

Describing and Measuring the “Switch-on” Effect in People Who Participate in Cognitive Stimulation Therapy

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Abstract

This study explored the “switch-on” effect, a recently identified outcome experienced by some participants of cognitive stimulation therapy (CST). CST is an evidence-based group intervention for improving cognitive function in people with mild to moderate dementia. The aim of the study was to attain a more comprehensive understanding of “switch-on”, a satisfying and little-known benefit of CST, by focusing on three research questions:

- What is the nature of the “switch-on” effect as described by people attending CST and their family or caregivers?
- At what time-points during and after the group is the “switch-on” effect reported?
- Are the changes described as the “switch-on” effect measurable using the Volitional Questionnaire?

A convergent parallel mixed methods design merging qualitative descriptive methodology and the single-subject A-B design was used for the inquiry. Qualitative data were collected via semi-structured face-to-face interviews with four community-dwelling CST attendees with dementia and their family member or caregiver before, during and after CST. Measurements using the Volitional Questionnaire (VQ), an observational measure of volition, were obtained with patient participants concomitantly. The interview data were analysed using NVivo-assisted thematic analysis, and the VQ measurement results were examined through descriptive statistics and visual analysis.

Thematic qualitative analysis of the interview data indicated that the “switch-on” effect was multi-dimensional in nature, with increased engagement in occupation and expanded scope in Doing, Feeling, Relating, and Thinking and Reflecting. The occurrence of the effect described by patient and family participants involved a noticeable onset of “switch-on” changes within the first three weeks of CST. The changes continued to consolidate towards the completion of the seven-week programme in both CST and home environments. Descriptive analysis of the VQ data

across the three time-points revealed concurrent improvement, mainly on the Achievement sub-scale, in three of the patient participants, although the instrument was deemed to not effectively capture the “switch-on” changes due to its ceiling effect.

This study generated a detailed description of the “switch-on” effect, a cluster of interrelated beneficial changes following participation in CST, as reported by the four patient participants and their family caregivers. It also contributed a range of newly discovered positive outcomes of CST as part of “switch-on”. These included intentional occupational adjustment at home in Doing; improved acceptance of living with dementia and improved appreciation and consideration towards family caregivers in Feeling; the subcultural dimension described as “fellowship” and “comradeship” within the CST group and improved spousal relationships at home in Relating; and extended thought patterns that oriented more towards sociality and the future rather than focusing on themselves and the past in Thinking and Reflecting. The mixed methods findings of the study further suggested the positive impact of the intervention on patient participant’s volition and volitional processes, a source of changes that has not been explored in past CST studies and is worth more investigation in future research.

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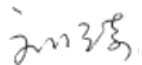
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Attestation of Authorship

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

Signed: 

Date: 18 November 2018

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Chapter 1 Introduction

Introduction

This mixed methods study aimed to describe and measure the “switch-on” effect of cognitive stimulation therapy (CST), a brief group therapy for people with mild to moderate dementia. There is accumulating evidence in the literature that CST improves cognitive function and quality of life (Spector et al., 2003; Woods, Aguirre, Spector, & Orrell, 2012); however, little is known about the “switch-on” effect; a positive and satisfying outcome of the intervention reported by some CST attendees and their families (Cheung & Peri, 2014; Spector, Gardner, & Orrell, 2011).

Four community-dwelling, older adults with mild dementia and their spouses participated in the study. The qualitative part of the study was guided by qualitative descriptive methodology (Stanley, 2015). Semi-structured interviews were conducted with the eight research participants before, during and after the CST programme to generate information about the nature and occurrence of the “switch-on” effect. Concurrently, following a single-subject A-B design (Carter & Lubinsky, 2015), patient participants were evaluated using the Volitional Questionnaire (de las Heras, Geist, Kielhofner, & Li, 2007), an observational measure of volition, to explore whether a “switch-on” effect was captured by the instrument. A convergent parallel mixed methods design (Crotty, 1998) was employed to compare and integrate the qualitative and quantitative data to build greater understanding of the “switch-on” effect of CST.

This chapter provides an introduction to the study and the structure of the thesis. Definitions of the key terms used in the paper are rendered first, followed by statements of the research purpose and questions. The contextual and theoretical foundations of the study are elaborated, along with my personal background and professional interests. The necessity and potential contribution of the study are discussed next. Finally, the chapters of the thesis are outlined and explained which gives an overview of the scope and coverage of the study.

Terms and Definitions

It is necessary to first define the key terms used in this study to ensure clarity and consistency throughout the thesis. These terms are dementia, severity of dementia, cognitive stimulation therapy, the “switch-on” effect, and volition.

Dementia

Dementia refers to a clinical syndrome caused by a variety of underlying neurocognitive conditions (such as Alzheimer’s Disease) that commonly affect older adults. It involves disturbances in memory, thinking, learning, communication and performance of daily activities (Alzheimer's Disease International, 2012). Apart from impinging on cognitive function, usually in a degenerative fashion, dementia may also lead to deterioration in “emotional control, social behaviour or motivation” (Alzheimer's Disease International, 2012, p. 7). The term is replaced by “major neurocognitive disorder” in the Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM–5) (American Psychiatric Association, 2013), largely owing to the negative connotation of the word. However, dementia remains an accepted and widely used term in research literature and clinical practice.

Severity of Dementia

In accordance with the CST literature (Spector et al., 2003; Woods et al., 2012), three stages of dementia (mild, moderate and severe) were applied in this study to ascertain severity of the illness and suitability for the intervention. Mild dementia refers to early stage of the illness, during which “deficits are evident in a number of areas (such as memory and personal care) but the person can still function”; moderate dementia relates to middle stage of the illness when “deficits become more obvious and severe”, with “increasing levels of assistance” required to “help the person maintain their functioning in the home and community”; and severe dementia pertains to late stage of the illness, “characterized by almost total dependence on the

care and supervision by others” (Australian Institute of Health and Welfare, 2012, p. 3).

Cognitive Stimulation Therapy

Cognitive stimulation refers to an intervention or a category of intervention for people with dementia that aims at “general enhancement of cognitive and social functioning” through engagement with a variety of activities and discussions, usually in a small group setting (Woods et al., 2012, p. 3). Cognitive stimulation therapy (CST), the focus of this study, is a specific type of cognitive stimulation that has the most robust evidence for its efficacy. CST was developed by Aimee Spector, a clinical psychologist, and her colleagues in the United Kingdom (Spector, Orrell, Davies, & Woods, 2001; Spector et al., 2003).

CST offers a seven-week, 14-session, carefully designed group programme, which enables members to participate in a range of themed, enjoyable social activities in a supportive learning environment (Spector, Thorgrimsen, Woods, & Orrell, 2005). The intervention was piloted first (Spector et al., 2001) and then tested in a large-scale, randomized controlled trial (RCT) (Spector et al., 2003) which demonstrated its effectiveness in improving cognitive function and self-rated quality of life for those with mild to moderate dementia. In this thesis, CST is also referred as “Spector’s cognitive stimulation therapy” to differentiate it from other types of cognition-oriented intervention that use the same term.

Cognitive stimulation should be distinguished from cognitive training and cognitive rehabilitation (Clare & Woods, 2004). Cognitive training is applied to improve cognitive function of specific domains and is usually delivered through paper-pen based or computerized tasks in either an individual or group format. Cognitive rehabilitation employs an individualized approach with a focus on improving performance of daily activities by addressing and compensating for cognitive impairment.

The “Switch-on” Effect

The “switch-on” effect is a beneficial outcome of CST that emerged from qualitative inquiries about the intervention in two studies (Cheung & Peri, 2014; Spector et al., 2011). The phrase “switch-on” describes a cluster of positive changes noted by these researchers in some people with dementia after participation in CST, including “a sense of being more switched on or wanting to attend to things more” (Spector et al., 2011, p. 948), and “new-found confidence, capabilities and vastly improved communication skills” (Cheung & Peri, 2014, p. 7). “Switch-on” seems to reflect an observer’s standpoint in representing the changes, and an equivalent, more subjective label for the effect used by CST attendees is “stimulation” or “feeling stimulated” (Cheung & Peri, 2014, p. 21). A typical description about “switch-on” was that “by the third or fourth session, it was like a switch went off, and he became more vocal. He was like that all the time after this” (Cheung & Peri, 2014, p. 21).

Volition

Volition is a central and foundational construct in the Model of Human Occupation (MOHO), a widely acknowledged and applied conceptual model in occupational therapy (Taylor, 2017). Volition is defined as “patterns of thoughts and feelings about oneself as an actor in one’s world which occur as one anticipates, chooses, experiences and interprets what one does” (Taylor, 2017, p. 54). Three components underlie a person’s volition, personal causation or perceived competence and effectiveness, values and interest. This concept of volition is what the Volitional Questionnaire (de las Heras et al., 2007) attempts to evaluate and measure. Selection of the VQ for use in this study is discussed in full in the research design chapter.

Research Purpose and Questions

The purpose of this study was to further explore the “switch-on” effect experienced by some people who participate in CST to build more understanding of this positive outcome of the intervention. In consideration of the scant knowledge about the

“switch-on” effect, it was sensible and attainable to first collect more descriptive information about its nature and onset. Further, given that the existing knowledge about “switch-on” was entirely acquired through qualitative research, it was reasonable to speculate whether the effect was measurable using an available instrument.

Three research questions were formulated based on the present understanding of “switch-on” and my professional interest and experience in occupational therapy. These research questions were

1. What is the nature of the “switch-on” effect as described by people attending CST and their family or caregivers?
2. At what time-points during and after the CST programme is the “switch-on” effect reported?
3. Are the changes described as the “switch-on” effect measurable using the Volitional Questionnaire (VQ) (de las Heras et al., 2007)?

Context of the Study

To appraise the usefulness of the research topic of the “switch-on” effect, it is imperative to first examine the context of the study in terms of the condition of dementia, the treatment of cognitive stimulation therapy, the New Zealand setting, and the theoretical basis relating to human occupation. The dementia context discusses the impact of dementia on the individuals, their families and the wider community and society. The CST context introduces background information about the intervention, including its development, therapeutic elements, and research needs. The New Zealand context of dementia care focuses on the research and implementation of CST in the country, particularly in Auckland. The theoretical context offers an overview of the Model of Human Occupation (MOHO) (Taylor, 2017) and its relevance to the study.

Dementia Context

Dementia is a chronic and debilitating brain disease that has no effective treatment for reversing its pathologies and progression at present (Alzheimer's Disease International, 2012). The DSM-5 proposes six cognitive domains that may be impaired in dementia or major neurocognitive disorders, including complex attention, executive function, memory and learning, expressive and receptive language, perceptual-motor function, and social cognition (American Psychiatric Association, 2013). These cognitive deficits may manifest in various dementia symptoms and impact on day-to-day functioning, such as difficulties with filtering out competing and irrelevant stimuli in the environment; multi-tasking or performing multi-stage tasks; recalling recent events or tracking storylines in a movie or novel; word-finding or labelling people and places by name; and recognizing social cues or facial expressions of emotion.

Despite impairment in immediate and short-term memory, very long-term semantic, autobiographical, and implicit memory may be relatively well-preserved in people with dementia (American Psychiatric Association, 2013). This is important because retaining memory of one's past can maintain the person's sense of "narrative coherence" (Higgs & Gilleard, 2016, p. 776), connection to self and continuity of identity.

In addition to cognitive impairments, almost all people with dementia may experience some behavioural and psychological symptoms of dementia (BPSD) during the course of their illness, with depression and apathy being the most common ones in Alzheimer's type dementia (Dyer, Harrison, Laver, Whitehead, & Crotty, 2018). While both depression and apathy may share features like social inactivity and loss of interest and initiative, the former is a mood disorder with presentations of sadness and emotional distress, and the latter is a motivational disorder characterized by concomitant diminution of goal-related behaviours, thought content and emotional responsivity (Marin, 1990).

T. M. Murray, Sachs, Stocking, and Shega (2012) investigated the symptom experiences of people with dementia who lived in the community. Their study found that instead of memory loss, pain, depression and activity disturbance were the three most bothersome symptoms reported by people with dementia and their caregivers. Further, family caregivers tended to report a wider range of dementia-specific symptoms, including thought disturbances, memory deficits and problems with daily activities; whereas patients only reported cognitive symptoms.

All these symptoms experienced by people with dementia will eventually jeopardize their performance and engagement in occupations and lead to dependence, restricted social participation, and diminished quality of life (Atchison & Dirette, 2012). As a progressive and disabling condition, dementia generates enormous challenges not only for people with the diagnosis, but also their family and caregivers. Moreover, it imposes substantial strain on the healthcare and social welfare systems (Alzheimer's Disease International, 2012). As a result, dementia care has been espoused as a public health priority by the World Health Organization (WHO) (Alzheimer's Disease International, 2012).

Dementia care has been influenced by Kitwood's (1997) original work on "personhood", which values the individual person and the impact of social environment above the biomedical processes of dementia. The term "person-centred care" that he coined has been evolved into a prevailing care model and philosophical framework for promoting good cares for people with dementia worldwide (Alzheimer's Disease International, 2012; Ministry of Health, 2013; National Institute for Health and Clinical Excellence, 2006). A recent literature review on evidence-based practice for person-centred dementia care highlighted the importance of providing "ongoing opportunities for meaningful engagement", building "authentic, caring relationships", and creating "a supportive community" for people with dementia, their families and caregiving staff (Fazio, Pace, Flinner, & Kallmyer, 2018, p. S18). The authors also identified the need for more research to "further assess the outcomes of person-centred care approaches and models" (p. S10).

CST is one of few evidence-based interventions for promoting cognition and quality of life in people with dementia (Spector et al., 2003). It also has an explicit affiliation to the concept of personhood and the person-centred care approach on the both theoretical and practical levels (Spector et al., 2005). Given that, it is worthwhile to obtain more understanding of its effects and benefits, including the “switch-on” effect, a positive yet little known outcome of CST.

Cognitive Stimulation Therapy Context

Cognitive stimulation therapy was developed in response to the need for a cognition-based therapy programme that could be provided for people with mild to moderate dementia in residential and day-care settings (Spector et al., 2001). Two precedent interventions supplied some “building blocks” for the CST programme (Spector et al., 2001), Reality Orientation (RO) (Spector, Orrell, Davies, & Woods, 2000), and a French version of cognitive stimulation (Breuil et al., 1994). Reality Orientation offered the technique of repeatedly presenting orientation information to enhance memory (Spector et al., 2001). The French version of cognitive stimulation (Breuil et al., 1994) rendered the practices of targeting “global cerebral stimulation” (p. 212), activating implicit memory and implicit learning, and using various perceptual modalities related to daily life situations. However, significant modifications were also made when adopting and incorporating these therapeutic elements. The concept of “personhood” (Kitwood, 1997) was embraced in the design and provision of CST, which transformed the rigid and insensitive style of RO while retaining its cognitive-enhancing effect. Unlike Breuil et al.’s (1994) clinical approach, CST made “cognitive stimulation” less overt and serious, but embedding it in a fun, “game-like” and “non-threatening” programme (Spector et al., 2001).

These fundamental elements shaped the philosophical and theoretical basis of CST as well as some distinctive features of the intervention (Spector et al., 2005). For example, in compliance with person-centeredness, the programme is delivered in a respectful, inclusive and light-hearted manner that encourages choice, enjoyment,

relationship building and maximization of strengths and potential. RO is reflected in the feature of using a “reality orientation board” in the group to reinforce remembering and processing of orientation information. Implicit learning is applied in several ways, including following consistent structures and procedures in each group session, supporting active engagement with the themed activities in the presence of abundant cues for retrieval, and encouraging production of opinions rather than recalling of facts.

CST has demonstrated efficacy in enhancing cognitive function, language and communication, and quality of life for people with mild to moderate dementia in quantitative studies (Hall, Orrell, Stott, & Spector, 2013; Spector, Orrell, & Woods, 2010; Spector et al., 2003; Woods et al., 2012). However, broader benefits of the intervention have been found in qualitative investigations (Cheung & Peri, 2014; Kelly et al., 2016; C. M. Murray, Gilbert-Hunt, Berndt, & de la Perrelle, 2016; Spector et al., 2011; Toh, Ghazali, & Subramaniam, 2016), including the “switch-on” effect. The present study looked at describing the nature and occurrence of “switch-on” and exploring a way of measuring it, which will contribute to more understanding of the impact of the comprehensive, multi-factorial intervention on the “whole” person.

New Zealand Context

As the population ages in New Zealand and internationally, it is anticipated that the number of people diagnosed with dementia will grow. According to the WHO, approximately 35.6 million of people were living with dementia worldwide in 2010, and the number is projected to nearly double every twenty years (Alzheimer's Disease International, 2012). In New Zealand, the estimated number of people who had dementia in 2016 was 62,287 people which accounted for 1.3% of the total population (Alzheimers New Zealand, 2017). This was an increase of roughly 29% over the previous estimate in 2011, and a total of about 78,000 people with dementia has been projected in 2026. The incremental increase in prevalence and incidence of dementia has brought about significant socioeconomic costs for the families and

society. The Ministry of Health has identified dementia care as one of the leading challenges for the health and disability system in New Zealand (Ministry of Health, 2018a). The national framework for dementia care (Ministry of Health, 2013) advocates “a person-centred and people-directed approach” (p. 7), alignment with “international trends and standards”, and use of “evidence and best practice models” (p. 8). Notably, Spector’s cognitive stimulation therapy was recognized as a best practice example in the framework.

Most health and disability services in New Zealand are publicly funded and accessible for eligible people, including those with dementia. Around three quarters of the health and disability resources are allocated to and administered by 20 District Health Boards (DHB) across the country (Ministry of Health, 2018b). Cheung and Peri (2014) conducted the first and the only published New Zealand study on CST and further developed a one-day CST facilitator training workshop in 2015, which they have delivered nationally to people working in various dementia settings from a wide range of professional and care backgrounds (Peri & Cheung, 2017). As a result of their work and effort, CST has become accessible free of charge for people with dementia in Auckland. CST providers include public mental health services for older adults in the Auckland DHBs (such as the Waitemata DHB), non-government organizations (NGOs) (such as Dementia Auckland), dementia day-care centres (such as Platinum Community Care, Enliven Auckland and Totara Club of the Equip Services), and aged care residential facilities (such as Selwyn Village and Seadrome Home and Hospital). Occupational therapists have been actively involved in driving, leading, and/or delivering some of these CST programmes, such as in Dementia Auckland, Enliven Auckland and Seadrome Home and Hospital.

However, according to Peri and Cheung (2017), CST has not yet been acknowledged and established as routine practice in community and residential settings for people with dementia. Implementation of the intervention has largely been dependent on factors like senior management decisions, availability of funding and resources, and the passion and interest of trained staff.

Considering that, it is reasonable to summarize that uptake of CST in New Zealand is a work in progress. As opposed to a “top-down” government push, implementation of CST has been mainly driven by individuals, including occupational therapists, who view the intervention as consistent with and supportive of their values, interests and work roles. This provides the contextual backdrop for the present study, with at least two implications. First, the expanding trend of applying the intervention in practice, particularly in Auckland, made it feasible to recruit research participants from an existing CST programme. Second, given the apparent needs for more New Zealand-based CST research and more government support, this study appears to be an appropriate and timely endeavour.

Theoretical Context

The study of the “switch-on” effect was informed and guided by an occupation-based theoretical perspective for two considerations. First, in occupational therapy, occupation refers to all activities in which a person engages in everyday life that are culturally and personally meaningful, including self-care, leisure and productivity (Townsend & Polatajko, 2007). Although developed as a psychological intervention, CST is essentially an activity-based social group that people with dementia attend and engage in regularly over seven weeks. Therefore, participation in CST itself can be regarded as an “occupation”, and its therapeutic outcomes, such as the “switch-on” effect, can be explored effectively using occupational therapy models and tools. Second, CST has been found to be congruent with occupational therapy values (Yuill & Hollis, 2011) on the common ground of “respectfulness of individuality, recognition of capacity for self-determination, encouragement of participation in meaningful activities, and optimization of overall well-being” (p. 168). The systematic review of CST literature also showed that occupational therapists, including occupational therapy students, have actively engaged in the research and provision of CST internationally (C. M. Murray et al., 2016; Rehling, Corr, Sixsmith, & Chard, 2015; Streater, Spector, Aguirre, & Orrell, 2016; Yuill & Hollis, 2011).

The Model of Human Occupation (MOHO) (Taylor, 2017) provided an appropriate theoretical framework and a useful tool, the Volitional Questionnaire (VQ) (de las Heras et al., 2007), for the study of the “switch-on” effect. MOHO explains how people are motivated to choose, organize and perform occupations, and how they actively interact with the social and physical environment during the process. The model also explicates how continued and patterned engagement in occupation affords positive changes in health and well-being as a therapeutic means and/or a desirable end. This dynamic view of occupational engagement in the health context was applied in understanding the “switch-on” effect as a positive outcome of participation in CST, a thoughtfully designed, occupation-based, social programme for people with dementia.

As one of the four basic elements of MOHO, the term volition refers to the way a person is inspired, propelled and energized to participate in an occupation. Volition comprises three relatively stable components; personal causation, values and interests, and is a dynamic and cyclic volitional process of a person anticipating, choosing, experiencing and interpreting the occupations they engage in (Taylor, 2017). Personal causation refers to “one’s sense of competence and effectiveness” (p. 54) that encompasses two dimensions; sense of capacity, which is “an active awareness of one’s capabilities” (p. 43), and sense of efficacy, which “concerns whether one’s efforts are sufficient to accomplish desired ends” (p. 44). Values are “what one finds important and meaningful to do” (p. 54), which often engenders personal conviction and sense of obligation. Interests are “what one finds enjoyable or satisfying to do” (p. 54), which can serve as an inspirational source of life and propel the formation of patterns of occupation.

The VQ is an observational tool developed by occupational therapists for evaluating the construct of volition in MOHO, particularly for people who have difficulty articulating their volitional experiences (de las Heras et al., 2007). The instrument consists of 14 behavioural indicators or items that are categorized into three volitional levels; exploration, competency and achievement, based on the assumption

that people may have more or less motivation for occupation on a volitional continuum. Exploration represents the lowest level of volition where the person exhibits “the basic desire to interact with the environment and can experience pleasure from doing so”. Competency builds on the exploration level of volition and gives the person “a sense of efficacy and enjoyment in doing things”. It is characterized by “the drive to actively engage and influence the environment”. Achievement is the highest level of volition founded on the previous two stages, which involves “consistent performance” in response to environmental demands, “a sense of capacity and efficacy”, and “a sense of pleasure” and meaning in acting”. This level of volition is featured with persistent “endeavours”, investment of “additional “attention and energy”, and seeking of “challenges and new responsibilities” in doing (pp. 6-7).

The VQ was selected as the measure for the “switch-on” effect attributable to several considerations, one of which was that indicators of the VQ items were found to closely align with descriptions of “switch-on” in the literature (Cheung & Peri, 2014; Spector et al., 2011). This will be presented and discussed in detail in the research design chapter.

Significance of the Study

The significance of the study is primarily linked with cognitive stimulation therapy being recognized as an evidence-based intervention for people with mild and moderate dementia in multiple systematic reviews (Dourado & Laks, 2016; Olazaran et al., 2010; Woods et al., 2012; Yuill & Hollis, 2011) and in clinical guidelines for dementia care (Alzheimer's Disease International, 2011; National Institute for Health and Clinical Excellence, 2018). Considering an overall paucity of evidence-based psychosocial interventions for people living with dementia, CST deserves more research, including a more complete understanding of its therapeutic effects. The focus of this study on the “switch-on” effect, a desirable but under-researched outcome of CST, fits with this premise.

Apart from addressing the knowledge gap about “switch-on”, this study is also important in that it strove to fathom the benefits of CST from a person-centred perspective. The umbrella term of “switch-on” reflects a holistic, top-down perspective in understanding the positive impact of CST on the “whole person”, rather than discrete parts of the person. The present study may not only contribute to more descriptive information about the nature and occurrence of the “switch-on” effect but may also glean overlooked benefits of CST that have tended to fall through the cracks of investigations using reductionistic research approaches.

Further, no previous study has examined the impact of CST on the person’s motivation or volition, and neither has the variable been included as an outcome measure. The Volitional Questionnaire (VQ) is an observational instrument for assessing volition (de las Heras et al., 2007). It is suitable for use with people who have dementia and may not be able to report their experience of volition. Preliminary, concomitant measurements using the VQ in the present study had potential to lend new insight and understanding about possible volitional changes in relation to the “switch-on” effect, particularly from an occupational engagement point of view.

Putting this together, this study endeavoured to contribute to a deeper understanding of the “switch-on” effect of CST by attaining more qualitative knowledge about the effect and identifying a way of measuring it. This may help build a basis for future studies to evaluate whether “switch-on” is an additional and beneficial effect of the intervention, particularly from a person-centred, occupational perspective.

Researcher’s “Sensitising Concepts”

The choice of research focus and questions can be considerably influenced by the researcher’s interests and preferences. Carpenter and Suto (2008) spoke of the role of “foreshadowed problems or clinical irritations” as a precursor for developing research questions in rehabilitation research. They suggested that researchers should disclose their “sensitising concepts” in the early phase of research, which they

defined as “the concepts that interest a researcher and develop from reflection-on-practice, discipline-specific concerns and one’s worldview” (p. 42).

As the primary researcher, I came from China and speak Mandarin as my first language. I practised Traditional Chinese Medicine for many years before I came to New Zealand. I completed my occupational therapy training at Otago Polytechnic and have been a New Zealand registered occupational therapist since 2007. I have mainly worked in mental health, with the most recent five years working in the older adult community mental health service of the Auckland District Health Board. I provide occupational therapy and clinical case management for people who present with some degree of behavioural and psychological symptoms of dementia, and this group of client accounts for at least half of my work caseload.

Several “sensitising concepts” arisen from my personal and professional experiences, interest and belief systems have contributed to the identified research focus and questions of the present study. These concepts were related to my interest in understanding occupation and its impact on human experience, the role of measurement in evidence-informed practice, the active and volitional nature of occupational engagement, and my holistic worldview rooted in Chinese culture and tradition.

First, occupation is regarded as encompassing both objective and subjective qualities (Townsend & Polatajko, 2007). On one hand, occupation refers to any type of daily activities that involves actual performance and cannot be observed until one engages. On the other hand, it is personal and “idiosyncratic” (p. 22) and contains subjective meaning that cannot be understood by mere observation. I’m always interested in understanding how engagement in occupation enhances and transforms a person’s subjective experience and sense of well-being, an example of which is the flow experience (Csikszentmihályi, 1990). Flow is a concept in positive psychology that is widely applied in occupational therapy in relation to the therapeutic value of the just-right challenge in occupation (Molineux, 2017). “Switch-on” sparked an immediate

interest in me because it seems to represent a type of human experience that is different from “flow” but arises similarly from occupational engagement.

Second, there is an increasing expectation in mental health that occupational therapists deliver services that are evidence-informed. Although I’m confident that occupation-focused interventions do “work”, I am concerned that occupational therapy is often regarded as having “soft” evidence. One of the contributing factors to this situation from my understanding is the difficulty with measuring or “proving” the benefits of an occupation-based intervention. I could have selected an inductive, qualitative research method to explore the “switch-on” effect, considering its minuscule knowledge base. However, my antecedent “irritations” about “evidence” and “measurement” gave rise to the choice of also including a measurement component in the present study to gain more confirming information about the existence of “switch-on”.

Third, I have embraced some of the foundational concepts in occupational therapy and science, such as viewing humans as ambitious, self-motivated, “occupational” beings and purposeful meaning-makers (Kielhofner, 2002; Law et al., 1996; Townsend & Polatajko, 2007). I always view my clients as active, volitional collaborators in occupation-focused interventions rather than passive recipients of therapy or treatment. Unlike medication, a successful psychosocial intervention should encompass the therapeutic ingredient of promoting intrinsic motivation and active engagement. These background thoughts and beliefs contributed to the choice of using a volitional measure, the VQ (de las Heras et al., 2007) to detect and quantify “switch-on”.

Lastly, I come from a collective culture and hold a holistic and dialectical worldview. An individual is believed to be part of the complex, dynamic ecological system of the world, where he or she can interact, adapt and self-regulate (Hu, 2016). From this perspective, human existence is defined and shaped by relations and transactions with others, either vertically with family and ancestors or horizontally with individuals,

groups and wider societies, in various physical and social environments. This frame of reference gives greater value and meaning for social connectivity than an individualistic worldview. Epistemologically, knowledge and truth cannot be obtained through studying the isolated subject or person without considering the surrounding people, environments and systems. Thus, information gained through a multi-faceted and multi-methods research design is more likely to provide a complete and thorough understanding of a phenomenon. These philosophical views were reflected in the composition of mixed inductive and deductive research questions for exploring the “switch-on” effect.

Organization of the Thesis

Chapter 1, the current chapter, has provided an overall introduction of the study. Contents have covered definitions of the key terms used in the thesis, the research purpose and questions, and the contextual backgrounds of the study related to dementia care, cognitive stimulation therapy, the New Zealand setting and occupation-based theoretical perspectives. The chapter has also discussed the significance of the research outcome as well as my personal and professional “sensitizing concepts” that have influenced the choice of the research focus and questions.

Chapter 2 presents a critical literature review on the “switch-on” effect and cognitive stimulation therapy. The literature review was based on a systematic database search that yielded 57 references, including 40 original studies and 17 systematic reviews. This leads to discussion and identification of the research gap in the current CST literature, which justifies the need and importance for further exploration of the “switch-on” effect, with incorporation of an occupation-focused perspective.

Chapter 3 explains the convergent parallel mixed methods design employed in this research project. It included a post-positivist philosophical orientation; methodologies guiding the qualitative, quantitative and mixed methods inquiries; and data collection and analysis methods and procedures. Ethical considerations are

discussed, along with aspects of the research design and process that targeted rigour and trustworthiness.

Chapter 4 presents the research findings of the study. Participant demographics are described first, followed by a detailed presentation of sub-themes. These sub-themes emerged from software-assisted qualitative analysis of 24 interviews in four thematic areas; Doing, Feeling, Relating and Thinking and Reflecting. Twelve measurement results using the VQ are depicted visually, which leads up to combined demonstration of qualitative and quantitative data in answering the three research questions.

Chapter 5 discusses the main research findings in the present study with reference to the literature review in Chapter 2. The strengths and limitations of the study are examined and articulated, with several implications for future research suggested. A conclusion statement is submitted in the end.

Chapter 2 Literature Review

Introduction

Cognitive stimulation therapy (CST) is a brief group therapy for people with mild to moderate dementia. The intervention aims to enhance cognitive function and quality of life through the provision of an optimal learning environment and opportunities to engage in enjoyable social activities (Spector et al., 2005). The “switch-on” effect was noted as a positive outcome of CST in some group members and is described as improved alertness, confidence, communication and engagement with activities (Cheung & Peri, 2014; Spector et al., 2011). However, research on this topic to date has been scant and preliminary.

This literature review starts with a detailed description of a systematic database search on Spector’s cognitive stimulation therapy. A careful evaluation of what is known about “switch-on” from the two identified references is presented first, followed by a thorough and critical examination of the broad CST literature, including 40 original studies and 17 systematic reviews. This provides a foundational understanding about the intervention and its “switch-on” effect. The research gap in the extant CST literature is then discussed, which provides the rationales for the chosen research topic and questions about “switch-on” in the present study.

Literature Search

A systematic literature search was conducted in July 2017 for all English-language studies and systematic reviews on CST, followed by an updated search in July 2018. Multiple databases were explored including CINAHL Plus and MEDLINE (via EBSCO Health); Scopus; PsycINFO (via Ovid); OTseeker; and Cochrane Library. The following keywords were used for searching these databases except for PsycINFO: [“cognitive stimulation therapy” OR “group cognitive stimulation” OR CST OR gCST OR iCST] AND [dementia OR alzheimer*]. The keywords used for PsycINFO were: [“cognitive

stimulation therapy” OR “group cognitive stimulation” OR “cognitive therapy” OR CST OR gCST OR iCST] AND [dementia OR alzheimer*]. Date delimitations were set from 1990 to July 2017 in the first search, and from July 2017 to July 2018 in the second. The same databases, keywords and searching methods were applied consistently in both searches.

The goal of the literature search was to locate original research studies or systematic reviews in peer-reviewed journals that examined the cognitive stimulation therapy developed or informed by Spector and her colleagues (Spector et al., 2003) as a treatment for people with mild or moderate dementia. Original studies on maintenance cognitive stimulation therapy (mCST) and individual cognitive stimulation therapy (iCST) that were developed secondary to Spector’s standard group CST were also included. In addition, systematic reviews on psychosocial or non-pharmacological interventions for people with dementia that included research about cognitive stimulation therapy were sought. To maintain the focus on Spector’s CST, the following exclusion criteria were applied to the articles retrieved in the search:

- cognitive stimulation as a treatment for the general population of elder people (including older adults with mild cognitive impairment), other age groups, or people with cognitive impairment associated with conditions other than dementia (such as alcoholism, schizophrenia, Parkinson’s disease, haemodialysis, brain injury)
- any stimulation therapy for people with dementia that had a focus on biological rather than social activities, such as transcranial magnetic stimulation, transcranial direct current stimulation, and percutaneous electrical nerve stimulation
- psychosocial or non-pharmacological interventions for people with dementia that were not consistent with the definition of cognitive stimulation therapy, such cognitive training, cognitive rehabilitation, multisensory stimulation, virtual reality memory training, motor and cognitive training, multi-stimulation group therapy, cognitive and physical stimulation therapy, robot

cognitive stimulation, computer-based cognitive intervention, brain training games, cognitive behavioural therapy, and mindfulness.

The first search generated 400 original results and the second 86, including some reproduced references due to overlapped time boundaries for the two searches. After removing duplicates and applying the exclusion criteria, 55 references remained (with 6 from the updated search), including 38 original studies and 17 systematic reviews. Among the original studies, 27 were focused on Spector's CST, five on mCST, and six on iCST. Thirteen original studies were conducted outside the United Kingdom, all of which were informed by Spector's CST, with four in English speaking nations, including Ireland, Australia and the United States, and eight in non-English speaking regions, including Japan, Italy, sub-Saharan Africa, India, and China. Among the 17 systematic reviews, nine involved general psychosocial or non-pharmacological interventions for people with dementia or Alzheimer's disease, and the remaining eight were focused on cognition-based interventions, including five specifically on cognitive stimulation or cognitive stimulation therapy.

The cited references of the identified studies were also explored and examined, including the French trial on cognitive stimulation (Breuil et al., 1994) that directly influenced the development of Spector's CST. The first New Zealand pilot study on cognitive stimulation therapy (Cheung & Peri, 2014) was not captured by the systematic database search, because it was published as a research project report rather than a journal article. Nevertheless, the study was included and reviewed thoroughly owing to its high relevance to the central focus of the study, the "switch-on" effect. Cheung and Peri (2014) used a mixed methods approach and described "the switch-on phenomenon" as a major qualitative finding of their research (p. 7).

In terms of research methods, most of the 40 identified original studies used a quantitative design, including five randomized controlled trials. Only eight studies employed a qualitative or mixed methods approach, with five on Spector's CST and three on mCST or iCST. These eight studies were recognized as most pertinent to the "switch-on" effect and were reviewed extensively. Among these five studies on

Spector's CST, two used a qualitative design (C. M. Murray et al., 2016; Spector et al., 2011), and the other three employed a mixed methods approach (Bailey, Kingston, Alford, Taylor, & Tolhurst, 2017; Cheung & Peri, 2014; Kelly et al., 2016). Among the 17 systematic reviews, two examined studies using a qualitative or mixed methods design, one reviewed psychosocial interventions for dementia (Dugmore, Orrell, & Spector, 2015) and the other focused specifically on cognitive stimulation therapy (Toh et al., 2016).

The "Switch-on" Effect

From the second systematic literature search in July 2018, there were only two studies that reported and described the "switch-on" effect as an emerging theme or sub-theme in their qualitative inquiries about CST. Spector et al. (2011) first used the phrase "switch-on" in their qualitative study investigating how the benefits of CST were experienced and perceived by community-dwelling CST attendees with mild dementia, their families and group facilitators. It described the most commonly reported cognitive improvement in "concentration and alertness" after attending CST, which gave the persons "a sense of being more switched on or wanting to attend to things more" (p. 948). This change emerged as a sub-theme from the semi-structured individual interviews and focus groups they analysed using Framework Analysis. The study also discovered a wide range of non-specific cognitive, social and occupational benefits of the intervention in both CST and everyday life contexts, such as feeling "more positive, relaxed and confident", more willing to talk and "finding it easier to talk", an increased sense of "togetherness and friendship" in the CST group, a broadened "outlook on life" through social interactions in the group, wanting to "trawl and drag up" information from memory more, and "engaging in more activities" at home (pp. 947-8). Linking "being more switched on" specifically to the cognitive benefits of the intervention reflected a deductive intention of the study to support the quantitative findings in the previous clinical trials (Knapp et al., 2006; Matsuda, 2007; Spector et al., 2003). This seemed to limit the exploration of the phenomenon.

Cheung and Peri (2014) piloted Spector's CST in the New Zealand context using a mixed methods approach and described "the switched-on phenomenon" as a key finding of their qualitative evaluation. "Switch-on" was used to describe the observations, mainly from family members and CST practitioners, that some participants with dementia presented with "new-found confidence, capabilities and vastly improved communication skills" (p. 7) and became "more communicative and sociable" (p. 27) after attending CST. "Switch-on" depicted the onset of the noticeable changes in the person as though "a switch went off" (p. 21) or "a light went on" (p. 25). The effect appeared to be characterized by improved alertness and social engagement, positive and intensified emotional display, and increased initiative and participation in occupations. "Switch-on" was typically noted after two to three sessions and was maintained throughout the programme in both group and home environments concurrently.

Parallel to the observable "switch-on" response was the notion of "feeling stimulated", or the subjective experience of stimulation, following participation in CST, which was a "most interesting and unexpected" finding of the research (Cheung & Peri, 2014, p. 21). According to Cheung and Peri (2014), the subjective experience of stimulation entailed "a sense of achievement" (p. 21) and an emotional feeling of excitement. CST participants' direct quotes suggested that their experiences of "feeling stimulated" encompassed a range of spontaneous and simultaneous changes in thinking, feeling and an increased desire for doing. For example, one participant described her experience of stimulation as "I wasn't in control of it, yet it sparked something in my mind" (Cheung & Peri, 2014, p. 21); another person commented that "I used to feel so good while I was there [CST session] and afterwards I would go home and think about what we had been talking about" (p. 21); and one more participant stated that "I no longer want to sit around at home like I did. I couldn't handle it. I want the group to go on forever" (p. 21). Further, all participants with dementia described extensively and consensually the supportive atmosphere and

positive social dynamics in the group which served as “a major attraction” and source of enjoyment (Cheung & Peri, 2014, p. 22).

It is also worth comparing the findings about “switch-on” with the quantitative results in Cheung and Peri’s (2014) study. Multiple measures were employed in the study, including the Mini Mental State Examination (MMSE) and the Alzheimer’s Disease Assessment Scale-cognitive subscale (ADAS-cog) for cognitive function; the Quality of Life-Alzheimer’s Disease (QOL-AD), both self-reported and family/staff-reported versions, for quality of life; the Geriatric Depression Scale-15 items (GDS-15) for mood and depression; and the Caregiver Burden Inventory (CBI) and the Medical Outcome Study 12-Item Short-Form Health Survey (SF-12) for family caregivers’ burden and health-related quality of life. The GDS-15 was found to be the only measure that improved significantly following the intervention ($p = 0.02$), which implied a possible correlation between affective improvement and “switch-on”. The study also found cognitive improvement on the MMSE (0.3 points) and the ADAS-cog (2 points) with an equivalent effect size to other CST studies; however, these results were statistically insignificant due to the small sample size ($n = 18$). Interestingly, the family/staff-reported QOL-AD showed a positive trend but not the self-reported version, despite the subjective reports about improved satisfaction and well-being from the qualitative inquiries.

Cheung and Peri (2014) further reviewed the recent literature on the cognitive benefits of social engagement for older people with dementia. They asserted that “the switch-on phenomenon” was a therapeutic outcome of the regular social engagement in the CST group and a “non-specific”, active ingredient of the intervention. Given that “switch-on” was valued by participants with dementia, their families and CST practitioners as “a more satisfying” benefit of CST in contrast with the moderate cognitive improvement, the researchers suggested that it should deserve more investigation and be considered as a primary outcome of CST in further research (p. 33).

Although a more comprehensive picture of “switch-on” was portrayed in Cheung and Peri’s (2014) study, the nature and scope of the phenomenon were not clearly delineated. Further, while the social component of CST was acknowledged as important as the themed activities in contributing to the “switch-on” effect, there was no evaluation or measurement conducted in the study to explore social and occupational participation within and outside the group.

Cognitive Stimulation Therapy

Considering the limited research and understanding about the “switch-on” effect, it was thought useful to systematically review the wider literature about cognitive stimulation therapy. Original studies and systematic reviews on Spector’s CST were examined and recapitulated respectively with a focus on the effects and benefits of the intervention. The aim was to provide a broad and sturdy knowledge base for the further exploration of “switch-on”, which has been identified as a positive outcome of CST.

Original Studies

Original studies on Spector’s CST using a quantitative, qualitative, or mixed methods approach were explored and appraised carefully. The quantitative and qualitative findings derived from the review are presented separately to attain clarity. Original studies on mCST and iCST were also included to maximize understandings, although these two types of cognitive stimulation therapy are not directly related to the “switch-on” effect.

Maintenance CST is typically provided once a week for 24 weeks following the standard seven-week, twice weekly CST. It has been found to improve quality of life and cognition when combined with acetylcholinesterase inhibitors (AChEI) at three months and six months, and performance in activities of daily living at three months (Orrell et al., 2014). Individual CST is usually delivered one-on-one by family or caregivers at home, consisting of up to three times weekly, 30-minute sessions over 25

weeks (Orgeta et al., 2015). There is a lack of evidence for iCST to benefit cognition, mood, behaviour and self-rated quality of life in participants with dementia or family carers' physical and mental health (Orrell et al., 2017). Poor adherence was thought to be a likely factor that might have compromised the effectiveness of this carer-led intervention (Yates, Orgeta, Leung, Spector, & Orrell, 2016). Findings from mCST and iCST studies were drawn on, where relevant and appropriate, particularly in exploring the active agents and mechanisms for Spector's CST that were pertinent to the "switch-on" effect.

Quantitative Findings

Evidence for the effectiveness of CST in improving cognition and quality of life was primarily derived from the large scale, single-blind randomized controlled trial (RCT, n=201) conducted by Spector and her colleagues (2003). People with mild or moderate dementia who received CST demonstrated significant improvement, relative to the control group, in cognitive functions measured by the Mini-Mental State Examination (MMSE, $p=0.044$) and the Alzheimer's Disease Assessment Scale - Cognition (ADAS-Cog, $p=0.014$) as well as quality of life measured by the self-rated version of the Quality of Life - Alzheimer's Disease scale (QoL-AD, $p=0.028$). Calculation of the number-needed-to-treat using the criteria of four points or more improvement on the ADAS-Cog showed a comparable degree of cognitive benefit to acetylcholinesterase inhibitors. However, no significant effects were detected on depression, measured by the Cornell Scale for Depression in dementia; anxiety, measured by the Rating Anxiety in Dementia (RAID); communication ability, measured by the Holden Communication Scale (HCS); or dependency and daily functioning, measured by the Clifton Assessment Procedures for the Elderly - Behaviour Rating Scale (CAPE-BRS).

Further studies attempting to identify specific cognitive areas that could benefit most from CST demonstrated some variability in their findings, which seemed to reflect the measures employed. Spector, Orrell and Woods (2010) used the same research data

from Spector et al.'s (2003) trial and examined the sub-scales of the ADAS-Cog. They re-grouped the 11 items of the ADAS-Cog into three sub-scales; memory and new learning, praxis, and language. Significant improvement was only found in the language sub-scale, consisting of commands, spoken language, naming, word-finding, and comprehension, despite the insignificant results on communication ability measured by HCS in the original trial (Spector et al., 2003). A later study using a neuropsychological test battery for measuring cognition (Hall et al., 2013) confirmed the effect of CST on language comprehension. Further, the researchers detected significant improvement in another two cognitive domains following the intervention, verbal and visual memory, and orientation to time and place.

In discussing the incompatible findings about memory in relation to Spector et al.'s study (2010), Hall et al. (2013) asserted that the effects of CST on memory demonstrated in their study were attributable to the employment of the story recall task; a more sensitive and ecologically valid measure of memory than the word-list recall task in the ADAS-Cog. Their positive findings about memory were supported by an earlier French study (Breuil et al., 1994), which also employed a battery of neurocognitive tests for evaluating cognition, and a more recent Italian study (Piras et al., 2017), which noted significant improvement in short-term/working memory using the backward digit span task.

In Spector et al.'s (2003) original study, it was unclear if changes in quality of life occurred as a result of cognitive improvements, or if they were associated with other factors. To explore the relationship between cognitive improvement and improvement in quality of life following CST, Woods and his colleagues (Woods, Thorgrimsen, Spector, Royan, & Orrell, 2006) conducted a mediation study using the data from Spector et al.'s trial (2003). The results indicated that quality of life measured by the QoL-AD at baseline was not associated with cognitive function or severity of dementia, as measured by the MMSE and the ADAS-Cog, but with levels of dependency and depression. However, improvement in quality of life following CST was correlated to increased cognitive function as well as other factors, including

being female, low quality of life at baseline, and reduced depression. In other words, this study suggested that severity of cognitive impairment in people with dementia does not determine the person's perception of quality of life; rather, it is the positive changes in cognition resulting from CST that make participants feel that their quality of life has improved.

Some studies found significant improvement on measures for depression and anxiety, including the Cornell Scale for Depression in Dementia (CSDD) (Spector et al., 2001; Stewart et al., 2017), the Geriatric Depression Scale (Cheung & Peri, 2014), the face scale for mood (Yamanaka et al., 2013), and the Rating Anxiety in Dementia (Paddick et al., 2017); however, that was not the case in Spector et al.'s RCT (2003) using the CSDD. Therefore, the evidence for the affective benefits of CST is unclear and inconclusive, despite the key principle of CST as providing "enjoyable" social activities and the consistent findings of positive emotional changes in the qualitative and mixed methods studies (Ballard, Khan, Clack, & Corbett, 2011; Cheung & Peri, 2014; C. M. Murray et al., 2016; Spector et al., 2011).

This leads to the question of whether these measures were responsive and valid enough for capturing the subtle changes in mood and affect following participation in CST. For example, the cut-off scores for a depressive disorder on the CSDD recommended by the original researchers are nine points or more (Alexopoulos, Abrams, Young, & Shamoian, 1988); whereas the CSDD scores for both treatment and control groups before and after CST in Spector et al.'s (2003) trial were all under nine points. This suggests that most people with dementia who participated in this study did not have depression against the CSDD diagnostic criteria. It also indicates the floor effect (Lewis-Beck, Bryman, & Liao, 2004) of this measure when used for evaluating depression with this research sample and therefore its uncertain validity as an outcome measure.

Further, according to Woods et al. (2006), quality of life was positively correlated with reduction of depression. This makes it reasonable to speculate that the emotional

changes induced by CST might, in part, have contributed to a sense of improved quality of life that was additional to the perceived improvement in cognition.

In order to understand the predictive factors for a positive response to CST, Aguirre et al. (2013) conducted an investigation with 272 people with mild to moderate dementia and compared their pre and post-intervention test results with Spector et al.'s trial (2003). Their findings demonstrated that positive outcomes of CST were associated with two demographic characteristics, older age and being female; however, positive outcomes were independent of the use of cognitive-enhancing medication.

Spector et al. (2003) didn't measure the whole range of behavioural and psychological symptoms of dementia (BPSD) in their trial except for depression and anxiety, with no significant improvement detected. However, three later studies on Spector's CST measured a wider range of BPSD using the Neuropsychiatric Inventory (NPI) (Cummings et al., 1994). The NPI is an informant-report based instrument for evaluating 12 common neuropsychiatric and behavioural disturbances in dementia, including depression, anxiety and apathy. Two studies found significant improvement on the measure following CST, especially in the community-dwelling participants with dementia (Aguirre, Hoare, et al., 2013; Paddick et al., 2017), although the other suggested no change (Capotosto et al., 2017). None of the three studies reported the sub-scales of the NPI results despite the heterogeneous nature of the measurement targets, and therefore no information was available about whether CST could improve specific BPSD, such as apathy. According to Brodaty and Burns (2012), apathy occurred in "up to 70%" (p. 550) of people with Alzheimer's Disease in studies using the NPI as the measurement for specific dementia behaviours. Despite that, no studies on Spector's CST thus far have specifically explored apathy or have included measurement of apathy in their research. The absence of evidence about apathy, or lack of motivation, may partially explain why the earlier studies did not identify the "switch-on" effect.

In terms of changes to people's occupations, several studies on Spector's CST evaluated daily functioning before and immediately after the intervention using the Clifton Assessment Procedures for the Elderly - Behaviour Rating Scale (CAPE-BRS) (Pattie & Gilleard, 1979) (Coen et al., 2011; Spector et al., 2001; Spector et al., 2003) or the Alzheimer's Disease Co-operative Study-Activities of Daily Living Inventory (ADCS-ADL) (Galasko et al., 1997) (Aguirre, Hoare, et al., 2013). None of the measurement results suggested that CST could improve performance in daily activities. However, the large-scale RCT (n=236) on mCST (Orrell et al., 2014) also employed the ADCS-ADL as the functional outcome measure and observed significant improvement at three-month follow-up. A possible explanation for the discrepancy could be the delayed benefits of Spector's CST for daily functional performance. Alternatively, it may be that such measures do not reliably capture the aspects of occupation that change as a result of CST.

Despite the increasing evidence for benefiting people with dementia, Spector's CST was found to have no effects on the family caregivers' health and quality of life, measured by the EQ-5D and the Short Form-12 UK Health Survey (SF-12) (Aguirre, Spector, & Orrell, 2014). This seemed to reflect the person-centred design of the CST programme; however, the authors also argued that these measures might not have captured the broader range of benefits for family caregivers. Moreover, no studies on Spector's CST have explored or evaluated the carer-patient relationships, although it was measured in the RCT on iCST (Orrell et al., 2017), with significant improvement detected.

Of note, cognitive stimulation aims to attain cognitive and social outcomes (Woods et al., 2012); however, no CST studies have attempted to directly investigate or measure social engagement and participation within or outside the CST groups, except for measuring quality of life. As the most commonly used measure for quality of life in CST literature, the Quality of Life - Alzheimer's Disease scale (QoL-AD) (Logsdon, Gibbons, McCurry, & Teri, 1999) includes items about family, marriage and friends that may signify social functioning; however, none of the CST studies that found

significant improvement on the scale examined its components (Capotosto et al., 2017; Coen et al., 2011; Paddick et al., 2017; Spector et al., 2003). Further, no study has investigated the effect of CST on social cognition, a newly recognized and included cognitive domain that may be impaired in people with dementia or major neurocognitive disorders in DSM-5 (American Psychiatric Association, 2013).

In summary, as a cognitive intervention, Spector's CST has demonstrated the efficacy to improve cognitive function, communication and social interactions, and self-reported quality of life for people with mild to moderate dementia in quantitative studies, including RCTs (Spector et al., 2003; Woods et al., 2012). These effects seemed to be in harmony with the qualitative descriptions of "switch-on" (Cheung & Peri, 2014; Spector et al., 2011). However, there is a lack of investigation or consistent evidence in the quantitative studies that CST could benefit areas like mood, behaviour, apathy/motivation, relationship and activities of daily living which were described as part of "switch-on". Notably, the sensitivity issue of measures was repeatedly discussed in the quantitative research on CST when it came down to the interpretation of discordant measurement results among studies.

Qualitative Findings

The eight original studies that used a qualitative or mixed methods design were explored and evaluated for the present review, including five on Spector's CST, two on iCST (Leung, Yates, Orgeta, Hamidi, & Orrell, 2017; Yates, Leung, Orgeta, Spector, & Orrell, 2015), and one on mCST (Aguirre, Spector, Streater, Burnell, & Orrell, 2011). Among the five studies on Spector's CST, two employed a qualitative approach (C. M. Murray et al., 2016; Spector et al., 2011) and three mixed methods (Bailey et al., 2017; Cheung & Peri, 2014; Kelly et al., 2016). All the qualitative inquiries in these studies, including semi-structured interviews and/or focus group, were conducted post-intervention. Lacking repeated data collection before or during the CST programme may limit detailed insights into changes that occurred over time.

Spector et al. (2011) conducted the first qualitative study on the intervention using Framework Analysis to explore how the effects of CST demonstrated by the quantitative studies were perceived by people with dementia, their families and group facilitators. Two themes emerged from the semi-structured interviews and focus groups: “positive experiences of being in the group” and “changes experienced in everyday life” (p. 948). Participant reports described improved emotion and cognitive function in general memory, concentration and alertness. The qualitative findings supported the conjecture in Spector et al.’s (2003) trial that the cognitive effects of CST could be transferred to real-world life contexts and produce generalized benefits for the person’s well-being and quality of life. It is notable, however, that the qualitative reports of changes in day-to-day life were not captured by the measures of daily functioning used in the RCT trial (Spector et al., 2003).

The four succeeding studies on Spector’s CST using a qualitative or mixed methods approach described a variety of similar, positive changes (Bailey et al., 2017; Cheung & Peri, 2014; Kelly et al., 2016; C. M. Murray et al., 2016), ranging from general cognitive improvement in memory and attention, to beneficial changes in mood and enjoyment, interest and motivation, verbal communication, social engagement and relationship, and participation in activities. The qualitative findings in these five studies will be demonstrated in detail to compare with the “switch-on” changes noted in the present study in Chapter 5. The positive impact of CST reported in the qualitative inquiries was consistent and generally more prolific than demonstrated in the quantitative experiments.

Of the qualitative studies exploring Spector’s CST that included quantitative methods, only two noted and described the “switch-on” effect in their qualitative inquiries (Cheung & Peri, 2014; Spector et al., 2011). These studies have been presented earlier in this chapter. However, the other three studies also reported some qualitative findings comparable to the effect (Bailey et al., 2017; Kelly et al., 2016; C. M. Murray et al., 2016).

Kelly et al. (2016) used mixed methods to evaluate a community-based CST programme that was delivered weekly with 90 minutes per session for 14 weeks in the Irish context. In their post-intervention interviews with CST participants, carers and facilitators, three direct benefits of the intervention were discovered, including “increased confidence”, “cognitive benefits” in “memory, attention and concentration”, and “increased enjoyment/improved mood” (Kelly et al., 2016, p. 7). The participant quotes supporting the three sub-themes showed some correspondence to descriptions about “switch-on”. For example, a patient participant commented that “I could see it in the rest of the people there too, they were all a lot more confident after a few weeks”; a facilitator participant reported that “at the beginning they would take ages to think of names [in the ball activity] but at the end they were flying through it”; and another participant with dementia said, “I don’t get frustrated with myself anymore. When I forget something I just relax and then it comes back to me. I used to get very frustrated, but I don’t anymore” (Kelly et al., 2016, p.7).

C. M. Murray et al. (2016) appraised an adapted CST programme (once weekly for 12 weeks) led by master’s occupational therapy students in Australia using a qualitative descriptive approach. Three themes emerged in their analysis, including “something to talk about” with family and care staff; “it was a new relationship” with people in the CST group; and “wanting to have a go” within and outside the group (C. M. Murray et al., 2016, pp. 624-5). They included some “switch-on” alike quotes from family carers and facility staff about the persons’ changed presentation after attending CST. Some examples were: “he was very upbeat and very stimulated and very awake”; “every time he’s been home after going there – immediately after he doesn’t stop talking ... he had such fun and laughed and they were really good”; and “even the guys who have ... mobility issues, but no he’ll get up and he’ll play golf with the rest of us without a problem, because he wants to participate and have a go” (C. M. Murray et al., 2016, pp. 624-5).

Bailey et al. (2017) used mixed methods to evaluate the benefits of a concomitant carer support group with a short, ten-session CST programme in the United Kingdom. Several comments from family carers about the impact of CST on the persons with dementia were relevant to the notion of “switch-on”. For example, “when she used to come home, she was always bouncy and full of it” (Bailey et al., 2017, p. 6); “he is actually taking an interest in things again, which again, that’s a huge improvement ... and he is very upbeat, he’s communicating more, he’s socializing more” (p. 8).

It was noted that the three qualitative studies on mCST and iCST (Leung et al., 2017; Yates et al., 2016 Aguirre, Spector, Streater, Burnell, & Orrell, 2011) discussed the concept of “mental stimulation” based on the general principle “use it or lose it”, which appeared to be close to the two synonyms of “switch-on” described in Cheung and Peri’s (2014) study, “the notion of stimulation” and “being stimulated”. Leung et al. (2017) attempted to understand the experience of “mental stimulation” following iCST and elaborated this term as “an activity that provided opportunities to keep ‘the brain going’, reflect, and stay alert” (p. e37). In comparison to what is known about “switch-on”, this conceptualization of “mental stimulation” seemed to have a narrower focus on the activity component of cognitive stimulation, which is not surprising given the missing “ingredient” of social engagement in iCST.

To summarize, without using the expression “switch-on”, the quoted descriptions about the positive outcomes of CST in the other three qualitative and mixed methods studies on Spector’s CST (Bailey et al., 2017; Kelly et al., 2016; C. M. Murray et al., 2016) considerably resembled the existing knowledge about the effect (Cheung & Peri, 2014; Spector et al., 2011). A possible interpretation of this could be that “switch-on” might be a rather pervasive and common therapeutic effect of CST but probably not sufficiently recognized and articulated. Relative to the concept of “mental stimulation” applied in the qualitative studies on mCST and iCST, “switch-on” seems to have broader implications.

Therapeutic Mechanisms

Although Spector's CST has been shown to improve cognitive function and quality of life in people with mild to moderate dementia, the active ingredients or therapeutic mechanisms for the positive changes remain unclear (Woods et al., 2012). Considering the intervention's multifactorial, complex psychosocial nature, Spector et al. (2003) suggested several possible processes that might underlie the effectiveness of CST. These processes included offering an optimal learning context with a focus on implicit memory; reinforcing self-esteem through counteracting the 'malignant social psychology' (p. 252) toward the dementia diagnosis; and reinforcing positive thinking and interactions with people, objects and environment. Further, the learning and benefits gained from the group might be extended to other activity contexts and environments.

Regarding the cognitive effects of the intervention, language and communication have been identified as beneficial areas (Hall et al., 2013; Spector et al., 2010; Woods et al., 2012). The intervention was also found to improve verbal and visual memory as well as orientation to time and place (Hall et al., 2013). Implicit learning and the supportive environment emphasised in the intervention were regarded as contributory to the language and memory improvements (Hall et al., 2013; Spector et al., 2010; Spector et al., 2003). Conversational skills were thought to be enhanced through the practice of generating opinions and constructing categorical links between words (Spector et al., 2010). Interactions in the CST group might also directly activate the neural pathways responsible for language programming ("syntax"), and encoding and retrieval of memory (Hall et al., 2013, p. 487). However, improvement in orientation was deemed to be the outcome of frequent and explicit rehearsing of orientation information about time and place in the groups (Hall et al., 2013).

With regards to the benefits for quality of life, Woods et al.'s (2006) mediation study suggested that it was the cognitive focus of the intervention that promoted the

positive changes in quality of life and well-being rather than merely the unspecific social component of CST. Spector et al. (2010) echoed that improvement in the cognitive area of language and communication would likely lead to generalized benefits in well-being, relationship with family, and quality of life.

Cheung and Peri (2014), who discovered “the switch-on phenomenon”, tended to attribute the positive outcomes of CST to the non-specific aspect of social engagement involved in CST; although the developers of the programme had carefully considered and designed the themes and activities that would enable optimal social learning and engagement (Spector et al., 2001; Spector et al., 2003). The lack of evidence for the efficacy of iCST and its weakness in treatment adherence (Orrell et al., 2017; Yates et al., 2016) seemed to conversely signify the value of social interaction, which is present in standard and maintenance CST but absent in iCST.

Systematic Reviews

The body of research on Spector’s cognitive stimulation therapy has been included in quantitative and qualitative systematic reviews on psychosocial treatment for people with dementia, ranging from more specific cognitive stimulation (Aguirre, Woods, Spector, & Orrell, 2013; Toh et al., 2016; Woods et al., 2012; Yuill & Hollis, 2011) and cognition-based interventions (Huntley, Gould, Liu, Smith, & Howard, 2015; Kurz, Leucht, & Lautenschlager, 2011; Spector, Orrell, & Hall, 2012) to non-pharmacological interventions in general (Ballard et al., 2011; Dugmore et al., 2015; Livingston, Johnston, Katona, Paton, & Lyketsos, 2005; Olazaran et al., 2010). There is consistent and accumulating evidence supporting the implementation of cognitive stimulation therapy in dementia care owing to its benefits for cognition and quality of life for people with mild to moderate dementia (Khan, Corbett, & Ballard, 2014).

Quantitative Reviews

Livingston et al. (2005) systematically reviewed the evidence for psychological interventions for dementia-associated neuropsychological symptoms using the Oxford Centre for Evidence-Based Medicine criteria. They included the two original

trials of CST (Spector et al., 2001; Spector et al., 2003) in their review and identified the latter (Spector et al., 2003) as high quality and level 1 evidence. It was one of nine trials found to provide high quality evidence among all the studies evaluated and the only one in the category of cognitive stimulation therapy. In a later systematic review on the best evidence for non-pharmacological therapies for Alzheimer's disease, Olazaran et al. (2010) ranked cognitive stimulation as a grade B treatment recommendation for improving cognitive function and behaviours in people with dementia as well as for maintaining caregivers' psychological wellbeing. Ballard et al. (2011) acknowledged that the efficacy of CST was moderate but significant and might be enhanced if combined with acetylcholinesterase inhibitors.

Of note, Yuill and Hollis (2011) conducted a systematic review on cognitive stimulation therapy from an occupational therapy perspective and suggested that the intervention was congruent with the conceptual models and values held by the profession. They also found clear evidence for the use of the intervention in delaying cognitive decline in older adults with mild to moderate dementia.

However, Huntley et al. (2015), who conducted a meta-analysis and meta-regression on cognitive interventions for dementia, criticized the RCTs on cognitive stimulation for their small to moderate effect size on the main cognitive measures; the MMSE (significant positive effect sizes (Hedges' g) $g=0.51$, 95% CI 0.29 to 0.69; $p<0.001$ when compared to non-active controls, and $g=0.35$, 95% CI 0.06 to 0.65; $p=0.019$ when compared to active controls) and the ADAS-Cog ($g=-0.26$, 95% CI -0.445 to -0.08 ; $p=0.005$). Huntley et al. (2015) therefore questioned the clinical meaningfulness of the cognitive improvement. This team also pointed out failures to control for placebo effects in the RCTs on cognitive stimulation, which compromised the quality and rigour of study results.

In relation to quality of life, Cooper et al. (2012) reviewed the non-pharmacological interventions for people with dementia and identified CST as the only intervention that provided high quality of evidence for its effectiveness. According to the

systematic review on cost-effectiveness of dementia care (Knapp, Lemmi, & Romeo, 2013), there was a larger body of evidence for anti-dementia medications than non-pharmacological interventions; acetylcholinesterase inhibitors for mild-to-moderate dementia and Memantine for moderate-to-severe dementia in particular. However, three non-pharmacological interventions showed relatively strong evidence for cost-effectiveness, and CST was one of them.

Irrespective of the criticisms and the unclear mechanisms for the positive changes in cognition and quality of life, there was robust enough evidence for the efficacy of CST to warrant its recommendation as an intervention for improving cognitive function and well-being for people with dementia in the clinical guidelines for dementia in the United Kingdom (National Institute for Health and Clinical Excellence, 2006, 2018). CST has become a reasonably well-established practice in dementia care in the United Kingdom. For example, 66% of people with dementia had received the intervention in 2013 (Streater, Spector, et al., 2016). Internationally, the 2011 World Alzheimer's Report (Alzheimer's Disease International, 2011) claimed that strong evidence from multiple RCTs had found that acetylcholinesterase inhibitors (for cognitive function and functional impairment) and cognitive stimulation (for cognitive function) were effective interventions for people with mild dementia. Based on that, they recommended that acetylcholinesterase inhibitors and cognitive stimulation may enhance cognitive function in people with mild Alzheimer's disease and therefore should be routinely offered.

Qualitative Reviews

The systematic reviews that synthesized quantitative studies, especially the RCTs, clearly suggested that cognitive stimulation therapy is a promising, evidence-based psychosocial intervention for people with dementia. In contrast to the relatively large number of quantitative systematic reviews, there were only two references identified in the literature search that systematically evaluated the qualitative and mixed methods studies, one on psychosocial interventions for people with dementia

(Dugmore et al., 2015) and the other specifically on cognitive stimulation therapy (Toh et al., 2016).

Dugmore et al. (2015) investigated a variety of psychosocial interventions for dementia, (including Spector's CST) using the thematic analysis method and identified five common "active mechanisms" that could make a psychosocial intervention "work". Some of them might be relevant to the "switch-on" effect, such as "gaining new information about dementia and the person behind the dementia", "enabling openness and acceptance of difficult experiences and emotions", and "peer identification, support and membership" (p. 964). The researchers also observed more positive findings in qualitative studies than in quantitative trials in general and attributed the discrepancy to two main factors; the sensitivity issue of measurement in quantitative studies in detecting changes that are fleeting or with low effect size, and the bias and subjectivity involved in the qualitative studies. This was also reflected in the CST literature as aforementioned in the section about the original studies. The greater positivity identified in qualitative inquiries could be taken to suggest that the occurrence of some effects, such as "switch-on", are not captured by measures used in the existing quantitative studies.

Toh et al. (2016) conducted a narrative review of both quantitative and qualitative/mixed methods studies on Spector's CST and iCST for older adults with dementia. They pointed out the insufficient evidence for the longer-term effects of CST in the literature as well as the unclear impact of CST on people with different severity levels. They also examined the disparity between the positive findings in qualitative studies and non-significant results in quantitative trials in relation to the benefits of group and individual CST for family caregivers. The lack of sensitivity for the outcome measures was discussed as a possible contributor to the discord, but equally, it should be considered that the measures are not designed to detect subtle psychosocial benefits such as the "switch-on" effect.

Research Summary

There is well established evidence for the efficacy of CST in improving cognitive function and self-rated quality of life for people with mild to moderate dementia (Spector et al., 2003; Woods et al., 2012). Overall, it remains unclear which cognitive domains will benefit most from CST; however, it is known that CST can improve language function and possibly memory and orientation to time and place as well (Hall et al., 2013; Spector et al., 2010). It is inconclusive whether CST can improve mood, although some studies found significant improvement on measures for depression and anxiety (Cheung & Peri, 2014; Paddick et al., 2017; Spector et al., 2001; Stewart et al., 2017; Yamanaka et al., 2013). Quality of life is a crucial outcome measure in dementia care and there is some evidence that improved quality of life following participation of CST is mediated by the cognitive effects of the intervention (Woods et al., 2006). The demonstrated benefits on quality of life measures also imply a broader range of therapeutic effects of CST, the extent and nature of which are yet to be understood (Spector et al., 2011). The “switch-on” effect that emerged from the qualitative evaluations of CST (Cheung & Peri, 2014; Spector et al., 2011) could be an example of these broader unknown benefits.

CST has been recognized as an evidence-based intervention in the clinical guidelines for dementia (Alzheimer's Disease International, 2011; National Institute for Health and Clinical Excellence, 2006). It has been recommended as a cognitive intervention for people with mild to moderate dementia not only because of the high-quality evidence from RCTs, but also because of its person-centeredness (Spector et al., 2005) and cost-effectiveness (Knapp et al., 2006). CST can be used in conjunction with cognitive enhancing medications to produce synergetic effects, particularly in the long-term maintenance CST (Orrell et al., 2014); however, its positive impact on cognitive function is regarded as independent of acetylcholinesterase inhibitors (Aguirre, Hoare, et al., 2013).

The principles underpinning CST are congruent with occupational therapy philosophy, values and practice (Streater, Spector, et al., 2016; Townsend & Polatajko, 2007; Yuill & Hollis, 2011). Occupational therapists seem to be actively involved and making valuable contributions to the research, evaluation, training, promotion and delivery of the intervention (C. M. Murray et al., 2016; Streater, Aguirre, Spector, & Orrell, 2016; Streater, Spector, et al., 2016; Yuill & Hollis, 2011). However, occupational benefits of CST have received little attention, and measurements of performance of daily activities have not shown significant changes (Aguirre, Hoare, et al., 2013; Coen et al., 2011; Spector et al., 2003; Woods et al., 2012), despite qualitative findings about changed experiences in daily life that appear to be meaningful to study participants and family/carers (Cheung & Peri, 2014; C. M. Murray et al., 2016; Spector et al., 2011). This may be associated with insufficient sensitivity of the measures researchers have used or that the measures do not target appropriate aspects of occupation, considering the general discrepancy noted between the quantitative and qualitative research findings (Dugmore et al., 2015; Toh et al., 2016).

Research Gap

In spite of the known efficacy of CST, the active mechanisms through which the intervention benefits cognition and quality of life for people with dementia are still to be clearly elucidated (Woods et al., 2012). The intervention seems to afford broader and more meaningful changes than those that have been demonstrated from the quantitative studies, such as in the areas of memory, mood and affect, motivation, social relationship and participation, and engagement with daily activities (Cheung & Peri, 2014; C. M. Murray et al., 2016; Spector et al., 2011). Given that, there is a need in future research to use more sensitive outcome measures for capturing the moderate but significant changes in cognition (Hall et al., 2013), social engagement (Cheung & Peri, 2014), and daily functioning (Yuill & Hollis, 2011). Moreover, high-quality qualitative research is also required to obtain more comprehensive and in-depth understanding about the positive impact of CST on people with dementia and their families (Toh et al., 2016).

In relation to research methodology and theoretical perspectives, CST research has been considerably influenced by positivism and the associated scientific approach (Grant & Giddings, 2002), a focus of which is to examine and measure the components of a phenomenon in an attempt to attain knowledge of the whole. This may have led to research gaps or “blind spots” in understanding this complex, multifactorial psychosocial intervention in several ways.

First, a neuropsychological basis for cognitive stimulation is the assumption that “cognitive functions are not used in isolation but as a functional whole” (Breuil et al., 1994, p. 212); however, the predominant approach used for examining the cognitive benefits and neurocognitive mechanism of CST has been guided by the domain-specific view of cognition (Aguirre, Hoare, et al., 2013; Hall et al., 2013; Spector et al., 2003). Second, there has been no study investigating the interplay of multiple, internal and external factors or the bio-psychosocial mechanisms that may be activated through CST to foster the positive changes. For example, given the unclear evidence for the affective benefits of CST, exploring the dynamics of mood and cognition in conjunction rather than studying these two aspects separately may give rise to more insightful understanding of the effects of the intervention. Lastly, CST is declared to be person-centred. However, there has been no study exploring how CST promotes quality of life and well-being through mobilization of the top-down resources of the person, such as hope, choice, volition, and determination.

Considering this, a holistic, whole-person approach in research is more compatible with the complexity of the intervention and therefore is much needed in future studies. The use of an umbrella term “switch-on” to illustrate a multi-dimensional effect of CST reflects such a perspective. While only two studies have described the “switch-on” effect as a favourable outcome of CST, as perceived by participants with dementia and their families (Cheung & Peri, 2014; Spector et al., 2011), similar effects have been suggested by wider qualitative and mixed methods inquiries (Bailey et al., 2017; Kelly et al., 2016; C. M. Murray et al., 2016).

A theoretical perspective based on the concept of “occupation” will enhance the study of “switch-on”, because the occupation-focused models are holistic and dynamic in nature and can provide appropriate frameworks for understanding the likely multi-dimensional “switch-on” effect of the intervention. Further, a conceptual occupational framework, the Model of Human Occupation (MHOP) (Taylor, 2017) provides a useful evaluation tool, the Volitional Questionnaire (VQ) (de las Heras et al., 2007), for measuring the “switch-on” effect. A study aiming to describe and measure the “switch-on” effect from an occupation-based frame of reference will contribute more insight and understanding of the psychosocial and occupational outcomes of CST that have been under-researched.

Conclusion

Cognitive stimulation therapy is an evidence-based psychosocial intervention for people with mild to moderate dementia, which has demonstrated its efficacy in promoting cognitive function and quality of life and delaying the deterioration process of dementia. The “switch-on” effect illustrates an array of positive outcomes of the intervention that emerged from qualitative inquiries in two studies exploring the benefits of CST from the perspectives of the participants with dementia, their families and group facilitators. This literature review critically evaluated the original studies and systematic reviews on the intervention in relation to the study focus on “switch-on”. The research gap identified from the review indicated the need for more understanding about the psychosocial and occupational outcomes of CST, including the “switch-on” effect. Based on that, three research questions, aiming to describe and measure the “switch-on” effect, were justified.

Chapter 3 Research Design, Methods and Methodologies

Introduction

Chapter 2 systematically reviewed the literature on cognitive stimulation therapy (CST), which provides the background for the research choice of describing and measuring the “switch-on” effect. A considerable and increasing body of research on CST has demonstrated its value for cognitive function and quality of life. However, there is scant knowledge about “switch-on”. Further, no study to date has explored or measured the impact of the intervention on the person’s motivation or volition as reflected in day-to-day occupations. In addition, there is a paucity of research that has endeavoured to understand the complex, multifactorial intervention from a top-down, whole person perspective.

This chapter starts with statements of the research purpose and three research questions, with reasons for the choice illustrated. The research design selected for this study, the convergent parallel mixed methods, is then elaborated upon with regards to its philosophical orientation, methodologies and associated methods for the qualitative, quantitative and mixed methods components. Ethical issues involved in the research process are explored next, along with considerations about rigour and trustworthiness in the study design.

Research Purpose and Questions

The purpose of the study was to describe and measure the “switch-on” effect experienced by people who participate in the standard, seven-week cognitive stimulation therapy group (Spector et al., 2005). Three research questions identified for this study were:

- What is the nature of the “switch-on” effect as described by people attending CST and their family/caregivers?
- At what time-points during and after the group is the “switch-on” effect reported?
- Are the changes described as the “switch-on” effect measurable using the Volitional Questionnaire?

Three considerations led to the choice of exploring the “switch-on” effect with family participants in addition to patient participants in the first two research questions. First, “switch-on” likely involves observable changes apart from changed subjective experiences, and therefore reports from observers would contribute valuable information to a “thick” descriptive summary about the effect. Second, people with dementia might not be able to give reliable accounts about history and events consistently due to impaired memory, and reports from informants would fill the gaps. Lastly, although “switch-on” was observed in both CST and home environments by CST facilitators and family or caregivers, the decision was made to investigate the effect in the home setting rather than the CST group. This would simplify the research process and satisfy the interest in exploring “switch-on” being a momentary as well as longer-lasting effect in real-life occupational contexts, which justified the choice of including family/caregivers, rather than group facilitators, in the study.

There were also reports about the likely time frame, three to four sessions into the CST programme, for noticing the “switched-on” presentations in CST attendees in Cheung and Peri’s (2014) study. This made it reasonable to include a temporal inquiry about the “switch-on” effect in the second research question.

The choice of the Volitional Questionnaire (de las Heras et al., 2007) as the measurement for the “switch-on” effect in the third research question was based on the pre-assumption about motivational changes involved in “switch-on”. It was also the outcome of a careful selection process for the instrument, which will be explained fully in the methods section as follows.

Theoretical Position

There is a need to identify the theoretical or philosophical assumptions that are embedded in a research design, including the mixed methods research (Creswell, 2014). A variety of terms are used by different authors to illustrate this aspect of research, ranging from worldview, paradigm, epistemology and ontology, theoretical or philosophical perspectives, to methodologies in a broad sense. For example, Crotty (1998) proposed four essential elements involved in any social research that is informed by one another in a hierarchical fashion: method, methodology, theoretical perspective, and epistemology. Method refers to the most tangible techniques and procedures used for collecting and analysing research data. Methodology is the less visible strategy or process that underlies choice of specific methods. Theoretical perspective is the philosophical stance that frames and guides methodology and thereby method. Epistemology is the theory of knowledge that underpins theoretical perspective and methodology.

Post-positivism is generally regarded as a common philosophical position for mixed methods research (Creswell, 2014). Post-positivism aligns with the realist ontological and objectivist epistemological foundations of positivism (Creswell, 2014). It acknowledges the existence of things as independent of consciousness and experience and that truth and meaning can be studied objectively (Crotty, 1998). However, post-positivism takes a critical stance towards the philosophical limitations of positivism and their emphasis on the traditional “scientific” methods for discovering truth, and therefore, promotes the use of qualitative inquiry and mixed methods, particularly in the field of health and social research (Grant & Giddings, 2002).

Creswell (2014) clarified several post-positivist stances in mixed methods research that are mostly inherited from positivism, including: “determination”, “reductionism”, “empirical observation and measurement”, and “theory verification” (pp. 35-36). Post-positivism upholds the deterministic worldview that concerns the cause-effect

relationships of events and phenomena. It also endorses the reductionist approach that endeavours to understand the “whole” through studying the “parts”. The objectivist view of post-positivism supports use of scientific observation and measurement as the necessary component of mixed methods research. Post-positivist adherents also believe in the order and laws of the world, and that these can be tested and verified through theory formation and hypothesis testing (Creswell, 2014).

However, post-positivism also involves further developments from positivism, a major one of which is related to determinism. Although agreeing with the positivist deterministic worldview, post-positivism asserts that an outcome can be determined by multiple and interactive causative factors in a non-linear way (Giddings & Grant, 2006). Further, post-positivism accepts multiple truths and plural and competing views about reality (Guba & Lincoln, 1982). It allows integration of multiple research methods and combination of quantitative and qualitative approaches to make inquiry about objective phenomena as well as subjective experiences (Grant & Giddings, 2002).

Post-positivism provides a suitable philosophical position for answering the three research questions of the present study. There are priori assumptions about “switch-on” being caused by the intervention of CST, and that it is “out there” and can be described, observed and measured. The selection of a volitional measure also implies a deductive research approach, given the underlying hypothesis about the relations between volition and “switch-on”. In addition, post-positivism ratifies an inductive and explorative approach to make qualitative inquiry about the nature and occurrence of “switch-on”, because there is limited knowledge about the effect, particularly from an occupation-based perspective. In addition, post-positivism supports the mixture of inductive and deductive research methods in generating more comprehensive and inclusive knowledge about “switch-on”, which encompasses idiosyncratic subjective experiences as well as observable common features.

Study Design

The choice of research design, methodology and methods should be informed by and appropriate for the identified research questions (Carpenter & Suto, 2008). A mixed methods design, the convergent parallel mixed methods design, was justified as a good match for answering the two qualitative questions about the nature and occurrence of “switch-on” and the quantitative research question about measuring the effect using the Volitional Questionnaire (VQ) (de las Heras et al., 2007).

Creswell (2014) defined mixed methods as “an approach to inquiry involving collecting both quantitative and qualitative data, integrating the two forms of data, and using distinct designs that may involve philosophical assumptions and theoretical frameworks” (p. 32). A basic assumption of mixed methods is that the combination of two research approaches has better value than each alone in generating a more complete understanding of a research question. There are various benefits for combining qualitative and quantitative research, such as providing verification for each other through triangulation, producing a variety of data and analyses, and contributing to “new modes of thinking” in response to contradictions emerged from the two datasets (Baran & Jones, 2016, p. 4).

Venkatesh, Brown, and Sullivan (2016) proposed that a mixed methods design is only appropriate when the researcher intends to “holistically explain a phenomenon for which extant research is fragmented, inconclusive, and/or equivocal” (p. 437), which is the case for evidence of a “switch-on” effect. There are two basic designs for mixed methods research, sequential and concurrent, depending on the time orientation of the qualitative and quantitative strands to be conducted (Venkatesh et al., 2016). The convergent parallel mixed methods design described by Creswell (2014) was selected because a concurrent process of collecting qualitative and quantitative data would provide a better chance of achieving a satisfactory understanding of the “switch-on” effect. Within the mixed methods design, qualitative descriptive methodology (Sandelowski, 2000) and thematic analysis (Stanley, 2015) were identified to guide

the qualitative data collection and analysis. The single-subject A-B design (Carter & Lubinsky, 2015) was followed for collecting measurements using the VQ, and descriptive statistics and visual analysis (Vogt, 2014) were chosen for demonstrating the quantitative data.

The Qualitative Component

Qualitative description is a basic and generic methodology for qualitative research that is rooted in naturalistic inquiry rather than any specific philosophical theories (Sandelowski, 2000). Qualitative descriptive studies intend to answer who, what, why and where questions and generate a descriptive summary using unambiguous, low-inference language. Typical design features of qualitative description involve “maximum variation sampling”, individual and/or focus group interviews with minimal to moderate structure and open questions, “qualitative content analysis”, and straightforward and “information-rich” descriptions as the end-product (pp. 337-338).

Compared with quantitative description, qualitative description is more interpretive and yields richer and fuller descriptions about data (Sandelowski, 2010). Further, it is not confined by pre-existing hypotheses or coding systems and has the advantage of addressing unanticipated findings. Compared with other qualitative methodologies, such as phenomenology and grounded theory, qualitative description is less interpretive and inferential and does not aim to render a grand theory or in-depth interpretation of data. This enables qualitative descriptive studies to more easily attain interpretive validity and consensus among researchers, although there has been confusion and debates about what degree of interpretation should be involved in the qualitative descriptive approach (Sandelowski, 2010).

Qualitative description has no affiliation to any particular philosophical position, which sometimes leads to the perception of being a “poor cousin” to qualitative research (Neergaard, Olesen, Andersen, & Sondergaard, 2009). Nevertheless, this also affords the approach to be “eclectic” and flexible in offering a range of techniques in

sampling, data collection, and analysis (Sandelowski, 2000, p. 334). Nayar and Stanley (2015) employed the concept of an interpretation continuum to assert that qualitative descriptive methodology sits on the more interpretive end of the continuum and is thus aligned with an interpretive paradigm.

Qualitative description is often graded low in the evidence-based research hierarchy due to being non-experimental, and it sometimes criticized for lacking rigour and theoretical foundations. However, with its qualitative and inductive nature, qualitative description is an appropriate methodology for the purposes of problem identification, hypothesis formulation, and intervention development or refinement in the healthcare setting (Neergaard, et al., 2009).

Qualitative description was deemed to be a suitable methodology for answering the two qualitative research questions for describing the nature and occurrence of the “switch-on” effect. The literature review indicated that “switch-on” is a positive response to CST, yet little is known about what is involved in the effect and in what time-points it is experienced by people attending CST. These considerations determined that this small-scale master’s study would be preliminary and should involve an inductive component that is descriptive and data-led. Further, the feature of low interpretation and closeness to data would also make the approach appropriate and advantageous in two ways. It could ensure interpretive validity in describing and reporting the findings about “switch-on”; and it could achieve better descriptive validity in comparison to quantitative description of the VQ measurement data.

The selected methods used were semi-structured interviews that would be conducted with research participants, including people with dementia who attended CST and their associated family/caregivers. Open-ended questions would be used in the interviews with minimal variations between the patient and family/caregiver versions.

The maximum variation sampling strategy (Sandelowski, 2000) was applied in attempting to recruit more female participants as previous research has indicated gender-based differences in participants responsiveness to CST (Aguirre, Hoare, et al., 2013); however, this was unsuccessful due to the time limitation of this study. Thematic analysis (Stanley, 2015) was used for analysing and interpreting the interview data with the assistance of NVivo 11 Pro, a qualitative data analysis software (QSR International, n.d.-b).

The Quantitative Component

A single-subject A-B design was selected as the methodology for the quantitative part of the study. Single-subject designs (SSD) refer to a set of diverse research designs, primarily developed for evaluating the efficacy of behavioural interventions through the study of a single subject(s) over a period of time or phases (Satake, Maxwell, & Jagaroo, 2007). Sometimes termed as single-case design, single-system design, $n=1$ design, single-subject experimental design, and individual baseline design, SSDs are often regarded as an alternative to traditional group designs that can also provide evidence for clinical practice (Johnston & Smith, 2010). The A-B design is the most basic type of SSDs, with A referring to baseline or phase of no treatment and B standing for phase of initial treatment (Carter & Lubinsky, 2015).

Carter and Lubinsky (2015) recognized SSDs as a third paradigm comparable to qualitative and quantitative paradigms. Single-subject paradigm shares the same philosophical foundations as the quantitative paradigm except for its idiographic approach. Like experimental group designs, SSDs also involve a priori theory, objective measurement, numerical data, and manipulation of variables; however, they apply purposive sampling as opposed to random assignment. While SSDs equivalently employ controls and target causation and generalization, they use the subject as their own control instead of other individuals. The aim is to attain “case-by-case generalization” rather than “sample-to-population generalization” (p. 140).

SSDs are characterized by baseline assessment; preferably with three or more data points, stable performance prior to treatment, continuous assessment to determine the nature of fluctuations, and visual analysis of different phases (Carter & Lubinsky, 2015). SSDs are most appropriate for health and behavioural research that examines the relationships between a dependent and an independent variable with a small number of participants (Satake et al., 2007). The A-B design is advantageous for its simplicity and ease of application. While it lacks control to address the confounding extraneous factors which leads to its weakness in internal validity, it may be corrected by replication (Satake et al., 2007).

The single-subject A-B design was selected for measuring the “switch-on” effect using the VQ because a limited number of participants would be involved in this small-scale study. Further, the uncertain occurrence of “switch-on” would make it impractical to conduct multiple measures, such as in an interrupted time-series design, within the scope of this study.

The study aimed for one or more measurements of the VQ during the baseline period (phase A), followed by a repeated measure during and after the CST programme respectively (phases B1 and B2). Taking one or more measurements at phase A was an attempt to confirm baseline stability. Repeated measurements during and after CST (phases B1 and B2) was consistent with the principle of continuous assessment of SSDs (Carter & Lubinsky, 2015). It was also targeted at obtaining more temporal information about the occurrence of “switch-on”. As Cheung and Peri (2014) noted “the switch-on phenomenon” started to show in some participants within two to three sessions of CST, a seemingly “settling in” timeframe for a new social environment (p. 21).

Two measures were selected for the study; the Addenbrooke’s Cognitive Examination-III (ACE-III) (Hsieh, Schubert, Hoon, Mioshi, & Hodges, 2013) for confirming cognitive function and severity of dementia diagnosis, and the Volitional Questionnaire (VQ) (de las Heras et al., 2007) for detecting volitional changes

involved in “switch-on”. Descriptive statistics and visual analysis (Vogt, 2014) were used to present and analyse these measurement results.

The ACE-III (Hsieh et al., 2013) is a screening neuropsychological test with sound psychometric properties for determining cognitive impairment and dementia. It is scored out of 100 possible points and the recommended cut-off scores for diagnosing dementia by the original researchers are 88 (sensitivity = 1.0; specificity = 0.96) and 82 (sensitivity = 0.93; specificity = 1.0). However, no study has examined the association between the ACE-III results and dementia staging, and based on clinical experiences, a New Zealand guideline for dementia and driving safety has suggested that an ACE-III score between 65 and 76 usually indicates mild dementia and a score between 35-64 indicates moderate dementia (Fisher & Thomson, 2014). The ACE-III was used in the study for confirming severity of dementia diagnosis and level of cognitive function rather than as an outcome measure. Although not popularly employed in the previous CST trials, the tool is widely used in clinical practice and is available with no cost for copyright. Another reason for the choice was that this was a familiar instrument that I used routinely in my occupational therapy practice.

The VQ (de las Heras et al., 2007) is an observational instrument developed and used by occupational therapists for measuring the construct of volition defined in the Model of Human Occupation (Taylor, 2017). A basic assumption of the measure is that people may experience different levels of volition for occupation, dependent on the dynamic interactions between “inner characteristics of the individual and external features of the environment” (de las Heras et al., 2007, p. 4). The VQ comprises of 14 items or behavioural indicators that evaluate three levels of volition on a volitional development continuum; Exploration, Competency and Achievement. Although the instrument also offers an environmental characteristic form for recording qualitative aspects of the assessment context, it was not used in this study because all the measurements were conducted in the person’s day-to-day home environment with few contextual variations.

The VQ was selected as a measure for detecting the “switch-on” effect based on several considerations and steps. First, descriptions about “switch-on” in the literature (Cheung & Peri, 2014; Spector et al., 2011) seem to involve not only changes in mental state, such as alertness and positive affect, but also improved engagement with activities within and outside the CST group. This led to the assumption that the nature of the effect is probably more than just a passive, short-lived, stimulus-response phenomenon, but also involves more active, long-lasting, top-down mental processes, such as motivation, choice, and effort. The consideration of using an existing motivational measure was instigated by this hypothesis.

Second, in selecting an appropriate motivational measure, a comparison between the VQ and the Apathy Evaluation Scale (AES) was conducted (see Appendix 1 Comparison between the Volitional Questionnaire and the Apathy Evaluation Scale). The AES is a reliable and valid measure of a dementia symptom; apathy or the lack of motivation (Marin, Biedrzycki, & Firinciogullari, 1991). The two measures were contrasted in terms of measuring construct, theoretical framework, features, psychometric properties, administration, user training, and applications in research. The VQ was regarded as more compatible for this study because of its acceptable psychometric properties and being an observational tool with less cognitive demands on people with dementia. More importantly, the VQ has better theoretical fitness with “switch-on” as reflected in the construct of volition. The concept of volition is articulated as patterns of thoughts and feelings about one’s actions during, and influenced by, the dynamic course of doing (Taylor, 2017). This is comparable to the experience of “switch-on” in the context of participation in social activities as well as the person-centred philosophies of CST (Spector et al., 2005). Although the AES has demonstrated better psychometric properties, particularly in reliability, than the VQ, it measures apathy, a symptom of dementia, which comes from a pathology-oriented, reductionist, biomedical framework (Marin et al., 1991).

Third, a further comparison was performed between descriptions about “switch-on” in the previous two CST studies (Cheung & Peri, 2014; Spector et al., 2011) and the

VQ indicators, as displayed in Table 3.1. The alignment between the two implies a theoretical agreement and further justified the choice of the VQ for use of measuring the “switch-on” effect in the present study.

Table 3. 1

Alignment between Indicators of the VQ and Descriptions of “Switch-on” in Literature

Level of Volition	Indicator of Volition	“Switch-on” Descriptions
Exploration	Shows curiosity	“Mum’s been interested enough to give her views” (Spector, et al., 2012, p. 947) “I was looking for something to do. I loved the association and hearing other people’s views and ideas.” (Cheung & Peri, 2014, p. 21)
	Initiates actions/tasks	“At the beginning I was a bit hesitant to say much, well you just think well if I’ve got something to say then I’ll say.” (Spector, et al., 2012, p. 947) “He would come home and phone our daughter to seek information.” (Cheung & Peri, 2014, p. 23)
	Tries new things	“I enjoyed it all even the sporty things as I’m not normally a sporty person.” (Cheung & Peri, 2014, p. 19)
	Shows preferences	“I no longer want to sit around at home like I did. I couldn’t handle it. I want the group to go on forever.” (Cheung & Peri, 2014, p. 21)
	Shows that an activity is special or significant	“I was so glad to be going to the meetings. I enjoy the company and the socialising. ... We have developed a bond between us.” (Cheung & Peri, 2014, p. 22)
Competency	Indicates goals	“I was surprised what he talked about; he would come home and phone our daughter to seek information.” (Cheung & Peri, 2014, p. 23)
	Stay engaged	“Mum had been more engaged with the activities they offer there. ... she’s been enjoying bingo and they had a singer going around ... and apparently mum had a whale of a time.” (Spector, et al., 2012, p. 948)
	Shows pride	“Answering the things the correct way felt good.” (Cheung & Peri, 2014, p. 19) “I have improved quite a bit and I feel good about it.” (Cheung & Peri, 2014, p. 21)
	Tries to solve problems	“We were doing the jigsaw puzzle... We were all trying to do it with not much luck but he picked up a piece and he was able to do it.” (Cheung & Peri, 2014, p. 21)
	Tries to correct mistakes	
Achievement	Pursues activities to completion/accomplishment	“Previously she would open up the computer to do Code Break and just stare at the screen for three to four hours, now she is back into actually playing the games.” (Cheung & Peri, 2014, p. 23)
	Invests additional energy/emotion/attention	“Although its sometimes difficult for her to trawl and drag up the information, she seems to want to do it a bit more.” (Spector, et al., 2012, p. 947) “I think it makes you concentrate more in everything you’re doing really.” (Spector, et al., 2012, p. 948)
	Seeks additional responsibilities	
	Seeks challenges	“The CST group brought out the ‘competitive side of himself’”. (Cheung & Peri, 2014, p. 19)

Lastly, psychometric properties of the VQ have been examined in a number of studies with reasonably good results. Chern, Kielhofner, de las Heras, and Magalhaes (1996) carried out a series of two studies on the VQ that they originally developed and then revised. The researchers found a good construct validity; 13 out of 14 revised items meeting criteria for unidimensionality on the mean square statistics (MnSq), and a valid representation of the volitional continuum in people with psychiatric disabilities and developmental delays who had difficulties reporting volitional experiences. However, they also noted that the instrument might not measure high levels of volition accurately. Li and Kielhofner (2004) evaluated the internal validity of the VQ (Version 4.0) with five raters and 36 participants with psychiatric disability and HIV/AIDS. They concluded that it was a valid (no item misfit on MnSq) and sensitive (item separation ratio = 3.40; reliability = 0.92) instrument for measuring volition and discriminating between different levels of volition in the participants (participant separation ratio = 2.43; reliability = 0.86), although the two lower ratings (“passive” and “hesitant”) were only used 20% of the time. The intra-rater reliability was consistently observed (no rater misfit on MnSq); however, the inter-rater reliability was questionable (rater separation ratio = 4.08). Therefore, they recommended the same assessor to complete the pre- and post-intervention scoring to ensure a valid and accurate evaluation of the changes.

Reid and Hirji (2004) used an older version (Version 3.0) of the VQ as an outcome measure for estimating the effectiveness of a virtual reality leisure-intervention programme for older adults who survived stroke. They noticed some correlation between the VQ scores and the scores for depression and life satisfaction. Agren and Kjellberg (2008) examined the content validity of the Swedish version of the VQ with 15 occupational therapists and 26 adults with intellectual disabilities and found that the instrument adequately measured volition across all clinical situations. Raber and Stone (2015) applied the VQ (Version 4.1) with three participants with moderate dementia who lived in residential care, to assist with their phenomenological exploration of carer perceptions of these residents’ volition for occupations. They

noted that the VQ yielded useful and additional information about the resident participants' volition that was not fully recognized by the carer participants.

Although the VQ has demonstrated some psychometric weaknesses, such as lacking inter-rater reliability (Li & Kielhofner, 2004), the possible ceiling effect for higher levels of volition (Chern et al., 1996), and the tendency of the two lower points on the scale being infrequently used by raters (Li & Kielhofner, 2004), the impact of these limitations was not overly serious considering the design of the present study. There was only one rater, myself, involved in the study which would provide consistency, given the good intra-rater reliability of the instrument (Li & Kielhofner, 2004). The scores were used in the single-subject A-B design primarily for intra-subject comparison in relation to the "switch-on" changes.

A four-point rating scale is used for scoring the 14 VQ items, including Passive, Hesitant, Involved, and Spontaneous; Passive being the lowest level of volition and Spontaneous the highest (de las Heras et al., 2007). The rating is based on the amount of support, structure or encouragement required from the therapist/rater for showing target behaviours; no input required for Spontaneous; minimal input required for Involved; maximal input required for Hesitant; and no display of target behaviours requiring maximal input for Passive. To quantify the ratings for statistical analysis, Passive, Hesitant, Involved and Spontaneous were converted into four integers, 1, 2, 3 and 4 consecutively. Measurement results were calculated by mean score rather than total score, as the instrument allows "no opportunity to observe" as a rating option. A mean score for the VQ and its sub-scales could eliminate the influence from any potential missing data and make the results more comparable over time and between participants. Means of the overall VQ and the three sub-scales (Exploration, Competency and Achievement) were calculated respectively for each participant with dementia over three time-points and then presented and analysed visually.

The Mixed Methods Component

This study adopted the convergent parallel mixed methods design described by Creswell (2014), under which the qualitative and quantitative data were collected concurrently guided by their respective methodologies. The two data sources were analysed and interpreted separately first and then jointly.

Figure 3.1 illustrates the recruitment and data collection plan following the convergent parallel mixed methods design. Research participants would be recruited from a seven-week, twice weekly CST programme(s), because it was from Spector's standard CST that the "switch-on" effect had been discovered in previous two studies (Cheung & Peri, 2014; Spector et al., 2011). Qualitative data collection was designed such that shorter and more frequent interviews with participants would be conducted in accordance with the single-subject design of the quantitative research component. Parallel to the A-B1-B2 design, interviews would be carried out with each participant at three or more time-points; once to twice pre-CST (phase A), with a four-week interval in-between the first and second interviews, once during-CST (phase B1), and once post-CST (phase B2).

Flowchart Illustrating the Recruitment and Data Collection Plan

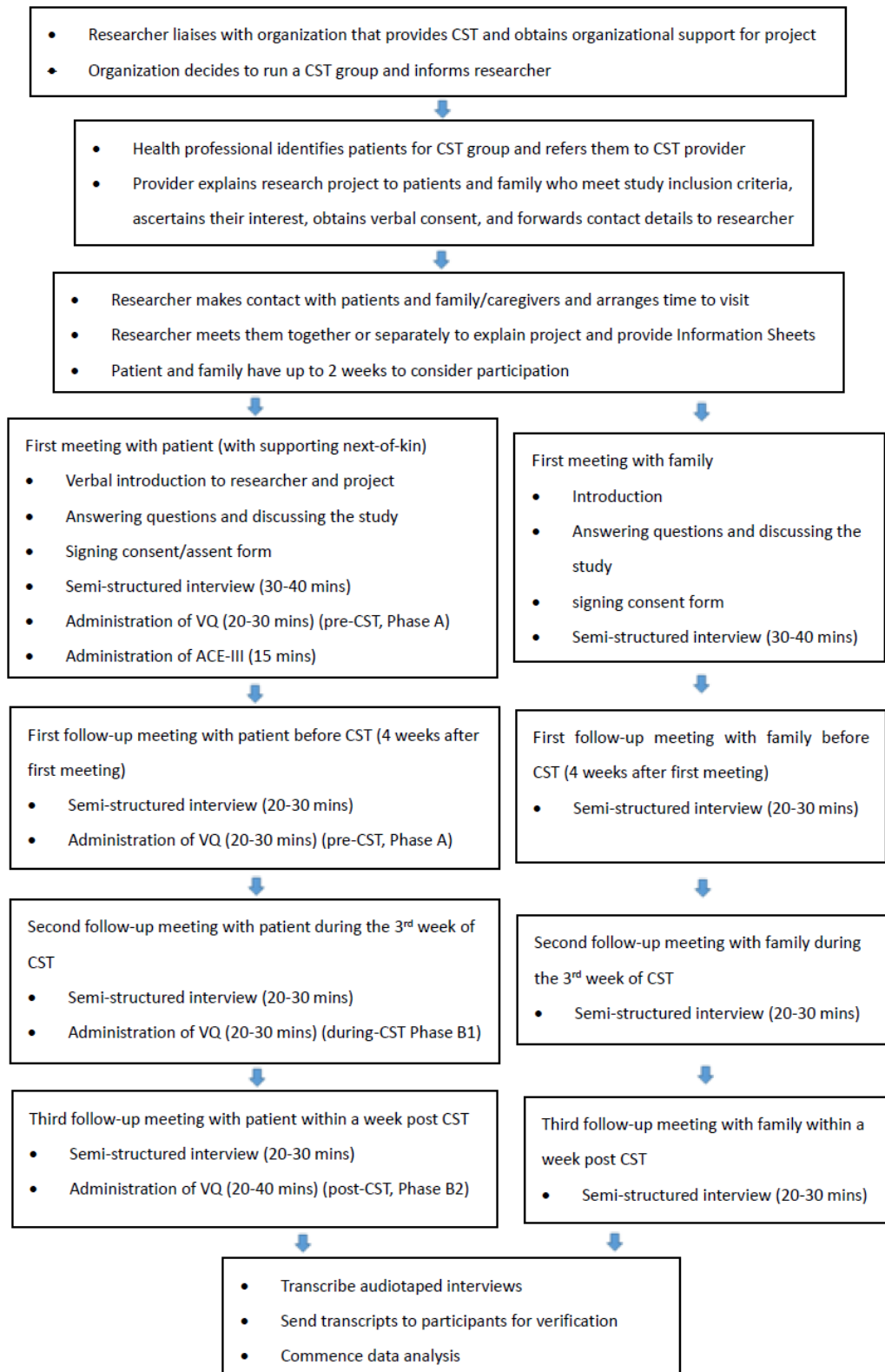


Figure 3. 1. Flowchart illustrating the recruitment and data collection plan

The parallel, combined design of qualitative and quantitative investigations had a few advantages. First, three short interviews with both patient and family participants that focused on exploring “switch-on” would provide a more timely, dynamic and temporal view about the effect. It would better answer the two research questions about the nature and occurrence of the “switch-on” effect than a single, lengthy interview. Second, the interviews provided rich information about the person’s experience and presentation at three time-points. This could possibly counteract the weakness of limited repeated measurements of the VQ at baseline in the quantitative design. Lastly, an open question about any recent significant life events and circumstances was added into the interview structure which could help address contextual influences and enhance the single-subject design.

The concurrent parallel design would allow the interview data and the VQ scores to be compared and merged during the analysis process. On one hand, the rich descriptions about “switch-on” that emerged from qualitative analysis would confirm accuracy of the VQ outcomes and offer a wealth of contextual information for interpreting the measurement results. On the other hand, interview data would ascertain the volitional aspect of “switch-on” and enhance validity and rigour of the qualitative findings. Together, the intention was that the qualitative and quantitative arms of the study would capture a more comprehensive and trustworthy picture of the “switch-on” effect.

Methods

Methods are the actual procedures, techniques and strategies used for collecting and manipulating data, which are informed and guided by the associated methodology (Crotty, 1998). Participant recruitment, data collection and data analysis in the present study were directed by the convergent parallel mixed methods design, which integrated the qualitative descriptive methodology (Stanley, 2015) and the single-subject A-B design (Carter & Lubinsky, 2015).

Participants

Research participants were identified as people with mild to moderate dementia who participated in a standard CST programme and/or their associated family or caregivers. The study aimed to recruit five to seven patient participants, and for each patient, a key family member/caregiver was also approached to participate. This made the possible participant number range from five to 14 in total. The plan allowed flexibility for the patients and their related family or caregivers to participate in the study alone or together, which was intended to strengthen the recruitment efficiency.

Inclusion criteria for the study aligned with criteria for acceptance into a CST programme. These included: diagnosis of mild or moderate dementia, ability to have a “meaningful” conversation, ability to hear well enough to participate in a small group discussion, adequate vision to see most of the pictures, and ability to remain in a group for 45 minutes. Inclusion criteria for recruiting participants who were a family member/caregiver included: being a family member or caregiver of the person who enrolled in CST, and regularly spending time with the person.

Exclusion criteria for participants with dementia included: being excluded from the CST programme due to major medical comorbidity or physical disability, high level of agitation, and inability to communicate in English. These exclusion criteria were the same as those for participating in CST. Additionally, since I work for the Auckland District Health Board and hold a caseload of clients with dementia, if the patient was under my care, then he or she would be excluded from the study to avoid any conflict of interest. Exclusion criterion for family/caregiver participants applied when their associated patient participant was excluded from the CST programme.

Recruitment

A variety of CST providers in Auckland were approached for assistance with recruiting potential research participants, including two aged care facilities (Selwyn Village and Seadrome Home and Hospital), two dementia day care centres (Platinum Community

Care and Totara Club), a community non-government organization (Dementia Auckland), and two clinical mental health services (Waitemata DHB Mental Health Services for Older Adults and Kingsley Mortimer Unit in the North Shore Hospital). Recruitment attempts with most CST providers were unsuccessful, either due to time frames not fitting or the significant adaptations being made to their programme, such as running the groups once weekly for 14 weeks instead of twice weekly for seven weeks.

Dementia Auckland was identified as a suitable CST provider for conducting the study with. They had recently appointed a senior and enthusiastic occupational therapist to take leadership for their group programmes, including CST. The programme leader was highly experienced in facilitating groups for people with dementia; however, she hadn't run a CST group herself although she had been involved in delivering the CST training in Auckland. Their plan was to start offering CST for their service users from early 2017 and to operate the programme at a community venue in a rotational fashion across their catchment areas in Auckland. The staff from their branches, spread all over Auckland, would identify their client needs for CST and assist with organizing and delivering the programme locally. The CST group would be facilitated by the programme leader and a staff member of the local area where the programme would be hosted. The case manager of the host branch would be assigned as the CST group organizer and would be responsible for advertising, enrolment and coordination of the programme.

The recruitment process is detailed in a flowchart (see Figure 3.1 Flowchart illustrating the recruitment and data collection plan). Organizational approval was obtained first with Dementia Auckland. Their CST programme leader was then contacted and provided with the research invitation flyer (see Appendix 3 Research invitation flyer) and a written summary of the study. The recruitment plan was that I would be informed by the programme leader once the organization confirmed to run a new CST group. Then I would liaise with the local CST group organizer to explain the study and provide the research invitation flyer via email for distribution to potential

participants. The CST organizer would explain the research project to the patients and family/caregivers who met the study inclusion criteria, ascertain their interest in the study, and obtain their verbal consent to forward their contact details onto me.

I would make contact with patients and their family/caregivers who expressed an interest in the study and arrange a face-to-face meeting with them to explain the research in more detail and provide an information sheet. Three versions of the information sheet were prepared, one for patient participant, one for the family/caregiver participant, and one for the next-of-kin to patient respectively (see Appendix 4 Information Sheets for patient participant, family participant and next-of-kin). The potential participants would be given up to two weeks to consider the information provided before being contacted again by me to confirm their willingness to participate. An appointment would be made for the first data collection meeting once confirmation was obtained.

Attempts were made to recruit participants from two seven-week CST groups provided by Dementia Auckland, commencing 27 March 2017 and 28 June 2017 respectively. For the first group, eight patients and seven family members were interested in participating in the study and completed an introduction meeting with me. However, two patient-family dyads were determined to be inappropriate for the CST group by Dementia Auckland and were consequently excluded from the study. Another dyad was unable to commit to the pre-CST data collection due to family circumstances, and therefore discontinued with the study. Further, one patient participant decided to withdraw from the CST group after the initial two weeks, as she was finding it difficult and time-consuming to drive to and from the group venue (over an hour for each way). As a result, she was excluded from the study. This left four pairs of patients and family caregivers remaining in the study.

For the second CST group provided by Dementia Auckland, I requested that only female patients and their family be referred to the study, because all the patient participants recruited from the first group were males. One female patient and her

family were interested and completed the introduction meeting with me; however, they didn't proceed further with the study as they were unable to complete the pre-CST data collection due to other commitments. Hence, no participant was successfully recruited from the second CST group.

Data Collection

Data collection was conducted with the eight participants recruited from the CST programme provided by Dementia Auckland between 27 March 2017 and 11 May 2017. Running of the group was closely guided by the CST manual (Spector et al., 2005). Two CST trained facilitators and six to eight people with mild to moderate dementia met at a community venue twice weekly for seven weeks, with each group session lasting 45 to 60 minutes.

The data collection process detailed in the flowchart in Figure 3.1 was followed except that the original plan of having a second pre-CST data collection meeting did not happen. That was mainly because the time interval between participants' confirmation of enrolment in the programme and commencement of CST groups was shorter than four weeks. All data were gathered at participants' homes at three time-points: before the CST group started (time 1), during the third week of the CST programme (time 2), and within a week after the CST group finished (time 3).

The consent forms were explained to and signed by the participants during the first data collection meeting. There were two versions of consent forms for patient participants and family/caregiver participants respectively (see Appendix 5 Research participant consent forms). The assent form and the next-of-kin form were prepared for participants with moderate dementia who might be unable to give informed consent. However, these forms were not used, because all the patient participants recruited into this study were able to provide informed consent on their own behalf.

For participants with dementia, the first data collection meeting involved obtaining brief demographic information, including: age, gender, ethnicity, highest education,

past occupations, and residential situation; a semi-structured interview; administration of an ACE-III test; and administration of the VQ through observations of the person carrying out two daily activities of their choice. Each follow-up data collection consisted of an interview and repeated administration of the VQ. For family participants, data collection was comprised of a concomitant semi-structured interview before, during and after the CST programme.

Qualitative Data Collection

Qualitative data were collected from the 24 interviews with eight participants at three time-points, before, during and post the CST programme (see Figure 3.1 Flowchart illustrating the recruitment and data collection plan). Each patient-family dyad was interviewed during the same home visit. Most interviews were conducted with the individual participant. However, there were a few interviews involving both patient and family participants, and in these cases, focus on the intended interviewees was maintained.

Open-ended questions were used to structure the interviews that were formulated based on the existing knowledge about “switch-on”. The same set of questions were applied for interviewing participants with dementia and their family caregiver although worded slightly differently to suit the interviewees’ status (see Appendix 6 Semi-structured interview questions for patient and family participants). These questions explored the patient participants’ engagement with daily activities, particularly in relation to their interests, routines, feelings, concentration and communication with others. Some questions also explored whether any recent changes were noted in participants with dementia and whether any contributory factors or life circumstances could be identified.

Most interviews completed were between 20-50 minutes in length, relatively shorter at time 2 (during-CST) than time 1 (pre-CST) and 3 (post-CST). All interviews were digitally audiotaped and then transcribed verbatim by two professional transcribers,

who had signed the confidentiality agreement forms (see Appendix 7 Confidential agreement form for the professional transcriber).

Quantitative Data Collection

Quantitative data collection with patient participants involved two parts, one-off measurement of cognitive function using the Addenbrooke's Cognitive Examination (ACE-III) (Hsieh et al., 2013) in the first data collection meeting, and rating of observable volition using the VQ (de las Heras et al., 2007) at three time-points. The ACE-III was administered with three of the four patient participants, because the other person was willing to provide the result of the same test that he had completed at the Auckland City Hospital within the past three months.

I had no previous experience with the VQ and therefore took some steps to familiarize myself with the instrument, including reading the user manual (de las Heras et al., 2007), trialling and practising the tool with five people with dementia at work, and discussing and reflecting on my experiences in supervision. I noted in the trials that my rating was skewed towards the higher end of the four-point scale, which was consistent with the literature that the two lower points, Hesitant and Passive, were less used (Li & Kielhofner, 2004). Further, when simple, routine activities were used for administering the VQ, the rating option of "no opportunity to observe" had to be used at times for some items, such as "tries new things" on the "exploration" level, and "seeks additional responsibilities" and "seeks challenges" on the "achievement" level.

I further developed some strategies and plans to accommodate these administering issues to ensure objectivity and consistency in applying the measure with research participants. First, simple adaptations were made to the original VQ form (de las Heras et al., 2007) (see Appendix 8 Volitional Questionnaire scoring sheet adapted) for ease-of-use in administering and later data analysis. This included adding more space on the scoring sheet for recording "setting and activity", indicating the three volitional levels and categorizing the 14 items under them. Second, performance and

behaviour during the interviewing process could be used for rating on the VQ in addition to the chosen daily activities, because that would provide more opportunities for observing behavioural indicators. Lastly, some prompting sheets were created in advance with probing questions or observations for rating each VQ item. This would enhance my ability to observe volitional behaviours during performance of simple activities, such as making a hot drink and showing someone around their garden. Appendix 9 is an example of the prompting sheets prepared for administering the VQ.

The VQ was administered with the four patient participants at three time-points, which produced 12 scoring sheets in total. The VQ user manual (de las Heras et al., 2007) was followed and the identified strategies were applied. The first two strategies worked well but not the last one. There was no time to look up the prompting sheets while interacting with the person and observing his engagement with the activity at hand. Nevertheless, the process of preparing these sheets was helpful for improving my confidence and competency in using the instrument. The VQ items were rated briefly on the paper scoring sheet during and straight after the data collection meeting. An electronic scoring sheet was completed at a later time of the day, with the information recorded on the paper scoring sheet transferred and more observation details added. The first few VQ results were discussed with my two supervisors in supervision with reference to the user manual (de las Heras et al., 2007) to ensure adherence and consistency in my scoring.

Data Analyses

Qualitative and quantitative data were first analysed using their respective methods, thematic analysis (Stanley, 2015) for the 24 interviews, and descriptive statistics and visual analysis (Vogt, 2014) for the 12 sets of VQ scores. The qualitative and quantitative data and findings were then coalesced and integrated (Creswell, 2014) under the convergent parallel mixed methods approach, aiming to reach a more comprehensive representation of the “switch-on” effect.

Qualitative Data Analysis

Thematic analysis informed by qualitative description (Stanley, 2015) is an inductive examination of transcript data that involves an analytic process of “open coding, grouping like codes and then collapsing those grouped codes into themes” (p. 28). Compared with content analysis, thematic analysis is more interpretive with a stronger focus on rich descriptions rather than counting word frequency. Thematic analysis under qualitative description requires interpretation and abstraction but stays close to the data. Further, articulation of analysis reflects a generic approach with no association with specific theoretic frameworks or methodologies.

Thematic analysis (Stanley, 2015) was applied to analyse the interview data in this study, with the assistance of NVivo 11 Pro (QSR International, n.d.-b), a qualitative data analysis software. In preparation for the data analysis, the digitally recorded interviews were transcribed verbatim into Word documents by one of two professional transcribers and the transcripts were checked against the digital recording by myself to ensure veracity in content and consistency in format. The corrected transcripts were then posted to the eight participants for checking accuracy. One family participant returned the transcripts with some minor corrections, which were subsequently addressed. The participant-checked transcripts were imported into NVivo for further analysis.

The three phases of qualitative analysis elaborated by Carpenter and Suto (2008) were pursued in the analytic process, including “data reduction, data display, and conclusion drawing and verification” (p. 114). Both manual analysis and electronic analysis using NVivo were conducted in different phases of analysis.

Manual analysis was performed in the early phase of the analysis in order to achieve “data reduction” (Carpenter & Suto, 2008, p. 114). I familiarized myself with the interview transcripts and manually completed a one-page outline for each interview. Appendix 10 is an example interview outline generated in manual analysis. The outlines represented the actual interview structures, with sub-headings created in

accordance with the interview questions, such as “things that stand out”, “interests”, “daily routines”, “communication”, “concentration”, “feeling about things”, and “recent changes”. Participants’ original words were used succinctly whenever possible. Arrows were drawn to illustrate the actual flow of the conversation, the logic and association within the person’s accounts, and the linked or repeated points under different sub-headings. Each outline provided a visual overview of the interview through the display of highly condensed data, which allowed a preliminary analysis of individual interview data. The one-page interview outlines also made it easy and flexible to explore and compare reports between patient and family participants and over the three time-points. The manual analysis process helped to understand the meaning of and the relationships between the data and to recognize similar and different patterns between individual participants as well as changes over time. Strength of this type of analytic process was the opportunities to link and relate the data in building a holistic understanding. This was a valuable and necessary step in the qualitative analysis, because in the subsequent coding process, breaking down the data into small units was the focus, which could have led to a sense of losing “the whole picture” without the prior manual analysis.

NVivo assisted analysis (QSR International, n.d.-b) was the major part of the analytic process, which served to reduce, display and conclude the interview data. The technique of open coding (Stanley, 2015) was performed by using the “theme nodes” functions of NVivo where references from the source materials were collected and coded into “nodes” (QSR International, n.d.-a). The process of grouping and collapsing of open codes in thematic analysis was achieved by organizing nodes into hierarchical folders as parent and child nodes.

A matrix was developed to contain the open codes and structure the coding process, with three columns representing three time-points and four to five rows categorizing different types of data by content. A few considerations contributed to the adoption of a matrix for assisting with the coding. First, the interviews occurred at different times before, during and after the CST programme, and a matrix with three columns

would help manage the temporal variable of the data more efficiently. Second, “switch-on” was anticipated to be multi-dimensional and idiographic in nature. The matrix rows coming out of the data would be beneficial for identifying and describing the diverse facets of the effect. Lastly, “switch-on” was associated with changed experience and presentation following participation in CST, and open codes and sub-themes contained in a matrix would demonstrate the changes more precisely and effectively.

Based on the impression from manual analysis, five rows or categories of the matrix were initially formulated and set up as theme nodes on NVivo, including “doing”, “feeling”, “thinking”, “relating” and “wanting”. The interview transcripts were imported into NVivo and examined against the criteria for the five categories or thematic areas as demonstrated in Table 3.2. Relevant text was extracted from the interview transcripts and loosely placed into the appropriate categories or theme nodes in preparation for the open coding procedures. Attention was paid to ascertain whether the reports or descriptions in the Time 2 and Time 3 interviews were changed or unchanged in comparison to the baseline data. This step of roughly discriminating and categorizing raw material helped to reduce the amount of interview data and affirm the configuration of the coding matrix.

Table 3. 2

Criteria for Categorizing Interview Data into Five Rows of the Coding Matrix

Categories (Rows)	Criteria and Features
Doing	<p>Reports about actual actions and behaviours that were observable to others, including</p> <ul style="list-style-type: none"> - what participants with dementia did in their day-to-day life previously and currently (patterns, routines and occupations) - what they did in relation to CST, within the group and at home - what they did to cope with illnesses (dementia, anxiety, depression, and physical health problems) and other difficult life circumstances (in ageing, social roles, relationships, routines, occupations, and environments)
Feeling	<p>Reports about mood, affect, emotions that were</p> <ul style="list-style-type: none"> - short-lived and/or long-lasting - subjectively experienced and/or objectively noticed - positive and/or negative - within the CST group and/or at home
Thinking and Reflecting	<p>Reports about subjective thoughts (interpretation, opinion, attitude, values and beliefs, awareness, desire, choice, decision, and plan) and/or objective mental processes (memory, concentration, perception, judgement, repetition, selectiveness, rumination, and self-absorption) that were</p> <ul style="list-style-type: none"> - expressed to the researcher directly or indirectly via family participants, and/or observed by family or the researcher - previously and/or currently experienced - related to and/or beyond CST
Relating	<p>Reports about the person's subjective sense of and/or observed connectiveness and relationships with others that were</p> <ul style="list-style-type: none"> - within the CST group (with other members and facilitators) and/or at home (with spouse, children and grandchildren, relatives, neighbours, friends and other people in the community) - recounts of social encounters and events, and/or subjective reflections on social experiences (interpretation, provoked thoughts and feelings, judgement, attitude, and decision)
Wanting	<p>Reports about thinking, feelings and doing that were</p> <ul style="list-style-type: none"> - indicative of motivation/volition, choice, decision, effort, determination, and persistence - directly or closely associated with subsequent actions or behavioural patterns - self-reported, observed, and/or inferred retrospectively from actual actions or behaviours

A node hierarchy corresponding to the coding matrix was developed on NVivo with the five categories set up as parent nodes (matrix rows), each of which contained three child nodes representing three time-points (matrix columns). The extracted and coarsely assorted interview transcripts in the five categories or thematic areas of “doing”, “feeling”, “thinking and reflecting”, “relating” and “wanting” were further interrogated and coded line-by-line using the open coding technique (Stanley, 2015). Codes were labelled descriptively, with participants’ original words used whenever possible. A text source could be referenced to multiple codes, and all codes and their references were placed and stored in the node hierarchy. Similar codes were grouped and collapsed with an aim to merge into sub-themes for each cell of the coding matrix. This analytic step was a lengthy and cyclical process, which involved repetitive collapsing and expanding of codes with an enormous amount of shifting and shuffling between parent and child nodes within and across the five categories.

It was during this process that “wanting” was removed from the coding matrix rows, because there were relatively fewer and more unified codes in this category than the others. Further, the data about “wanting” were often embedded in or inferred from reports about “doing”, “feeling” and “thinking and reflecting”, and extraction of the data tended to fragment the sentences. This gave the impression of this category being somewhat “artificial” and therefore probably unnecessary. With the redundancy of “wanting”, there were four rows and three columns in the final coding matrix as illustrated in Table 3.3. The main outcome of thematic analysis of the interview data would be identification of three sub-themes for each matrix cell, the synthesis of which would generate a “thick” description of the nature and occurrence of the “switch-on” effect. Appendix 11 is an excerpt of the codebook exported from NVivo for “relating”, which exemplified the coding process and how the sub-themes emerged at three time-points respectively.

Table 3. 3

The Coding Matrix (Blank)

	Time 1 (pre-CST)	Time 2 (during-CST)	Time 3 (post-CST)
Doing			
Feeling			
Relating			
Thinking and Reflecting			

It is worth mentioning that I come from a different cultural background and speak English as a second language. To ensure precise understanding and interpretation of the interview data, I routinely took advantage of the online dictionary, thesaurus and translation tools during the coding and qualitative analytic process. I also consulted with my supervisors if I came cross any transcript text that I was unsure about in relation to colloquialism or cultural nuances.

Quantitative Data Analysis

Descriptive statistics is the portrait of “actual data” and is defined as “not inferential, not multivariate, or not causal” (Vogt, 2014, p. 206). The quantitative component of this study had a small sample size and did not intend to explore causation, and therefore inferential statistical analysis would not be applicable. Affiliated to descriptive analysis, graphic depiction and visual analysis are commonly used for presenting numeric results and exploring patterns in single-subject designs (Carter & Lubinsky, 2015).

Descriptive statistics were used in the present study to calculate means of the VQ scores and demonstrate the demographic data, including the ACE-III results. Graphic depiction and visual analysis were employed to display the VQ data, including the overall scores and sub-scores for each participant with dementia across three time-points, under the single-subject A-B design (Carter & Lubinsky, 2015).

Mixed Methods Analysis

The mixed methods analysis involved bringing together the qualitative and quantitative data, guided by the convergent parallel mixed methods (Creswell, 2014). The sub-themes that emerged from qualitative thematic analysis were compared to the VQ results that were presented graphically, including the overall and sub-scale scores. The integration of quantitative analysis would help to clarify whether volitional changes were part of “switch-on” and hereby contribute to answering the two qualitative research questions about the nature and occurrence of the effect. The outcomes of this combined analysis would be a “thick” description about the nature of “switch-on” and an evaluation of the occurring pattern and timeframe. On the other hand, qualitative analysis of the interview data would ascertain whether the patient participants experienced “switch-on”. This information would be considered in conjunction with the VQ results to answer the third research question about whether the measure captured the “switch-on” effect.

Ethical Considerations

Ethical principles for health research (National Ethics Advisory Committee, 2012) were considered and followed carefully during the planning and data collection phases of this study. The ethics approval was applied for from the Auckland University of Technology Ethics Committee (AUTEC) and was granted on 21 November 2016 before the recruitment was commenced. The AUTEC reference number was 16/396 (see Appendix 2 Ethics approval).

Several ethical considerations were incorporated into the design of the present study and implemented strictly in the research process. First, participants’ choice, dignity, and consent were totally respected and protected in the recruitment and data collection process. Participants were fully aware of their right to withdraw from the research prior to data analysis without needing to give a reason. They were reminded that they were free to say as little or as much as they wanted during the interviews and could stop the interview at any stage without needing to provide an explanation.

To apply the principle of informed consent, an introduction meeting was arranged with potential patient participants and their family/caregivers at their homes. The study was explained, and the Information Sheets were provided for their consideration. Potential participants were given time to think and make the decision about their participation in the study, and all participants signed the consent form prior to commencement of data collection.

Second, care and respect were given to people with dementia as vulnerable participants. Their family or next-of-kin were consulted and invited to the introduction meeting to support with the person's understanding and decision making. Simplified language and pictures were used in the patient version of the Information Sheet to accommodate their cognitive abilities (see Appendix 4 Information Sheet for patient participants). Further, according to Goodman et al. (2011), "people with dementia, who may have memory lapse, can consent in the moment" (p. 481). Apart from the initial written consent, patients were checked on their consent verbally at each follow-up meeting to ensure their continued willingness to participate. There were additional considerations in the research design that catered for vulnerability of participants with dementia, such as relatively short interviews, using the VQ (de las Heras et al., 2007), an observational measure of volition that was developed for people with reduced abilities to report volition, and encouraging participants with dementia to have a support person present during their interviews and observational sessions.

Third, participants' privacy and confidentiality were respected and safeguarded. All data collection sessions occurred at participants' homes to protect their privacy. Pseudonyms and numbers were applied to mask participants' identity, and any recognizable personal information has been removed from the writing. This protection will also apply to dissemination of the research findings. Electronic research data were kept in private, password-protected computers, and paper documents were stored in secure locations.

Lastly, potential conflict of interest was addressed and managed. Given that I work as a clinician for the Auckland District Health Board, I was not involved in the organization and provision of the CST programme. Further, it was an exclusion criterion that patients under my care would not be included in the research to avoid potential coercion and imbalanced power relationships.

Rigour and Trustworthiness

Criteria for evaluating rigour and trustworthiness were considered carefully in the design and implementation of this research project. Although presented separately, the three research components, qualitative, quantitative and mixed methods, were taken into consideration as a whole to optimize the methodological strengths of the study design.

The Qualitative Component

Guba and Lincoln (1982) postulated four widely adopted criteria for evaluating trustworthiness of a naturalistic inquiry in qualitative research: “credibility”; “transferability”; “dependability”; and “confirmability”. The equivalent rigour criteria in rationalistic or traditional scientific research are “internal validity”, “external validity”, “reliability” and “objectivity”, with internal validity and external validity constituting generalizability (pp. 246-248).

Guided by the qualitative descriptive methodology (Sandelowski, 2000), the qualitative part of the present study aimed to produce a “thick” description (Guba & Lincoln, 1982, p. 241) about “switch-on”, which would include detailed accounts about various contextual factors as well as methods and procedures used in the research process. This would make it possible for the research findings to withstand scrutiny for truthfulness and credibility. Further, the research outcomes could be evaluated against consistency and transferability in future studies, providing the same circumstances applied.

A feature of the qualitative design in the present study was repeated interviews with both patients and family participants at three time-points. This could enhance the credibility of the study outcomes, owing to increased opportunities for “prolonged engagement” and “persistent observations” with participants over time, and for “triangulation” of different perspectives between patients and family caregivers (Guba & Lincoln, 1982, p. 247). Further, the perspective triangulation could also improve the objectivity of the research data and make the study more confirmable (Guba & Lincoln, 1982).

According to Carpenter and Suto (2008), reflexivity is an essential and important characteristic of qualitative study. These authors hold that given the interpretive nature of qualitative study, researchers should make their personal values, interests and assumptions transparent and actively engage in self-reflective activities, including keeping a reflexive journal and constructing a reflexive account. Guba and Lincoln (1982) asserted that practice of reflexivity could serve the function of objectifying the research data and improving confirmability of a naturalistic inquiry. In this study, reflexivity was practised throughout the research process. I claimed my personal worldview, epistemological assumptions and preferences in deciding the research questions. I also kept reflective notes using the Memo and Maps functions on NVivo (QSR International, n.d.-a) while performing the coding and data analysis.

Another important contributor to rigour of this study was peer review of analytic decisions with my supervisors (Guba & Lincoln, 1982), which occurred on several occasions during the interview data analysis process. Some decisions were questioned and after discussion, agreement was reached, with some items re-coded and re-structured. This procedure supported credibility and dependability of the qualitative findings.

The Quantitative Component

According to Johnston and Smith (2010), rigour of single-subject designs is determined by multiple factors related to measurement, analysis, effects of context,

and sub-type. The most suitable measures for SSDs should show good validity and reliability and be technically easy to capture changes. Measurement should ideally be blinded or masked to ensure objectivity and minimal bias. A larger number of repeated measures is desirable, which will help ascertain baseline stability and clarify variations of targeted outcomes. Visual analysis is a simple and commonly used analytical method in SSDs; however, care needs to be taken when there is a small effect size. The extraneous factors in the person's life circumstances should be considered carefully, as they may impact on the outcomes and confound the research findings. Among SSDs, the A-B design is the easiest to implement but least rigorous due to the absence of control which compromises internal validity. The weakness of the A-B design can be addressed by applying meta-analysis on a large body of well-conducted studies (Johnston & Smith, 2010).

The VQ is a technical measure that can be administered easily in any setting, and it has reasonable psychometric properties in construct validity, internal consistency and intra-rater reliability (Chern et al., 1996; Li & Kielhofner, 2004). These features of the VQ supported its application in the single-subject design of the present study and contributed to rigour of the research design.

No blinding strategies were applied for the measurements in this study; in addition, raters' subjective input is generally allowed and encouraged in administering the VQ (de las Heras et al., 2007). In fact, differentiations between the four points on the rating scale are primarily based on the degree of encouragement that is required to elicit the indicating behaviours. This attribute of the VQ is probably associated with its purpose for guiding therapy and its theoretical assumption about volition tending to vary and fluctuate depending on the contextual variables. Daily activities in the home environment were observed for rating the VQ in this study, and the consistent administration condition could control variation of volition and thereby improve reliability of the measurements.

The Mixed Methods Component

According to Creswell (2014), rigour and validity for a mixed methods design is largely dependent on the respective qualitative and quantitative components. The advantages of the convergent parallel mixed methods were carefully considered and embraced in designing the qualitative and quantitative arms of the current study to optimize rigour and trustworthiness.

On one hand, the parallel design of repeated interviews with both patient and family participants at three time-points could strengthen the trustworthiness of the qualitative inquiry. It could also help compensate the weaknesses of the A-B design for the quantitative investigation, such as lacking repeated pre-CST measurements to confirm baseline stability and not addressing the contextual circumstances that might confound the VQ results.

On the other hand, although the single-subject A-B design is generally regarded as not robust enough to determine causation, it was adequate for this mixed methods study that had a stronger focus on inductive exploration of the “switch-on” effect. The A-B design could provide supporting information about the possible correlation between volitional changes and “switch-on”. It could also serve as a triangulation strategy for improving the credibility and confirmability of the qualitative findings.

In addition, there are rigour considerations more specific for mixed methods, such as equal sample sizes between the qualitative and quantitative arms, consistent use of concepts and constructs, and discussions about incomparable findings (Creswell, 2014). All of these were followed and adhered to in the present study, with the first two considerations presented earlier in this chapter and the last one to be illustrated in the following chapter.

Conclusion

This chapter presented the research design used in this study for answering the three research questions about describing and measuring the “switch-on” effect. The

convergent parallel mixed methods design was elaborated and justified, including its qualitative and quantitative components guided by qualitative descriptive methodology and the single-subject A-B design respectively. Underpinning the mixed methods research is the philosophical stance rooted in post-positivism. Methods and procedures for conducting the research project were described in detail, including data collection and data analysis that were guided by the qualitative, quantitative and mixed methods research designs. Ethical considerations related to planning and implementing the study were explained, especially those acknowledging people with dementia as vulnerable participants. Criteria and guidelines for rigour and trustworthiness in research were explored and discussed in relation to the qualitative, quantitative and mixed methods components of the study design.

Chapter 4 Findings

Introduction

This chapter starts with demographics of the patient participants to provide background information for reporting the findings about the “switch-on” effect. The qualitative findings that emerged from thematic analysis of the semi-structured interview data are presented, following the structure of the coding matrix mentioned in Chapter 3. The quantitative results from the Volitional Questionnaire (VQ) (de las Heras et al., 2007) are demonstrated graphically. The parallel convergent mixed methods procedures are applied to compare and merge the qualitative and quantitative findings in relation to the research questions, which lays the groundwork for the discussion and conclusions in the final chapter. All the names used in this chapter are pseudonyms.

Demographics

Four male participants diagnosed with dementia and their spouses participated in the study. Table 4.1 displays the demographic information of the patient participants. Three participants with dementia were New Zealand European and the other Polynesian, with age ranging from 69 to 82 years. All of them lived in the community with their wives, who were their main caregivers, and two participants also had other family members living with them. In terms of past occupations, two participants were retired engineers and the other two participants worked in the building and construction industry.

All four participants had a diagnosis of dementia as a prerequisite for entering the CST programme provided by Dementia Auckland, although with unknown sub-type, which seems to be common and acceptable in CST research (Spector et al., 2001; Spector et al., 2003). Their diagnosis was also confirmed by their ACE-III scores, none of which was more than the two recommended cut-off scores (88 and 82) for

diagnosing dementia (Hsieh et al., 2013). Further, according to the interview data and the VQ observations, all patient participants were able to manage day-to-day living in the community with support from their wives. This was consistent with the criteria for mild or early stage dementia, during which the person has “difficulties in a number of areas” but is “still able to function with minimal assistance” (Alzheimers New Zealand, 2017, p. 18). Their ACE-III scores also supported that they had mild or early stage of dementia. Frank, John and Peter were scored more than “64/100”, the recommended cut-off score for dividing mild and moderate dementia in New Zealand (Fisher & Thomson, 2014, p. 10). Although Mark’s score (52/100) was below the threshold, his performance on the ACE-III was likely an under-estimation of his cognitive function because of his limited school education and more importantly, speaking English as a second language.

Table 4. 1

Patient Participant Demographics

Name	Gender	Age	Ethnicity	Highest Education	Past Occupations	ACE-III
Frank	Male	82	European	Diploma in engineering	Engineer	82/100
John	Male	79	European	Secondary school	Carpenter and joiner; labour contractor; cost pricing manager	69/100
Mark	Male	69	Polynesian	Intermediate school	Boxer; construction labourer; traffic controller	52/100
Peter	Male	81	European	Trade Certificate in engineering	Engineer; educator of engineering	70/100

Qualitative Findings

A coding matrix, consisting of four rows of thematic categories labelled “doing”, “feeling”, “relating”, and “thinking and reflecting”, and three columns of time-points before, during and after CST, was used to assist with thematic analysis of the interview data. As described in detail in Chapter 3, “doing” referred to reports about actual actions or behavioural patterns; “feeling” consisted of descriptions about emotion, affect and mood experienced by the person; “relating” contained reports

about the person's sense of connection and relatedness to other people; "thinking and reflecting" included objective and often observable information processing ("thinking"), such as attention, orientation, decision making, learning, memory, and language, as well as subjective thoughts, insight, opinion, decision, attitude, and values and beliefs ("reflecting"). Table 4.2 summarizes the sub-themes that emerged from the analysis for each cell of the matrix.

Table 4. 2

The Coding Matrix and Sub-themes for Describing "Switch-on"

	Time 1 (pre-CST)	Time 2 (during-CST)	Time 3 (post-CST)
Doing	<ul style="list-style-type: none"> - Doing things becoming problematic - Seeming to occupy himself - Likes to still be involved and do things 	<ul style="list-style-type: none"> - Active participation in CST - Intentional adjustment in doing things at home - Our days go in the same manner 	<ul style="list-style-type: none"> - Doing CST as an occupation - Occupational adjustment at home - Going on his normal pattern pretty well
Feeling	<ul style="list-style-type: none"> - Getting enjoyment and positive feelings in life - I've got to accept my limitations - Feeling down and frustrated at times 	<ul style="list-style-type: none"> - Getting more enjoyment - Feeling happier and more positive - More interested and motivated 	<ul style="list-style-type: none"> - Getting more enjoyment - Feeling good and more accepting - More interested and motivated
Relating	<ul style="list-style-type: none"> - Getting social contact and support - Relating to others becoming problematic - Difficulties impacting on wife 	<ul style="list-style-type: none"> - Meeting like-minded people and having fun in CST - Doing little things to help wife - Improved relationship with wife 	<ul style="list-style-type: none"> - Bonding and comradeship in CST - Improved relationship with wife - Improved social participation
Thinking and Reflecting	<ul style="list-style-type: none"> - Having trouble with memory and thinking - Dementia hasn't proceeded as fast as I thought - Thinking about life and the past 	<ul style="list-style-type: none"> - CST gets him and wakes him up - CST shows me where the memory blanks are - Positive impact on memory 	<ul style="list-style-type: none"> - CST has given me stimulation to think about things - Thinking about life and the future - Positive impact on memory

In the discussion below, baseline findings in Doing, Feeling, Relating, and Thinking and Reflecting were primarily based on interviews at time 1; however, they were also informed by data from interviews at times 2 and 3 when participants referred back to their experiences prior to CST or compared what was happening then to how things had been previously. Findings that emerged from interviews at times 2 and 3 are

presented together, because that helps illustrate the changes over time more efficiently.

Doing

Doing at Baseline

A major sub-theme coming out from the analysis was “doing things becoming problematic”. All four participants with dementia experienced some degree of difficulties with doing things that resulted in reduced mastery of and participation in daily activities, loss of interests and hobbies, finding occupation a “mission”, and problem behaviours, such as frequently repeating questions. All these issues with doing had some impact on their spouses, who tried to keep their husbands occupied and took more responsibilities for their shared family lives.

He’s just dropped it bit by bit as he’s found things more difficult to do. He sort of dropped a lot of things he used to get into. He used to keep himself busy all the time, making things, doing things, fixing things, messing around with stuff, trying to get radios going and one thing and another. He just doesn’t do all that sort of thing now. In fact, it’s a bit of a mission trying to think of something to do with him. (John’s wife, interview time 2)

Reading was an activity that all participants with dementia found more difficult to engage in. For example, Frank reported “getting more fussy about books” that he read, and his wife described “he’s finding it harder to read more serious books. He does read that, but he normally falls asleep after a couple of pages. It takes him a long time to read a book”.

While acknowledging their reduced ability to do things, all the wives thought their husbands didn’t try as much as they could for various reasons, ranging from lacking confidence and motivation to not trying hard enough and easily “giving up”. However, participants with dementia might have different perspectives on this. For example, Peter’s wife found him “not as motivated” with things like gardening and she was trying to do things with him and to “make sure he’s not sitting at home, but it’s really

hard sometimes because he won't go out." Whereas, according to Peter, doing less appeared to be a coping strategy to enable him to prioritize things that were more important to do.

What I'm trying to do is only do one thing, not try and think about two or three things at once, just try and just simplify my life. Try to make sure I do the exercise that I need for my body. ... I have my bad days when I don't feel like doing a thing, and physically because I just don't physically have the energy. When I get like that, I find it hard to say, "bugger this, I'm going to just get up and do it". ... I've said to June [wife] that "I didn't feel like going out with you this afternoon, because this morning I was thinking I'm quite happy to have a rest and have a lazy time". I am inclined to be a bit lazy. ... But I will try do if I can see things [that need to be done], try because of partnership. (Peter, interview time 1)

Lack of initiation with tasks was also a common problem, as reported by three family participants, although their husbands would join in once they started an activity.

He realizes it has to be done. I don't think he would initiate. ... But often when I start something, he either comes and helps me or takes over the job. And sometimes I wonder why I start it, whether it's to get him to do it, I don't know. (Frank's wife, interview time 1)

Regardless of that, three of the men expressed their preference for getting things done properly, according to their standards, which their wives might view as unnecessary or problematic.

He doesn't use his motivation to do it but when I go to do the job, that's when he goes and says, "oh this is not the way I want it". And then he'll do it his way. ... If I say to him not to do that, he won't remember not to do that. He'll keep doing it. ... He always does the opposite of what I want of him. He doesn't want to be told to do. (Mark's wife, interview time 1)

While experiencing various issues with doing things, all participants with dementia seemed to be able "occupy" themselves and engage in activities of their choice in self-care, recreation and home maintenance. Going for a walk, watching television and watching the news on television or the internet were common daily activities for

all of them. For example, Peter described “I always try to get time up [get up in time so] that I can watch the news. If it’s after 9 am, I’ll go plus one. ... So I like to see what the news is every day”.

Aside from these common routines, three participants described their choice of engaging in some specific activities that were intentional and meaningful for them. John described his regular activity of recording a television programme and editing out the advertisements, saying “I try and do it once a week at least, because if I go for too long I’ve forgotten how to do it, so I make myself do it”. Peter tried to adhere to a “fixed” breakfast making routine that involved completing multiple tasks within a certain time frame, as “that’s how you try to teach a person to put an engine together, if you want to try and meet the standard rate that you’ve got”. Frank had focused on painting the front door that “was sealed in and now I’ve had to paint it and repair it and all the rest of it”, which his wife thought was “very therapeutic” for him.

Two participants with dementia reported or were noted to have recently improved motivation at baseline. Peter’s wife noted that he had started doing more vacuuming since she had an injury three weeks before and appeared to be even more “motivated” with activities after he had heard about the CST programme, although he had a pattern of seeming to “get motivated to do something and he’ll do something for a week, maybe two weeks and then the interest in it has gone”. Despite the “progressing” and “escalating” decline reported by his wife, John found himself more “proactive” in doing things lately, “like, well something needs fixing, I’ll say, ‘I’m going down to Mitre 10 [hardware store]’ and I go straight away”.

The other emerging sub-theme, “likes to still be involved and do things”, grouped the data that captured the person’s willingness to play a role in activities that they were no longer able to do on their own. All of them helped their wives and shared some household chores. With support, three participants went out with their wives or family regularly and participated in some forms of social activities either at home or in the community.

When our son-in-law was putting up the blind yesterday, Peter was involved and tried to help. ... It would just have been a drama if he'd done it on his own, he couldn't have done it on his own. He likes to still be involved and do things but, it's more of a case of other people doing it and him pottering along beside them.
(Peter's wife, interview time 1)

In summary, at baseline, all participants with dementia were experiencing various difficulties with doing things as a result of their dementia, which they and their spouses were trying to accommodate. They still wanted and were able to make choices and engage in activities that were important, meaningful, and interesting to them, albeit with input from their wives or others. It was common that the participants with dementia and their family caregivers had different views about their occupations and their choices of occupations, which at times was as a source of problems and stress experienced by their family supporters. Generally, while participants with dementia were reasonably contented with how they were doing, the wives tended to think that they had the potential to take more initiative and make more effort with activities.

Changes in Doing

Changes in Doing at times 2 and 3 were similarly characterized by active and energetic participation in the CST programme and purposeful adjustment of activities and routines at home. The changes started to appear at time 2 and continued to develop, strengthen and solidify towards time 3. All participants demonstrated the same trend, although there was variation in timing. For example, Frank's wife didn't notice any behavioural changes at home until time 3; whereas Peter seemed "more motivated' immediately after learning about CST, even before the programme got started.

A commonality in terms of engagement with CST among all four participants was their keenness to attend and high commitment to the programme. Mark's wife reported that he used to be reluctant to go a community group; however, after

joining in the CST group, he “would get ready” to go even on days when there was no group. Similarly, Peter’s wife commented that he was always “in a hurry to get there [the CST group]”. John’s wife reported that he didn’t like “the gamey things” in the CST programme and found it “difficult; however, he “stuck with it” and “wanted to be there, he didn’t miss one”. Frank recounted his dedication to the group.

I look forward to that. I thought I was going to miss one as I had to go for my brain scan because I didn’t know how long it was going to take. ... I was [only] in there for 10 minutes. ... So I was there [the CST group] on time cos I didn’t want to miss it. Even if I’d have been late, I would have gone. (Frank, interview time 3)

Three participants reminisced in detail about how they actively and passionately engaged in the CST programme in their own different ways, which was also echoed in their wives’ accounts. An example was John’s self-reports and his wife’s descriptions about his “determined” preparation for giving a speech on current events to the group.

When I’ve found this thing about Teslar, my concentration for about three or four days was fantastic, because I was intent on getting to the bottom of all this. And I wrote it down in long hand and then thought “no, that doesn’t sound right”. And I’d write another one and I had about five pages before I sent it out to what was the real meat in the sandwich. (John, interview time 2)

I think when he goes to these sessions, he gets goals like things to do, and he busies himself with that. He gets stuck in and spends hours like doing the last one he did and that was on current events and he went into it with great guns, and to present his little speech! And it was cool that he was doing all that. So, it kind of, it almost got him quite excited. I think he really quite enjoyed it. (John’s wife, interview time 2)

Participants with dementia also described the positive interactions in the group, including their observations about other people’s actions and reactions. Peter described that when he suggested “lubricators” as the group name, people came up with different words such as “slippery” and “grease”. Mark didn’t describe much about his participation in the CST group; however, it was revealed in Frank’s accounts.

One of the guys on the group [Mark], he's from the islands. ... But he's very quiet. He's used to sit there, and he didn't have a lot of response to some of the things. And then one day, she [CST facilitator] had some photos [for] ... people to comment. ... There was this picture of an island and she passed it to him. And it was the island opened [him] up. [He] told us all about where he lived and who lived there and what they did, and it just brought him into the group! (Frank, interview time 3)

Parallel to the active engagement with CST was the intentional and purposeful adjustment of doing things at home. A marked common change at time 2 was that all participants were "talking more about stuff", where previously, according to John's wife, "we sort of got to the stage he didn't have much to say about anything". In addition, two of the men became more "proactive" with their daily activities. For example, Mark said, "I just do it myself and when you finished, I'm happy cos she [wife] is not going to argue me back. I've done the job". His wife echoed:

We have a calendar in the room, he ticks the days. He ... remembers to do, not every day but he's better. I noticed he's better on that. He's not repeating. As soon as he hears the radio saying, "oh, today is Wednesday", then he goes and ticks the calendar. So, he's starting to do things for himself than asking me. (Mark's wife, interview time 2)

At time 3, all participants showed improved initiative and engagement with activities that they felt interested in, competent at, or found meaningful to do, particularly in taking more responsibility for the household chores with an intention to help their wives. Meanwhile, they chose to let go of activities and responsibilities that they had held on to but felt no longer necessary and realistic.

I'm taking less responsibility because Ann [wife] is doing so much more. That's about it. But I actually probably do a little bit more around the house. ... Well if there's any washing up to do in the evening, I generally do it or I get it sorted so it can go in the dryer. Otherwise Ann would do it. And if she wanted any help, she'd ask for it. Now she doesn't have to, I just go and do it. (Frank, interview time 3)

They also made an effort to resume old routines or develop new habits, patterns and strategies in maintaining their independence and quality of life. For example, Peter spoke of wanting to take the bus to attend CST by himself at time 2, an activity that he had stopped doing in the last 12 to 18 months. He managed to achieve this goal by time 3, and according to his wife, he also started using a “GPS tracker” to make them both “confident”. Frank became more diligent in dealing with his word finding difficulties.

He admitted that he does a lot of getting-round problems. If he forgets a word, he uses another word and he’s got good basic language, so he can always substitute another word. And sometimes I spot it. I thought he wouldn’t normally use that, it’s the correct word but not one he’d normally use. But that’s fine if he can get round the problem, that’s using his brain by doing that.
(Frank’s wife, interview time 3)

Along with the positive changes in doing, Peter’s wife raised concerns about him starting to do too many puzzles at night, which interfered with his sleep. She also noted increased agitation and restlessness, sometimes associated with being “so keen” to get to the CST group. It seemed to indicate that over-doing could be a possible side effect of CST.

Overall, all participants with dementia engaged in and committed to CST actively and enthusiastically. They also intentionally and autonomously adjusted how they participated in activities of daily living, which entailed pursuing more activities that were meaningful and achievable as well as disengaging from routines and patterns that were no longer important, necessary or applicable. Further, all demonstrated increased deliberation, initiation and effort in their actions and coping behaviours in both CST and home environments. Changes in Doing were generally wilful and satisfying to the four men and were regarded as adaptive and plausible to their spouses.

Feeling

Feeling at Baseline

All participants with dementia reported getting enjoyment and positive feelings from life, usually associated with doing things, at baseline. Some enjoyable activities described were “walking along the beaches”, “going out with my wife”, seeing a “good” movie with his wife, “doing different things I haven’t done before”, “playing on the computer”, and “doing the small jobs that need to be done”. They also expressed an interest and willingness to keep doing things to make them feel good.

I suppose you can get bored. That’s why I try and keep up with doing things like [recording some interesting television programmes and] taking the ads out of [them], those sorts of things. It makes me think and I like to think and try and feel like I’m achieving what I want to do, and to keep them [the recorded television programmes] clean [without ads] and that sort of thing.
(John, interview time 1)

On the other hand, all CST participants reported feeling down, depressed and sad at times, largely associated with their diagnosis and reduced ability to do things. For example, Frank reported feeling “a little depressed” because “not only do I have this whatever I’m getting, a loss of memory, my body is also mucking me about. Can’t do this and can’t do that, can’t have coffee”. Mark’s wife reported that “he’s been tearful, if something is not the things he likes. He’ll get emotional, like he’s concerned about me a lot, even though I’m okay”. John’s wife spoke of him “starting to be a bit of lost soul” when he looked “depressed” and had started saying, “they should give you a pill when you’re like me”, because he was always worried about getting to a point that he would no longer recognize his wife.

Three of the men reported feeling frustrated sometimes. For example, John commented “it drives me crazy because all my life I’ve always wanted to know people’s names and remember them and call them by their name. Now it’s, howdy-doody!” Peter’s wife noted that he “was getting frustrated” with his hobbies because “he wasn’t able to do it as easily”. Other negative emotions included feeling worried,

angry, bored, agitated with noise, insecure and lacking confidence, and being regretful about the past.

However, all participants with dementia expressed some degree of acceptance of their diagnosis and problems. Peter stated, “I’ve got to accept my limitations and I have accepted my limitations”. Mark acknowledged “it’s just my life”. According to John’s wife, acceptance brought about both pros and cons.

When it was frustrating him, he couldn’t, he just wouldn’t accept that he couldn’t do it. And now, it’s kind of a sort of acceptance has come into it, I think, which means he can just kind of relax a bit. But it is, it’s more sad now, because, he’s kind of giving up.
(John’s wife, interview time 1)

Generally, at baseline, all participants with dementia experienced some degree of emotional disturbance mostly related to their diagnosis and their reduced abilities to remember and do things; however, they could still get enjoyment from life and were interested and motivated to engage in certain activities. All CST participants appeared to be in a stable emotional state, although one of them had just recovered from a recent “manic” episode. Three expressed contentment and acceptance of the diagnosis as well as their social and occupational status.

Changes in Feeling

Changes in feelings were similarly reported at times 2 and 3, in that all participants with dementia experienced a range of enhanced positive emotions that seemed to permeate between the CST and home environments, including happiness, enjoyment, interest, motivation, satisfaction, relaxation, greater acceptance, and confidence. They also spontaneously expressed their positive emotional feelings through affective display, body language and behaviours, which was noticeable to others.

For example, Frank commented at time 2 “when I come away, I always feel good, had a good time. I look forward to going to it”. His happiness and enjoyment were also noted and reported by his wife.

I think the main thing that stands out is he's so happy to go to this course and talk about it afterwards. It's so unusual for him to want to go be with a group of people, especially as he didn't know any of them before, not even Judy, the course leader, everyone was new, but he enjoys it. (Frank's wife, interview time 2)

John's wife noted some similar affective changes at time 2, characterized by increased curiosity, energy and spontaneous expression through talking and sharing. However, she also reported that "I did think at one point there he was getting a bit stropky, but then I thought maybe it's because he's waking up a bit".

Something is different. He's just kind of more interested in other things or doing other things. ... He's more animated. He's sharing a lot more what he feels without being asked. Instead of me pumping him with how he feels about things, I don't even have to do that really. He's quite happy, he just comes out with it. (John's wife, interview time 2)

The differences between times 2 and 3 were mainly in the range and degree of emotional feelings that the men experienced and displayed. For example, Peter's wife commented "he's really good. He's just blossomed on that course". Peter reported "I've been quite good, and I feel life is well worth living" and further described:

I've started enjoying doing puzzles, and I've enjoyed sort of thinking about things and writing, recording stuff that I've done. ... I enjoy people coming and visiting. ... I am enjoying life, I am really enjoying, even liking watching that, what's her name? making a 3D pack. I've done three 3D puzzles, and they are quite stimulating. They're not very hard to do but I get a bit of enjoyment out of it. (Peter, interview time 3)

In addition, all participants with dementia reported improved acceptance of their diagnosis and life conditions at time 3, seemingly associated with going to the CST group. Mark's wife commented "he is accepting things better and understanding things better, not to be selfish and greedy and demanding". Frank reported that acceptance made him feel "more relaxed". Peter described how acceptance enabled him to overcome the perceived stigma towards dementia.

I've always had the confidence. I can talk to anybody, but I've sort of pulled my head in a little bit because I've got dementia. I've got to put on a [cover]. Well I don't want to put on [a cover], I just want to be me. I want to be happy, and I want to be able to talk to people okay. I'm not ashamed to say to someone, "look I've got dementia", if someone asks me. It's where I am, and I'm going to be there and enjoy what's there. (Peter, interview time 3)

However, acceptance seemed to generate more complex feelings for John, who, according to his wife, mixed acceptance with increased awareness of loss, intensified grief, and periods of anger, frustration and impatience. Despite all that, he still reported being "quite happy in my own self".

The strength of positive feelings expressed through body language by two participants wasn't fully captured by the audio recorder. At time 2 interview, Frank extended his arms wide open and gave me a warm and exaggerated hand-shake with his both hands. He told me that he really enjoyed the CST group and thanked me greatly for having led him to it. During the interview at time 3, he broke into tears when trying to describe how he felt about listening to Beethoven's music in a CST session.

There were also emotionally intense moments during the time 3 interview with John and his wife, who both broke into tears when he was trying to express his appreciation towards her for taking care of him and his apologies for not doing enough to make her happy. He said in tears and with smiles that "I'm allowed to cry because I'm happy". He became teary again at a later point when he was commenting "just pray God everything will be okay", which appeared to be a newly attained resolution for his long-standing worries about his wife passing before him. I also noted the impact of this interview on my own emotional state at the time and thereafter, which was unexpected.

Of note, there were considerable reports about positive feelings closely associated with social interactions in the CST group and improved spousal relationships at home. These will be presented with more detail in the "relating" section that follows.

To sum up, positive changes in Feeling were consistently reported by all participants with dementia following CST, including feelings of pleasure, calmness, curiosity, confidence and acceptance. Intensity of these emotional changes was manifested through their words, non-verbal affect display, actions and behaviours as well as the inter-subjective experience of myself as the researcher. However, increased experience of negative emotions was also described at times 2 and 3, likely associated with improved reality orientation and acceptance, such as sadness, frustration and grief. The changes in Feeling associated with CST seemed to be characterized by increased experience and expression of positive emotions as well as an expansion in affective valence and range (variety and depth).

Relating

Relating at Baseline

All participants with dementia had opportunities to participate in various forms of social activities at baseline; however, the opportunities were mostly organized and supported by their families.

The kids are very good like [daughter] will pop in a couple of times a week, and once, she took him out for a bushwalk. The granddaughter, who's 28, took him out once and they went playing mini golf, trying to keep him [busy]. (Peter's wife, interview time 1)

It was evident that all the men had some difficulties with remembering people's names and addressing them by name, even when meeting those who were familiar to them. This seemed to have impacted on how they interacted and related to other people. For example, Peter reported "I can't remember the name when I meet the person if they do tell me, and I don't ask them their name. I've got a habit of not asking the person's name". While three of them generally felt that they were able to talk to people freely, Mark preferred his wife to be present and supporting him in social occasions.

Two participants with dementia reported some mild relationship issues with family at time 1. Frank reported that he and his wife had their “ups and downs” and that it was “getting worse” because “when I’m answering a question, I muck around instead of giving her the answer she wants to hear”. Peter reported some issues with grandchildren and stated that “I’ve got to bite my tongue a little bit, and I don’t like if I asked one of the grandkids to do something and they ignore me”.

In contrast with the relatively positive reports of participants with dementia about their social life, all family participants reported some issues in this area. Three wives reported concerns about their husbands’ social withdrawal. For example, Frank’s wife described that “he often just stands around staring. I don’t know what he’s thinking about. Quite often I will come up to him, and he doesn’t realize that I’m there. He’s just in his own little world, as I call it”; and John’s wife commented that “he was there but he wasn’t really participating in what we [family] were doing or anything. He tends to tune out when we’re all together”. Moreover, Mark’s wife spoke of him being “cheeky and challenging sometimes” and not understanding of her need for “time-out”.

All family participants felt that their own lives had been affected by the demands and responsibilities for taking care of and supporting their husbands. For example, John’s wife commented “just those sorts of things but to me they’re big, because he is asking me things all the time, because he really doesn’t know” and that “he just needs help all the time’. Peter’s wife reported that “I’m trying to do things like that with him and trying to make sure he’s not sitting at home, but it’s really hard sometimes because he won’t go out” and that “I’m so tired and particularly if it’s a time when he’s flat”.

Changes in Relating

Changes in Relating at time 2 consisted of positive interactions with peers in the CST group and improved relationships with their wives as the main caregivers at home. These changes continued to unfold and strengthen towards time 3. Further, the trend

of improvement in Relating was expanded to wider social contexts, although more apparent in some patient participants than the others.

Relating to People in CST

Reports about relating to people in CST at time 2 resembled a “warm-up” phase of relationship formation, revolving around the sub-theme of “meeting the like-minded people and having fun”. A sense of belonging and togetherness seemed to be experienced at the early stage of CST and served as a source of positive emotional experiences, including enjoyment, interest, relaxation and acceptance, as well as a motivating factor for their active and persistent engagement with the programme.

Everybody has that problem, so nobody worries about when somebody can't answer this or gets this wrong or anything. We just, we accept it, we try sort of improve on it, it doesn't worry us. It's been interesting being with a group of like-minded people, because that's what we are. (Frank, interview time 2)

Three participants with dementia started to use the plural pronouns “we” and “us” when referring to their positive experiences in the group. For example, Mark said, “we are funny, we are all laughing”; Peter commented that “we're enjoying the class so much that she [his wife] can't stop us”; and Frank reported “I think we all feel the same, an hour is not long enough. We have an hour and we still run over because most of us are having quite a good time”.

John described how the membership motivated him to prepare a speech for the group at time 2, and he said, “I was determined that it had to be done, all ready to go on Monday, because I couldn't sit there like an idiot and not say anything after getting involved in it”. Frank also elaborated the importance of having a meaningful “platform” that gave him the reason for making an effort to remember the names of people in the group.

The connections among the group members were strengthened and deepened at time 3. This was also evident from the fact that all participants wanted to continue the relationships and looked forward to the follow-up maintenance group.

It's improved the whole time in as much as we've got to know one another. And not only that, we've found that we feel like it's almost bonded in a way, because we've got to know each other to a point where we're more communicative, and we can laugh at each other's jokes or what's going on. And so, it's been good in that way. (John, interview time 3)

Regarding the nature of the relationships among the CST group members, Frank's wife commented at time 3 that "they're friends but it's not sort of friendships that will [carry on outside the group]. They won't be ringing each other up or anything like that". John described a similar view and labelled the relationships in the group as "fellowship" rather than friendship, as he said, "you can have the fellowship in a meeting you go to, but you'd probably never be able to have the time or everything to pop into this person's place at 20 miles away".

John further pointed out that it was the "like-minded", a word also used by Frank, that "infiltrates the whole lot of us". He also spoke of "comradeship" as a deeper interpersonal connection established in the CST group while they endeavoured to battle the "downhill" trajectory together. To him, "comradeship" served as a source of "stimulation" for an individual as well as the collective whole of the group.

I think the stimulation really comes from the group, and it's what they bring to and from each other that does the stimulating. You can't make things stimulated if the people aren't stimulated within themselves and get the comradeship that you feel for one another. And I don't know how bigger thing that could ever become anyway, because there's a limit to what [you can do] in your downhill approach in life. ... You feel for each other cos you know you're in the same boat. And they are so different and yet all so likeable. (John, interview time 3)

Two of the men talked about their consideration and empathy towards other group members at time 3. Frank spoke of his deliberate choice of a "quiet" communication style in the group after realizing that his illness was not as "advanced" as others', because "I don't like appearing to show off in front of a group like that, not my way at all". Whereas John described more explicitly about an epiphany that enabled him to

reach an empathetic understanding of the group member who had picked the theme song that he hadn't liked.

I knew one thing that day when we were there finally that I suddenly realized that you must never criticize what the other people singing or saying or doing because they are from such a WIDE background. You wouldn't believe some of the upbringing and the tribulations they've gone through, and so you accept everyone for who they are. As I say, they've been a great bunch, you have a feeling for they are, for the type of person they are, no matter what background. (John, interview time 3)

Relating to Their Wives

Three participants with dementia became more appreciative and considerate of their wives with a decision and actions to help more with chores at time 2. Further, John started "sharing a lot more what he feels without being asked", and to his wife, "it's quite a big difference. It's more like he's taking more notice of what's going on. He's started sharing. He's part of it". Mark was noted to become more understanding and less "shadowing" and "demanding" of his wife, and he described his improved insight into his repetitiveness, empathetic understanding of his wife's response, and changed attitudes towards the situation.

But sometime when I talk to her, like she [did] not answer me back and then I say, "hey did you hear what I just said to you?" Cos I want her to answer me what I want. And then I say, "oh" and I laugh, "okay, okay". ... And then I [thought] "you didn't answer me my questions when I asked". And then I know that, and then "I'm sorry". (Mark, interview 2)

All these changes were noted and well received by the three family participants.

I've noticed that there's still that being very self-centred, but since I think he's done this course, it has expanded it and that if he sees I'm struggling, he'll get up and do something whereas before he wouldn't, and that he's never been like that. He's always been quite sensitive to your needs and we've always worked as a team. (Peter's wife, interview time 2)

At time 3, Frank's wife also reported similar "quite noticeable" changes in him, including "general appreciation", "more aware and more helpful", "less internalising", and "more willing to work with other people". Further, two husbands became increasingly reflective and insightful of the impact of their problems on their wives at time 3. They also expressed their willingness and determination to give back to their wives, along with actual changes in action.

For example, John reflected that "I keep reiterating, 'oh what did you say' or 'what's that' and I keep 'what's that', and it must drive her crackers because you can't bring it to mind". He further reported that "it's got better because I think I'm more attentive, because I know it's getting harder for her too". Mark expressed that "I feel sorry for my wife cos [she] only do it for me. And I said, 'that's my job, I was told to do it, so I have to do it myself'", and to him, "nobody can make her happy, so I have to make her happy. I'm her husband". It was also evident in the interview analysis that Mark acted on his goal of making his wife "happy" in multiple ways, including becoming more independent with personal cares like shaving, taking more initiative and responsibility for household chores he used to be disinterested in, and prioritizing his wife's enjoyment over his own in their recreational outings.

All family participants commented about getting some benefit from their husbands' improvements at time 2 and/or time 3. For example, two wives reported feeling "more relaxed" from time 2, as their husbands became more helpful and independent. All wives confirmed improved relationships or changed dynamics with their husbands at time 3. For example, Mark's wife commented about herself becoming more "understanding", "loving" and "caring" of her husband. Frank's wife reported that her husband "gave me a hug and that's unusual. Sometimes I've tried to hug him and there was this rigid thing there, like hugging a lamp post, he was not willing to give. But he had a lovely hug!" John's wife gave an account about the subtle changes of their dynamics.

He's starting to [be] bit considerate, whereas before it was sort of both, and it could be partly my fault cos I was trying to make him

happy with whatever we were doing, and you don't really say much about how you feel. You're doing what you think will make him happy, and now I start to answer him back a bit sometimes. (John's wife, interview time 3)

Relating to Other People in the Family and Community

All participants with dementia experienced some positive changes in relating to other people in the family or in the community at time 3, with improvement in talking and communicating with others. For example, Mark's wife commented that "I think going to the groups has helped Mark a lot, even if you see him today talking freely [in the interview], like he's not holding back, like he's just happy to talk"; and Peter's wife stated that "I think I liked the group, and that has given him the confidence to talk to people again".

Two of the men became more involved and engaged in their family lives. Mark's wife noted that he was more willing to answer the phone calls and therefore, had more interactions with other family members by phone, while "before, he used to ignore answering the phone". He also started "trying to be more responsible" for the household chores, such as "feeding the chickens, taking the rubbish bin out", which he was previously not interested in doing. All this was viewed by his wife as him trying to "play a part in the home" to maintain his social roles and contribution to the family. John's wife also reported:

What did the girls say the other day? "He did something that was like the old Dad" yeah. His personality is changing a little back to [his old self], he's getting more [involved], he's making jokes about things. He always did make jokes a bit about things, and he tends to play with words a lot and he loves making jokes about words. ... It's just part of his personality really, it's something he always has done, and he didn't for a while. But now he's sort of starting to do it again, and it's quite funny, I quite like that. (John's wife, interview time 3)

The other two men started to have more interactions with people outside the family, including starting to openly talk about their diagnosis of dementia and participation in CST. Frank's wife reported that "he has told a neighbour over there, a young couple,

that he has dementia, early stages, and that's a huge step forward in my mind". While Peter reported:

We'll go to the next-door neighbour and talk about what I have done in the cognitive study, and they've been quite interested, very interested in hearing about it. And that's Rob [neighbour] that was here earlier. I've shown him all my titbits I've made, and I've discussed it with them what I've done. (Peter, interview time 3)

To summarize, all the participants with dementia reported positive and enjoyable experiences in socializing with the "like-minded" people in the CST group and developing a sense of belonging, connection and "comradeship" in the face of dementia. The interactions in the group made them more confident and proficient in talking and relating to others in broader social contexts as well as more reflective and empathetic in their social relationships, particularly with their wives. Improved spousal relationships were experienced and described by all research participants following CST, which was associated with the men's improved social awareness and appreciation of their wives, increased desire and confidence to give care for their wives in return, improved sharing and communication, and more considerate attitudes and actions. In addition, all participants with dementia became more involved and responsible in their family lives to regain and retain their social roles, which made three of them "more like his old self" and the other a "much nicer" person to their families.

Thinking and Reflecting

Thinking and Reflecting at Baseline

Reports about Thinking and Reflecting at time 1 were clearly different in content between the patient and family participants. While the wives were more focused on reporting difficulties and problems that their husbands experienced and the impact on themselves as caregivers, narratives from the men mostly revolved around their personal history, past occupations, and life stories.

A range of problems with memory and thinking were reported by family participants. A common difficulty experienced by all participants with dementia was not being able to name people and places satisfactorily.

He can't define exactly what area something is in but he'll say, 'oh you know the one up over there' and point vaguely, because he can't remember names and he can't remember exactly where it is, but it's over there. (Peter's wife, interview time 1)

John's wife explained further that "this isn't just forgetfulness, you're losing skills that really are, you could do it standing on your head. It was just totally out of kilter". Moreover, according to Frank's wife, "he just concentrates on the problem, to my mind, it probably grows bigger in his mind".

Three family participants gave detailed accounts about how their husbands were diagnosed and had progressed. Frank's wife commented that "I think it's been a very very slow progression of things getting worse, certainly worse than when I first suspected that this was a problem, but that was nine months ago". Peter's wife noticed that in the past year or two, "every six months, there's a bit of a down, and he levels out again" and that he became more "muddly than he was a few weeks ago". John's wife reported that "I've really noticed it in the last 3 months. I keep, you keep noticing it in steps, that suddenly he's not doing certain things" and that "he's definitely getting worse, like more confused. He can't use things that he could a month ago". Mark's wife was the only family participant who reported some recent improvement in memory and learning. For example, he seemed to remember better to shave himself and had recently learned how to play floor puzzles.

Two wives expressed hope and a positive view of their husbands' going to the CST programme. Peter's wife commented that "in some ways, he's shut down but other ways, he isn't. And that's why I think this programme would be really good for him to keep him going and keep him stimulated". Frank's wife remarked that "he also felt that now, okay if I have dementia there's nothing that can be done about it, but this [CST] is good because it shows him something can be done".

All participants with dementia talked about their family and early experiences, education and training, previous occupations and achievements, and significant life events. They tended to narrate in a relatively neutral manner, and three of them reminisced extensively about their life stories.

The electronic side of things was more my interest than anything else, even building, and that's because my grand...no he was an uncle, he suggested to my father that I didn't go into carpentry, that I should go into that sort of side of things, and because when I was about 13, I made my first little, it wasn't a transistor it was a, you used to get a, now what was it called? A germanium diode and you'd wind coils around cardboard, and you'd hook it all up and then you'd put a wire up to a stick outside your window or things like that. (John, interview time 1)

While they also spoke of their difficulties with memory and thinking, including how the problems were initially experienced and recognized, the amount was much less than in their wives' accounts. Three of them expressed a rather positive view about the progression of their dementia. Peter said, "I don't feel as if I'm useless and going downhill"; Mark commented "I think it's still the same, like I'm okay, because if your wife is no good and then you have problems, but my wife is always good to me"; and John thought "I'm probably getting off the beaten track here but I think in a lot of ways, the Alzheimer's is, how shall I put it? has not proceeded as fast as I thought it might have".

To sum up, at baseline, there was an obvious dissimilarity in the reports about Thinking and Reflecting between participants with dementia and their family caregivers, which aligned with their different standpoints in dealing with the impact of dementia. While family participants endeavoured to accommodate the impact of dementia and to fulfil their spouses' support needs, participants with dementia became habituated to the sheltered social and living situations and adapted to a thinking pattern that converged on the past and themselves.

Changes in Thinking and Reflecting

Changes in Thinking and Reflecting at time 2 were characterized by an altered, more energetic and lively display described as “waking up”, together with improved reflection, awareness and memory. These changes were sustained and advanced as the CST programme continued and became more established at time 3. The additional emerging sub-theme at time 3 was thinking patterns that were more positive and more oriented to relationships and the future, rather than self and the past.

The changed outlook reported by three family participants at time 2 featured increased arousal and alertness, expanded scope of attention and interest, and a higher level of engagement with activities. For example, John’s wife found him “brightened up” after attending CST. She described “it didn’t excite him exactly, but it sort of gets him and it wakes him up” and that “he is just more interested in what’s going on around him”. Corresponding to her observations was John’s subjective report of feeling “more animated”. Similarly, Peter’s wife found him “brighter” at time 2; and Mark’s wife noticed that “he is more alert”, which made him quicker with things “he used to be slow at”. These changes were maintained in these three men at time 3. For example, John’s wife noted that he remained “more interested in what’s going on” and said, “I just like the fact that at least he woke up a bit over this other stuff [‘delving into a subject’]”.

Apart from the outward changes, two participants with dementia started to become more reflective, with improved awareness and insight about themselves and others at time 2. For example, Peter revealed that “one of the things in the group you really know that it’s, you think you can do it and all of a sudden you can’t”. John described his increased contemplation, reminiscence, and reflection on a wide range of topics, including “all the things that have happened to my friends”, the realization that “I’ve been a loner all my life because of the jobs that I did”, the history books he used to read and enjoy in relation to his speech on “current events”, and his relationship with

his wife that “through all we’ve been through our lives I realize that I owe her a lot more than I perhaps give out”.

I think I’ve been lax in appreciating her [wife] that she has to put up with what I don’t give out in return. I don’t know whether it’s a thing I can [change]. I feel bad about things that have gone on in the past that I used to work a lot. Work long hours, work Saturday mornings. I did a lot of labour-only work. There was only me to do the job. ... And I suppose that’s the other thing, I’ve been a loner all my life because of the jobs that I did. I was a loner and didn’t [make many friends], apart from my early friends and some that I got to know in the workplace perhaps and that I had worked with. I tended to be a loner. (John, interview time 2)

All participants with dementia reported and demonstrated increase quantity, quality and effort in Thinking and Reflecting at time 3. Two of them reported that CST gave them “stimulation to think more about things”. It was also evident in the interview transcripts that they both started to embrace the word and new concept of “stimulation” in their vocabulary and thinking.

Peter’s experience of stimulation seemed to be directly associated with doing things. On one hand, he “found a lot of stimulation in doing things”, particularly “trying to do something and achieving it”; on the other hand, he spoke of feeling “more stimulated” after attending CST, which motivated him share more chores at home to help his wife.

The other day we [were] sitting down. I said, “oh you stay here, I’ll trot off and put the soup on and put the toast to have some toast and soup for lunch”. The other day I cooked tea for [wife], so it’s just helped out like that, and I felt more stimulated to [do so]. She’s been doing the dishes, [and I will] hop up and get a tea towel and dry up and that sort of thing. (Peter, interview time 3)

John also reflected extensively on “stimulation” and interpreted it as “input” that he used to get from his work but then lost considerably after he stopped working. He further articulated a few ingredients that made participation in CST stimulating for him, including being “given a subject” or goal to work on, “thinking and making your brain work”, getting “enjoyment”, and the pursuit being “worthwhile”. In addition, he

asserted that “the stimulation really comes from the group”, a perception that has been presented in the Relating section.

So for stimulation, I’ve found it has helped because if we’ve been given a subject, it is for the next time we go. I’d have to dig into something and have a think about it. ... It’s enjoyment and thinking and making your brain work to do what you think is a worthwhile attempt at doing something for the next challenge. (John, interview time 3)

Moreover, all four men expressed some qualitative changes in their thoughts, ideas, opinions, and attitudes at time 3. For example, Peter’s wife commented “one of the biggest things from quite early in the course, he learnt that there’s no shame in writing things down”. Two men appeared to become more positive in their thinking patterns. For example, Mark commented “never think about the bad future, think about the good future”; and Frank said, “our problem [basement flooding] is nothing compared with some other people, they’ve lost their houses completely”.

All the men became more forward-looking, either envisaging more for the future in a practical way, or contemplating life and death in a philosophical or spiritual sense. Peter spoke of having sold his under-used lathe, with a future plan of using the freed space in the garage to “do more puzzles and work with hand tools”. Frank recited a poem that he had presented to the group in a CST session, “’tis all a checker-board of nights and days, where destiny for pieces plays: hither and thither moves, and mates, and slays, and one by one back into the coffin lays”. It was noted that he somehow used “coffin” to replace the original word “closet” in the poem, which clearly indicated his intention of associating this poem with his philosophical contemplation of death and the meaning of life. The other two participants talked extensively about their religion, faith and belief in the afterlife.

Sometimes ... I start to think about some other part. I don’t know what happened, which one of us gonna go, cos that’s life. We all gonna die anyway, I told her that. There’s a place up there where we all gonna go. We die we go to heaven and that’s the only place you go, gonna meet again. (Mark, interview time 3)

All participants with dementia reported or were noted to have shown some mild improvement in memory, particularly in memorizing names, at time 2 and/or 3, and two of them became more oriented to day and date. Multiple factors seemed to have contributed to the improvement, including being more “alert”, “attentive” and “interested”, making more effort to recall and remember, regular reinforcement in the group, and the changed attitude towards writing things down. For example, John’s wife reported at time 2 that “he remembers some of them, not all of them. There’re about four of them he remembers constantly, and he’s interested in what they do”. Mark seemed to use self-talk to help him recall as he said, “because sometimes I want to do things, I want to do that, ‘how I’m going to do it?’ And then I remember what my wife told me”. Peter described his attitudinal change and investment of more effort to memorize better.

I had a bad blank [in the CST group] in catching the ball and say name, one of your grandchildren, and absolutely nothing there at all. But I went back, and I think I can name most of them now after the follow up that I did with [the family tree]. Instead of saying “woo, I’ve lost it”, “let’s find it again”. So I went back and wrote out my family tree. (Peter, interview time 3)

All family participants acknowledged improvement in some areas following CST at time 3; however, only Mark’s wife thought that his overall memory was slightly better. This was consistent with self-reports by the men. In fact, two wives noted more memory “gaps” in daily conversations, which Peter’s wife attributed to him becoming more willing to talk rather than covering up his deficits.

Of note, all participants with dementia reported or demonstrated a changed thinking pattern that “expanded” from centring around themselves to encompassing more of others and relationships with others in both CST and home contexts. An example was that all of them reported an intentional goal to “help” their wife, “make her happy”, or “give” care to her in return. This has been detailed in the “Relating” section.

In summary, all participants with dementia experienced increased Thinking and Reflecting in quantity, quality and effort as they participated in, interacted with and

reflected on the CST programme. This led to “expanded” awareness and thinking patterns that were less revolved around themselves and the past and more oriented towards relationships and the future. Corresponding to the subjective changes were the altered external presentations, onset of which at time 2 was typically portrayed as “waking up”, with attributes of increased alertness, attention and animation. Some mild improvement in memory and thinking was also reported, mostly associated with increased attentiveness, effort and more adaptive attitudes and strategies.

Quantitative Findings

Table 4.3 summarizes the activities that were used for administering the VQ with each patient participant at the three time-points. Two or more daily activities during each data collection session were observed and rated according to the 14 items of the VQ. In line with the research design, the activities were self-selected by the participants.

Table 4. 3

Activities Used for Scoring the VQ with Each Patient Participant at Three Time-points

Participant Name	Time 1 Pre-CST	Time 2 During CST	Time 3 Post CST
Peter	Playing Sudoku; operating an electronic jig saw to carve a wooden toy for grandchild; showing the researcher a book ("Wooden toys") and his history folder about steam engines and locomotives	Playing Sudoku; elaborating and demonstrating what cogs and machinery lubrication mean in relation to the CST group name "lubricators" that he had suggested	Recounting and demonstrating the activities that he had engaged in the CST group with reference to his CST folder; playing Sudoku; playing the family jigsaw puzzle (1000 pieces); going out for a short walk; playing music with a CD player
Mark	Making a cup of tea for himself; playing a card game (Sweep) with his wife and the researcher	Playing floor puzzles with his wife and the researcher; showing the researcher how he used his calendar	Making three hot drinks for himself, his wife and the researcher; tidying up the lounge room; feeding the chickens in the garden
John	Showing the researcher his collection of older photographs; talking and reminiscing about the people, places and events on the photos; finding out the date and time for the upcoming CST group	Showing the researcher his DIY workshop and some past projects; setting up the recorder in preparation for recording a TV programme later in the evening	Recounting the activities that he had engaged in at CST (current events vs alternating/direct current; the Tesla-Edison feud); explaining to the researcher what "terminological inexactitude" means; demonstrating how to operate the recorder to delete the advertisements on a recorded TV program
Frank	Showing the researcher his house painting project; demonstrating his camera and some photographs; playing Freecell, a solitaire computer game; demonstrating his routine activities on the computer	Showing the researcher around in the garden; showing the searcher his previous work station in the basement	Getting a glass of water for the researcher to help ease her coughs; showing and talking about a novel that he had been reading

Table 4.4 presents means of the overall VQ scores and three sub-scores for each participant with dementia at the three time-points, before the commencement of CST; during the 3rd week of CST; and within a week after the programme was finished. As discussed in Chapter 3, original grades on the four-point rating scale of Passive, Hesitant, Involved and Spontaneous were converted to consecutive integers from 1 to 4, which made the mean overall VQ scores and means of the three sub-scales (Exploration, Competency and Achievement) range from 1 to 4. Noticeably, one

participant (John) attained the maximum in all measurements, including the overall VQ scores and three sub-scores at three time-points.

Table 4. 4

Means of Overall VQ Scores and Sub-scores for Each Participant at Three Time-points

	Time 1 (pre-CST)				Time 2 (during-CST)				Time 3 (post-CST)			
	E	C	A	VQ	E	C	A	VQ	E	C	A	VQ
Peter	4	4	3.25	3.75	4	4	3.75	3.93	4	4	4	4
Mark	3.6	4	3	3.57	3.8	4	3.25	3.71	4	4	4	4
John	4	4	4	4	4	4	4	4	4	4	4	4
Frank	4	3.8	1.25	3.14	4	4	2.25	3.46	4	4	3.75	3.93
Mean	3.9	3.95	2.88	3.62	3.95	4	3.31	3.78	4	4	3.94	3.98

Note. E, C and A refer to three VQ sub-scores representing three volitional levels, Exploration, Competency and Achievement. VQ refers to the overall VQ score.

The same data are visually depicted using line charts in Figures 4.1 and 4.2 and bar charts in Figure 4.3. Figure 4.1 illustrates the changes of the mean overall VQ scores over three time-points, with four different coloured-lines representing four participants with dementia. It shows all of them had high overall scores, even at baseline. While John stayed at the maximum consistently, there was an increasing trend towards the maximal score over time for the other three participants.

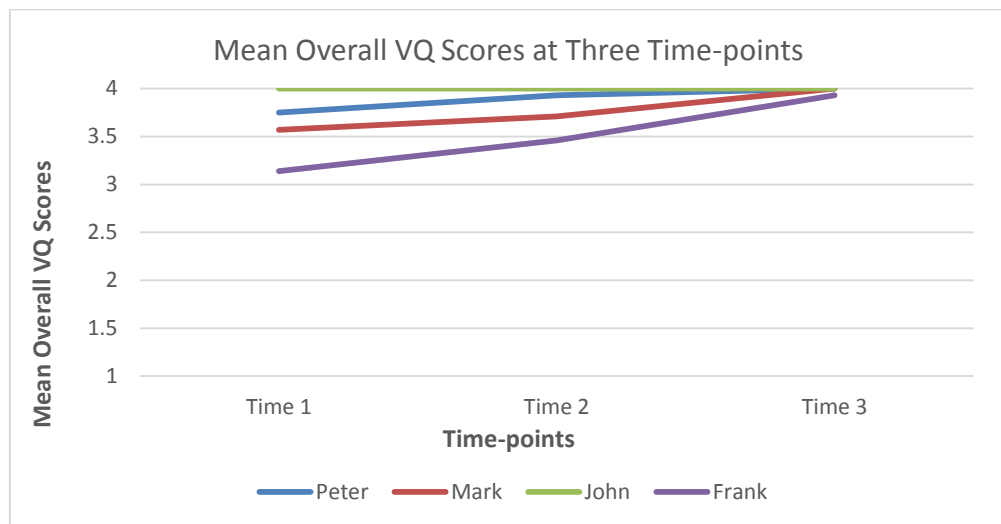


Figure 4. 1. Mean overall VQ scores for each participant at three time-points

Figure 4.2 depicts the mean Achievement sub-scores for each participant over three time-points. It presents a similar increasing trend towards the maximum over time in

three participants; however, their mean Achievement sub-scores were all lower than the mean overall VQ scores at baseline.

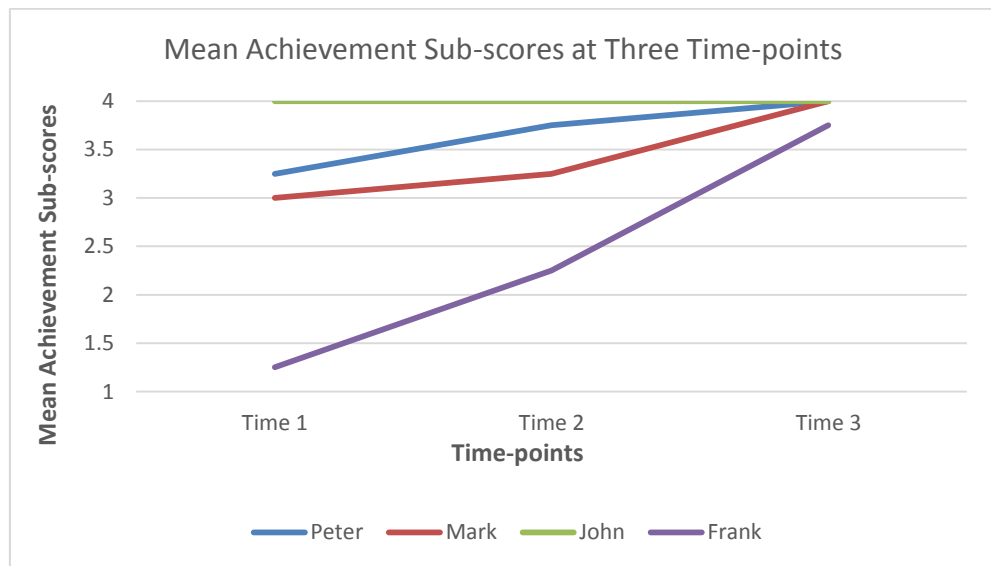


Figure 4. 2. Mean Achievement sub-scores for each participant at three time-points

Achievement represents the highest level of volition for the person to strive towards goals and attain internal satisfaction (de las Heras et al., 2007). The indicators for Achievement level of volition include “pursues activity to completion or accomplishment”, “invests additional energy, emotion or attention”, “seeks additional responsibility”, and “seeks challenges” (p. 7). Individually, Peter was rated as Passive on the Achievement item of “pursues activity to completion or accomplishment” at time 1, Involved at time 2 and Spontaneous at time 3. Mark was scored Involved on “seeks additional responsibility” and Passive on “seeks challenges” at time 1, Spontaneous on the former item and Passive on the latter at time 2, and Spontaneous on both items at time 3. Frank was rated Hesitant on “pursues activity to completion or accomplishment” and Passive on the other three items at time 1, Spontaneous on the first item, Involved on “invests additional energy, emotion or attention” and Passive on the other two items at time 2, and Involved on “seeks additional responsibility” and Spontaneous on the other three items at time 3.

Figure 4.3 further presents the divided sub-scores on three volitional levels for each participant at three time-points. It demonstrates that the mean sub-scores for Exploration and Competency were high in all participants, even at baseline; however, Achievement appeared to be the volitional level that was rated relatively low at baseline and improved steadily over time in three participants, although Mark also made some improvement on the Exploration sub-scale and Peter on the Competency sub-scale over time. This indicates that the increased Achievement sub-scores were the main contributor to the improved overall VQ scores over time in these three participants.

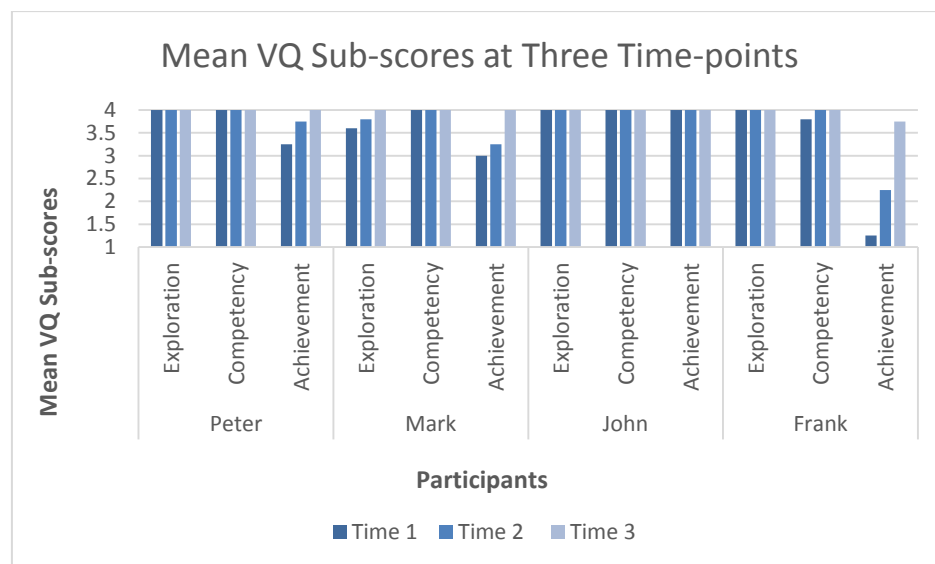


Figure 4. 3. Mean VQ sub-scores for each participant at three time-points

Mixed Methods Findings

Under the post-positivist paradigm, qualitative and quantitative research methods as well as inductive and deductive approaches can be harmonized philosophically and practically (Giddings & Grant, 2006). A mixed methods design, the convergent parallel mixed methods approach, described by Creswell (2014), was employed to integrate and present the qualitative and quantitative data of the study in answering three research questions:

- What is the nature of the “switch-on” effect as described by participants attending CST and their family/caregivers?
- At what time-points during and after the CST group is the “switch-on” effect reported?
- Are the changes described as the “switch-on” effect measurable using the VQ?

Nature of “Switch-on”

The activities used for rating the VQ were outside of the CST group and showed improved scores for three participants following the intervention; the fourth participant achieved maximum scores at all three time-points. This was congruent with the qualitative findings about “switch-on” that were reported in both CST and home contexts. Without any specific support or facilitation, the learning and improvement in Doing, Feeling, Relating, and Thinking and Reflecting gained in the therapeutic sessions seemed to be transferred spontaneously to other settings. This indicated the pervasive and voluntary nature of the “switch-on” effect.

Consistent with the improved Achievement sub-scores for three participants, qualitative data also showed comparable changes as part of “switch-on”, including increased determination and effort and investment of energy. For example, Peter deliberately tried to address people by name in the CST group before they put on the name tags. He conscientiously changed his attitudes towards his memory problems from “woah, I’ve lost it” to “let’s find it again”. He also diligently “wrote out my family tree” to be able recall names of his grandchildren in the CST group. These changes were consistent with his improved ratings on the Achievement VQ item following CST, “pursues activity to completion or accomplishment”. Mark used more initiative and was more committed in pursuing a range of daily activities at home. He became more considerate and responsible in relating to his wife and trying to resume his social roles in the family. He was also more active in using the self-talk strategy to recall and remember. These changes were congruent with his improved scores for the two Achievement items following CST, “seeks additional responsibility”, and “seeks

challenges”. These quantitative and qualitative data suggested the intentional and deliberate nature of the “switch-on” effect.

The VQ acknowledges “the person’s desire, confidence, and satisfaction from or in doing” as essential components of volition and includes items for evaluating emotional involvement at three volitional levels (de las Heras et al., 2007, p. 11). Frank had improved ratings on the Achievement VQ indicator following CST, “invests additional energy, emotion or attention”. This was consistent with his experience of “switch-on” as indicated by qualitative analysis. For example, he became happier, “more relaxed” and “more accepting” in Feeling; more appreciative, considerate and “nicer” in Relating to his wife; more positive, forward-looking and “less internalizing” in Thinking and Reflecting; and “more helpful” and more initiative with household chores in Doing. This implied the emotional and intuitive nature of the “switch-on” effect.

Occurrence of “Switch-on”

All the men with dementia and their wives reported some degree of positive changes at time 2, the third week of the CST programme, which was sustained and strengthened toward the end of the group. The occurrence of “switch-on” appeared to be a gradual and advancing process for all of them, although each man appeared to have his own trajectory of “switch-on”. This occurrence pattern was consistent with the ascending trend of the VQ results, including the overall VQ scores and the Achievement sub-scores, for three participants over three time-points, which suggested the “switch-on” effect was a steady, dynamic process rather than a transient or static phenomenon.

Onset presentations and timing were primarily based on reports and observations from family participants in the home environment. The timing of “switch-on” was individual and variable and overall, tended to occur at an early phase of the programme prior to time 2. Onset presentations appeared to be diverse, subtle and gradual but observable and apparent, because three family participants were able to

clearly report the approximate time range. Presentations of “switch-on” tended to be more similar at time 3 with shared themes, as presented in the section about the nature of “switch-on”.

Peter’s wife commented about him becoming “a bit more motivated” in anticipating CST even at time 1, and she noticed changes “as soon as he started the group right from day one”. Similarly, Frank’s wife noted his earnest and joyful participation in CST straight after the first session. However, she didn’t notice changes in other areas until the last two weeks of the CST programme, as she commented at time 3 that “it has been gradual, up to then there was no noticeable change”. She attributed the delayed improvement to “the problems we were having with the drainage [around their house] and so on”. John’s wife described a more specific, noticeable onset of changes from the fourth and fifth sessions of CST, an occurrence pattern that most resembled “the switch-on phenomenon” described in Cheung and Peri’s (2014) study.

He’s been really, just like getting on great since he’s been going to the group. Not the first week, the first week is much the same as usual but he just, quite quickly started changing really. Well he’s only been to five. Yeah especially the last two. (John’s wife, interview time 2)

Although the interview data indicated occurrence of “switch-on” in all four participants with dementia, the VQ only detected improvement for three of them. The discrepancies between the qualitative and quantitative findings are presented further as follows.

Measurement of “Switch-on”

As presented previously, three participants with dementia obtained high VQ scores at baseline and continued to improve towards the maximum in the follow-up two measurements. These improvements were mainly attributable to the improved Achievement sub-scores. However, the other participant, John, achieved the maximum rating at baseline and maintained thereafter. Comparison between parallel qualitative and quantities data showed general consistency at baseline and following

CST; however, some incompatible aspects were also indicated in relation to the question whether the VQ effectively detected the “switch-on” effect.

The baseline VQ results were comparable to the qualitative findings, particularly in Doing and Feeling. The qualitative sub-themes that emerged from the baseline analysis in Doing indicated that all the men with dementia were still able to make volitional choices to participate in activities in which they felt competent, interested and that were important to do. Some problems with Doing were associated with reduced skills and task mastery due to dementia, and others were regarded by their wives as stemming from their lack of confidence, drive, initiation, effort or persistence. The reports about Feeling at baseline demonstrated that all participants with dementia could experience enjoyment in their daily living and were generally interested and motivated to participate in occupation, despite experiencing negative emotions at times. These qualitative data were congruent with the high overall VQ scores for all participants and the relatively low achievement sub-scores for three participants at baseline.

The VQ results following CST also corresponded to qualitative data in a twofold way. First, qualitative analysis suggested a gradually improving trend over time in all four areas of Doing, Feeling, Relating, and Thinking and Reflecting, which agreed with the VQ curves for three patient participants. Second, increasing deliberation, effort or investment of energy was evident in qualitative reports about changes in Doing, Feeling, Relating, and Thinking and Reflecting following CST, which aligned with the improved Achievement level of volition for three participants with dementia.

However, a major discrepancy between the qualitative and quantitative findings was the VQ’s fail to capture the “switch-on” changes in John. It was evident in the qualitative data that he experienced “switch-on” changes in multiple areas, which were not reflected in his VQ measurement results due to his maximum scores before, during and after CST.

Further, the VQ seemed to be more sensitive to capturing some of the “switch-on” changes. The theoretical basis for the VQ is the construct of volition in the Model of Human Occupation, which concerns the thinking and feeling patterns that drive one’s actions (Taylor, 2017). As an observational instrument, the VQ appeared to capture some aspects of “switched-on” in Doing, Feeling, Relating, and Thinking and Reflecting that were objective or more visible. For example, the measure detected increased initiation and participation in Doing for Peter, Mark and Frank, improved communication and/or responsibility in Relating for Mark and Frank, and increased positive affect in Feeling for Frank. However, it didn’t pick up changes that were subjective and less visible in Doing, Feeling, Relating, and Thinking and Relating. For example, letting go of hobbies and responsibilities as part of intentional adjustment in Doing; some positive emotions, such as calmness and acceptance in Feeling, that were not necessarily apparent or motivating; the less tangible aspects of social relationships in Relating; and unexpressed thoughts, ideas, and opinions in Thinking and Reflecting.

Conclusion

Investigations with four patient participants and their family caregivers, using qualitative exploration as part of a convergent parallel mixed methods design, demonstrated the nature of the “switch-on” effect involving positive changes in four thematic areas of Doing, Feeling, Relating, and Thinking and Reflecting. The “switch-on” changes consisted of: active engagement with the CST programme and intentional adjustment at home in Doing; increased experience and expression of positive emotions in Feeling; improved social engagement and relationships in CST and at home in Relating; and enhanced quantity, quality and effort in Thinking and Reflecting. These changes were pervasive across environments, deliberate with intentional goals, and intuitively driven by positive emotions.

Occurrence of the “switch-on” effect was indicated as gradual, continuous and advancing throughout the CST programme. The onset of “switch-on” was noted in the

early phase of the intervention prior to time 2, although was variable in timing for each participant with dementia. Presentations of “switch-on” varied at commencement but tended to converge towards time 3.

The VQ results demonstrated a similar pattern of changes to the qualitative findings in three participants with dementia. However, the fourth person was rated maximally at all three time-points and therefore no changes were detected on the measure. This was inconsistent with the qualitative data. The VQ measurements provided supporting and useful information about “switch-on”, although the instrument appeared to capture some aspects of the effect better than others.

Chapter 5 Discussion

Introduction

This chapter discusses the findings of the study which aimed to explore the “switch-on” effect experienced by people with dementia who participate in cognitive stimulation therapy. It considers the answers generated to the three research questions about the nature and occurrence of the effect, and whether the effect is measurable using the Volitional Questionnaire (VQ) (de las Heras et al., 2007). Descriptions about the “switched-on” changes in Doing, Feeling, Relating, and Thinking and Reflecting together with measurement results using the VQ are reviewed with reference to CST literature and occupational therapy perspectives. The strengths and limitations of the study are then examined and discussed. The implications of the results for future CST research are explored and suggested. This leads to a conclusion statement for the chapter and the thesis.

Summary of Findings

Contrasting and merging the qualitative and quantitative data collected with four participants with dementia and their wives indicated that the nature of the “switch-on” effect encompassed simultaneous, positive changes in multiple areas of function. These changes were pervasive across environments, deliberate with intentional goals, and intuitively driven by positive feelings. The “switched-on” areas and changes were:

- **Doing:** active participation in CST as an occupation, and intentional adjustment of engagement in daily occupations at home
- **Feeling:** increased experience and expression of positive emotions in terms of getting more enjoyment, feeling more interested in and motivated to participate in occupations, having a sense of achievement and satisfaction from participation, and becoming more positive, confident and accepting of living with dementia

- **Relating:** developing a sense of “comradeship” and bonding with the “like-minded” participants in the CST group, becoming more considerate of and helpful to their wives with improved spousal relationship, and increased communication and social engagement in the family and community
- **Thinking and Reflecting:** “waking up” and becoming more aware of what was going on, making more effort to remember and remembering better, being “stimulated” to think more about things, considering more of others and relationships with others, and contemplating more about life and the future.

The “switch-on” effect occurred concomitantly in the CST and home environments for all the study participants. Although an individualized trajectory was reported, the onset of “switch-on” was experienced at an early phase of the CST programme before time 2. The onset presentation seemed to be mild but observable to family caregivers, and three wives were able to provide reasonably specific information about the “switch-on” timing and presentation of changes in their husbands. Once “switched-on”, the changes didn’t subside but sustained and continued to consolidate towards time 3 in a gradual and progressive fashion.

Measurements using the Volitional Questionnaire (VQ) (de las Heras et al., 2007) captured a similar pattern of gradual improvement over time to that seen in the qualitative findings in three participants with dementia, particularly on the sub-scale for the higher Achievement level of volition. However, the measure failed to pick up the “switch-on” changes in the fourth person due to his attainment of the maximum score at all three time-points. This suggested that the VQ did not fully and effectively capture the “switch-on” effect in this study.

Discussion of Findings

The findings of the present study are discussed in relation to the three research questions about the nature, occurrence and measurement of the “switch-on” effect. Interpretations of the findings are rendered with reference to relevant CST literature and occupation-based concepts and theories.

Nature of “Switch-on”

The “switch-on” effect revealed in this study consisted of a wide range of positive changes in multiple areas of Doing, Feeling, Relating, and Thinking and Reflecting in both CST and home environments. These changes were broadly consistent with the qualitative findings about the benefits of CST reported in the two studies that specifically described “switch-on” (Cheung & Peri, 2014; Spector et al., 2011). See table 5.1. To a more limited extent, the study themes also align with the descriptions of positive changes noted in the other three qualitative inquiries about CST (Bailey et al., 2017; Kelly et al., 2016; C. M. Murray et al., 2016). See Table 5.2. In developing these tables, all the information that related to benefits or positive outcomes of CST in the qualitative/mixed methods studies were identified and then categorized into the four thematic areas of Doing, Feeling, Relating, and Thinking and Reflecting. Consistency between the identified themes in the present study and information from these qualitative/mixed methods studies lends support to my research findings.

Table 5. 1

Consideration of Qualitative Findings from the Two Studies on Spector's CST that Described "Switch-on" against the Four Thematic Areas of "Switch-on" Found in the Present Study

	Doing	Feeling	Relating	Thinking & Reflecting
Spector et al., 2011 (pp. 946-948)	"Listening to others in the group"; "talking more easily" in the group and at home; "more willing to engage in conversations" at home; "engaging in more activities such as personal care, conversations and watching TV" at home; "looking forward to attending" CST; wanting to "continue with the group"	Finding CST "fun and enjoyable"; "more positive, relaxed, and confident" in the group and at home; enjoying activities like "bingo" more outside CST	Seeing oneself as "on the same boat" with others in the group; "becoming close to people"; having "more motivation to engage each other" in the group	"A sense of being more switched on or wanting to attend to things more"; having a broadened "outlook on life" that gave a sense of achievement; "retaining new information" better; wanting to "trawl and drag up the information" more
Cheung & Peri, 2014 (pp. 20-24, 26)	"Getting something special out of the sessions", e.g. "talking about things from the past"; listening to other people's "ideas and views" in the group; "it was like a switch went off and he became more vocal"; "I no longer want to sit around at home"; "I want the group to go on forever"; "they didn't talk about the disease" in the group; doing the jigsaw puzzle together; phoned "our daughter to seek information"; "looking forward to the sessions"; "more engaged" with computer games; more "talkative" at home; asking son to "google search more information" to take to the group	"Answering the things the correct way felt good"; "I have improved quite a bit and I feel good about it"; enjoying activities in the group and having fun; feeling "stimulated" which gave "a sense of "achievement" and excitement; gaining more confidence; more "interested in expressing his affect"	"Within two to three sessions we were laughing and having fun"; "We have developed a bond between us"; feeling "supported" and "empathy" for other members; "we all just relaxed then and became friends"; "don't worry they said to me"; socialization being "a major attraction"; "enjoying the company of others"; "enthusiastically engages other residents at the facility"; becoming "emotionally engaged with his wife and son again"	"It sparked something in my mind"; "your brain would be going"; "I would go home and think about what we had been talking about"; "this allowed them the opportunity to forget about the worries at home"; "it does help the memory"; "I now have learned the names of some people in the group"; more "alert" and "reactive"

Table 5. 2

Consideration of Qualitative Findings in the Other Three Qualitative or Mixed Methods Studies on Spector's CST against the Four Thematic Areas of "Switch-on" Found in the Present Study

	Doing	Feeling	Relating	Thinking & Reflecting
Bailey et al., 2017 (pp. 990-993)	"They were all talking to each other"; discovering "she likes to sing-a-long" which "has really changed things for us"; having done "a bit of painting"	"They seemed to enjoy it really, very much"; "very upbeat"; "doesn't feel so scared to make a fool of herself"; "they all felt at ease"; taking "an interest in things again"; "she was always bouncy and full of it"	Improved "ability and desire to socialize"; Starting to "communicate with people and talk about life"; "she made friends there as well"; "we are interacting now, more than me [carer] trying to reach him ... He is actually talking to me first"	
Kelly et al., 2016 (pp.162-163)	"I'd love to do it [CST] again"; "it encouraged her to do things more"	"Increased confidence" (a sub-theme); "I felt good after it. I was disappointed when it ended"; "she came out to me a brighter, happier person"; "I don't get frustrated with myself anymore"		"Cognitive benefits" in "memory, attention and concentration" (a sub-theme); "I still use the techniques and things I learned"; "When I forget something I just relax and then it comes back to me"
C. M. Murray et al., 2016 (pp. 624-625)	"They could talk about" things; "immediately after [home] he doesn't stop talking"; "he wants to participate and have a go"	"Being happy and stimulated during the sessions"; "fun and laughter"; "sustained enjoyment" after CST; "got a bit more interested in life"	"Talk about it and tell us what he'd actually done for the day. Sort of brought him out"; "developed relationships" within CST which "seemed to promote positive feelings"; "they bonded as a group" and developed new friendship	"When he came home from the days out he felt more stimulated and probably more alert"; "very upbeat and very stimulated and very awake"

In addition, a qualitative study on the carer-led, individual CST using Framework Analysis (Leung et al., 2017) also reported some positive changes in feeling, thinking and relating. Changes included “the feelings of enjoyment and achievement”; “mental stimulation” described as “feeling alert”; more “awareness of what is happening” and thinking “better”; and bringing the person with dementia and the caregiver “together” (pp. e38-9). However, the quality, intensity and range of the changes in Leung et al.’s (2017) work were not comparable to the “switch-on” findings in the present study. Further, no changes in doing or engagement with daily activities were described by Leung et al. (2017) except for participating in the iCST, in which “many” family caregivers “had difficulty delivering all the sessions as planned” (p. e34) and which “nearly 20%” of the patient participants didn’t find “stimulating enough” (p. e39).

Overall, the “switch-on” themes in the present study encompassed almost all the positive outcomes of the intervention that were described in these past five studies, with Cheung and Peri’s (2014) reports bearing the closest resemblance. However, there were also new findings about “switch-on” across all four areas of Doing, Feeling, Relating, and Thinking and Reflecting that were not captured in any previous studies. These new findings are discussed in detail as follows.

“Switched-on” Changes in Doing

Consistent with the five earlier studies (Bailey et al., 2017; Cheung & Peri, 2014; Kelly et al., 2016; C. M. Murray et al., 2016; Spector et al., 2011), active participation in CST was a prominent, recurrent finding in Doing, including “looking forward to” attending CST, listening to and talking with other people in the group, engaging in discussions and activities in the programme, and wanting to continue with the group when it was finished. Further, “talking more about stuff” at home, using more initiative towards and engaging more in daily occupations were also repeatedly described both in the present and earlier studies (Bailey et al., 2017; Cheung & Peri, 2014; Kelly et al., 2016; C. M. Murray et al., 2016; Spector et al., 2011).

Corresponding with the finding of “getting something special out of the sessions” in Cheung and Peri’s (2014, p. 20) study, all participants with dementia in this study had opportunities to engage in some forms of activity within the group that was individually meaningful and satisfying. Some examples were listening to Beethoven’s music that provoked a strong emotional connection for Frank; and talking about the picture of an island that “opened up” Mark and “brought him into the group”. Moreover, aligning with data in two previous studies (Bailey et al., 2017; Cheung & Peri, 2014), active engagement with the CST programme was extended to home environments, either through doing the CST homework, such as John’s “delving into” a subject in preparation for his speech about current events; or transferring newly discovered activities or interests from the programme to home, such as playing 3D puzzles as a new hobby for Peter. This was regarded as a remarkable benefit of CST by some participants with dementia and their family caregivers in the present study, because engagement with CST-related activities at home provided more opportunities or ideas for meaningful occupation, something that had been identified as a challenge at baseline.

The “switched-on” changes in Doing uncovered in this study also involved intentional and effortful goal-directed actions in participating in CST and daily activities at home, which was not explicitly represented in previous qualitative inquiries. Deliberate performance stimulated by the challenge of participating in CST was clearly articulated by the men with dementia and their wives. This was illustrated in John and his wife’s accounts about him being “determined” to engage with and complete the programme, Peter’s deliberation of “making your brain work”, and Mark’s firm decision to do things by himself to “help [my] wife”. Further, the current study revealed occupational adjustment of participants at home, comprised of not only doing more, trying harder, and taking more initiative or responsibility in a purposeful way, but also sensibly letting go of some hobbies, routines, habits, and responsibilities that were no longer realistic, necessary, satisfying or meaningful. Striving towards and achieving goals required the exercise of higher levels of

motivation in the person, which was consistent with the improved Achievement level of volition found in the quantitative part of this study.

The “switched-on” changes in Doing were important, considering the baseline reports about “doing things becoming problematic” in this study. Further, issues and disturbances in daily occupations have been recurrently recognized in earlier qualitative inquiries about CST (Bailey et al., 2017; Cheung & Peri, 2014) and quantitative investigations about commonly experienced, bothersome dementia symptoms for community-dwelling patients in general (T. M. Murray et al., 2012). In addition, this finding added more qualitative data to affirm the benefits of CST for activities of daily living, which have not been effectively detected in previous quantitative studies on CST (Aguirre, Hoare, et al., 2013; Coen et al., 2011; Spector et al., 2001; Spector et al., 2003).

“Switched-on” Changes in Feeling

The “switched-on” changes in Feeling comprised of increased experience of a range of positive feelings that have consistently been noted in all previous qualitative inquiries about CST (Bailey et al., 2017; Cheung & Peri, 2014; Kelly et al., 2016; C. M. Murray et al., 2016; Spector et al., 2011), including fun and enjoyment, happiness and satisfaction, confidence, and calmness. There was also a cluster of increased emotions that were frequently reported in some of the previous literature (Bailey et al., 2017; Cheung & Peri, 2014; C. M. Murray et al., 2016; Spector et al., 2011), such as interest, curiosity and a desire to express, act or socialize. It appeared in this study, that these positive feelings were initially experienced in the CST group but seemed to have also permeated out to home environments. These feelings could be associated with socialization and/or engagement with specific activities either within or outside the CST group.

Congruent with some of the previous studies (Cheung & Peri, 2014; Kelly et al., 2016; C. M. Murray et al., 2016; Spector et al., 2011), the “switched-on” positive feelings were also spontaneously expressed and noted at home, either through affect display

described as “brighter”, “more interested”, “more animated”, “more confident” and “blossomed”, or behaviours, such as increased sharing and talking. The heightened affective and behavioural presentations of positive feelings seemed to be the major feature of “the switch-on phenomenon” described in Cheung and Peri’s (2014) study. The intensity of “switched-on” feelings in some participants with dementia was also manifested through the inter-subjective emotional experience of myself as the researcher in the present study.

The “switched-on” feelings discovered in this study that were not formerly reported in the CST literature were improved acceptance and increased appreciation and consideration of family caregivers. Without prompting, all the men with dementia spontaneously expressed some degree of acceptance of their diagnosis and life situations at baseline, and increased acceptance following participation in CST seemed to have different implications for each person. While being “more accepting” helped Frank to feel “more relaxed”, it made Mark “more understanding”, and assisted Peter to counteract self-stigma and shame towards the dementia diagnosis; it generated more complex and mixed feelings for John, including an increased sense of loss, grieving, sadness, anger and frustration.

Further, all husbands expressed, either explicitly through their words, or implicitly through changed behavioural patterns that were noted by their wives, their increased appreciation and consideration of their wives, which contributed to improved relationships and dynamics between the couples. This was a salient and somewhat unexpected finding of this study because this aspect has not been signalled in previous qualitative research of CST outcomes.

“Switched-on” Changes in Relating

The “switched-on” changes in Relating that have been recurrently reported in the literature were a sense of association and togetherness, being “in the same boat” and bonding within the CST group; improved social interactions, engagement and relationships in the home environments; and increased desire, confidence and ability

to socialize within and outside the CST group (Bailey et al., 2017; Cheung & Peri, 2014; C. M. Murray et al., 2016; Spector et al., 2011). Further echoing Cheung and Peri's (2014) study, the social context of CST was described by some participants with dementia in this study as being a major, meaningful motivating factor for their active participation in the programme.

There were two positive changes in Relating that were newly discovered in the present study with regards to the nature of the relationships in the CST group and the changed spousal dynamics at home. First, although three previous studies referred to the social relationships formed in the CST group as "friendship" (Bailey et al., 2017; Cheung & Peri, 2014; C. M. Murray et al., 2016), John explicitly clarified that it was "fellowship" and "comradeship", which was echoed by Frank's wife. He further articulated that the social dynamics and "the comradeship" in the group was a source of "stimulation", because "it's what they bring to and from each other that does the stimulation". This seemed to suggest a cultural dimension to the relationships within the CST group. All the men developed a sense of collective identity and belonging to a sub-cultural group on the common ground of being "like-minded" and "in the same boat" in confronting their shared dementia challenge. Further, this finding also indicated that "switch-on" might have a "contagious" feature, considering the mutual, inter-personal influences between the group members. In other words, a "switched-on" person could be an integral part of the social environment for others, and vice versa. This gave rise to the speculation of whether "switch-on" could be an individual experience as well as a collective phenomenon, given the social and cultural elements of CST.

Second, it is well recognized in the dementia literature that taking care of a partner who has dementia can transform the marital relationships dramatically (Egilstrod, Ravn, & Petersen, 2018). All couples in the study described some positive changes in their relationships and dynamics following CST, attributable to the husbands becoming not only more communicative and expressive of affection but also more "understanding", "appreciative", "considerate", and "helpful" to their wives. The

improvements reflected the dyadic nature of their relationships as a married couple and as a patient-carer duo, and the therapeutic effects of CST on both aspects. These “switched-on” changes in the husbands, particularly their improved awareness and appreciation of their wives’ caregiving role, were well received and regarded as beneficial by all the wives. This finding seemed to be inconsistent with a quantitative study that failed to detect any significant benefits from the intervention on family caregivers’ health and quality of life (Aguirre, Hoare, Spector, Woods, & Orrell, 2014).

“Switched-on” Changes in Thinking and Reflecting

Reflective of the cognitive focus of the intervention, a common and recurrent “switch-on” change following participation in CST in the qualitative and mixed methods literature has been improved thinking and information processing, particularly in the domains of alertness, attention, concentration, and general memory (Cheung & Peri, 2014; Kelly et al., 2016; C. M. Murray et al., 2016; Spector et al., 2011). The improvement was specifically described as “more switched on” in Spector et al.’s (2011) study and was referred to by family participants as “more alert”, “brighter”, “brighten up” and “waking up” in the current study. Consistent with some previous studies (Kelly et al., 2016; Spector et al., 2011), the “switched-on” changes in Thinking and Reflecting in the present study also involved making more effort to attend, remember, recall and apply memory strategies, which contributed to the improved performance of day-to-day occupations. A less frequently reported change in Thinking and Reflecting was increased “empathy” towards other CST group members (Cheung & Peri, 2014), which was extensively described by two participants with dementia in this study. This seemed to indicate that CST might improve social cognition, a newly added cognitive domain in DSM-5 (American Psychiatric Association, 2013) that may be impaired in people with dementia.

These “switched-on” changes in Thinking, together with the improved talking and communication presented in the earlier Doing section, supported the cognitive benefits of CST identified in quantitative studies (Spector et al., 2003; Woods et al.,

2012). The variety of the improvements found in the present study was also reflective of the aim and feature of CST in stimulating global cognition rather than specific cognitive domains (Spector et al., 2001).

Although two previous studies mentioned increased thinking and reflection after attending the CST sessions (Cheung & Peri, 2014; Spector et al., 2011), the intensity, depth and extent of the “switched-on” changes in Thinking and Reflecting revealed in the present study were new and rather unexpected. All participants demonstrated expanded thought patterns that were less focused on themselves and the past, but oriented more towards sociality and the future. Three men explicitly described their intense and in-depth contemplation about life and death in a philosophical and spiritual sense, which suggested that living with dementia was an existential situation for the person (Freter, 2015). It also indicated that participation in CST, as an occupational event, provided them with a “platform”, reason and material to reflect on their spirituality in terms of addressing their loss, fear and suffering associated with dementia, reconnecting with themselves, others and the world, and finding hope, meaning and purpose in life.

Occurrence of “Switch-on”

Although, in the present study, the onset timing and presentation of “switch-on” varied in each participant with dementia, the effect tended to occur at the early phase of the CST programme prior to time 2 data collection and continued to strengthen and consolidate in a gradual and progressive fashion towards time 3. Further, corresponding to past qualitative investigations of CST (Bailey et al., 2017; Cheung & Peri, 2014; Kelly et al., 2016; C. M. Murray et al., 2016; Spector et al., 2011), the “switched-on” changes occurred concurrently and comparably in both CST and home contexts, which implied the spontaneous transfer of the “switch-on” effect across environments. All this seemed to indicate that “switch-on” did not occur as an isolated, reactive and transient phenomenon but involved a pervasive, intentional and sustainable process. The parallel VQ measurement results also suggested a slight

and gradually improving pattern of volitional changes in three participants with dementia, particularly on the Achievement sub-scale, which was congruent with the qualitative descriptions.

The occurrence of “switch-on” shown in this study reflected implicit learning, a therapeutic element and principle of CST. Explicit learning stresses intuitive learning, instead of explicit teaching and rehearsing, through provision of an optimized learning environment and encouraging expression of opinions rather than fact retrieval (Spector et al., 2011; Spector et al., 2001). From an occupational therapy point of view, the occurrence of “switch-on” was also an outcome of the transactional dynamics between the person, environments and occupations during the course of the CST programme (Law et al., 1996). Although the person-environment interactions were most evident in the “switched-on” changes in Relating, and the person-occupation interactions were mostly reported in the “switched-on” changes in Doing; the environmental and occupational contexts were interrelated and inseparable, particularly in the CST group setting.

Further, the temporal and spatial features of the occurrence of “switch-on” and the VQ measurement results in this study also signalled the involvement of the volitional process theorized in the Model of Human Occupation (MOHO) (Taylor, 2017). The volitional process of a person entails the interconnected and cyclic steps of anticipating, choosing, experiencing and interpreting one’s experiences. It also consists of three stable components, personal causation, values and interest, which have “a pervasive influence” (p. 52) on how the person pursues life through choosing and engaging in meaningful occupations.

In this study, an exercise of the volitional process was represented through the participants’ engagement in occupations within the CST and at home. For example, all the men with dementia looked forward to and got prepared for attending CST (“anticipating”); they made choices about how to engage with the programme in an individualized way, which reflected their perceived competency, values and interest

("choosing"); they pursued the programme through taking actions, getting involved emotionally, interacting with others, and thinking and processing information as required ("experiencing"); and they appraised their experiences in terms of how capable they were as a "cause" for things to happen and what provided meaning and satisfaction ("interpreting"). All of them reported some positive volitional outcomes following participation in CST, including improved confidence and self-efficacy ("personal causation"), a greater sense of meaning, purpose and connection ("values"), and increased enjoyment and satisfaction ("interest"). These changes seemed to provide self-motivation for the men to choose and engage in more goal-directed actions at home, such as "talking more" about things, and doing more housework to "help" their wives.

Measurement of "Switch-on"

To evaluate whether the VQ captured the "switch-on" effect of CST, the measurement results in the study and several aspects of the instrument were scrutinised. The VQ generated useful data in understanding the volitional changes involved in "switch-on"; however, it lacked viability as an outcome measure for the effect for three considerations.

First, the considerably high scores for all participants, especially at baseline, suggested generally high volitional levels in this group of research participants. It could be related to the weakness of lacking repeated baseline measurements in the present research design, because pre-CST interview data showed recently improved motivation in two patient participants (Peter and John), likely associated with their positive expectation of the upcoming CST group. In other words, if they had been measured at an early time-point, such as a month prior, their VQ scores might have been lower. Nevertheless, the high baseline VQ results could also indicate the ceiling effect of the measure (Salkind, 2010), or the lack of efficiency in differentiating changes within higher levels of volition. This has been noted as a potential weakness of the measure in the VQ literature (Chern et al., 1996). The ceiling effect of the VQ

will restrict its usefulness for measuring the “switch-on” effect, and attainment of maximal scores in all measurements in John’s case reflected this limitation.

Second, the theoretical basis for the VQ is the construct of volition in the Model of Human Occupation, which is concerned with thinking and feeling patterns that mobilize one’s actions (Taylor, 2017). As an observational instrument, the VQ items seemed to be more effective in detecting “switched-on” changes in Doing, Feeling and Thinking, but were less effective in showing changes in Reflecting and Relating in the present study.

Lastly, as an interactive assessment tool, administration of the VQ allows encouragement and facilitation from the assessor (de las Heras et al., 2007). This can be an advantage of the measure in the therapeutic or clinical settings, although may serve as a potential confounding factor in research use. It was noted in this study that the research process itself seemed to have some positive impact on the participants’ volition, independent of attending the CST programme. For example, Frank explicitly attributed his enrolment in CST to my input as he said, “if it wasn’t for you, I wouldn’t be going”. Mark and John also expressed their interest and anticipation for being visited and interviewed by me. Given that, it would be difficult to ascertain if the improved VQ observations were due to CST rather than my input, particularly in the single-subject design of this study, which involved multiple measurements and, therefore, offered opportunities for rapport building between the participants and myself. Subjective input from the assessor has been identified as possibly contributing to the lack of inter-rater reliability of the VQ measure (Li & Kielhofner, 2004), which makes it plausible to speculate that subjective input might also have influenced participants’ performance. This may have also impacted on the qualitative data analysis as a limitation.

Strengths of the Study

This was the first study that specifically explored the “switch-on” effect that has been observed in participants of CST. It used a parallel convergent mixed methods design

(Creswell, 2014), aiming to provide a comprehensive description about “switch-on” and sought a way to measure the changes that occur in some CST participants. Informed by qualitative descriptive methodology and thematic analysis (Stanley, 2015), the semi-structured individual interviews involved both patient and family participants and were conducted before, during and after the CST programme. This design and process generated remarkably rich qualitative data and captured changes related to “switch-on” following the intervention in a timely manner. These features were a strength of the study, because all previous qualitative inquiries about CST were conducted only once, post intervention (Bailey et al., 2017; Cheung & Peri, 2014; Kelly et al., 2016; C. M. Murray et al., 2016; Spector et al., 2011).

Further, previous qualitative studies of CST had a specific focus on the intervention when structuring their interview or focus group questions. In contrast, this study purposefully devised open-ended questions to explore the participants’ daily life experiences and changes without an overt emphasis on the intervention. This reflected the occupation-based perspective of the study in understanding “switch-on” in the person’s real-life context, a perspective which was congruent with the concept of “participation” as defined in the International Classification of Functioning, Disability and Health (ICF) (World Health Organization, 2002). The interview focus on daily occupations, rather than CST itself, may have helped to minimize the response bias (Salkind, 2010) of the research participants, in that they would have felt less obligated to provide positive reports about the intervention. In fact, some mild adverse changes were noted in this study associated with the “switch-on” effect, such as overdoing “stimulating activities” like puzzles in Peter’s case, and the complex and not-all positive emotions associated with increased reality awareness, acceptance and grieving over loss in John’s case. These findings were valuable for establishing a more complete understanding of “switch-on”, particularly in relation to participation in occupation in the natural environment.

In addition, concurrently with the semi-structured interviews at three time-points, this study explored and measured volition using the VQ with patient participants,

guided by a single-subject A-B design (Carter & Lubinsky, 2015). Although preliminary, it generated useful information, as no previous studies in CST literature have investigated or measured the impact of CST on the person's motivation, volition, apathy or lack of motivation (Marin et al., 1991). Apathy or lack of motivation has been identified as the most prevalent behavioural symptom in people with Alzheimer's type dementia (Dyer et al., 2018). The improving trend on the VQ, particularly the Achievement sub-scale, suggested the volitional nature of "switch-on" and the motivational benefits of the intervention.

Limitations of the Study

This was a small-scale study which involved only four community-dwelling patient-carer dyads from the same CST group. The four participants with dementia shared a lot of commonalities in personal characteristics, such as being male, married, living with a wife who was the main caregiver, and having a similar interest or background in engineering, technology or construction. All of them had mild dementia with a similar level of functioning at the baseline, which were equivalent to the patient samples in two previous studies of the "switch-on" effect, one involving only participants with mild dementia (Spector et al., 2011) and the other all community-dwelling participants with dementia (Cheung & Peri, 2014). The lack of variety in participant characteristics in this study limits the transferability of the findings. In other words, the descriptions about the nature and occurrence of "switch-on" and the VQ measurement results presented in this study may not be applicable for female participants, people who have moderate dementia, or are living on their own in the community, or in a residential care home. Moreover, the qualitative data showed that all four participants with dementia in this study experienced "switch-on", although only some CST participants did in Cheung and Peri's (2014) study. This confined the ability to interpret the overall VQ scores or the Achievement sub-scores as capturing the "switch-on" effect, because results might have been the same for people who do not "switch on".

Further, guided by qualitative descriptive methodology (Stanley, 2015), the qualitative inquiry of the current study rendered a “thick” description about “switch-on” with “low-inference” interpretation and therefore could reach “easier consensus” among reviewers (Sandelowski, 2000, p. 335). However, the inquiry wasn’t designed for exploring “switch-on” in terms of its deep meaning or lived experience for the individuals with dementia and their family caregivers. Neither did the study intend to examine the active mechanisms that underlay “switch-on”, the internal dynamic relations between the “switched-on” areas, or the exact timing of its occurrence. Instead, the study design placed more emphasis on real-life participation in the home environments. However, the findings from the qualitative data analysis also demonstrated that attending the CST group was an occupation itself. If the study had also included the CST facilitators as participants, more useful data about the social and occupational participation within the group could have been collected to provide greater understanding about the nature and occurrence of “switch-on”.

There were also a few limitations of this study that related to the measurement using the VQ following the Single-subject A-B design (Carter & Lubinsky, 2015). First, this study didn’t achieve multiple baseline measurements as required by the A-B designs. This was due to opportunistic recruitment from a community CST provider, which limited the data that could be collected about the baseline status of participants prior to beginning CST. The absence of an extended non-treatment phase (phase A) for establishing baseline stability compromised the rigour of the research design (Carter & Lubinsky, 2015). Second, the psychometric properties of the VQ were not optimal, particularly given its lack of proficiency in differentiating high levels of volition (Chern et al., 1996) and the tendency for the two lower ratings on the four-point scale to be less frequently used (Li & Kielhofner, 2004). Similarly, the measure showed a ceiling effect (Salkind, 2010) in this study, in that all participants obtained high scores at three time-points with one person achieving the maximum in all measurements. This restricted its usefulness for this study and draws into question its application to measure the “switch-on” effect in future research. Lastly, it was me who

administered the VQ rather than an independent rater due to the small scope and financial constraints of the study. This had the potential to result in observer bias (Lewis-Beck et al., 2004) and may have affected the rigour of the study.

Implications for Future Research

The “switch-on” effect revealed in this study comprised of simultaneously enhanced activity and strength in multiple areas of the person. The effect occurred spontaneously across CST and home environments in a gradual and progressive fashion, following a noticeable onset prior to the 3rd week of the programme. The VQ measurement results further suggested the involvement of volitional changes, particularly those at the Achievement level of volition, as part of the “switch-on” effect. These findings about “switch-on” suggested that it is a common and beneficial outcome of CST that deserves more research, particularly from an occupation-based perspective.

Although complex and multi-dimensional in presentation, the nature and occurrence of “switch-on” was comparable to the concept of occupational engagement (Law et al., 1996; Townsend & Polatajko, 2007), considering the effect being a positive outcome of participating in CST as an occupation. Future studies using occupational theoretical frameworks will strengthen and broaden the current understanding of CST and its “switch-on” effect.

Spector’s CST has been regarded as ineffective for improving performance in activities of daily living (Aguirre, Hoare, et al., 2013; Coen et al., 2011; Spector et al., 2003; Woods et al., 2012). Exploration of “switch-on” in the present study clearly demonstrated improved social and occupational engagement within and outside the CST group, which was satisfying to participants with dementia and valued by their family caregivers. An important implication is that previous outcome measures for daily functioning were focused on occupational performance rather than engagement, which are two distinctive concepts in occupational therapy (Townsend & Polatajko, 2007). Occupational engagement is regarded as a human need and a justice issue,

which can be jeopardized by disabilities, such as dementia. From this point of view, measurement of engagement rather than performance reflects a stance towards a more inclusive social model of disability that stresses participation (World Health Organization, 2002). It also aligns with the person-centred philosophy of CST (Spector et al., 2005). The Engagement in Meaningful Activities Survey (EMAS) developed by occupational therapists (Goldberg, Brintnell, & Goldberg, 2002) may be a promising outcome measure for CST in relation to its functional benefits. It may also be a more suitable measure for the “switch-on” effect, given the dissatisfactory measurement outcomes using the VQ in the present study. The EMAS has demonstrated sound psychometric properties, including good validity for measuring meaningful activity in older adults (Eakman, Carlson, & Clark, 2010).

Further, considering “switch-on” is a highly valued outcome of CST, and has a multi-dimensional effect, it would be worthwhile to either develop a new, specific measure for the “switch-on” effect or explore more sensitive existing instruments for detecting the subtle and yet satisfying “switched-on” changes, particularly the affective and motivational benefits for participants with dementia and the positive impact on family caregivers.

As a cognition-based intervention, the cognitive effects of CST have been well-researched in previous studies with a domain-based approach predominantly (Aguirre, Hoare, et al., 2013; Hall et al., 2013; Spector et al., 2010). The present study suggests the need for exploring and applying a more holistic, inclusive and functional view of cognition in further CST studies, an implication of which is to develop a specific measure for the “switch-on” effect. Qualitative analysis in this study demonstrated that multiple contributors worked together to generate the “switched-on” changes in Thinking and Reflecting, which were closely related to the cognitive benefits of the intervention. Contributors included more intuitive and effortless factors, such as improved alertness, arousal and interest in “what’s going on”, and enhanced positive affect described as “brighten up”, “more animated” or “more stimulated”. Contributors also included factors that were more deliberate and effortful, such as

being “more attentive”, “determination”, increased effort and intentionality to process information, and use of memory strategies. This demonstrated that not only global cognition, but also the affective, intellectual and volitional areas and resources of the whole person were “switched-on” and mobilized to perform occupations that required thinking and processing. The quantitative data also verify the involvement of volitional changes in the “switch-on” effect, particularly the activation of the higher Achievement level of volition.

These findings were consistent with recent research in cognitive neuroscience, psychology and ageing, which has found some evidence for the interactions between motivation, cognition and affect. Such research suggests the need for “a more unified and cross-disciplinary approach” in the study of motivation-cognition interaction (Braver et al., 2014, p. 444). Some of the evidence examples are: as a component of affect and motivation, arousal can also energize cognitive processing and behaviours; older adults tend to distribute more cognitive resources to “affectively positive items or events”, which is hypothesized as “positive effect” (p. 447); motivation can influence cognitive processing through lateral prefrontal cortex activity, either via “a transient, stimulus-trigger, reactive mode” or a “tonic and anticipatory, proactive mode” (p. 457); and there are “bidirectional affective-motivational interactions” (p. 461), in that setting a desirable cognitive goal may lead to increased experience of positive affect, and vice versa. All this is relevant to the focus of “switch-on” in this study, which appeared to encompass internal dynamics in multiple areas of the person, involving changes in affect, cognition, volition and behaviour. Given that, it is plausible to speculate on the benefits of developing a “switch-on” measure for future research that would capture these multi-dimensional changes inclusively and holistically.

The affective benefits of CST were recurrently described in this study and in previous qualitative inquiries about the intervention (Bailey et al., 2017; Cheung & Peri, 2014; Kelly et al., 2016; C. M. Murray et al., 2016; Spector et al., 2011). However, as discussed in Chapter 2, depression measures, such as the Cornell Scale for Depression

in Dementia (CSDD), seem to lack sensitivity in detecting the positive impact of CST on mood and affect due to the floor effect (Spector, et al., 2003). Therefore, the findings of this study support using a more sensitive instrument for measuring the effects on mood and affect in further studies.

This study primarily measured volition, a concept based on the MOHO, which concerns patterns of thoughts and feelings about one's perceived competence, values and interest that motivate goal-directed actions (Taylor, 2017). A positive trend of the VQ results, particularly the Achievement sub-scores, paralleled the described "switch-on" changes in three of the participants with dementia. This suggested that apart from benefiting cognition and affect, CST might induce positive changes in motivation and thus, could be a potential treatment for apathy, a common behavioural symptom of dementia characterized by lack of motivation (Brodaty & Burns, 2012; Dyer et al., 2018). Considering that, more qualitative or quantitative research assessing the motivational benefits of CST using an appropriate measure will be warranted.

All wives in this study described some positive impact from CST on themselves, which was inconsistent with CST literature that the intervention has little benefit for family caregivers (Aguirre, Hoare, et al., 2014; Woods et al., 2012). It was noted in prior studies of Spector's CST that measurements of family benefits were mainly focused on caregivers' health and burden (Aguirre, Hoare, et al., 2014; Cheung & Peri, 2014; Spector et al., 2001), rather than patient-carer relationships. A more suitable means of evaluating outcomes for family can be a potential area to examine further in future CST studies.

Finally, it was an unexpected finding about "switch-on" in the present study that three participants with dementia revealed their deep, intense and adaptive reflections on the existential, spiritual and relational issues associated with their diagnosis and experience of dementia. This was congruent with dementia literature that people with dementia have increased spiritual needs and that spirituality can serve as an important means of "finding hope, meaning and linkage with past,

present and future” for them to cope with the illness (Daly, Fahey-McCarthy, & Timmins, 2016, p. 1). However, no previous CST study has explored the spiritual benefits of the intervention or has examined whether spirituality is a contributing factor to the improvement in self-reported quality of life. Considering the positive findings in the present study and the research gap, it would be valuable for future studies to investigate more specifically on CST participants’ experience of spirituality in relation to the “switch-on” effect and the positive outcomes of the intervention. A spirituality framework proposed by occupational therapists can be considered to explore the spiritual value of CST empirically (Jones, Topping, Wattis, & Smith, 2016), which focuses on “mobilising patients’ spiritual coping strategies to engender meaning and purpose” and “restore a sense of well-being” (p. 38).

Conclusion

This chapter examined and discussed the main findings of the present study with reference to CST literature and occupation-based theories in producing answers for the research questions about the “switch-on” effect. The strengths and weaknesses of the study were reflected. Several implications for future CST research were considered and elaborated.

This research project was the first study to explore the “switch-on” effect of CST using a parallel convergent mixed methods design (Creswell, 2014) and incorporating an occupation-based perspective (Law et al., 1996; Taylor, 2017; Townsend & Polatajko, 2007). The findings of the study indicated that the “switch-on” effect was multi-dimensional in nature, which consisted of positive changes in the areas of Doing, Feeling, Relating, and Thinking and Reflecting simultaneously. The “switch-on” changes occurred in both CST and home environments concomitantly, with a noticeable onset before the 3rd week of CST which continued to consolidate and strengthen towards the completion of the programme. Concurrent with the “switch-on” descriptions were the improving trend of the VQ scores, particularly on the Achievement sub-scale, in three of the participants. Although the instrument was

deemed to not effectively capture the “switch-on” changes due to its ceiling effect (Salkind, 2010), this was the first study that measured and explored volition in relation to the positive outcomes of the intervention.

The findings in the study provide a more comprehensive understanding of the “switch-on” effect, a beneficial and satisfying outcome of CST, with implications identified for future CST research. More exploration of the social and occupational outcomes of the intervention is required, particularly from the perspectives of social participation and occupational engagement, rather than emphasizing performance in daily activities. It is unclear if investigation about whether or not CST generates motivational benefits is warranted, as no previous CST studies have posed this question. In conclusion, more sensitive measures are needed for detecting the “switch-on” changes, including the development of a specific, new measure for this effect.

References

- Agren, K. A., & Kjellberg, A. (2008). Utilization and content validity of the Swedish version of the Volitional Questionnaire (VQ-S). *Occupational Therapy Health Care*, 22(2-3), 163-176. <https://doi.org/10.1080/07380570802135456>
- Aguirre, E., Hoare, Z., Spector, A., Woods, R. T., & Orrell, M. (2014). The effects of a cognitive stimulation therapy (CST) programme for people with dementia on family caregivers' health. *BMC Geriatrics*, 14, 31. <https://doi.org/10.1186/1471-2318-14-31>
- Aguirre, E., Hoare, Z., Streater, A., Spector, A., Woods, B., Hoe, J., & Orrell, M. (2013). Cognitive stimulation therapy (CST) for people with dementia: Who benefits most? *International Journal of Geriatric Psychiatry*, 28(3), 284-290. <https://doi.org/10.1002/gps.3823>
- Aguirre, E., Spector, A., & Orrell, M. (2014). Guidelines for adapting cognitive stimulation therapy to other cultures. *Clinical Interventions in Aging*, 9, 1003-1007. <https://doi.org/10.2147/cia.s61849>
- Aguirre, E., Spector, A., Streater, A., Burnell, K., & Orrell, M. (2011). Service users' involvement in the development of a maintenance cognitive stimulation therapy (CST) programme: A comparison of the views of people with dementia, staff and family carers. *Dementia*, 10(4), 459-473. <https://doi.org/10.1177/1471301211417170>
- Aguirre, E., Woods, R. T., Spector, A., & Orrell, M. (2013). Cognitive stimulation for dementia: A systematic review of the evidence of effectiveness from randomised controlled trials. *Ageing Research Reviews*, 12(1), 253-262. <https://doi.org/10.1016/j.arr.2012.07.001>
- Alexopoulos, G. S., Abrams, R. C., Young, R. C., & Shamoian, C. A. (1988). Cornell Scale for Depression in Dementia. *Biological Psychiatry*, 23(3), 271-284.
- Alzheimer's Disease International. (2011). *World Alzheimer report 2011: The benefits of early diagnosis and intervention (executive summary)*. Retrieved from <https://www.alz.co.uk/research/WorldAlzheimerReport2011ExecutiveSummary.pdf>
- Alzheimer's Disease International. (2012). *Dementia: A public health priority*. Geneva, Switzerland: WHO Press.
- Alzheimers New Zealand. (2017). *Dementia economic impact report 2016*. Retrieved from <http://www.alzheimers.org.nz/getmedia/79f7fd09-93fe-43b0-a837-771027bb23c0/Economic-Impacts-of-Dementia-2017.pdf>
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5* (5th ed.). Washington, DC: Author.
- Atchison, B., & Dirette, D. K. (2012). *Conditions in occupational therapy: Effect on occupational performance*. Philadelphia, PA: Wolters Kluwer/Lippincott Williams & Wilkins. Retrieved from https://books.google.co.nz/books?id=tAgNQ2rAj_8C
- Australian Institute of Health and Welfare. (2012). *Dementia in Australia*. Canberra, Australia: Australian Institute of Health and Welfare.

- Bailey, J., Kingston, P., Alford, S., Taylor, L., & Tolhurst, E. (2017). An evaluation of cognitive stimulation therapy sessions for people with dementia and a concomitant support group for their carers. *Dementia*, 16(8), 985-1003. <https://doi.org/10.1177/1471301215626851>
- Ballard, C., Khan, Z., Clack, H., & Corbett, A. (2011). Nonpharmacological treatment of Alzheimer disease. *Canadian Journal of Psychiatry*, 56(10), 589-595. <https://doi.org/10.1177/070674371105601004>
- Baran, M. L., & Jones, J. (2016). *Mixed methods research for improved scientific study*. Hershey, PA: IGI Global.
- Braver, T. S., Krug, M. K., Chiew, K. S., Kool, W., Westbrook, J. A., Clement, N. J., . . . Somerville, L. H. (2014). Mechanisms of motivation-cognition interaction: Challenges and opportunities. *Cognitive Affective Behavioral Neuroscience*, 14(2), 443-472. <https://doi.org/10.3758/s13415-014-0300-0>
- Breuil, V., De Rotrou, J., Forette, F., Tortrat, D., Ganansia-Ganem, A., Frambourt, A., . . . Boller, F. (1994). Cognitive stimulation of patients with dementia: Preliminary results. *International Journal of Geriatric Psychiatry*, 9(3), 211-217. <https://doi.org/10.1002/gps.930090306>
- Brodaty, H., & Burns, K. (2012). Nonpharmacological management of apathy in dementia: A systematic review. *American Journal of Geriatric Psychiatry*, 20(7), 549-564. <https://doi.org/10.1097/JGP.0b013e31822be242>
- Buettner, L. L., Fitzsimmons, S., Atav, S., & Sink, K. (2011). Cognitive stimulation for apathy in probable early-stage Alzheimer's. *Journal of Aging Research*, 2011, 6. <https://doi.org/10.4061/2011/480890>
- Capotosto, E., Belacchi, C., Gardini, S., Faggian, S., Piras, F., Mantoan, V., . . . Borella, E. (2017). Cognitive stimulation therapy in the Italian context: Its efficacy in cognitive and non-cognitive measures in older adults with dementia. *International Journal of Geriatric Psychiatry*, 32(3), 331-340. <https://doi.org/10.1002/gps.4521>
- Carpenter, C., & Suto, M. (2008). *Qualitative research for occupational and physical therapists: A practical guide*. Oxford, United Kingdom: Blackwell Publishing.
- Carter, R., & Lubinsky, L. (2015). *Rehabilitation research: Principles and applications* (5th ed.). St. Louis, MO: Elsevier Health Sciences.
- Chern, J. S., Kielhofner, G., de las Heras, C. G., & Magalhaes, L. C. (1996). The Volitional Questionnaire: Psychometric development and practical use. *American Journal of Occupational Therapy*, 50(7), 516-525. <https://doi.org/10.5014/ajot.50.7.516>
- Cheung, G., & Peri, K. (2014). *Cognitive stimulation therapy: A New Zealand pilot*. Auckland, New Zealand: Te Pou o Te Whakaaro Nui.
- Clare, L., & Woods, R. T. (2004). Cognitive training and cognitive rehabilitation for people with early-stage Alzheimer's disease: A review. *Neuropsychological Rehabilitation*, 14(4), 385-401. <https://doi.org/10.1080/09602010443000074>
- Clarke, D. E., Reekum, R., Simard, M., Streiner, D. L., Freedman, M., & Conn, D. (2007). Apathy in dementia: An examination of the psychometric properties of the apathy evaluation scale. *Journal of Neuropsychiatry Clinical Neuroscience*, 19(1), 57-64. <https://doi.org/10.1176/jnp.2007.19.1.57>
- Coen, R., Flynn, B., Rigney, E., O'Connor, E., Fitzgerald, L., Murray, C., . . . Edgeworth, J. (2011). Efficacy of a cognitive stimulation therapy programme for people with

- dementia. *Irish Journal of Psychological Medicine*, 28(3), 145-147.
<https://doi.org/10.1017/S0790966700012131>
- Cooper, C., Mukadam, N., Katona, C., Lyketsos, C. G., Ames, D., Rabins, P., . . . Livingston, G. (2012). Systematic review of the effectiveness of non-pharmacological interventions to improve quality of life of people with dementia. *International Psychogeriatrics*, 24(6), 856-870.
<https://doi.org/10.1017/s1041610211002614>
- Creswell, J. W. (2014). *Research design: Qualitative, quantitative, and mixed methods approaches* (4th ed.). Los Angeles, CA: Sage.
- Crotty, M. (1998). *The foundations of social research: Meaning and perspective in the research process*. Crows Nest, Australia: Allen & Unwin.
- Csikszentmihályi, M. (1990). *Flow : The psychology of optimal experience*. New York, NY: Harper & Row.
- Cummings, J. L., Mega, M., Gray, K., Rosenberg-Thompson, S., Carusi, D. A., & Gornbein, J. (1994). The Neuropsychiatric Inventory: Comprehensive assessment of psychopathology in dementia. *Neurology*, 44(12), 2308-2314.
- Daly, L., Fahey-McCarthy, E., & Timmins, F. (2016). The experience of spirituality from the perspective of people living with dementia: A systematic review and meta-synthesis. *Dementia*. Advanced online publication.
<https://doi.org/10.1177/1471301216680425>
- de las Heras, C. G., Geist, R., Kielhofner, G., & Li, Y. (2007). *A user's manual to the Volitional Questionnaire (VQ) (Version 4.1)*. Chicago, IL: University of Illinois.
- Dourado, M. C. N., & Laks, J. (2016). Psychological interventions for neuropsychiatric disturbances in mild and moderate Alzheimer's disease: Current evidences and future directions. *Current Alzheimer Research*, 13(10), 1100-1111.
<https://doi.org/10.2174/1567205013666160728143123>
- Dugmore, O., Orrell, M., & Spector, A. (2015). Qualitative studies of psychosocial interventions for dementia: A systematic review. *Aging & Mental Health*, 19(11), 955-967. <https://doi.org/10.1080/13607863.2015.1011079>
- Dyer, S. M., Harrison, S. L., Laver, K., Whitehead, C., & Crotty, M. (2018). An overview of systematic reviews of pharmacological and non-pharmacological interventions for the treatment of behavioral and psychological symptoms of dementia. *International Psychogeriatrics*, 30(3), 295-309.
<https://doi.org/10.1017/s1041610217002344>
- Eakman, A. M., Carlson, M., & Clark, F. (2010). Factor structure, reliability and convergent validity of the Engagement in Meaningful Activities Survey for older adults. *OTJR: Occupation, Participation and Health*, 30(3), 111-121.
<https://doi.org/10.3928/15394492-20090518-01>
- Egilstrod, B., Ravn, M. B., & Petersen, K. S. (2018). Living with a partner with dementia: A systematic review and thematic synthesis of spouses' lived experiences of changes in their everyday lives. *Aging & Mental Health*, 1-10. Retrieved from <https://doi.org/10.1080/13607863.2018.1433634>
- Fazio, S., Pace, D., Flinner, J., & Kallmyer, B. (2018). The fundamentals of person-centered care for individuals with dementia. *Gerontologist*, 58(suppl_1), S10-S19. <https://doi.org/10.1093/geront/gnx122>

- Fisher, M., & Thomson, S. (2014). *Dementia and driving safety: A clinical guideline (Version 3)*. Retrieved from http://www.alzheimers.org.nz/getmedia/7c988632-6e93-43d7-b0de-871df0bd2663/Dementia_and_Driving.pdf.aspx
- Freter, B. (2015). On the existential situation of a person with dementia: The drama of mankind is repeated in the drama of dementia. *Journal of Health Science*, 3, 205-216. <https://doi.org/10.17265/2328-7136/2015.05.002>
- Galasko, D., Bennett, D., Sano, M., Ernesto, C., Thomas, R., Grundman, M., & Ferris, S. (1997). An inventory to assess activities of daily living for clinical trials in Alzheimer's disease. *Alzheimer Disease & Associated Disorders*, 11 (Suppl. 2), S33-S39. <https://doi.org/10.1097/00002093-199700112-00005>
- Giddings, L. S., & Grant, B. M. (2006). Mixed methods research for the novice researcher. *Contemporary Nurse*, 23(1), 3-11. <https://doi.org/10.5555/conu.2006.23.1.3>
- Goldberg, B., Brintnell, E. S., & Goldberg, J. (2002). The relationship between engagement in meaningful activities and quality of life in persons disabled by mental illness. *Occupational Therapy in Mental Health*, 18(2), 17-44. https://doi.org/10.1300/J004v18n02_03
- Goodman, C., Baron, N. L., Machen, I., Stevenson, E., Evans, C., Davies, S. L., & Iliffe, S. (2011). Culture, consent, costs and care homes: Enabling older people with dementia to participate in research. *Aging & Mental Health*, 15(4), 475-481. <https://doi.org/10.1080/13607863.2010.543659>
- Grant, B. M., & Giddings, L. S. (2002). Making sense of methodologies: A paradigm framework for the novice researcher. *Contemporary Nurse*, 13(1), 10-28. <https://doi.org/10.5172/conu.13.1.10>
- Guba, E. G., & Lincoln, Y. S. (1982). Epistemological and methodological bases of naturalistic inquiry. *Educational Communication and Technology*, 30(4), 233-252. <https://doi.org/10.1007/BF02765185>
- Hall, L., Orrell, M., Stott, J., & Spector, A. (2013). Cognitive stimulation therapy (CST): Neuropsychological mechanisms of change. *International Psychogeriatrics*, 25(3), 479-489. <https://doi.org/10.1017/s1041610212001822>
- Higgs, P., & Gilleard, C. (2016). Interrogating personhood and dementia. *Aging & Mental Health*, 20(8), 773-780. <https://doi.org/10.1080/13607863.2015.1118012>
- Hsieh, S., Schubert, S., Hoon, C., Mioshi, E., & Hodges, J. R. (2013). Validation of the Addenbrooke's Cognitive Examination III in frontotemporal dementia and Alzheimer's disease. *Dementia and Geriatric Cognitive Disorders*, 36(3-4), 242-250. <https://doi.org/10.1159/000351671>
- Hu, D. (2016). *Traditional Chinese medicine: Theory and principles*. Beijing, China: De Gruyter.
- Huntley, J. D., Gould, R. L., Liu, K., Smith, M., & Howard, R. J. (2015). Do cognitive interventions improve general cognition in dementia? A meta-analysis and meta-regression. *BMJ Open*, 5(4). <https://doi.org/10.1136/bmjopen-2014-005247>
- Johnston, M. V., & Smith, R. O. (2010). Single subject designs: Current methodologies and future directions. *OTJR: Occupation, Participation and Health*, 30(1), 4-10. <https://doi.org/10.3928/15394492-20091214-02>
- Jones, J., Topping, A., Wattis, J., & Smith, J. (2016). A concept analysis of spirituality in occupational therapy practice. *Journal for the Study of Spirituality*, 6(1), 38-57. <https://doi.org/10.1080/20440243.2016.1158455>

- Kelly, M. E., Finan, S., Lawless, M., Scully, N., Fitzpatrick, J., Quigley, M., . . . Devane, A. (2016). An evaluation of community-based cognitive stimulation therapy: A pilot study with an Irish population of people with dementia. *Irish Journal of Psychological Medicine*, 34(3), 157-167. <https://doi.org/10.1017/ipm.2016.23>
- Khan, Z., Corbett, A., & Ballard, C. (2014). Cognitive stimulation therapy: Training, maintenance and implementation in clinical trials. *Pragmatic and Observational Research*, 5, 15-19. <https://doi.org/10.2147/POR.S56000>
- Kielhofner, G. (2002). *A model of human occupation: Theory and application* (3rd ed.). Philadelphia, PA: Lippincott Williams & Wilkins.
- Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Buckingham, England: Open University Press.
- Knapp, M., Lemmi, V., & Romeo, R. (2013). Dementia care costs and outcomes: A systematic review. *International Journal of Geriatric Psychiatry*, 28(6), 551-561. <https://doi.org/10.1002/gps.3864>
- Knapp, M., Thorgrimsen, L., Patel, A., Spector, A., Hallam, A., Woods, B., & Orrell, M. (2006). Cognitive stimulation therapy for people with dementia: Cost-effectiveness analysis. *British Journal of Psychiatry*, 188, 574-580. <https://doi.org/10.1192/bjp.bp.105.010561>
- Kurz, A. F., Leucht, S., & Lautenschlager, N. T. (2011). The clinical significance of cognition-focused interventions for cognitively impaired older adults: A systematic review of randomized controlled trials. *International Psychogeriatrics*, 23(9), 1364-1375. <https://doi.org/10.1017/S1041610211001001>
- Law, M., Cooper, B., Strong, S., Stewart, D., Rigby, P., & Letts, L. (1996). The person-environment-occupation model: A transactive approach to occupational performance. *Canadian Journal of Occupational Therapy*, 63(1), 9-23. <https://doi.org/10.1177/000841749606300103>
- Leung, P., Yates, L., Orgeta, V., Hamidi, F., & Orrell, M. (2017). The experiences of people with dementia and their carers participating in individual cognitive stimulation therapy. *International Journal of Geriatric Psychiatry*, 32(12), e34-42. <https://doi.org/10.1002/gps.4648>
- Lewis-Beck, M. S., Bryman, A., & Liao, T. F. (2004). *The Sage encyclopedia of social science research methods*. Thousand Oaks, CA: Sage Publications.
- Li, Y., & Kielhofner, G. (2004). Psychometric properties of the Volitional Questionnaire. *Israel Journal of Occupational Therapy*, 13, E85-E98.
- Livingston, G., Johnston, K., Katona, C., Paton, J., & Lyketsos, C. G. (2005). Systematic review of psychological approaches to the management of neuropsychiatric symptoms of dementia. *American Journal of Psychiatry*, 162(11), 1996-2021. <https://doi.org/10.1176/appi.ajp.162.11.1996>
- Logsdon, R. G., Gibbons, L. E., McCurry, S. M., & Teri, L. (1999). Quality of life in Alzheimer's disease: Patient and caregiver reports. *Journal of Mental Health and Aging*, 5(1), 21-32.
- Marin, R. S. (1990). Differential diagnosis and classification of apathy. *American Journal of Psychiatry*, 147(1), 22-30. <https://doi.org/10.1176/ajp.147.1.22>
- Marin, R. S. (n.d.). Guidelines for apathy evaluation scale. Retrieved from <https://pdfs.semanticscholar.org/fe06/7d2af1a8d1287ce98dfc70f5f5b28498983e.pdf>
- Marin, R. S., Biedrzycki, R. C., & Firinciogullari, S. (1991). Reliability and validity of the Apathy Evaluation Scale. *Psychiatry Research*, 38(2), 143-162.

- Matsuda, O. (2007). Cognitive stimulation therapy for Alzheimer's disease: The effect of cognitive stimulation therapy on the progression of mild Alzheimer's disease in patients treated with donepezil. *International Psychogeriatrics*, 19(2), 241-252. <https://doi.org/10.1017/s1041610206004194>
- Ministry of Health. (2013). *New Zealand framework for dementia care*. Wellington, New Zealand: Ministry of Health.
- Ministry of Health. (2018a). *Challenges and opportunities*. Retrieved July 7, 2018, from <https://www.health.govt.nz/new-zealand-health-system/new-zealand-health-strategy-future-direction/challenges-and-opportunities>
- Ministry of Health. (2018b). *Overview of the health system*. Retrieved July 7, 2018, from <https://www.health.govt.nz/new-zealand-health-system/overview-health-system>
- Molineux, M. (2017). *A dictionary of occupational science and occupational therapy*. <https://doi.org/10.1093/acref/9780191773624.001.0001>
- Murray, C. M., Gilbert-Hunt, S., Berndt, A., & de la Perrelle, L. (2016). Promoting participation and engagement for people with dementia through a cognitive stimulation therapy programme delivered by students: A descriptive qualitative study. *British Journal of Occupational Therapy*, 79(10), 620-628. <https://doi.org/10.1177/0308022616653972>
- Murray, T. M., Sachs, G. A., Stocking, C., & Shega, J. W. (2012). The symptom experience of community-dwelling persons with dementia: Self and caregiver report and comparison with standardized symptom assessment measures. *American Journal of Geriatric Psychiatry*, 20(4), 298-305. <https://doi.org/10.1097/JGP.0b013e318235b758>
- National Ethics Advisory Committee. (2012). *Ethical guidelines for observational studies: Observational research, audits and related activities (Revised edition)*. Wellington, New Zealand: Ministry of Health.
- National Institute for Health and Clinical Excellence. (2006). *Dementia: Supporting people with dementia and their carers in health and social care (NICE CG 42)*. Retrieved from www.nice.org.uk/guidance/cg42
- National Institute for Health and Clinical Excellence. (2018). *Dementia: Assessment, management and support for people living with dementia and their carers (NICE NG 97)*. Retrieved from <https://www.nice.org.uk/guidance/ng97/resources/dementia-assessment-management-and-support-for-people-living-with-dementia-and-their-carers-pdf-1837760199109>
- Neergaard, M. A., Olesen, F., Andersen, R. S., & Sondergaard, J. (2009). Qualitative description: The poor cousin of health research? *BMC Medical Research Methodology*, 9, 52. <https://doi.org/10.1186/1471-2288-9-52>
- Olazaran, J., Reisberg, B., Clare, L., Cruz, I., Pena-Casanova, J., Del Ser, T., . . . Muniz, R. (2010). Nonpharmacological therapies in Alzheimer's disease: A systematic review of efficacy. *Dementia and Geriatric Cognitive Disorders*, 30(2), 161-178. <https://doi.org/10.1159/000316119>
- Orgeta, V., Leung, P., Yates, L., Kang, S., Hoare, Z., Henderson, C., . . . Orrell, M. (2015). Individual cognitive stimulation therapy for dementia: A clinical effectiveness and cost-effectiveness pragmatic, multicentre, randomised controlled trial. *Health Technology Assessment*, 19(64), 1-108. <https://doi.org/10.3310/hta19640>

- Orrell, M., Aguirre, E., Spector, A., Hoare, Z., Woods, R. T., Streater, A., . . . Russell, I. (2014). Maintenance cognitive stimulation therapy for dementia: Single-blind, multicentre, pragmatic randomised controlled trial. *British Journal of Psychiatry*, 204(6), 454-461. <https://doi.org/10.1192/bjp.bp.113.137414>
- Orrell, M., Yates, L., Leung, P., Kang, S., Hoare, Z., Whitaker, C., . . . Orgeta, V. (2017). The impact of individual cognitive stimulation therapy (iCST) on cognition, quality of life, caregiver health, and family relationships in dementia: A randomised controlled trial. *Plos Medicine*, 14(3), e1002269-e1002269. <https://doi.org/10.1371/journal.pmed.1002269>
- Paddick, S.-M., Mkenda, S., Mbowe, G., Kisoli, A., Gray, W. K., Dotchin, C. L., . . . Walker, R. W. (2017). Cognitive stimulation therapy as a sustainable intervention for dementia in sub-Saharan Africa: Feasibility and clinical efficacy using a stepped-wedge design. *International Psychogeriatrics*, 29(6), 979-989. <https://doi.org/10.1017/S1041610217000163>
- Pattie, A. H., & Gilleard, C. J. (1979). *Clifton Assessment Procedures for the Elderly (CAPE)*. Sevenoaks, United Kingdom: Hodder & Stoughton.
- Peri, K., & Cheung, G. (2017). *Cognitive stimulation therapy in New Zealand: The journey*. Unpublished manuscript.
- Piras, F., Carbone, E., Faggian, S., Salvalaio, E., Gardini, S., & Borella, E. (2017). Efficacy of cognitive stimulation therapy for older adults with vascular dementia. *Dementia & Neuropsychologia*, 11(4), 434-441. <https://doi.org/10.1590/1980-57642016dn11-040014>
- QSR International. (n.d.-a). *NVivo 11 for Windows help*. Retrieved July 7, 2018, from http://help-nv11.qsrinternational.com/desktop/concepts/About_theme_nodes.htm
- QSR International. (n.d.-b). *NVivo 11 Pro for Windows: Getting started guide*. Retrieved from <http://download.qsrinternational.com/Document/NVivo11/11.3.0/en-US/NVivo11-Getting-Started-Guide-Pro-edition.pdf>
- Raber, C., & Stone, M. (2015). An exploration of volition: Caregiver perceptions of persons with dementia. *Open Journal of Occupational Therapy*, 3(1), Art.3 1-21. <https://doi.org/10.15453/2168-6408.1075>
- Rehling, T., Corr, S., Sixsmith, J., & Chard, G. (2015). Cognitive stimulation therapy (CST) and occupational performance in dementia care. *British Journal of Occupational Therapy*, 78, 8-8.
- Reid, D., & Hirji, T. (2004). The influence of a virtual reality leisure intervention program on the motivation of older adult stroke survivors: A pilot study. *Physical and Occupational Therapy In Geriatrics*, 21(4), 1-19. https://doi.org/10.1080/J148v21n04_01
- Salkind, N. J. (2010). *Encyclopedia of research design*. Thousand Oaks, CA: SAGE Publications, Inc.
- Sandelowski, M. (2000). Focus on research methods: Whatever happened to qualitative description? *Research in Nursing & Health*, 23(4), 334-340. [https://doi.org/10.1002/1098-240X\(200008\)23:4<334::AID-NUR9>3.0.CO;2-G](https://doi.org/10.1002/1098-240X(200008)23:4<334::AID-NUR9>3.0.CO;2-G)
- Sandelowski, M. (2010). What's in a name? Qualitative description revisited. *Research in Nursing & Health*, 33(1), 77-84. <https://doi.org/10.1002/nur.20362>

- Satake, E., Maxwell, D. L., & Jagaroo, V. (2007). *Odyssey of the voice : Single subject design*. Retrieved from <http://ebookcentral.proquest.com/lib/aut/detail.action?docID=2051351>
- Spector, A., Gardner, C., & Orrell, M. (2011). The impact of cognitive stimulation therapy groups on people with dementia: Views from participants, their carers and group facilitators. *Aging & Mental Health*, 15(8), 945-949. <https://doi.org/10.1080/13607863.2011.586622>
- Spector, A., Orrell, M., Davies, S., & Woods, B. (2000). Reality orientation for dementia. *Cochrane Database of Systematic Reviews*, 2000(2), CD001119. <https://doi.org/10.1002/14651858.Cd001119>
- Spector, A., Orrell, M., Davies, S., & Woods, B. (2001). Can reality orientation be rehabilitated? Development and piloting of an evidence-based programme of cognition-based therapies for people with dementia. *Neuropsychological Rehabilitation*, 11(3-4), 377-397. <https://doi.org/10.1080/09602010143000068>
- Spector, A., Orrell, M., & Hall, L. (2012). Systematic review of neuropsychological outcomes in dementia from cognition-based psychological interventions. *Dementia and Geriatric Cognitive Disorders*, 34(3-4), 244-255. <https://doi.org/10.1159/000343931>
- Spector, A., Orrell, M., & Woods, B. (2010). Cognitive stimulation therapy (CST): Effects on different areas of cognitive function for people with dementia. *International Journal of Geriatric Psychiatry*, 25(12), 1253-1258. <https://doi.org/10.1002/gps.2464>
- Spector, A., Thorgrimsen, L., Woods, B., & Orrell, M. (2005). *Making a difference: An evidence-based group programme to offer cognitive stimulation therapy (CST) to people with dementia*. London, United Kingdom: Hawker Publications.
- Spector, A., Thorgrimsen, L., Woods, B., Royan, L., Davies, S., Butterworth, M., & Orrell, M. (2003). Efficacy of an evidence-based cognitive stimulation therapy programme for people with dementia: Randomised controlled trial. *British Journal of Psychiatry*, 183, 248-254. <https://doi.org/10.1192/bjp.183.3.248>
- Stanley, M. (2015). Qualitative descriptive: A very good place to start. In S. Nayar & M. Stanley (Eds.), *Qualitative research methodologies for occupational science and therapy*. Abingdon, United Kingdom: Routledge.
- Stewart, D. B., Berg-Weger, M., Tebb, S., Sakamoto, M., Roselle, K., Downing, L., . . . Hayden, D. (2017). Making a difference: A study of cognitive stimulation therapy for persons with dementia. *Journal Of Gerontological Social Work*, 60(4), 300-312. <https://doi.org/10.1080/01634372.2017.1318196>
- Streater, A., Aguirre, E., Spector, A., & Orrell, M. (2016). Cognitive stimulation therapy for people with dementia in practice: A service evaluation. *British Journal of Occupational Therapy*, 79(9), 574-580. <https://doi.org/10.1177/0308022616659886>
- Streater, A., Spector, A., Aguirre, E., & Orrell, M. (2016). Cognitive stimulation therapy (CST) for people with dementia in practice: An observational study. *British Journal of Occupational Therapy*, 79(12), 762-767. <https://doi.org/10.1177/0308022616668358>
- Taylor, R. (2017). *Kielhofner's model of human occupation: Theory and application* (5th ed.). Philadelphia, PA: Lippincott Williams & Wilkins.

- Toh, H. M., Ghazali, S. E., & Subramaniam, P. (2016). The acceptability and usefulness of cognitive stimulation therapy for older adults with dementia: A narrative review. *International Journal of Alzheimer's Disease*, 2016, 5131570. <https://doi.org/10.1155/2016/5131570>
- Townsend, E. A., & Polatajko, H. J. (2007). *Enabling occupation II: Advancing an occupational therapy vision for health, well-being and justice through occupation*. Ottawa, Canada: CAOT Publications.
- Venkatesh, V., Brown, S. A., & Sullivan, Y. W. (2016). Guidelines for conducting mixed-methods research: An extension and illustration,. *Journal of the Association for Information Systems*, 17(7), Article 2. Retrieved from <http://aisel.aisnet.org/jais/vol17/iss7/2>
- Vogt, W. P. (2014). *Selecting the right analyses for your data : Quantitative, qualitative and mixed methods*. New York, NY: The Guilford Press.
- Woods, B., Aguirre, E., Spector, A. E., & Orrell, M. (2012). Cognitive stimulation to improve cognitive functioning in people with dementia. *Cochrane Database of Systematic Reviews*, 2012(2), CD005562. <https://doi.org/10.1002/14651858.CD005562.pub2>
- Woods, B., Thorgrimsen, L., Spector, A., Royan, L., & Orrell, M. (2006). Improved quality of life and cognitive stimulation therapy in dementia. *Aging & Mental Health*, 10(3), 219-226. <https://doi.org/10.1080/13607860500431652>
- World Health Organization. (2002). *Towards a common language for functions, disability and health*. Retrieved from <http://www.who.int/classifications/icf/training/icfbeginnersguide.pdf>
- Yamanaka, K., Kawano, Y., Noguchi, D., Nakaaki, S., Watanabe, N., Amano, T., & Spector, A. (2013). Effects of cognitive stimulation therapy Japanese version (CST-J) for people with dementia: A single-blind, controlled clinical trial. *Aging & Mental Health*, 17(5), 579-586. <https://doi.org/10.1080/13607863.2013.777395>
- Yates, L. A., Leung, P., Orgeta, V., Spector, A., & Orrell, M. (2015). The development of individual cognitive stimulation therapy (iCST) for dementia. *Clinical Interventions in Aging*, 10, 95-104. <https://doi.org/10.2147/cia.s73844>
- Yates, L. A., Orgeta, V., Leung, P., Spector, A., & Orrell, M. (2016). Field-testing phase of the development of individual cognitive stimulation therapy (iCST) for dementia. *BMC Health Services Research*, 16, 233. <https://doi.org/10.1186/s12913-016-1499-y>
- Yuill, N., & Hollis, V. (2011). A systematic review of cognitive stimulation therapy for older adults with mild to moderate dementia: An occupational therapy perspective. *Occupational Therapy International*, 18(4), 163-186. <https://doi.org/10.1002/oti.315>

Appendices

Appendix 1 Comparison between the Volitional Questionnaire and the Apathy Evaluation Scale

	The Volitional Questionnaire (VQ)	The Apathy Evaluation Scale (AES)
Measuring Construct	Volition/motivation	Apathy /lack of motivation
Theoretic Framework	The concept of volition in the Model of Human Occupation consists of “(a) a stable structure of dispositions and self-awareness and (b) a dynamic process of anticipating, choosing, experiencing, and reflecting on one's actions. Dispositions refer to innate and acquired emotional and cognitive orientations toward the world. Self-knowledge refers to the image of self as an actor that is built up from experience. Three areas comprise volitional self-knowledge and dispositions, personal causation, values, and interests” (Chern et al., 1996, p. 516).	Marin's (1990) conception of apathy is lack of motivation to the extent that patients show changes in the behavioural, cognitive, and emotional aspects of goal-directed behaviour, not attributable to diminished level of consciousness, cognitive impairment, or emotional distress. Operationally, apathy is defined by simultaneous deficits in the overt behavioural, cognitive, and emotional concomitants of goal-directed behaviour.
Description of Measure	The VQ is an observational assessment tool suitable to evaluate volition in people who have significant limitations in cognitive, verbal, or physical abilities. It is comprised of a 4-point rating scale (termed as Passive, Hesitant, Involved, and Spontaneous) to assess 14 behavioural items (at three levels, Exploration, Competency, and Achievement) and an Environmental Characteristic Form (de las Heras et al., 2007).	Three versions of the AES, clinician, informant, and self-rated (Marin, n.d.). A total of 18 item scored on a 4-point Likert-type scale with four categories: Not at All True, Slightly True, Somewhat True, and Very True. For the AES-C, the comparable terms are: Not at All Characteristic, Slightly Characteristic, Somewhat Characteristic, and Very Characteristic.
Psychometric Properties	Chern et al. (1996) found a good construct validity and a valid representation of the volitional continuum however this might not measure high levels of volition accurately. Li and Kielhofner (2004) evaluated Version 4.0 and found it valid and sensitive for measuring volition and discriminating between different levels. Intra-rater reliability was consistently observed; however, inter-rater reliability was questionable. Reid and Hirji (2004) used Version 3.0 as an outcome and noticed correlation between the VQ scores and the scores for depression and	Multiple forms of reliability (internal consistency, test-retest, and interrater) were satisfactory (Marin et al., 1991). Several types of validity evidence were presented: ability of the AES to discriminate between groups, discriminability of apathy ratings from standard measures of depression and anxiety, convergent validity between the three versions of the scale, and predictive validity (Marin et al., 1991). In dementia, the AES-C was found to have fairly good psychometric properties. However, from a

	<p>life satisfaction. Agren and Kjellberg (2008) examined Swedish version and found it adequately measured volition across all clinical situations. Raber and Stone (2015) applied Version 4.1 with people with moderate dementia in residential setting and found it useful.</p>	<p>diagnostic point of view, the AES-I provided the greatest sensitivity and the strongest positive and negative predictive values. Generally, the AES-S performed poorly compared with the AES-C and AES-I (Clarke et al., 2007).</p>
Administration	<p>Each occasion of observation includes completing the volitional rating form(s) and records qualitative information regarding characteristics of the person's environment. The situation of observation can be flexible and may take place during any self-care, leisure or productive activity contexts in a wide range of environments (natural, transitional or therapeutic). Length of observation period is highly variable generally between 5-30 minutes (de las Heras et al., 2007).</p>	<p>The AES-I and the AES-S are administered as paper and pencil tests. The AES-C is administered as a semi-structured interview based on current functioning as evident from the subject's "thoughts, feelings, and actions" during the past 4 weeks. The ratings are based on the clinician's assessment of the patient's self-report except for the 4 self-evaluations items (Marin, n.d.).</p>
User Training	<p>The training consists of review of information in the manual and of practice using the Volitional Questionnaire. Thus, it is conceivable that occupational therapists could learn to use the instrument effectively from the manual and practice alone, but this remains to be demonstrated (Chern et al., 1996).</p>	<p>Bachelor's level raters can be introduced to the concept of apathy and taught to use the AES with adequate reliability with only 4-6 hours experiences. Research levels of inter-rater agreement can be reached by experienced clinicians by rating as few as 5-10 subjects (Marin, n.d.).</p>
Application in Research	<p>The VQ was used in people with moderate dementia in a residential care setting (Raber & Stone, 2015). It required several observational sessions to complete as well as a pre-observation planning meeting with the activity staff member.</p>	<p>The AES was used in the randomized clinical trial by Buettner, Fitzsimmons, Atav, and Sink (2011) to evaluation the effectiveness of the classroom style mentally stimulating activities (MSAs). The results showed that the MSA group had significantly lower levels of apathy and significantly lower symptoms of depression than the control group.</p>

Appendix 2 Ethics Approval

21 November 2016

Margaret Anne Jones
Faculty of Health and Environmental Sciences

Dear Margaret Anne

Re Ethics Application: **16/396 Describing and measuring the 'switch-on' effect in people with mild to moderate dementia who participate in cognitive stimulation therapy.**

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

Your ethics application has been approved for three years until 21 November 2019.

As part of the ethics approval process, you are required to submit the following to AUTC:

- A brief annual progress report using form EA2, which is available online through <http://www.aut.ac.nz/researchethics>. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on 21 November 2019;
- A brief report on the status of the project using form EA3, which is available online through <http://www.aut.ac.nz/researchethics>. This report is to be submitted either when the approval expires on 21 November 2019 or on completion of the project.

It is a condition of approval that AUTC is notified of any adverse events or if the research does not commence. AUTC approval needs to be sought for any alteration to the research, including any alteration of or addition to any documents that are provided to participants. You are responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

AUTC grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to obtain this.

To enable us to provide you with efficient service, please use the application number and study title in all correspondence with us. If you have any enquiries about this application, or anything else, please do contact us at ethics@aut.ac.nz.

All the very best with your research,



Kate O'Connor
Executive Secretary
Auckland University of Technology Ethics Committee

Cc: qil@adhb.govt.nz; Clare Hocking

Appendix 3 Research Invitation Flyer



Research Invitation



My name is **Qi (pronounced Chee) Liu**. I am a student of the Auckland University of Technology (AUT) studying towards a Master degree in health science. I am undertaking a research project exploring some of the positive changes noticed in people attending Cognitive Stimulation Therapy (CST) groups. These changes are called **the “switch on” effect**.

People who are planning to attend the cognitive stimulation therapy (CST) group, and/or their family members or caregivers are warmly invited to take part in my study.

Participation in the study will involve **a total of 3-4 visits** with me at your home; one or two before the group starts, one during and one after the CST programme. As a CST group member, you will be asked to talk about your experience of everyday life, and will take part in a measure of motivation based on observations of how you carry out 2 simple daily activities of your choice. As a family member or caregiver, you will be interviewed about the daily activities of the CST group member you are associated with.

To take part in my study or ask any questions, please let the person who referred you to the CST group know that you are interested. Alternately, you could phone me on **623 6474 ext 26493**, text me on **021 036 8187** or email knm2152@autuni.ac.nz.

Thank you for considering this invitation and I look forward to hearing from you.

Kind Regards,

Qi Liu

This project is supervised by **Dr. Margaret Jones** and **Professor Clare Hocking** from AUT.

Appendix 4 Information Sheets for Research Participants

Information Sheet for Patient Participants

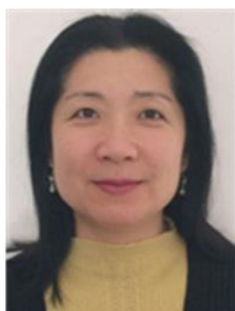
Participant Information Sheet

Person Attending Cognitive Stimulation Therapy Group

Describing and measuring the “switch-on” effect in people who participate in cognitive stimulation therapy (CST)

Project Supervisors: Dr Margaret Jones, Professor Clare Hocking

Project Researcher: Qi Liu



You are invited to take part in an AUT study of the “switch-on” effect of cognitive stimulation therapy

My name is **Qi (pronounced Chee) Liu**. I am a student studying at Auckland University of Technology. I also work as an occupational therapy supervisor at the Auckland District Health Board.

You are invited to take part in this research project that will help me complete my Master’s degree. **Your participation is your choice.** If you do participate, you can change your mind and withdraw at any time, and you don’t need to provide a reason. If you choose to not participate, it will not affect the care you are getting.

This Information Sheet will help you decide if you would like to take part. I will help you go through it and it may take 20 minutes. **You don’t have to make the decision today.** Please feel free to talk with other people about it, such as your family/whanau, friends, carer, or health professionals.

What is the purpose of this research?

- This research will explore the positive changes that some people experience after attending cognitive stimulation therapy groups. These changes are called **the “switch-on” effect**.
- When people experience the “switch-on” effect, they may communicate more and take part more in activities.

- The study will try to describe and measure the “switch-on” effect. It will help us understand the benefits of cognitive stimulation therapy.

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

- You are invited because **you have enrolled in a 7-week cognitive stimulation therapy group**. The group consists of enjoyable and stimulating activities for people like yourself who have some memory problems, such as singing, games and talking about childhood memories, food and newspaper articles.
- A family member or caregiver is also invited to join the study. Their perspective will help us understand if cognitive stimulation therapy is helpful. If no one from your family wants to join the study, you can still join in.

How do I agree to participate in this research?

You will need to **complete a Consent Form** to agree to participate in this research.

What will happen in this research?

- You will have **3-4 meetings** with me at home, once or twice before the group starts, once during and once after the cognitive stimulation therapy programme. The first meeting will take an hour to an hour and a half. Follow up meetings will each take about an hour.
- You will **be asked some questions about your experience of everyday living** in each meeting. The interviews will be audiotaped and then typed. The typed interviews will be sent back to you to check if you wish.

You will take part in a measure of motivation called the Volitional Questionnaire in each meeting. For this, you will **carry out one or two everyday activities of your choice** while I observe.



- You **may need to conduct a cognitive test** (the Addenbrooke's Cognitive Examination (ACE-III)) in the first meeting. It is a paper and pencil test that usually takes 15 minutes. If you have done it within the past 6 months, you won't need to do it again. However, you will need to give consent for me to contact your healthcare provider to obtain the results.



- The information gathered from you will be used for this research project only.

What are the discomforts and risks?

It is very unlikely you will experience any discomfort or risk in the research.

What are the benefits?

- You may find it interesting to talk about your daily experiences.
- You will be helping us learn more about the positive effects of cognitive stimulation. This information may help other people in the future.
- You will be helping me complete my thesis and Master's degree

How will my privacy be protected?

- **We won't share your information** with anyone else without your consent.
- We won't use your name in the report and will remove any information that might identify you.
- Only my supervisors and I can access the research information.
- All the research data will be stored safely and protected with a password at AUT.

What are the costs of participating in this research?

This research won't cost you any money. However, you will spend your time with me, likely **4 to 6 hours in total**.

What opportunity do I have to consider this invitation?

You will have **at least a week** to think about whether or not you would like to take part in the study.

Will I receive feedback on the results of this research?

Yes. If you would like, at the end of all the assessments, I can send you the results from the motivation assessments. At the end of the study, I can also post you a summary of the findings. A meeting at your home can be arranged if you would like to have face-to-face feedback.

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

- Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, **Dr Margaret Jones**, *margaret.jones@aut.ac.nz* , **09 921 9999 ext 7781**.
- Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEK, Kate O'Connor, *ethics@aut.ac.nz* , 09 921 9999 ext 6038.

Whom do I contact for further information about this research?

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

Researcher Contact Details:

Qi Liu, *knm2152@autuni.ac.nz* , **09 623 6474 ext 26493** or 021 036 8187.

Project Supervisors Contact Details:

Dr. Margaret Jones, *margaret.jones@aut.ac.nz* , 09 921 9999 ext 7781.

Professor Clare Hocking, *clare.hocking@aut.ac.nz* , 09 921 9162.

**Approved by the Auckland University of Technology Ethics Committee on
21/11/2016**

AUTEK Reference number 16/396

Information Sheet for Family Participants

Participant Information Sheet

Family Member or Caregiver

Describing and measuring the “switch-on” effect in people who participate in cognitive stimulation therapy (CST)

Project Supervisors: Dr Margaret Jones, Professor Clare Hocking

Project Researcher: Qi Liu

You are invited to take part in an AUT study of the “switch-on” effect of cognitive stimulation therapy

My name is **Qi (pronounced Chee) Liu**. I’m a student of the Auckland University of Technology studying towards the Master of Health Science. I also work as an occupational therapy practice supervisor at the Auckland District Health Board.

You are invited to participate in this research project that will help me learn more about the effects of cognitive stimulation therapy for people with dementia. It will also help me produce a thesis and complete my Master’s degree. This Information Sheet will help you make the decision about whether or not you would like to take part. **Your participation is entirely voluntary.** You have no obligation to partake and have the right to withdraw from the research at any time without needing to provide a reason.

What is the purpose of this research?

The purpose of this research is to **explore the nature and occurrence of the “switch-on” effect**, a positive outcome experienced by some people with mild to moderate dementia who participate in cognitive stimulation therapy (CST).

Cognitive stimulation is defined as engagement in a range of activities and discussions, usually in a social setting, providing general stimulation for thinking, concentration and memory. CST is a structured and manualised group programme that offers 14 enjoyable activity sessions over the period of 7 weeks. Each group session runs 45 minutes, content including reality orientated activities (such as welcoming all members by name, singing the selected group theme song, discussing about current time, place and newspaper), and a main activity with a theme like games, sounds, childhood, food, faces/scene and so on.

CST is one of the few effective interventions for people with mild to moderate dementia that improves cognitive functioning and quality of life. The “switch-on” effect was a finding from some CST studies that people became more sociable and engaged with activities after attending CST.

This research aims to describe and measure the “switch-on” effect through interviewing CST group members and observing how they engage with everyday activities, and by interviewing family members or caregivers. The results will contribute further information about the “switch-on” effect and the health and social benefits of cognitive stimulation for people with dementia.

The research project will lead to academic publications (such as a journal article) and presentations in professional and community settings.

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

You were identified as a potential participant because you are a family member/caregiver of the person who is going to join the CST group and you regularly spend time with him/her. You are eligible to participate even if your family member decides not to.

How do I agree to participate in this research?

You will need to complete a Consent Form to agree to participate in this research.

What will happen in this research?

You will have **3-4 meetings with me at your home or a venue of your choice** once or twice before the CST starts, once during the programme, and once after CST. Allow **40-50 minutes for the first meeting with me and 20-30 minutes for follow up meetings**. You will be interviewed about what the person who attends the CST group has been doing and how he or she presents. The interviews will be audiotaped and typed fully. The transcripts will be sent back to you for checking.

The information you provide will only be used for this research.

What are the discomforts and risks?

It is very unlikely you will experience any discomfort or risk in the research.

What are the benefits?

This study will provide opportunities for the person with dementia to have additional social contact and talk about his or her daily experiences. The information will be used to gain more understanding about the positive effects of CST, which may help inform the decisions about providing CST as an intervention for people with dementia.

This project will provide me with the benefits of exploring a topic that I feel passionate about, learning how to conduct scientific research, and obtaining a Master's qualification.

How will my privacy be protected?

No information will be shared with a third party without your consent. You can nominate a pseudonym to be used in the final report and publications. No identifiable personal information will be included in that report or in publications.

Access to research information will be strictly limited to myself and my supervisors during the data collection and analysis stages. After the findings have been produced, all the research data will be stored safely and confidentially in the AUT premises. The data will be kept for 10 years before they are destroyed appropriately. There is no plan for any future use of the research data that is beyond the project described here.

What are the costs of participating in this research?

The major cost of participating in this research will be your time. The overall estimated time for participating in the research is **likely between 2.5 to 3.5 hours**.

What opportunity do I have to consider this invitation?

You will have **up to 2 weeks** to consider this invitation before any further contact is made.

Will I receive feedback on the results of this research?

Yes. On completion of this study, a summary of the research findings will be posted to your home address.

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

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Dr Margaret Jones, margaret.jones@aut.ac.nz , 09 921 9999 ext 7781.

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTECH, Kate O'Connor, ethics@aut.ac.nz , 921 9999 ext 6038.

Whom do I contact for further information about this research?

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

Researcher Contact Details:

Qi Liu, knm2152@autuni.ac.nz , 09 623 6474 ext 26493 or 021 036 8187.

Project Supervisors Contact Details:

Dr Margaret Jones, margaret.jones@aut.ac.nz , 09 921 9999 ext 7781

Professor Clare Hocking, clare.hocking@aut.ac.nz , 09 921 9162.

**Approved by the Auckland University of Technology Ethics Committee on
21/11/2016**

AUTEC Reference number 16/396

Information Sheet for Next-of-kin

Participant Information Sheet

Next of Kin

Describing and measuring the “switch-on” effect in people who participate in cognitive stimulation therapy (CST)

Project Supervisors: Dr Margaret Jones, Professor Clare Hocking

Project Researcher: Qi Liu

Your relative is invited to take part in an AUT study of the “switch-on” effect of cognitive stimulation therapy

My name is **Qi (pronounced Chee) Liu**. I’m a student of the Auckland University of Technology studying towards the Master of Health Science. I also work as an occupational therapy practice supervisor at the Auckland District Health Board.

I am inviting your relative to participate in this research project that will help me learn more about the effects of cognitive stimulation therapy for people with dementia. It will also help me produce a thesis and complete the Master’s degree. I understand that your relative has been given a diagnosis of dementia and has enrolled in a cognitive stimulation therapy group, which is why they are invited to take part in the study.

Your involvement as a next of kin is important as some people with dementia may need support to make the informed decision about participating in the research. It is your relative’s choice whether or not to take part in the study; however, we would like you to provide support for them to make the decision and ensure their autonomy and best interest is taken care of.

This Information Sheet will help you understand the research so that you can support your relative to make the decision about whether or not they would like to take part. **Your relative’s participation is entirely voluntary.** They have no obligation to partake and have the right to withdraw from the research at any time without needing to provide a reason.

If you and your relative decide to take part in the study, you will be asked to sign a Next of Kin Form to assure the process of supported decision making.

What is the purpose of this research?

The purpose of this research is to **explore the nature and occurrence of the “switch-on” effect**, a positive outcome experienced by some people with mild to moderate dementia who participate in cognitive stimulation therapy (CST).

Cognitive stimulation is defined as engagement in a range of activities and discussions, usually in a social setting, providing general stimulation for thinking, concentration and memory. CST is a structured and manualised group programme that offers 14 enjoyable activity sessions over the period of 7 weeks. Each group session runs 45 minutes, content including reality orientated activities (such as welcoming all members by name, singing the selected group theme song, discussing about current time, place and newspaper), and a main activity with a theme like games, sounds, childhood, food, faces/scene and so on.

CST is one of the few effective interventions for people with mild to moderate dementia that improves cognitive functioning and quality of life. The “switch-on” effect was a finding from some CST studies that people became more sociable and engaged with activities after attending CST.

This research aims to describe and measure the “switch-on” effect through interviewing CST group members and observing how they engage with everyday activities, and by interviewing family members or caregivers. The results will contribute further information about the “switch-on” effect and the health and social benefits of cognitive stimulation for people with dementia.

The research project will lead to academic publications (such as a journal article) and presentations in professional and community settings.

How was my relative identified and why are they being invited to participate in this research?

Your relative was identified as a potential participant because they **have a diagnosis of mild or moderate dementia** and **have enrolled in a 7-week cognitive stimulation therapy group**.

A family member or caregiver (may or may not be yourself) who regularly spends time with your relative will be invited to take part in the study as well. Their perspective will help us understand the impact of CST and whether or not the person experiences the “switch-on” effect.

If the family member or caregiver doesn’t want to join the study, the person with dementia will still be eligible for taking part; and vice versa.

How does my relative agree to participate in this research?

With your support, your relative will need to complete an **Assent Form** to agree to participate in this research. You will need to sign the **Next of Kin Form**.

What will happen in this research?

Your relative will have **3-4 meetings with me at their home or a venue of their choice** once or twice before the CST starts, once during the programme, and once after CST. The first meeting will take 60-90 minutes, and each follow up meeting will take 60 minutes.

Your relative **will be interviewed** about their experience of everyday living in each meeting and the interviews will be audiotaped and typed fully. The transcripts will be set back to your relative for checking.

Your relative **will take part in a measure of motivation** called the Volitional Questionnaire (VQ) in each meeting. They will be asked to carry out two everyday activities of their choice and I will be observing and then complete the scoring of the VQ.

Your relative **will need to conduct a cognitive test** called the Addenbrooke's Cognitive Examination (ACE-III) in the first meeting. It is a paper and pencil test that usually takes 15 minutes.

The information gathered from the meetings with your relative will only be used for this research.

What are the discomforts and risks?

It is very unlikely your relative will experience any discomfort or risk in the research.

What are the benefits?

This study will provide opportunities for your relative to have additional social contact and talk about their daily experiences. The information will be used to gain more understanding about the positive effects of CST, which may help inform the decisions about providing CST as an intervention for people with dementia.

This project will provide me with the benefits of exploring a topic that I feel passionate about, learning how to conduct scientific research, and obtaining a Master's qualification.

How will my relative's privacy be protected?

No information will be shared with a third party without your and your relative's consent. Your relative can nominate a pseudonym to be used in the final report and publications. No identifiable personal information will be included in that report or in publications.

Access to research information will be strictly limited to myself and my supervisors during the data collection and analysis stages. After the findings have been produced, all the research data will be stored safely and confidentially in the AUT premises. The data will be kept for 10 years before they are destroyed appropriately. There is no plan for any future use of the research data that is beyond the project described here.

What are the costs of participating in this research?

The major cost of participating in this research will be your relative's time. The overall estimated time for participating in the research is **likely between 4 to 6 hours**.

What opportunity does my relative have to consider this invitation?

You and your relative will have **up to 2 weeks** to consider this invitation before any further contact is made.

Will my relative receive feedback on the results of this research?

Yes. On completion of data gathering, the Volitional Questionnaire results will be provided to your relative if he or she requests them. On completion of this study, a summary of the research findings will be posted to your relative's home address if they request them.

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

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Dr Margaret Jones, margaret.jones@aut.ac.nz , 09 921 9999 ext 7781.

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTC, Kate O'Connor, ethics@aut.ac.nz , 921 9999 ext 6038.

Whom do I contact for further information about this research?

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

Researcher Contact Details:

Qi Liu, knm2152@autuni.ac.nz , 09 623 6474 ext 26493 or 021 036 8187.

Project Supervisors Contact Details:

Dr Margaret Jones, margaret.jones@aut.ac.nz , 09 921 9999 ext 7781

Professor Clare Hocking, clare.hocking@aut.ac.nz , 09 921 9162.

**Approved by the Auckland University of Technology Ethics Committee on
24/01/2017**

AUTC Reference number 16/396

Appendix 5 Research Participant Consent Forms

Research Consent Form for Patient Participants

Consent Form

Person Attending Cognitive Stimulation Therapy Group



Project Title: Describing and measuring the “switch-on” effect in people who participate in cognitive stimulation therapy

Project Supervisors: Dr. Margaret Jones, Professor Clare Hocking

Project Researcher: Qi Liu

- ☐ I have read and understood the Information Sheet dated 21/11/2016.
- ☐ I understand I do not have to take part. It is my choice.
- ☐ I understand I may withdraw from the study at any time without being disadvantaged in any way.
- ☐ I understand I may withdraw from the study at any time without if affecting my involvement in the cognitive stimulation therapy group.
- ☐ I have had time to think about whether or not I would like to take part.
- ☐ I have had an opportunity to ask questions and to have them answered.
- ☐ I understand I will have interviews. They will be audio-taped and transcribed.
- ☐ I understand I will carry out some simple daily activities of my choice. The researcher will observe how I conduct the activities.
- ☐ I understand I may need to do a cognitive test if I haven't done it recently.
- ☐ I agree to take part in this research.
- ☐ I wish to receive the results of my motivation assessments (Volitional Questionnaire) (please tick one): Yes ☐ No ☐
- ☐ I wish to receive a summary of the research findings (please tick one):
Yes ☐ No ☐
- ☐ I agree that the researcher can contact my healthcare provider to obtain information about my cognitive testing (the Addenbrooke Cognitive Examination - III) within the last 6 months (please tick one):
Yes ☐ No ☐

Participant's signature:

.....

Participant's name:

.....

Participant's Contact Details (if appropriate):

.....

.....

.....

.....

Date:

***Approved by the Auckland University of Technology Ethics Committee on
21/11/2016, AUTECH Reference number 16/396.***

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

Research Consent Form for Family Participants

Consent Form

Family Member or Caregiver



Project title: Describing and measuring the “switch-on” effect in people who participate in cognitive stimulation therapy

Project Supervisors: Dr. Margaret Jones, Professor Clare Hocking

Project Researcher: Qi Liu

- ☐ I have read and understood the information provided about this research project in the Information Sheet dated 21/11/2016.
- ☐ I have had an opportunity to ask questions and to have them answered.
- ☐ I understand that notes will be taken during the interviews and that they will also be audio-taped and transcribed.
- ☐ I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without being disadvantaged in any way.
- ☐ I understand that if I withdraw from the study then I will be offered the choice between having any data that is identifiable as belonging to me removed or allowing it to continue to be used. However, once the findings have been produced, removal of my data may not be possible.
- ☐ I agree to take part in this research.
- ☐ I wish to receive a summary of the research findings (please tick one): Yes ☐ No ☐

Participant's signature:

.....

Participant's name:

Participant's Contact Details (if appropriate):

.....
.....
.....
.....

Date:

Approved by the Auckland University of Technology Ethics Committee on 21/11/16

AUTEC Reference number 16/396

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

Appendix 6 Semi-structured Interview Questions

Semi-structured Interview Questions for Patient Participants

1. How have you been doing over the last month? What are some of the things you have been doing that stand out to you?
2. What sorts of things do you enjoy doing within home or outside, alone or with other people? How did you get on with these things lately?
3. Can you tell me how you spend your time on a typical day, starting from waking up in the morning?
4. How have you been feeling about things lately?
5. What sorts of activities have you been doing where you needed to concentrate? How did you get on with these things?
6. How did you find communicating with your family and other people around you lately?
7. Thinking about the things you've done over the last few days – has your experience of doing them changed? Can you tell me about that?
8. Have you noticed any changes between what you're describing to me now, and how things were a month ago? Can you tell me about that?
9. Have you experienced any major life changes that would account for that? If yes, what are they?

Semi-structured Interview Questions for Family Participants

1. How has the person been doing over the last month? What are some of the things he/she has been doing that stand out to you?
2. What sorts of things does the person enjoy doing within home or outside, alone or with other people? How did he/she get on with these things lately?
3. Can you tell me how the person spends his/her time on a typical day, starting from waking up in the morning?
4. How has the person been feeling about things lately from your understanding?
5. What sorts of activities has the person been doing where he/she needed to concentrate? How did he/she get on with these things?
6. How did you find the person communicating with his/her family and other people around him/her lately?
7. Thinking about the things the person has done over the last few days – have you noticed any difference? Can you tell me about that?
8. Have you noticed any changes between what you're describing to me now, and how things were a month ago? Can you tell me about that?
9. Has the person experienced any major life changes that would account for that? If yes, what are they?

Appendix 7 Confidentiality Agreement Form for Professional Transcriber



Confidentiality Agreement

For Professional Transcriber

Project title: **Describing and measuring the “switch-on” effect in people with mild and moderate dementia who participate in cognitive stimulation therapy (CST)**

Project Supervisors: **Dr. Margaret Jones, Professor. Clare Hocking**

Researcher: **Qi Liu**

- ☐ I understand that all the material I will be asked to transcribe is confidential.
- ☐ I understand that the contents of the tapes or recordings can only be discussed with the researchers.
- ☐ I will not keep any copies of the transcripts nor allow third parties access to them.

Transcriber's signature:

Transcriber's name:

Transcriber's Contact Details (if appropriate):

.....
.....
.....
.....

Date:

Project Supervisors' Contact Details (if appropriate):

Dr. Margaret Jones

Email: margaret.jones@aut.ac.nz

Tel: 09 921 9999 ext 7781

Professor Clare Hocking

Email: clare.hocking@aut.ac.nz

Tel: 09 921 9162.

Approved by the Auckland University of Technology Ethics Committee on 21/11/16

AUTEC Reference number 16/396

Appendix 8 Volitional Questionnaire Scoring Sheet (Adapted)

Volitional Questionnaire Scoring Sheet

Participant ID:

Diagnosis:

Date:

Demographic Information:

Setting and Activity:

E = Exploration C = Competency A = Achievement P = Passive H = Hesitant I = Involved S = Spontaneous N/O = No opportunity to observe

VQ Items	Ratings	Comments
E1. Shows curiosity	P H I S N/O	
E2. Initiates actions/tasks	P H I S N/O	
E3. Tries new things	P H I S N/O	
E4. Shows preferences	P H I S N/O	
E5. Shows that an activity is special or significant	P H I S N/O	
C1. Indicates goals	P H I S N/O	
C2. Stays engaged	P H I S N/O	
C3. Shows pride	P H I S N/O	
C4. Tries to solve problems	P H I S N/O	
C5. Tries to correct mistakes	P H I S N/O	
A1. Pursues activity to completion/accomplishment	P H I S N/O	
A2. Invests additional energy/emotion/attention	P H I S N/O	
A3. Seeks additional responsibilities	P H I S N/O	
A4. Seeks challenges	P H I S N/O	

Appendix 9 An Example Prompting Sheet for Administering the VQ

Indicators for Rating the VQ Items (Passive, Hesitant, Involved, and Spontaneous)

Activity Type(s): Making a hot drink

E: exploratory level; C: competence level; A: achievement level

VQ Items	Indicators (observation & questions)
E1. Shows curiosity	Whether showing attention or exploring something new in the task context
E2. Initiates actions/tasks	Whether beginning the task and the next step towards completion – allowed to receive initial instruction, orientation and necessary assistance. Whether going away from the task and refuse to re-engage.
E3. Tries new things	Asking if willing to try new brands, methods/procedures or a new drink Requires less motivation than A4
E4. Shows preferences	Asking preferences about timing, tea vs coffee, sugar, milk, with snacks etc
E5. Shows that an activity is special or significant	Whether showing pleasure or easily distracted.
C1. Indicates goals	Whether verbally and non-verbally selecting/indicating an objective to accomplish in the immediate future.
C2. Stays engaged	Whether showing ongoing/sustained affective connections to what is done. Requires higher motivation than E5. One can have high C2 and low A1
C3. Shows pride	Whether making positive/negative statements; whether showing/hiding products to others. Giving compliments and observing responses. Beware cultural differences in expressing pride.
C4. Tries to solve problems	Whether remaining involved in a task when difficulties/obstacles arise: washing, up the cup before using it, attempting to move an object that is blocking the view. May point out problems or ask “what if” questions to elicit response: what if running out of teabag/coffee/milk. Scored low if stopping, becoming upset or refusing help
C5. Tries to correct mistakes	Whether showing intention to fix or improve: spilling a drink and trying to clean up May point out mistakes or ask “what if” questions to elicit response. Scored low if becoming flustered, afraid or too frustrated to try.
A1. Pursues activity to completion/accomplishment	Whether persisting/sustaining effort until the goal/objective is reached.
A2. Invests additional energy/emotion/attention	Whether investing additional emotion and effort, eg. trying harder, visually more aroused, verbalizing excitement.
A3. Seeks additional responsibilities	Whether readily accepting a higher level of duty or obligation. Asking whether willing to do more.
A4. Seeks challenges	Whether readily accept or looking for additional quantity, quality, complexity, duration, standard of performance.

Appendix 11 Excerpt of NVivo Codebook for “Relating”

Name	Description	Source	References
Relating – Time 1	Before CST	0	0
Getting social contact and support		0	0
Able to talk to people		7	14
I don't ask people their names		3	4
I don't let people push me		1	1
I like to listen and learn from others		1	1
Making jokes		1	2
Wanting to address people by name		1	1
Children often come around		3	4
Enjoyed the company of people		1	1
Most people are very good		1	1
Supportive relationship with wife		4	9
Appreciative of wife		3	8
Wanting to make wife proud of me		1	1
Wanting to taking care of wife		3	5
Wife trying to keep him happy busy and happy		2	6
Impacting on wife		2	4
Asking or repeating all the time		0	0
Getting angry if wife didn't tell him		1	1
He really doesn't know		2	4
If I put it wrong, then I get in trouble		1	1
Saying he loves wife many times a day		1	3
Stressful home situation		1	2
Wife feeling sad for him		1	1
Wife wanting time out		2	2
Relating to others becoming problematic		0	0
He is cheeky and challenging sometimes		2	2
Arguing about little things		2	6
Doesn't understand wife needing time out		1	4
Overly worried about wife		1	3
Just in his own little world		2	6
Difficult to communicate at home		1	3
Has never been a social person		2	3
Starting to be a lost soul		0	0
He didn't have much to say about anything		1	1
He was there but wasn't really participating		2	4
Nearly all my mates are dead		1	3
Obsessed with what's happening to him		1	1
Some of his understanding is muted		1	1
Talking about euthanasia		1	1
Withdrawing into himself		1	3
I have to bite my tongue		1	5
Relating – Time 2	During CST	0	0
Doing little things to help wife		5	10
Improved relationship with wife		0	0
He is more understanding		1	4

Less shadowing	1	1
He's part of it	2	5
He is more like his old self	1	1
Unchanged relationship	1	1
Asking questions all the time	1	1
Difference in getting things done	2	4
Stressful home situation	1	2
We have never talked a lot	1	1
Wife getting the benefits	3	11
Meeting like-minded people and having fun in CST	0	0
Being offered reading glasses in the group	1	1
Getting to know people and have fun in CST	5	5
Good to meet like-minded people	4	8
Relating – Time 3	Post CST	
Bonding and fellowship in CST	2	3
It's not there to show other people	1	1
Feeling happy and embarrassed	1	6
Giving answers to questions in the group	1	1
I didn't drive the other way home	1	1
More considerate of others	1	2
Improved relationship with wife	6	14
Feeling able and wanting to give	3	11
Feeling apologetic towards wife	2	5
More appreciative of wife	4	16
More considerate of wife	8	17
I'm more attentive	1	2
More aware and more helpful	4	7
Unchanged relationship with wife	0	0
Loving wife and dependent on her	1	8
We just talk about the same things	4	4
Wife getting benefits	4	9
Improved social participation	0	0
Going out looking for company	1	1
Improved interactions with family	3	5
Coming back to joke about words	1	4
Talking about new things from way back	2	3
More confident to talk and meet with people	2	3
More willing to work with others	1	1
Talking more freely	1	3
Talking to neighbours about dementia and CST	2	3
Trying to play a part in family	1	1
Answering the phone sometimes	1	2
Unchanged social participation	Reports unchanged post CST	0
I have no problem talking to people		2
Shutting off in family gathering		1
Socializing with the same people		1