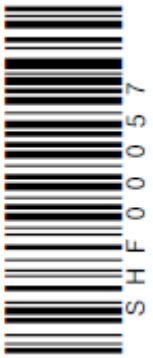

SHF00057

6. What are the possible benefits of taking part?

There will be no immediate benefit to the participant if they participate in this research project. However, involvement will help to provide information about whether or not this goal setting tool can be used for people with dementia and mild cognitive impairment to set measurable and meaningful goals to assist with their recovery.

7. What are the possible risks and disadvantages of taking part?

If the participant becomes upset or distressed as a result of participating in this research, a member of the research team will be able to arrange for counselling or other appropriate support. Any counselling or support will be provided by qualified staff who are not members of the research project team. This counselling will be provided free of charge.



8. What if I withdraw from this research project?

If you decide to withdraw the participant from this research project, please notify a member of the research team. If you do decide to withdraw the participant, the research team will not collect additional personal information from them, although personal information already collected will be retained to ensure that the results of the research project can be measured properly and to comply with law. If you do withdraw the participant, you will be asked to complete and sign a withdrawal of Consent form; this will be provided to you by the research team.

9. Could this research project be stopped unexpectedly?

We do not anticipate that this project would be unexpectedly stopped.

10. What happens when the research project ends?

The results will be reported in academic publications and presented at conferences. Only group summary data will be presented, and it will not be possible to identify any individual from the results. If you would like to receive a copy of the research report, please let a member of the research team know and one will be provided to you in the form of a one page summary outlining the research findings.

Part 2 How is the research project being conducted?

11. What will happen to information about the participant?

By signing the consent form you consent to the research team collecting personal information about the participant such as their age, gender and reason for admission for the research project. All information collected will be stored for a period of 7 years on a password protected computer system at Kingston Centre. Only the research team based at Kingston Centre, will have access to the personal data.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that the participant cannot be identified.

The data collected could be used in a future research project, however at this stage there are no such plans. If the data were to be used approval from the Human Research Ethics Committee (HREC) will be required

12. Complaints and compensation

If the participant suffers any injuries or complications as a result of this research project, you should contact the research team as soon as possible and you will be assisted with arranging appropriate medical treatment. If the participant is eligible for Medicare, they can receive any medical treatment required to treat the injury or complication, free of charge, as a public patient in any Australian public hospital.

13. Who is organising and funding the research?

This research project is being conducted at Kingston Centre by Occupational Therapist, Mrs. Praneeta Jogie. No external funding has been sought to conduct this study.

No member of the research team will receive a personal financial benefit from your involvement in this research project (other than their ordinary wages).

14. Who has reviewed the research project?

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this research project have been approved by the HREC of Monash Health.

This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (2018)*. This statement has been developed to protect the interests of people who agree to participate in human research studies.

15. Further information and who to contact

If you want any further information concerning this research project you can contact:

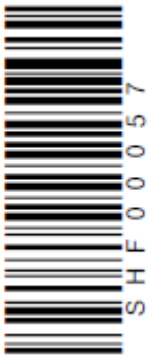
Name	Praneeta Jogie
Position	Senior Occupational Therapist
Telephone	03 9265 1405
Email	Praneeta.Jogie@monashhealth.org

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact:

Monash Health HREC Office / Complaints Contact Person

Name	Ms Deborah Dell
Position	Manager Research Support Services and Human Research Ethics Committee
Telephone	(03) 9594 4611
Email	research@monashhealth.org.au

Please quote the following project number:69866



Consent Form - *Person responsible/Medical treatment decision maker consenting on behalf of participant*

Title	To explore the validity and responsiveness of the Goal Attainment Scale when used with people with Mild Cognitive Impairment or mild symptoms of Dementia
Project Number	69866
Project Sponsor	Monash Health
Principal Investigator(s)	Mrs. Praneeta Jogie Mrs Jacqui Salway
Associate Investigator(s)	A/Prof. Kate Laver Dr. Miia Rahja Dr. Maayken van den Berg
Location	Kingston Centre, Monash Health

Declaration by Person Responsible/Medical treatment decision maker

I have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to the participant participating in this research project as described and understand that

I am free to withdraw at any time during the project without affecting their future health care.

I understand that I will be given a signed copy of this document to keep.

Name of Participant (please print) _____

Name of Person providing consent (please print) _____

Relationship of Person providing consent to Participant_____

Signature of Person providing consent _____ Date _____

Declaration by Researcher

I have given a verbal explanation of the research project, its procedures and risks and I believe that the person responsible/medical treatment decision maker for the participant has understood that explanation.

Name of Researcher† please print) _____

Signature _____ Date _____

† An appropriately qualified member of the research team must provide the explanation of, and information concerning, the research project.

Declaration - for Person Responsible/Medical treatment decision maker unable to read the information and consent form
Witness to the informed consent process
Name (please print) _____
Signature _____ Date _____
* Witness is not to be the Investigator, a member of the study team or their delegate. Witness must be 18 years or older.

Note: All parties signing the consent section must date their own signature.

Form for Withdrawal of Participation - *Person responsible/Medical treatment decision maker consenting on behalf of participant*

Title	To explore the validity and responsiveness of the Goal Attainment Scale when used with people with Mild Cognitive Impairment or mild symptoms of Dementia
Protocol Number	69866
Project Sponsor	Monash Health
Principal Investigator(s)	Mrs. Praneeta Jogie Mrs. Jacqui Salway
Associate Investigator (s)	A/Prof. Kate Laver Dr. Miia Rahja Dr. Maayken van den Berg
Location	Kingston Centre, Monash Health

Declaration by Person Responsible/Medical treatment decision maker

I wish to withdraw the participant from taking part in the above research project and understand that such withdrawal will not affect their routine care, or relationships with the researchers or Monash Health.

Name of Participant (please print) _____

Name of Person providing consent (please print) _____

Relationship of Person providing consent to Participant _____

Signature of Person providing consent _____ Date _____

In the event that the participant's decision to withdraw is communicated verbally, the Researcher will need to provide a description of the circumstances below.

Declaration by Researcher†

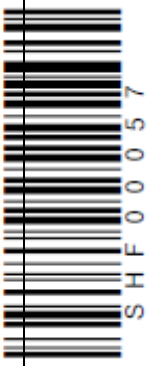
I have given a verbal explanation of the implications of withdrawal from the research project and I believe that the person responsible/medical treatment decision maker for the participant has understood that explanation.

Name of Researcher† (please print) _____

Signature _____ Date _____

† A member of the research team must provide the explanation of and information concerning withdrawal from the research project. Note:

All parties signing the consent section must date their own signature.



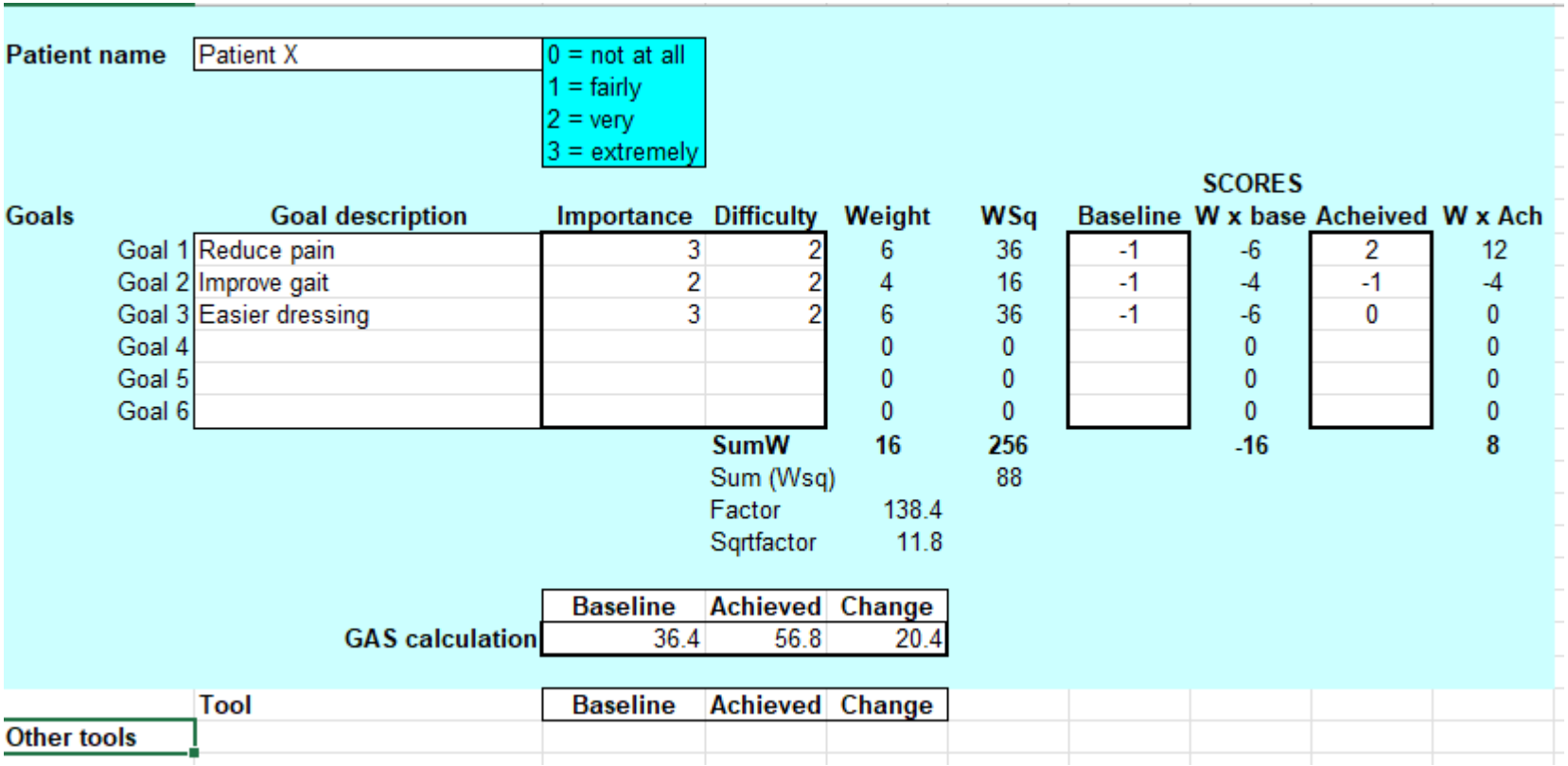
APPENDIX G Quantitative study; GAS verbal record sheet

STUDY ID: _____ **Admission date:** _____ **Discharge date:** _____				**Importance to patient**: score Important, very Important, extremely important. **Difficulty** of achieving (professionals): score Not difficult, Minor difficulty, Moderate difficulty, Extreme difficulty Goal attainment **baseline**: usually set at some function, or No function, (as bad as it can be) **Goal attainment score**: As expected = achieves goal as expected. partially achieved = some improvement but goal not achieved, same as baseline = no change, a little better = achieved more than the goal, Much better – overachieved goal.				
	Patient stated goal	**SMART goal**	**Importance**	**Difficulty of achieving**	**Baseline**	**Achieved**		**Variance** (Describe achievement if differs from expected)
1		Date Set……	❒ **Imp** ❒ **v.imp** ❒ **Ex.imp**	❒ **Not difficult** ❒ **Minor difficulty** ❒ **Mod difficulty** ❒ **Extreme difficulty**	❒ **Some** function ❒ **No** function (as bad as can be)	□ Yes □ No	❒ Much better ❒ A little better ❒ **As expected** ❒ Part achieved ❒ Same as baseline ❒ Worse	Date ……. …..
			Baseline function					

2		Date Set……	❒ **Imp** ❒ **v.imp** ❒ **Ex.imp**	❒ **Not difficult** ❒ **Minor difficulty** ❒ **Mod difficulty** ❒ **Extreme difficulty**	❒ **Some** function ❒ **No** function (as bad as can be)	□ Yes □ No	❒ Much better ❒ A little better ❒ **As expected** ❒ Part achieved ❒ Same as baseline ❒ Worse	Date ……..…..
			Baseline function					

Baseline GAS T-score:	**Achieved GAS T-score**	**Change in GAS T Score**	**Date……**

APPENDIX H Quantitative study; GAS calculation sheet



Patient name	Patient X	0 = not at all 1 = fairly 2 = very 3 = extremely								
							SCORES			
Goals		**Goal description**	**Importance**	**Difficulty**	**Weight**	**WSq**	**Baseline**	**W x base**	**Acheived**	**W x Ach**
	Goal 1	Reduce pain	3	2	6	36	-1	-6	2	12
	Goal 2	Improve gait	2	2	4	16	-1	-4	-1	-4
	Goal 3	Easier dressing	3	2	6	36	-1	-6	0	0
	Goal 4				0	0		0		0
	Goal 5				0	0		0		0
	Goal 6				0	0		0		0
				SumW	**16**	**256**		**-16**		**8**
				Sum (Wsq)		88				
				Factor	138.4					
				Sqrtfactor	11.8					
			Baseline	**Achieved**	**Change**					
		GAS calculation	36.4	56.8	20.4					
	Tool		**Baseline**	**Achieved**	**Change**					
Other tools										

(Turner-Stokes, 2009)

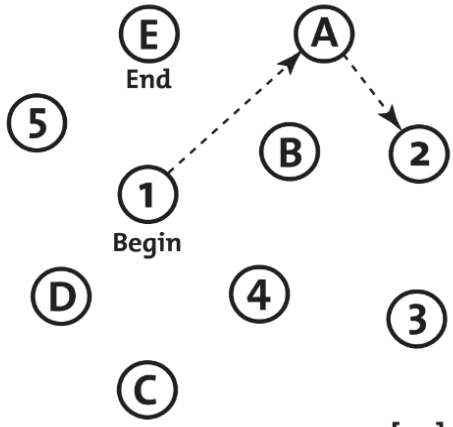
STUDY ID: _____

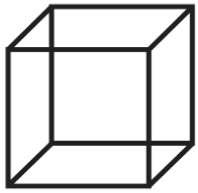
MONTREAL COGNITIVE ASSESSMENT (MOCA)

Education :
Sex :

Date of birth :
DATE :

VISUOSPATIAL / EXECUTIVE





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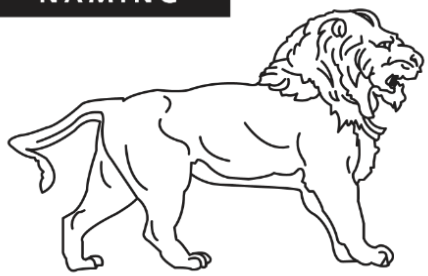
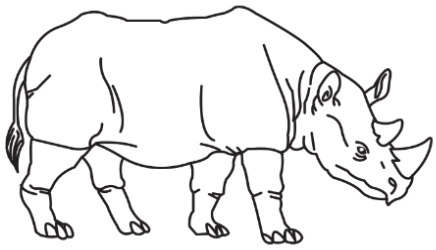
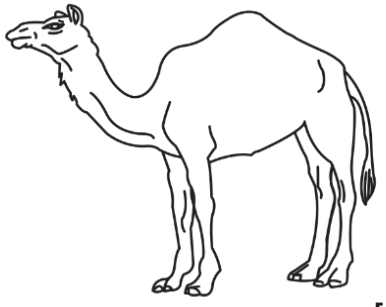
POINTS ___/5

NAMING







[ ] [ ] [ ]

___/3

MEMORY

Read list of words, subject must repeat them. Do 2 trials. Do a recall after 5 minutes.

	FACE	VELVET	CHURCH	DAISY	RED
1st trial					
2nd trial					

No points

ATTENTION

Read list of digits (1 digit/ sec.).
Subject has to repeat them in the forward order [ ] 2 1 8 5 4
Subject has to repeat them in the backward order [ ] 7 4 2

___/2

Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors

[ ] F B A C M N A A J K L B A F A K D E A A A J A M O F A A B

___/1

Serial 7 subtraction starting at 100 [ ] 93 [ ] 86 [ ] 79 [ ] 72 [ ] 65

4 or 5 correct subtractions: **3 pts**, 2 or 3 correct: **2 pts**, 1 correct: **1 pt**, 0 correct: **0 pt**

___/3

LANGUAGE

Repeat : I only know that John is the one to help today. [ ]
The cat always hid under the couch when dogs were in the room. [ ]

___/2

Fluency / Name maximum number of words in one minute that begin with the letter F [ ] _____ (N ≥ 11 words)

___/1

ABSTRACTION

Similarity between e.g. banana - orange = fruit [ ] train – bicycle [ ] watch - ruler

___/2

DELAYED RECALL

	Has to recall words WITH NO CUE	FACE [ ]	VELVET [ ]	CHURCH [ ]	DAISY [ ]	RED [ ]	Points for UNCUED recall only
Optional	Category cue						
	Multiple choice cue						

___/5

ORIENTATION

[ ] Date [ ] Month [ ] Year [ ] Day [ ] Place [ ] City

___/6

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Normal ≥ 26 / 30

TOTAL ___/30

Add 1 point if ≤ 12 yr edu

Script 1:

I am an occupational therapist working here at Kingston Centre and I am currently involved in a research project which is about setting goals.
I've come to see you today as I would like to invite you to be involved in the project.
The project is for people with memory and thinking problems which is common in older Australians.
Often when older people are admitted to hospital, they lose some of their physical fitness and take time to recover.
Setting goals for you recovery is a good first step and helps us understand what is important for you.
If you are interested in being a part of the study, I first need to make sure that you meet all the criteria.
One of the criteria involves completing a short assessment of your memory and thinking. Is it okay if we complete it now?

Script 2:

Thank you for agreeing to complete the assessment.
Your score shows that you meet the criteria for the study.
Taking part in the study involves two sessions.
In the first session we'll talk about what you would like to achieve or work on before leaving the hospital and you and I will agree on 3-4 things that are important for you.
I will let your team know what these goals are and write it in your file.
I will then come to see you before you leave the hospital, and you will look at your goals and we will talk about if you have met them or not.

I will also ask your therapist if you have met them or not.
This is some written information about the project which I will leave for you.
Would you like to read it a bit more before agreeing to be involved?

Script 3:

Thank you for agreeing to meet with me today.
I am here to discuss your goals for your recovery.
Setting goals is a good first step and helps us understand what is important for you.
What would you like to work on or achieve before leaving the hospital?
What is important for you?

Script 4:

When you first arrived in the hospital, you and I met and agreed on XXX goals for your recovery.
I have these goals written down here.
Your first goal was XXX.
Do you think you have achieved this goal? Yes or No.
If yes: Do you think you have achieved this goal as expected, a little better or much better?
If no: Do you think you may have partly achieved this goal (there is some improvement, but you have not achieved you goal) Or do you think you are the same as you were when you first arrived in the hospital (there is no change) or much worse?