

Exploring the Requirements for Technology Design to Support People with MCI or Early-Onset Dementia at Work

by

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Author's Declaration

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

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Abstract

Work is an integral and meaningful part of many people's lives. Research has shown that the consequences of mild cognitive impairment (MCI) and Early-Onset Dementia (EOD) before the age of sixty-five can profoundly affect a person's vocational situation. Assistive technology plays an important role in supporting different abilities for people with MCI/EOD at communities and at home; however, there is little research to investigate the role of technology and address the technological requirements of people with MCI/EOD at work who are employed. This thesis proposes the cognitive task analysis - decision-centered design (CTA-DCD) model; a systematic human factors model to study people's tasks, activities, and requirements with the objective of developing a criteria for designing technology to support people with MCI/EOD at work. The CTA-DCD model was piloted with in-depth interviews with six people living with MCI/EOD and one caregiver. By characterizing the barriers or problems faced by people with MCI/EOD in the context of cognitive work, individual barriers of the participants in terms of macrocognitive activities and cognitive support requirements were characterized. The three design decisions that were derived for future technology design to support people with MCI/EOD at work were (1) having instruction options, (2) functions that support planning, and (3) display of important information and reminder prompts. The CTA-DCD model can be used systematically in different occupational contexts and domains in providing design decisions.

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Dedication

To my mother, Sonia.

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Chapter 1

Introduction

Occupation is broadly defined by occupational therapists to include paid work, leisure and instrumental activities of daily living (IADL's) and is a fundamental factor of quality of life and wellbeing [69]. Being employed is an important occupation that is far more than just a means to earn a wage. Work provides a person with the membership of a social group and the opportunity to contribute to society [141].

While the consequences of dementia in the aging population are the subject of extensive research, less attention has been paid to those who experience dementia before the age of retirement [101]. While engaging in a vocation has traditionally been seen as the domain of younger people, the workforce in many countries is aging [100]. An older workforce combined with earlier detection methods and more cognitive-intense vocations mean that conditions such as dementia are increasingly being detected while the person is still employed. However, relatively little is known about what happens when a worker develops dementia [37]. Mild cognitive impairment (MCI) is a syndrome defined as cognitive decline greater than that expected for an individual's age and education level but that does not interfere notably with activities of daily life [45]. The impact of people with dementia or MCI continuing to engage in productive remunerative employment is an emerging public health issue [40]. There is little information about how workplace reacts when a worker who develops dementia or what types of support are appropriate and useful.

Diagnoses of mild cognitive impairment (MCI) or early-onset dementia (EOD) (i.e.

diagnosis below the age of 65) often comes at a time when people are living with the demands of a family and are counting on income from several more years of employment. It is widely recognized that younger people with dementia are more likely to be in employment at the time of their diagnosis [49]. Financial obligations such as mortgages, supporting family members (including children and aging parents), and insufficient retirement funds can all contribute to an overwhelming sense of stress, chaos, and confusion. At the same time the person with MCI/EOD and their family must start exploring how to live with their diagnosis [7]. Studies also report some positive aspects of leaving vocation for people with MCI/EOD, such as a sense of relief [77, 101] and a sense of renewed purpose through telling their story of living with dementia [27, 101]; however, many people with MCI/EOD would prefer to remain employed.

Technology, by definition, is developed to fulfill a purpose. It is artificial, rather than naturally occurring [129]. Everyday technologies, also known as mainstream technologies, include not only common electromechanical and computerized items, but also include tools which are not necessarily digitally powered, intended for a broad range of users. Examples of everyday technology at vocation are computers, printers, phones, and post-it notes. They are distinct from assistive technology (AT) in their user populations [64]. Formally, ATs refer to any product (including devices, equipment, instruments, and software), especially produced or generally available, used by or for persons with disability [61]. Mobility devices, visual aids, and augmentative and alternative communication devices all fit into the AT category.

Research has found that AT can provide some types of support to people living with dementia to compensate for their functional losses and maintain independent living; its use could be an important and cost-effective compensatory strategy [121]. Technology aimed for people living with dementia and MCI has a focus on late-onset dementia in the elderly, with significant efforts in digital technologies to support individuals and their carers [9]. There are very few studies that document the role of technology in vocation for supporting people with MCI/EOD and none to the author's knowledge that focus specifically on technology designed for people with MCI/EOD in the vocation context. There is a need to explore AT that are specifically targeted to support MCI/EOD in vocation and can be used by the person living with MCI/EOD [63].

1.1 Objectives

The research presented in this thesis focuses on gaining an understanding of the experiences of people with MCI/EOD in the context of their vocation. The goal of this thesis is to leverage human factors (HF) and human-computer interaction (HCI) methods to: 1) develop a user-centered design model for designing technology for and with people with MCI/EOD and 2) derive design recommendations for creating technology for people with MCI/EOD at work.

The research questions guiding this thesis are:

1. What human factors framework can be used to identify design decisions for developing technology to support people with MCI/EOD at work?
2. How can we understand the unmet needs and challenges of people with MCI/EOD at work through a cognitive systems engineering approach?

1.2 Thesis Organization and Contribution

Table 1.1 shows the organization of the chapters in the thesis and their description.

This thesis makes the following main contributions:

1. First systematic research to explore design recommendations of technology for people with MCI/EOD at work.
2. Creates and pilots the CTA-DCD, which is a cognitive systems engineering model that can be used for designing technology for people with MCI/EOD.
3. Part of the trans-Atlantic project titled ‘MCI@Work’ (<http://mciatwork.org>), a collaborative project between Sweden, Finland, and Canada. This project will use knowledge generated from this research to create a digital tool to support role planning for people with MCI/EOD and their employers at work.

Table 1.1: Thesis Organization

Chapter	Description
1. Introduction	Research motivation, research questions, thesis organization and contribution
2. Background	Literature review of MCI/EOD, technology design, vocation and MCI/EOD, CTA-DCD
3. CTA-DCD Model	Overview of the CTA-DCD model and model rationale.
4. Piloting the CTA-DCD model	Description of all six phases of the model.
5. Discussion	Summarizes the overall findings of thesis research and describes their implications.
6. Conclusion	Contributions to HCI and HF fields and future research opportunities.

Insights from this thesis could be beneficial for designers inventing new tools for people with MCI/EOD as well as tools for other occupations (like leisure and IADL's) and contexts including designing technologies for people with MCI/EOD in non-vocational contexts.

Chapter 2

Background

This chapter reviews the related literature and positions the research described in this thesis with respect to the fields of HCI and HF. This includes an overview of MCI/EOD, the prevalence of MCI/EOD in the workplace, technology available for people with MCI/EOD, and design approaches to create technology to support people with MCI/EOD.

2.1 Mild Cognitive Impairment (MCI) and Early-Onset Dementia (EOD)

In 1906, Alois Alzheimer presented the results of his postmortem studies of a 51-year-old patient, Auguste D, who developed dementia at a young age. She became the first patient who suffered from what was later called Alzheimer's disease (AD) [133]. The first symptom was jealousy toward her husband, and soon afterward she developed rapid loss of memory and disorientation in her own home. Alzheimer also described the presence of severe language disturbances and apraxia. She died four and half years after the disease onset and postmortem examination revealed an atrophic brain with neurofibrillary pathology and unusual deposits in the cortex [74]. Nowadays, these features are recognized as typical for AD [14, 62]. Although less prevalent before the age of 65 years, AD is still the most frequent cause of early-onset dementia followed by frontotemporal dementia [74].

Dementia is an umbrella term for progressive, irreversible neurological disorders involving a decline in cognitive functioning [19]. In 2015, an estimated 46.8 million people were living with dementia globally and that number is predicted to rise to 131.5 million by 2050 [107]. Dementia is a public health priority that significantly impacts persons who are living with cognitive impairment, their families, and the health system [145]. Approximately 50 million people worldwide are living with dementia and the global prevalence of young onset dementia in the general population ranges from 0 to 700 per 100000 [139].

Mild cognitive impairment (MCI) involves subtle changes in memory, language, thinking, or judgment that exceed expectations of normal aging, and is consistently shown to have a high risk of progression to dementia, particularly of the Alzheimer type [45]. The diagnosis of MCI has been acknowledged as an early stage of dementia; however, not all people with MCI develop dementia [136]. Reviews of several studies have indicated that these individuals (people with MCI) are at an increasing risk of developing AD ranging from 1% to 25% per year [25].

Early-onset dementia (EOD) or “Presenile Dementia” defines all dementia related conditions onset before 65 years of age [46, 53]. As such, EOD corresponds with a time a person is most likely to be managing a young family, aging parents, and paid employment [104]. Although there is now a history of studies focusing on people with EOD [85], they are still a relatively marginalized group and are largely absent from active involvement in the development of services [108].

It is important to note that MCI and EOD are not the same and are usually distinguished by the severity of the difficulty with everyday activities and by the presence or absence of dementia-related symptoms. The term ‘MCI/EOD’ is used in this thesis as a blended term for people living with memory deficits due to suspected dementia, persons with clinically diagnosed dementia, and persons with clinically diagnosed MCI as indicated by other studies [101, 58, 120]. This has been done to reflect that while subjective memory complaints can be a strong predictor of dementia [126], obtaining a diagnosis of dementia is more difficult before the age of 65 years [82]. Consequently, symptoms may be present for several years before a conclusive diagnosis is obtained [16, 81].

Cases of undiagnosis of EOD are common [139]. Undiagnosis is partly attributed to

the general perception that dementia is a condition of old age, therefore MCI/EOD is not recognized and undiagnosed. Younger people who develop the condition are also more likely to present with a wider variety of symptoms compared with those older than 65 years [104], which can complicate matters. Memory loss and cognitive impairments, which are strongly associated with dementia, may not be the main presenting problem for a younger person. People with frontotemporal dementia, for example, can initially present with personality changes as their primary symptom, and younger people may also have difficulties with visuospatial and semantic tasks [114]. The sometimes ill-defined symptoms that characterize the initial stages of EOD are also often ascribed to other conditions such as depression or stress [85, 51]. Another reason why people with EOD are currently viewed as a marginalized population may be related to the psycho-social limitations that the condition can impose [82]. This often includes social isolation [6] and fears of stigma [114]. As a result, the likelihood that a person will become engaged in public activism or campaigning is lower than with the older adult population, resulting in a relatively underrepresented of the condition [51].

Younger people with dementia are more likely to be employed when they are diagnosed [112, 50], yet the specific needs of young working individuals are under-examined [17, 21, 33]. People with EOD are generally fit and in good physical health compared to older adults. This, together with their marked age difference and life-stage goals, makes the integration into mainstream dementia services difficult [146, 3, 63]. This is mainly because most supportive services are designed to support older adults, therefore there are limited age-appropriate services available for people living with MCI/EOD. In addition to this, the carer or partner of a person with MCI/EOD is more likely to face higher levels of anxiety, depression, and relationship problems than those partners or caregivers of older adults with dementia [146].

2.2 Vocation and MCI/EOD

Most people below age 65 are employed when they first experience symptoms [49]. As the workplace often demands skills that are impacted by dementia (e.g., memory and other

cognitive tasks), the first signs of dementia are often first noticed in the context of the workplace [111] and manifest as difficulties at work [107, 1]. Examples of difficulties experienced at work include memory problems, problems with communication, visuo-spatial difficulties, and an impaired ability to learn and process information. The impact of the symptoms varies depending on the types of jobs and activities that people with MCI/EOD are employed to do [112].

The consequences of the cognitive manifestations of the disease can result in problems with work performance and functioning and can threaten employment retention [101, 113]. The impact on working individuals can also extend more broadly, leading to loss of identity, increased neurocognitive challenges, work and financial stress, feelings of depression, poor memory and concentration, and withdrawing from employment along with activities of daily living and even the community [117, 86, 113].

Considering the timing of onset and impact on one's life, involving workplaces in the detection and support of cognitive decline is ideal. Existing literature advocates for the critical role of employers in hiring and supporting young people with dementia as well as supporting the current workforce to work effectively in conjunction with individuals with varying cognitive abilities.

While these initial studies recognize the importance of workplaces on the experiences of individuals with young-onset dementia/MCI, there is a paucity of research on the experience of dementia at work and in the understanding of the experiences of individuals with dementia or MCI in the workplace. However, initial insights suggest that employers appear to lack knowledge that would enable them to support someone with dementia in the workplace [101]. Furthermore, they often fail to provide reasonable adjustments and often made decisions that caused further distress on the job (e.g., new training requirements) and even sudden job loss [20]. Given the potentially far-reaching impact of dementia/MCI on individuals, their employers and workplaces, developing strategies to assist with sustaining employment and improving transition out of work are a priority.

Literature considering a diagnosis of dementia for those of working age has focused on the social and economic consequences of the loss of the work role for the person with dementia and their family. This could be the loss of the provider role and financial difficulties

[49, 82, 137]; the loss of the worker role and consequent changes in their sense of identity and self-worth [27, 49, 77]. In addition, changes in levels of social contact and a loss of meaningful occupation due to leaving employment have also been noted [114].

Previous research has highlighted that getting a diagnosis of dementia can be a lengthy process, especially for a younger person [49, 115]; it is common in this period for a person with dementia to either leave work or go on sick leave before they have a diagnosis due to the stress associated with trying to cope in the workplace without knowing what is wrong [101]

Continuing employment post-diagnosis of dementia could have many advantages for the individual and the wider organization. Notwithstanding the financial benefits of continued employment and recognizing not every person with MCI/EOD would choose to remain in the workforce, there can be many social and psychological benefits for the individual; however, this requires people with MCI/EOD have more choices about how to engage or disengage with work.

Despite the many stereotypes that accompany dementia, some people have the desire and capacity to remain in the workforce after receiving their diagnosis of dementia [37]. People with dementia have been successfully engaged in a range of different settings, including a hospital [32], a green farm [26, 127], a zoo [70], and a hardware store [116]. However, support for people with dementia to remain in the workforce still appears to be very limited and further exploration is needed to better understand what workplace strategies will help younger people with dementia to remain at work for as long as possible [37].

2.3 Technology for People with MCI/EOD

Assistive technology (AT) may support the ability of an individual to master some of the tasks of everyday living, and also assists caregivers by enhancing safety, security, accessibility, and quality of services. To date, technology aimed for people living with dementia and MCI has a focus on late-onset dementia in the elderly, with significant efforts in digital technologies to support individuals and their carers [9]. This includes designing devices for

recreation and leisure, such as through music and reminiscence [38] as well as technologies providing safety for people living with dementia [22, 83, 118].

The examples of ATs for cognition in literature are prospective memory aids (PMAs) and retrospective memory aids (RMAs). PMAs, for example are aimed at increasing the performance of multiple tasks daily (eg, memory glasses). Particularly, the memory glasses which is a context-aware memory aid [28] can help people with dementia since these kinds of technological devices can enormously contribute to recalling people's names and recognizing them in an easy manner. Technologies like the COACH prompting system [87] have been developed to help people with dementia complete daily tasks such as washing hands, brushing teeth, and using the toilet. That said, memory aids do not necessarily have to be high-tech. Previous research [101] has shown strategies like writing memos, notes, and tape recorders were initiated by people with MCI/EOD to compensate for memory loss. [44, 75] mention developing a cognitive assistive system incorporating the use of tactile, auditory, and visual error feedback for assembly tasks is one of the few ATs designed for people with cognitive impairment in vocation.

Some researchers have highlighted that people with MCI/EOD are likely to be more digitally literate than those with late-onset dementia [8, 99]. While these efforts provide great support for cognitive, physical, emotional and social well-being in the elderly population [9]. There is a need to explore types of AT that are significant for MCI/EOD, and can be used without creating an extra workload for their carers [63].

Interface continues to be a major design issue for all these systems [124]. The very cognitive disability that these tools seek to address may make adoption of the product challenging. Researchers [42] argue that ATs are not achieving the full level of success because instead of reducing the cognitive load, systems increase cognitive burden by requiring complex and unfamiliar interactions.

2.4 Technology Design Approaches for People with dementia

Before embarking on new ways to design technology for people with MCI/EOD, it is useful to consider established approaches to date regarding technology for supporting dementia in general. While these may not have been or will directly be used for people with MCI/EOD, they are generic enough to be considered as the starting point upon which new methods might be developed [142].

Designing new technologies to support the lived experience of dementia is of increasing interest, including within the human-computer interaction (HCI) community. [9]’s work is the only documented study that was found that explores how HCI researchers can conduct research with people with EOD. Their work presents insights into methods and approaches used with people with EOD, where people with EOD were engaged as co-researchers in a co-directed inquiry into their lived experiences. Their work encourages researchers and designers to actively involves people with MCI/EOD to be a collaborator, rather than a participant, designing technology for/with people living with MCI/EOD.

A growing area of HCI involves designing for the diverse lived experiences of individuals throughout the course of dementia, and in turn, understanding how to engage these individuals in research [76]. Researchers have become more concerned with context, values, the situatedness of technology use and its study, and the process of meaning-making. Some have suggested that these shifts represent a new intellectual wave of research, referred to as the Third Paradigm [52] or Third Wave [11, 12] of HCI; namely, the latest form of computer-based design, the first relating to human factors and second, to computer-supported cooperative work. This vein of HCI research has begun to influence studies of computing and people with disabilities, including calls for critical analyses of technology and the experience of disability [43, 84] and reflection on how AT problems are defined.

The following are a few methods that have been used to capture the experiences of people living with dementia in order to better inform design:

User-sensitive Inclusive Design (USID) is an inclusive design methodology that emphasizes empathy, using methods such as informal social gatherings and theatre [98]. It is

well established and widely used in the case of older adults and those with dementia, it also advocates recruiting a diverse set of extraordinary users or outriders for initial development purposes [97].

The Responding, Enabling, Augmenting and Failure-free Framework (REAFF) emphasizes sensitivity to both user needs and emotional states. It presents a set of general design principles aimed at functional and psychological aspects of use, such as the principle of failure-free operation [4]. The REAFF framework fundamentally regards people living with dementia as a user of technology [4].

The Ecological Model of Quality of Life is a systems approach, offering a qualitative analysis tool divided into six dimensions: personal aspects; support network; social network; physical environment; cultural/spiritual environment; and personal meaning and well-being [131]. Because it is a psychosocial framework, like the REAFF, there is no technical dimension. This is a guiding framework for design, intended to enhance the psychological well-being of those with dementia [131].

The Neurological Dependability Assessment Matrix (NDAM) emphasizes a systems approach and details characteristics of home technology design for users with neurological conditions. The characteristics are collected under four high-level categories: fitness for purpose, trustworthiness, adaptability, and acceptability [30]. Each category is subdivided further. Values concerning acceptability, for instance, include aesthetics, cost, learnability, and usability. The NDAM offers a useful categorization of system factors and has been used as an evaluation tool [30]. The NDAM addresses the neurological conditions of older and disabled users [132].

Systems Approach from the classification of rehabilitation and engineering. The International Classification of Functioning, Disability and Health (ICF) framework lists a multitude of factors relevant to an individual's well-being [102]. Five top-level sections make up the framework 'body structures' and 'functions', 'activities', 'participation' and 'context' [102, 134]. Context, in turn, accounts for environmental factors including technologies. This has been studied in the context of Alzheimer's disease [95], requirements analysis [130] and dementia and technology [125]. Systems approaches have been used to understand environmental constraints of people with dementia [64].

All designers of technology in some sense believe they are taking a ‘human-centered’ approach, however, their own intuitions of ‘what the user needs’ can often get in the way.

Talking to a proxy (for example caregiver) is a well-established research approach in the methods discussed above when working with people with dementia [9]. However, as [31, 29, 93] noted, this approach to research has tended to marginalize the experiences of those with dementia as it may not be a true reflection of the participant’s (person with dementia) experience/opinion. Recently, social researchers [18, 135] have challenged the use of a proxy and sought to empower people with dementia by allowing them to be directly involved in the research and design process.

2.5 Chapter Summary

This chapter provides a review of peer-reviewed literature related to MCI/EOD in the workplace. We discuss the prevalence of MCI/EOD and how it can impact vocation. The chapter also reviews the AT available for people living with dementia and the technology design approaches coupled with the growing area of HCI involving designing for people with dementia. While there is guidance on qualitative research methods to use in areas such as dementia, there is no evidence whether or not they are appropriate for a younger demographic [9]. For instance, research has shown that people with EOD and their families face unique and complex challenges, including feelings of social isolation, dependency, and boredom, when compared to the elderly population with dementia [51]. Thus any methods that are used for extracting data for supporting technology development should complement such considerations and needs. There is also potential that technologies designed for and adopted by people at the EOD stage may well continue to provide them with benefits as the symptoms of dementia progress, so long as they continue to provide appropriate support [9]. This understanding of the use of technology by people with MCI/EOD may be beneficial in designing new technologies, however, in HCI the development of a nuanced understanding of the ways people with MCI/EOD are currently using technologies does not exist.

As the above review demonstrates, it is imperative that technology developers are able

to access and complement what people with MCI/EOD want and need if they are to build useful and usable solutions. The next chapter will discuss the HF-systems approach taken to understand the problem space of designing technology for people with MCI/EOD at work.

Chapter 3

Cognitive Task Analysis - Decision-Centered Design Model

This chapter introduces the cognitive task analysis - decision-centered design (CTA-DCD) model as a systematic way to analyze people’s needs at work. The goal of the chapter is to describe the CTA and DCD frameworks, describe the construction of the proposed CTA-DCD model, and put forward why it is appropriate for ascertaining design requirements for technology for supporting people with complex tasks in the workplace. This includes identification of barriers related to work, contextualizing work-flow, and providing recommendations for designing technologies.

3.1 Cognitive Task Analysis (CTA)

Cognitive task analysis (CTA) is an established human factors framework that offers a systematic approach for understanding the cognitive processes, cognitive challenges, and cognitive requirements that underlie proficient performance in complex socio-technical domains [79]. A socio-technical system contains both social (human-related) and technological (non-human) aspects that interact together to pursue a common goal [110]. [55] define cognitive task analysis (CTA) as “the determination of the cognitive skills, strate-

gies and the knowledge required to perform tasks”. CTA is used to seek out information about knowledge, thought processes, decision-making, and problem-solving strategies that underlie observable task performance [144]. Furthermore, [55] describe CTA as a methodology for the empirical study of workplaces and work patterns, resulting in (a) descriptions of cognitive processes, (b) explanations of work activity in terms of cognitive phenomena and processes, and (c) application of the results to betterment of work and the quality of working life by creating better work spaces, better supporting artifacts (i.e., technologies).

CTA studies aim to capture what people know and how they reason, including what they pay attention to in an occupational context; the strategies they are using to make decisions or detect problems, what they try to accomplish, and what they know about the way a process or system works [79]. The CTA framework helps form the critical decisions and judgments, the decision strategies used to make them, and the information requirements of those decisions and judgments.

CTA involves asking people questions through methods that have roots in introspection, for example the use of interviews to capture cognition. Research can use the CTA to help understand and describe how a population of interest view the work they are doing and how they make sense of events. This involves asking people questions that reflect the challenging tasks at work and probe on why they occurred [55]. The responses are then analyzed and represented through inductive or deductive thematic analysis to identify what people know and how they reason.

Today, CTA is regarded by research agencies worldwide as being an important component of research and development efforts for complex human-computer interactions as well as a necessary component of work that is being analyzed as cognitive work [55]. CTA is commonly conducted with the intent of informing the design decisions to support technology [88], such as the military command and control [55] and has also been applied to social/technical systems in healthcare [65]. CTA methods have been important for research and applications in areas such as design of interfaces and work-stations [55].

3.2 Decision-Centered Design (DCD)

Decision-centered design (DCD) [60, 24] is a design approach that focuses on understanding and supporting cognitive tasks. The approach consists of task analysis, design, and evaluation [57]. Using DCD facilitates a thorough understanding of decision support requirements from an end-user perspective as a foundation for design [89]. Research in the areas of naturalistic decision making and expertise has provided the cognitive models and analytic methods that enable this approach. DCD provides a means for communication and understanding between designers and the individuals for whom the interventions are being designed. It targets the critical and often challenging cognitive tasks confronting these individuals, including individual tasks in which cognitive performance may break down and team-level tasks that require collaboration and coordination.

DCD is considered to be a subset of user-centered or human-centered design approaches. It is also one approach of several that can be described under the cognitive systems engineering approach [147]. The DCD framework builds from CTA, the addition being the use of the elicited decision requirements from CTA methods to transition into design concepts and determine how to best support the end-user with decision making. DCD methods also aid in design evaluation by determining which metrics (e.g. cognitive heuristics) could best measure performance of end-users and recommend redesigns to provide greater support [79].

The key distinction that separates the DCD approach from other user-centered design approaches is the focus of the design on describing, analyzing, understanding, and supporting complex cognitive activities. User-centered and human-centered design take the perspective of the human user, but their focus is not on cognition [57]. DCD is intended to provide the designer with techniques to work with the end user to help them articulate cognitive task performance. It then supports the analysis of the task in terms of its decision-making and judgment components. Finally, it uses those findings to guide design decisions [57].

3.3 The CTA-DCD Model

As technology for supporting people’s challenging tasks at work requires an understanding of cognitive strategies (which can be captured using the CTA) as well as design requirements for tools that support cognitive task performance (which can be done using the DCD), a key contribution of this thesis research is to combine the CTA methods with DCD to create a systematic approach for the collaborative synthesis of user-centered design recommendations. Namely, the proposed CTA-DCD approach enables designers elicit design recommendations for technology that are explicitly intended to support the end user in the cognitively challenging aspects of tasks [57]. Figure 3.1 shows how the two frameworks are combined to provide the design recommendations with the goal to support the cognitively challenging aspects of work. Each phase and its functionality is described in the following subsections.

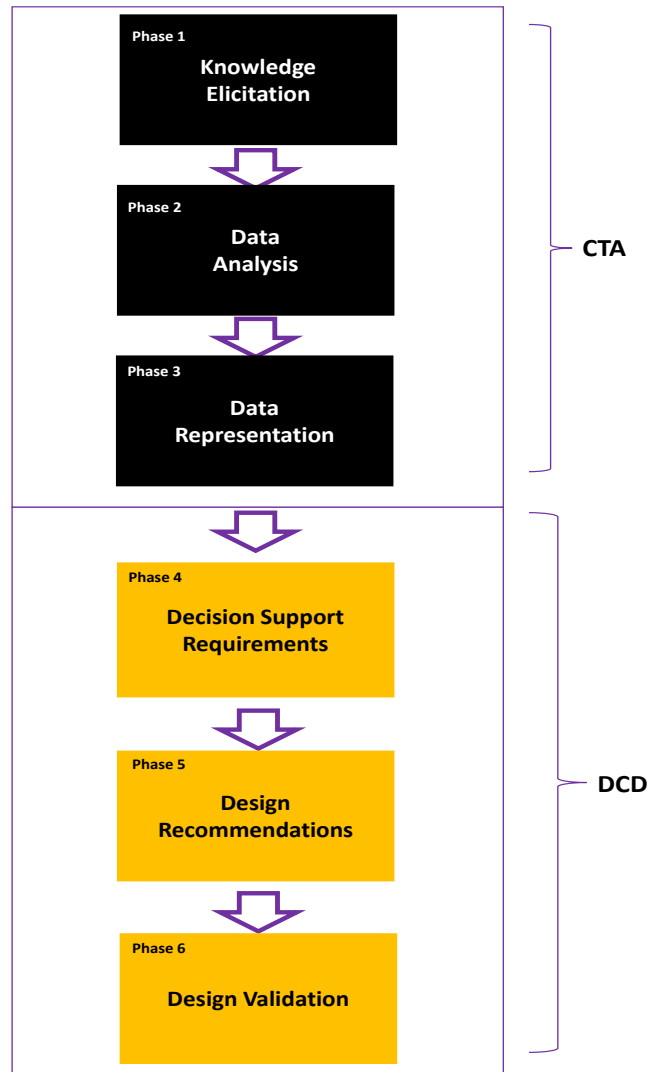


Figure 3.1: Overview of the CTA-DCD model

3.3.1 Knowledge Elicitation

Knowledge elicitation methods are used to obtain information about what people think, including strategies, knowledge, and skills that underlie work. Ethnographic observation is a common knowledge elicitation technique used in other frameworks like the cognitive work analysis (CWA) (discussed later in this chapter) because of the authenticity and depth of information that can be obtained. However, ethnographic observation is difficult to employ in many situations. For example, people with MCI/EOD often do not disclose their condition or challenges with their employer and/or co-workers and/or people with MCI/EOD having already left work or are on sick-leave [20]. This makes observing a person with MCI/EOD in their workplace context difficult or impossible.

Interviewing is often used in the CTA to minimize data collection time with participants. Interviewing through focus groups, in particular, provides a format that helps ensure necessary areas are covered, potentially further reducing data collection time. Interviewing has potential drawbacks as it is retrospective and not fully representative in that it could be influenced by the biases of the interviewee and reduces opportunities to learn about things that were not predicted in advance to be important [91].

3.3.2 Data Analysis

Data analysis is the process of structuring, integrating, and synthesizing data. Data elicited from CTA can be analyzed in many different ways including: cataloguing cues and patterns; identifying themes; coding categories and re-coding them to seek consensus; creating narrative accounts of incidents and examples [79]. The CTA imposes a reasoning structure that uncovers themes in a systematic manner using thematic analysis through deductive analysis to identify cognitive support requirements, macrocognitive activities, and produce design criteria for technologies.

3.3.3 Data Representation

Data representation is the third phase of the CTA-DCD model. It helps in contextualizing the work-flow of the participants through a visual lens.

The “flow model” from contextual design [10] is used to describe work from the point of view of the person who was interviewed. The work-flow model (traditionally called ‘flow model’) helps in understanding how people’s roles are defined and how they communicate to get a job done. The work-flow model represents the communication and coordination necessary to make work happen [10]. The work-flow model contextualizes the workplace of people through retrospective interviews and is intended to fill the gap of not being able to carry out an in-workplace ethnographic study.

How do job responsibilities get assigned to people? What are the different roles people take on to get work done? How do new tasks get passed to a person? Who do they get help from? Who do they have to work with to accomplish tasks? Who do they give results to and in what form? Work-flow model is the rich pattern of work as it shuttles between people, the interweaving jobs and job responsibilities that gets the work done. [10].

3.3.4 Decision Support Requirements

The first phase of the DCD approach is capturing the decision support requirements of the end-user, that is, key decisions, the decision strategies, and the information requirements that are critical to effective performance of their work domain context [57]. It is this focus on these critical decisions and judgements that extends the approach from a purely cognitive systems engineering approach like the CTA into DCD. This critical strength provides the designer with an understanding of the complex contexts in which their system or systems will be used. In DCD, decision requirements are the drivers of design. In the CTA-DCD model, data analysis phase from the previous CTA phase is used to drive this first stage of the DCD approach.

3.3.5 Design Recommendations

Design recommendations are the result of combining the decision requirements with the appropriate design concepts to address identified needs. These design recommendations can be represented in a number of ways, such as a systems requirements document, a functional specification, paper storyboards, electronic storyboards, and/or functional prototypes (varying from parts of the system to a whole system prototype) [57]. Taking the example of military work context, the design recommendations could range from specific display elements to support situation assessment, to the complex integration of multiple systems to support information gathering, filtering, and display in a command post. The decision strategies will provide information about what processes must be supported and the key decisions and information requirements will provide the input for what must be supported and what content must be provided.

3.3.6 Design Validation

Testing of the system or design should address the decision-making environment in which the system is to perform. The decision requirements captured through CTA-DCD can provide valuable insight into key challenges that must be presented to the system to flex it, and the end-users using it, through the design of evaluation scenarios and contexts [57]. For example, system testing (like cognitive walk-throughs or usability tests) and the data from the testing can be fed back into the design process, making it an iterative process.

3.4 Why the CTA-DCD Over Other Frameworks?

The CTA-DCD framework was selected over other established human factors frameworks for the elicitation of technology design requirements for people with MCI/EOD for a few reasons. The design recommendations from the CTA-DCD model (Figure 3.1) aim to support the cognitively challenging aspects of work. This is especially important for people with MCI/EOD. For most people with MCI/EOD, many cognitive aspects of work that were manageable before become increasingly challenging [37]. This is why we need to: (a)

identify what these cognitively challenging tasks are and (b) understand how technology can support in assisting with these challenges. The CTA-DCD model provides a systematic approach to identify the cognitively challenging aspects of work (through CTA) and consequently recommend criteria for technology design (through DCD).

To design better systems for people with MCI/EOD, we need to understand support requirements because these are central to what most interfaces and systems are expected to support [72]. This is especially true when considering many people with MCI/EOD have increased difficulty with learning new tasks or ways of doing things. We compare CTA-DCD to three other major cognitive systems engineering frameworks: cognitive work analysis (CWA), distributed cognition, and situation awareness (SA) - oriented design.

Cognitive Work Analysis (CWA)

Cognitive Work Analysis (CWA) [109] is described as a philosophy or framework for studying work. Namely, CWA offers a holistic perspective on design encompassing personal, technical, social/organizational, and environmental dimensions. Notably, it also offers analytical tools such as abstraction hierarchy (AH). CWA and CTA share many goals, however they are distinctly different approaches [138]. Whereas CTA is generally considered to be a set of particular, specified methods for understanding the cognitive aspects of work [55], CWA has a focus on the environmental constraints that impact the cognitive aspects of work.

A CWA-based analysis would have been appropriate if an ethnographic study could be carried out. For example, CWA methods have been used as a constraint-based analysis to study people with dementia placing phone calls [64] through technology walk-through and demonstration in the context of the participant's environment. However, most participants in the interviews of this thesis research (described in [chapter 4](#)) have either not disclosed their challenges with MCI/EOD to their employers or have transitioned out of work recently. As a consequence, an ethnographic study (i.e. observing the participant in their work context) cannot be performed. As such, a method that does not require in-context ethnographic research is required for our application.

Distributed Cognition

Distributed cognition [56, 41] is a framework that is used to explain cognitive activities as embodied and situated within the work settings in which they occur. By explicitly adopting this broad focus, the distributed cognition approach provides a framework for analyzing complex, socially distributed work activities of which a diversity of artifacts (i.e., “things ” of the work - it can be physical like a computer or conceptual like a strategy to communicate) are an indispensable part. The applied aim of distributed cognition is to contribute to system design and implementation. This entails going into the workplace and spending time determining and analyzing the problems with the existing technology and work practices and then suggesting recommendations as to what needs to be preserved and what systems and work practices need to be redesigned to support and improve the collaboration and coordination of work activities.

An important differentiation is that distributed cognition refers to a perspective on all of cognition, rather than a particular kind of cognition. A distributed cognition approach could have been appropriate if it were possible to conduct an ethnographic study to observe artifact interaction in the workplace. While similar, CTA aids in understanding several different artifacts and their purpose in understanding people with MCI/EOD’s artifact/technology interaction at work. Distributed cognition methods investigate activities of work coupled with the artifacts involved. A CTA-DCD approach, however, describes the design of new systems (through DCD) using the knowledge captured (through CTA).

Situation Awareness (SA) - Oriented Design

Situation awareness (SA)-oriented design [35] provides an explicit and replicable mechanism for achieving user-centered design, including goal-directed task analysis (GDTA). SA captures not only information requirements but also how that information is used in the decision process [79]. SA methods like the GDTA focus on the specific tasks of the individual under observation in the workplace. CTA is different from SA methods like GDTA in terms that GDTA seeks to be technology-free, focusing on what decisions need to be made and the information needed to make them, independent of how that might be

done in the current system. That way, entirely new ways of creating and delivering the needed information can be developed [77]. SA-oriented design could have been appropriate for this research if the constantly changing environment of people with MCI/EOD was known; however, it is not feasible to capture the full range of possible goals and sub-goals for people with MCI/EOD at work due to lack of an ethnographic observation.

3.5 Chapter Summary

While several HF approaches exist, none were considered to be appropriate for the elicitation of design requirements when eliciting information from people with MCI/EOD outside of their workplace. This chapter puts forward the CTA-DCD model as a systematic approach to eliciting design recommendations as well as rationale for this approach. This chapter then gave an overview of each component of the model, including their purpose and rationale for the CTA-DCD approach over others. The next chapter presents piloting the CTA-DCD model, findings from the model, and their design implications.

Chapter 4

Piloting the CTA-DCD Model

This chapter discusses the application of all the phases of the CTA-DCD model, as seen in Figure 4.1. This chapter intends to outline a systematic approach that uses the CTA-DCD to identify the design criteria for technologies that can support cognitive work for people with MCI/EOD.

The questions guiding this chapter are:

1. What is the applicability of the CTA-DCD model as a human factors framework for designing technology for people with MCI/EOD at work?
2. What are some design criteria for technology for people with MCI/EOD at work that support these challenges?
 - What are some of the unmet needs and challenges in the workplace for people with MCI/EOD?
 - What tools/technology/artifacts do people with MCI/EOD use at work?
 - What are the cognitively challenging tasks for people with MCI/EOD at work?

The two questions guiding this chapter are used to aid the overarching research questions set out earlier in this thesis. The remainder of this chapter demonstrates the application of the CTA-DCD model to elicit information related to these questions.

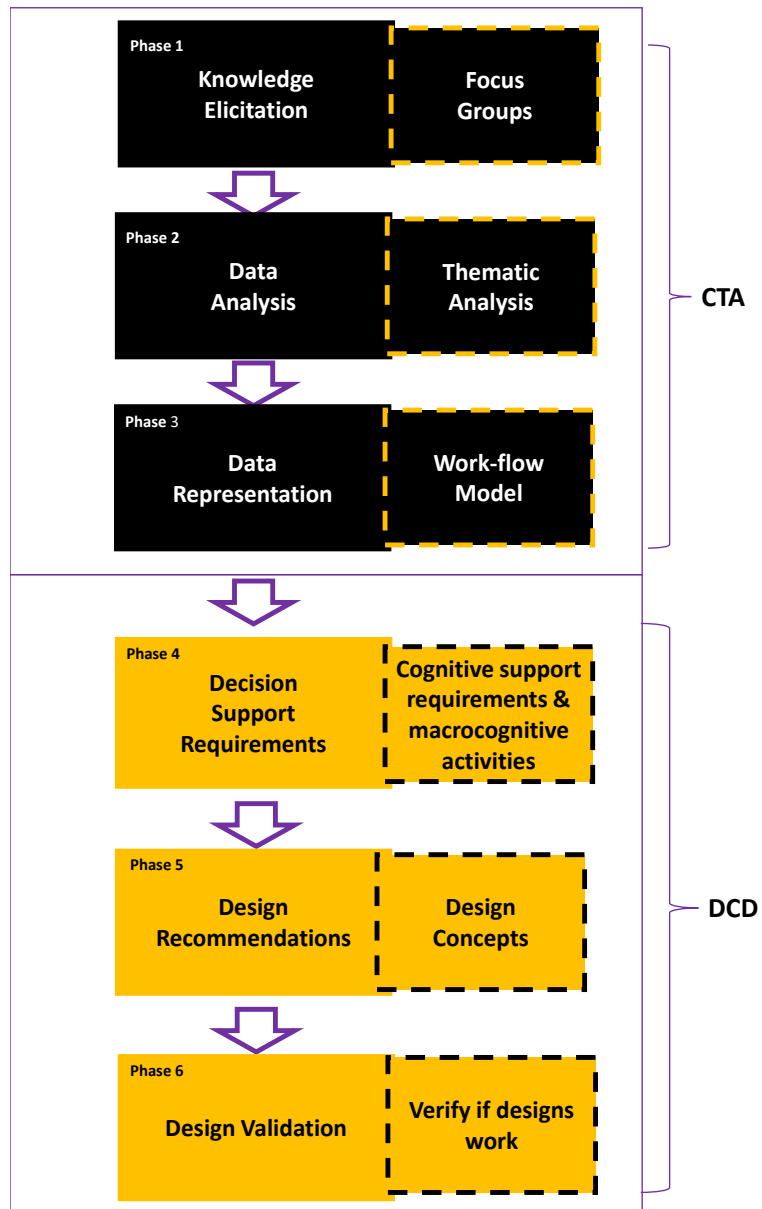


Figure 4.1: An overview of the methods used in piloting the CTA-DCD model

4.1 Phase 1 - Knowledge Elicitation: Focus Groups and Interviews

4.1.1 Study Design

In qualitative research, there are three fundamental types of research interviews used for data collection: structured, semi-structured, and unstructured interviews [47]. Semi-structured interviews consist of several key questions that help to define the areas to be explored, but also allows the interviewer or interviewee to diverge to pursue an idea or response in more detail [105]. Focus groups are used for generating information on collective views and the meanings that lie behind those views. They are also useful in generating a rich understanding of participants experiences and beliefs [94].

Both semi-structured interviews and semi-structured focus groups were carried out for data collection (knowledge elicitation) in this research. Interviews were done with the intent of qualitatively exploring experiences of individuals with MCI/EOD, their families, as well as employers of people with MCI/EOD.

4.1.2 Ethics

All procedures obtained clearance from the University of Waterloo Office of Research Ethics (ORE) under the project #40051 titled “Dementia or mild cognitive impairment: at work in progress ”.

During the interviews and focus groups with people with MCI/EOD, an on-going consent procedure was followed by regularly asking them if they were still comfortable with their participation. A safe environment was created by spending time getting to know the participants, giving positive feedback, emphasizing the importance of their participation, looking for signs of discomfort, and supporting withdrawal from the study should the participant wish to do so [96].

4.1.3 Participants

Semi-structured focus groups and one-on-one interviews were carried out in collaboration with researchers from occupational therapy, psychology, and engineering. The interviews were carried out with people with MCI/EOD and their caregivers.

Participants recruited were from the Waterloo-Wellington and Durham regions, Canada. The recruitment process involved communicating study information by posting flyers (Appendix G) to local businesses' bulletin boards, local dementia organizations, organization e-newsletters, and social media. The study was advertised to employers or pertinent workplace personnel who have worked with someone with cognitive impairment in their workplace or may have influence over the company policies and work-adjustments of the person affected by the diagnosis of MCI/EOD.

The inclusion criteria for the target population for the study were:

1. a) Diagnosed with MCI/EOD or b) be a nominated family member/friend or nominated workplace personnel supporting an individual who has been diagnosed with MCI/EOD.
2. Individual with MCI/EOD must have recently received a diagnosis.
3. Must be currently employed part time or full time or employed within the last 5 years.
4. Must have capacity to provide consent
5. Must speak and understand English well enough to participate in discussion.

4.1.4 Interview Procedure

The research questions guiding the interviews were:

1. What are the experiences of individuals who have been diagnosed with MCI/EOD families, and employers?

2. What is the role of technology in adapting to and managing cognitive impairment at work?
3. How do policies impact continued work or transition from work?

The participants were screened using a screening questionnaire (Appendix B) over the phone and participants who met the inclusion criteria and were interested in participating in the study were interviewed.

Before commencing the interview and discussion, each participant filled out a demographic questionnaire (appendices C and D). After receiving written and oral information about the research and prior to participation in the focus groups and interviews, all participants signed an informed consent form (appendices E and F). All interviews were audio and video recorded for later transcription and analysis.

4.1.5 Interview Questions

Appendix G outlines the semi-structured interview protocol, which used a combination of predetermined open questions with free-form questions. The interviews started off with a discussion of the participant's general experience of being in the workplace with MCI/EOD and covered three key areas of discussion: 1) the impact of their diagnosis on their work; 2) the policies surrounding MCI/EOD at work, and 3) technology/tool interaction. A structured list of eight questions was used. Relevant responses were probed through unstructured questions during the interview.

4.1.6 Results

Each interview presented a personal experience of MCI/EOD in the workplace. A total of seven people, three male and four female (six people with MCI/EOD and one caregiver), participated in the study. Table 4.1 shows participant demographics.

Interviews were carried out in-person at the participants' preferred location from December 2018 to March 2019. Each interview lasted an average of 106 minutes with the

shortest being 59 minutes and longest 174 minutes. Each interview transcription generated between 20-40 pages of single-spaced text.

While recruitment was extended to employers, all participants were employees (i.e., there were no participants who were employers, co-workers, supervisors, etc.).

Table 4.1: Participant demographic

P ID	Age	Gender	Participant Type	Diag -nosis	Occupation	Interview Type	Vocation Status
P1	54	Male	MCI/EOD	MCI	Seasonal worker	One-on-one	Employed (seasonal)
P2	57	Female	MCI/EOD	MCI	Training coordinator	One-on-one	Employed (sick leave)
P3	62	Female	MCI/EOD	EOD	Customer services coordinator	One-on-one	Employed (full-time)
P4	46	Male	MCI/EOD	EOD	Manager in economic development	One-on-one	Unemployed
P5	46	Female	Caregiver	None (caregiver)	Not known	One-on-one	Employed
P6	65	Male	MCI/EOD	EOD	Support missionary	Focus group	Retired
P7	59	Female	MCI/EOD	EOD	Case manager	Focus group	Retired

4.2 Phase 2 - Data Analysis: Thematic Analysis

Thematic Analysis is a widely used qualitative method used in social, behavioral, and applied sciences. The goal of thematic analysis is to identify, analyze, and systematically report patterns (themes) to answer a research question(s) [15].

Patterns are often identified through a rigorous process of data familiarizing, data coding, and theme development. First, the method of thematic analysis is discussed and the findings using the systematic approach is discussed.

Collected data were analyzed using transcribed recordings of interviews and focus groups, jotted notes and more detailed field-notes of observational research, and reflective notes made during the research.

In general, qualitative research does not seek to quantify data. Qualitative sampling strategies do not aim to identify a statistically representative set of respondents, so expressing results in relative frequencies may be misleading. Simple counts are sometimes used and may provide a useful summary of some aspects of the analysis. In most qualitative analyses the data are preserved in their textual form and indexed to generate or develop analytical categories and theoretical explanations [105].

It is important to follow the data while making an effort to exclude all bias. It is equally important to identify the biases as researchers and see how to minimize, or ideally, remove them while analyzing qualitative data. The data was systematically analyzed (inductively) with the research questions guiding the process.

The audio and video recordings were transcribed and anonymized prior to analysis. Thematic analysis was used to explore the commonalities of experience of the participants [112].

The dataset was structured using qualitative research software (NVivo 12 Pro). Passages were coded and arranged according to research questions. Coded passages were analyzed thematically using a multi-phased process, which included becoming familiar with the dataset; identifying preliminary codes; exploring possible themes; assessing and revising codes and themes; and finalizing and defining themes. This is similar to the approach used by [15]. A structured data-driven process of data coding and identification of themes was used. The data were summarized from the one-on-one interviews and focus groups under trigger research question headings [39].

4.2.1 Results

The relevant codes were arranged under the research question as seen in Tables 4.2 and 4.3. Similarities and differences between separate groups of data emerged at this stage, indicating areas of consensus in response to the research questions and areas of potential conflict [39]. Emerged themes from the inductive thematic analysis are discussed below. P[] denotes the participant and IV denotes the interviewer at the end of the quote.

Table 4.2: Themes under unmet needs and challenges

What are the unmet needs and challenges of people with MCI/EOD?		
Codes	Themes	Sub-themes
accommodate employer problems communication	accommodations made	types of accommodations
age boring mental stimulation memory	challenges that were not cognitive-related	physical challenges

Accommodations made

For many, diagnosis meant either early retirement or sick leave, something that is not planned. Participants mentioned the employer’s management of the worker in terms of the changes or accommodations made in the workplace. P1 and P2 describe the type of accommodations, P4 had no accommodations made, P6 had more flexibility at work, and P7 mentioned not wanting any accommodations made. Literature suggests that employers lack knowledge to support people with MCI/EOD in the workplace [111].

Accommodations were made by the employer in P1’s vocation by the employer, however, this was done to compensate for physical challenges.

“...because there’s nothing. Everything here [workplace] is heavier than five pounds so from that limitation until she removes that restriction or raises it, we can’t work within that. So when she [HR] finally did raise it, um, then I was able to come back and at least do most of what I was doing before cause not doing a whole lot of lifting anyway, but um, but you have to do some lifting ” [P1].

The employer in P2’s case made accommodations by reducing the number of work hours, this accommodation was not honored all throughout, however.

“And, um, I was off work following, um, and following the surgery in 2002. I went back to work in [year] and I was accommodated with, I went back part-time, like just, like I was doing 9 hours a week and then 12 hours a week” [P2].

No accommodations were made by the employer in P4’s case.

“It didnt sound like it. Like he [P4]... If it did I dont know what it was. No ones ever said anything thats... Even in the document that they supplied to HR, um, giving their reasons, didnt say well we did this accommodation and still this was a problem, or we did that accommodation and it was still a problem. Like it doesnt, it didnt give anything but they said that they did help” [P5].

P6 mentioned flexibility with his job.

“Total understanding at work. No, not a problem, just do what you can” [P6].

P7 did not want any accommodation from the employer.

“And, um, (pause) oh. Um, one of the things that, I dont know if we already talked about this on the phone or something, but like, you know, could I have stayed in my job longer. And the answer would be like absolutely not. Theres no way. Um, I mean, theyd have to bring in another case manager to hold my hand so, you know what I mean? And uh, there would be no job that I could do in that agency because on one level or nothing, or one level or another, were all looking at the well-being of vulnerable people” [P7].

Challenges that were not cognitive-related

This theme highlights challenges that were not necessarily cognitive-related. It is important to note that challenges (for example, speech with P4) may be specific to the nature of EOD which, does not always involve memory challenges [122].

P1 mentioned physical challenges which impacted his work.

“...and what can I do, right, and now because of over the, you know, the physical part is now I need to change focus because my body is not, something that I’ve been able to use all along is no longer working with me. So I need to find a different way” [P1].

P2 mentioned physical challenges along with sleeping problems.

“[DATE] 2015, all of a sudden woke up that morning and I couldn’t move my leg. I was exhausted too, and I couldn’t move my leg. And I nearly passed out twice while I was having lunch with somebody. And then that was the start of everything, because the other thing that had happened is it had exacerbated so much my symptoms, like I said I wasn’t sleeping. I was in pain. I was in pain in my jaw. I was in pain Parts of my body that I didn’t even know (laughter) could reach that level of pain” [P2].

P5 (caregiver) mentioned speech problems that P4 had.

“As a spouse I found it very frustrating because, um, I wasn’t able to find, like He [P4], hes not able, hes not able to express, um, a lot. When you ask a question, sometimes youre not, um, getting the full answer so I needed to get the information.” [P5].

P6 mentioned fatigue at work.

“huge power tools and not sure how Id react to every situation. Then I started to get some fatigue” [P6].

Managing symptoms

Many participants mentioned different tools and artifacts that were used to manage their day-to-day work. These tools were closely related to the strategies that the participants

Table 4.3: Themes under technology/tool/artifact use and interaction

What tools/technology/artifact do people MCI/EOD use at work?		
Codes	Themes	Sub-themes
artifacts technology self-initiated strategies subject matter experts	managing symptoms	pen and paper, co-worker dynamic, relying on people
self-initiated strategies strategy that may help	strategies and solutions that may work	tech-based strategies, work-buddies, education

were using at work to deal with challenges of MCI/EOD (as mentioned in the theme above and will be mentioned in the cognitive support requirements section, later in this chapter).

Each participant presented a personal experience of using technology in the workplace. However, it was clear that technology was important to the participants and there were many shared experiences. This theme explores the experiences with using technology whilst in employment. The technology/artifacts described in this theme are not necessarily digitally powered tools, they may be artifacts for example, paper and pen, sticky notes, strategies, etc (see Appendix A for list of technology/artifacts).

P1 mentioned writing things down to manage his memory challenges as well as mentioning a co-worker who would help with his work tasks.

“...And I go about my job and then I might forget to look at the work order. And I look at the work order and I go (sigh) I shouldve looked at this at the beginning. Cause now theres something that I shouldve done thats over in the other part of the city but I was there three hours ago and I couldve done it but now I gotta drive all the way back across the city and go do that, you know. So that kind of thing, um, and you know, and Im thinking in my head what I need to do. I mean, I should be writing it down. Thats what Im learning, that I need to write it down so that its there in front of me if I remember, and hopefully I remember to look at it” [P1].

“So, um, but then like with the one guy that I do work with, like, a great guy, he also has,

had medical issues in the past and stuff and he goes, um, you know, don't lift anything. If you need something call me" [P1].

P2 mentioned to-do lists to manage her day along with assistants who she would delegate certain work tasks with.

"And my to-do lists. I always had, like, I used (inaudible 88:47) forwards. Um, I had a system in place for myself in my email of how I would know if something was actioned or not, and I did that. Um, I would make sure, for example, that So I had a, I had.. I developed my own" [P2]

"And then your, um, phone which you had your home phone, as well as your cell, your Blackberry. Were there any other technologies that were used or technological tools that were used, um, to do your work?" [IV]

"Well does it count I had, I had assistants. And so they would have certain tools" [P2].

P5 mentioned use of lists as way to trigger certain tasks for P4.

"No. The only thing that Ive been told could be helpful are lists for him [P4], um, lists. But other than that, um..."[P5]

" Did you say lists?" [IV]

"Lists. Like list things that could trigger for him to do certain things and keep him focused when, you know, trying to get a task, to get a task down" [P5].

"Would it be a paper list" [IV]

"Yeah" [P5].

"or electronic list?" [IV]

"Paper list" [P5]

P6 mentioned managing his day through paper.

"How did you manage your day? How did you manage your schedule? How did you" [IV]

"On paper" [P6].

P7 mentioned delegating work tasks to co-worker, a personal support worker (PSW) in her case.

“...And, um, it wasnt about It was maybe like six or eight months after my PSW took a leave of absence to go back to school and she was gone for a year. And about, I dont know, six, seven, eight months into it I realized that, um, things werent getting done. And, um, eventually I guess I realized that she was filling in for me a lot. She was doing like more than her job, like part of mine, and um.” [P7].

Strategies and solutions that may work

Almost all participants had mentioned potential tools or solutions that may have made their work easier.

P1 mentioned need for a break to decompress from work tasks. P5 mentioned a personal working space for P4 could have helped him at work.

“...We all have set breaks. There are times where if I have been on a difficult call and I just know that I didnt handle it as well I, you know, should or used to or whatever it was, then I just might need, um, five or ten minutes to just, you know, sort of decompress. Cause I, I get angry at myself when stuff like that happens” [P1].

“And I think just that, hes [P4] already dealing with, um, concentration problems. I think it wouldve probably been helpful, um, to be in a quiet space for himself” [P5].

P2 mentioned a tech-based solution, a dictaphone to help her with tasks.

“...So if I had something like that, I would rest assured, Ive got it here, awesome, right? Maybe, and then the only thing I might need to do is then I set a time, like every day I take that, my little gizmo, and I listen to it. And I action it. Anyways, there you go. (laughter)” [P2].

P6 and P7 mention need for educating co-workers, employers about MCI/EOD at the workplace.

“Someone coming in officially and educating those around me as I was going through it over there. There was no one really offering any kind of information in any circle I moved in over there. There was no education” [P6].

“Well educate, you know, the big boss, the agencies, like educating I mean thats what we did to bring, um, the whole idea of people with developmental disabilities dont have to live in institutions. They can have lives, right? So thats what we did is educate. We did a lot of educating. And then eventually were able to bring them into the community, and now all the institutions are closed. But theres gonna have to be some kind of movement like that, I believe, with young onset dementia because people just dont have any idea” [P7].

4.2.2 Discussion

As experienced by others as well (e.g., [105]), transcripts and notes provided a descriptive record of the research, but they cannot offer explanations. The data was further explored by sifting and interpreting them using systematic inductive thematic analysis methods and CTA-DCD modelling, which are discussed in this chapter.

One explanation for the accommodations made/not made could be attributed to the employers not being aware of what changes could be made to assist the employee with MCI/EOD. While there was evidence of accommodations made in assisting people with MCI/EOD, there was no clear consensus if the accommodations helped. What was deemed appropriate support was linked to the type of vocation, the challenges the person with MCI/EOD experienced and the resources the employer had to provide to support. The different accommodation types highlights the need to have a tailored approach to supporting continued employment [112].

These results showed that the difficulties in the vocational situation had surprisingly far-reaching consequences for the participant’s lives, overall. The physical challenges mentioned by P1 did not only have an impact on his vocation, given his job involved lifting at parks and fields, but also affected his job search for future opportunities. P2’s sleep challenges along with her physical challenges were something that kept coming up during the interview. There was also frequent mention of stress and anxiety due to her new-found challenges and changed the employer-employee relationship. Experiences of increasing and diffuse difficulties in MCI/EOD have also been described as an ever-present, stressful and threatening factor in other studies [119, 101].

All the technology/tool/artifact mentioned by the participant can be seen in Appendix

A. Pen and paper use through day-books and post-it notes coupled with delegating work to and seeking help from people were mentioned by most participants. People using pen and paper and seeking co-workers at vocation for help is not necessarily specific to people with MCI/EOD. This implied that people with MCI/EOD are currently not using any AT or tool specifically designed to aid with their challenges. Interestingly, the experiences of ATs like memory aids are negative among those who have tried them in literature around people with MCI/EOD in vocation [101]. Researchers also call for further research on the development and use of ATS for people with MCI/EOD [101].

Participants also mentioned the importance of making the employer and co-worker aware of MCI/EOD. Participants (P6 and P7) felt that employers and co-workers (especially younger co-workers) needed to be aware of what MCI/EOD looks like in vocation. Educating their vocation may be important to them due to potentially being vulnerable at work. Some participants did experience difficulties managing changing vocation relationships and the negative reactions from co-workers (P2 and P7, for example). As a consequence, some participants may be more vulnerable to conflict at work [37]. There was also mention of the employer not acknowledging the cognitive challenges (P3). The ignorance of cognitive deficits in the workplace seems surprising. One possible explanation may be that many employees work independently [101].

There were other aspects of work observed from the data that were out of the scope of this thesis. For example, a lot of aspects of the accommodations mentioned above had led the participants to talk about work-unions and policies around them.

4.3 Phase 3 - Data Representation: Work-flow Model

The work-flow model is a visual representation of work for design. It represents how people work and was chosen for data representation because it helps in contextualizing a person's workplace, in the absence of an ethnographic observation. The work-flow model is developed from the perspective of the participant for each participant and their recollection of tasks and challenges at work and is used to contextualize their workplace. The work-flow model for each participant is recreated from [2] and are shown in Figures 4.2, 4.3, 4.4, 4.5,

4.6, and 4.7. The components of each work-flow model are as follows:

People are shown as bubble. Bubbles and place on the work-flow model is annotated with responsibilities.

The *flow* is the communication between people to get work done. Flow may consist of informal talk and coordination or it may consist of passing artifacts. Flow is shown as arrows between individuals.

Artifacts are the “things” related with or used at work. An artifact may be physical, such as a document or diary. It may also be conceptual; for example, a strategy like verbal recollection. Artifacts are shown as small boxes overlaid on flow.

Places that people go in and out of in order to get their work done, if it is central to the work of coordinating and collaborating. It is shown as a large box annotated with name of place.

Pressure points or problems in communication and coordination, represented as a red lightning bolt.

The pressure points were derived by going through the coded transcripts and looking for the challenges and problems people face at work.

4.3.1 Results

The findings, including identification of pressure points from the work-flow model (Figure 4.1), are presented here.

P1’s (Figure 4.2) pressure points included not being aware of where he was while driving at work in his vehicle, forgetting work orders given by his supervisor, and difficulties in working with certain co-workers.

P2’s (Figure 4.3) pressure points included problems with her work-computer, and the accommodation provided to her not being enough.

P3’s (Figure 4.4) pressure points included challenges with completing some tasks.

P4’s (Figure 4.5) pressure points included challenges with using a new technology introduced at work and with writing reports on his computer.

P6's (Figure 4.6) pressure points included with challenges in completing work tasks.

P7's (Figure 4.7) pressure points included problems with her supervisor and with completing tasks on her work-computer.

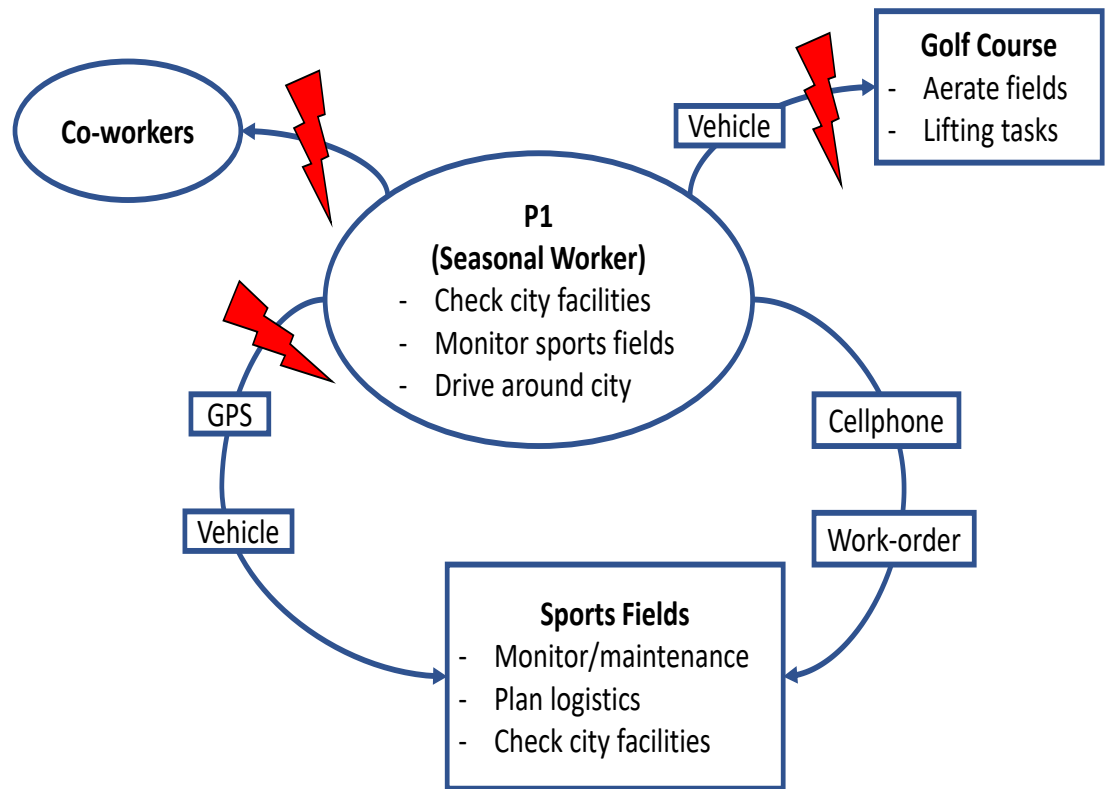


Figure 4.2: Work-flow model for P1

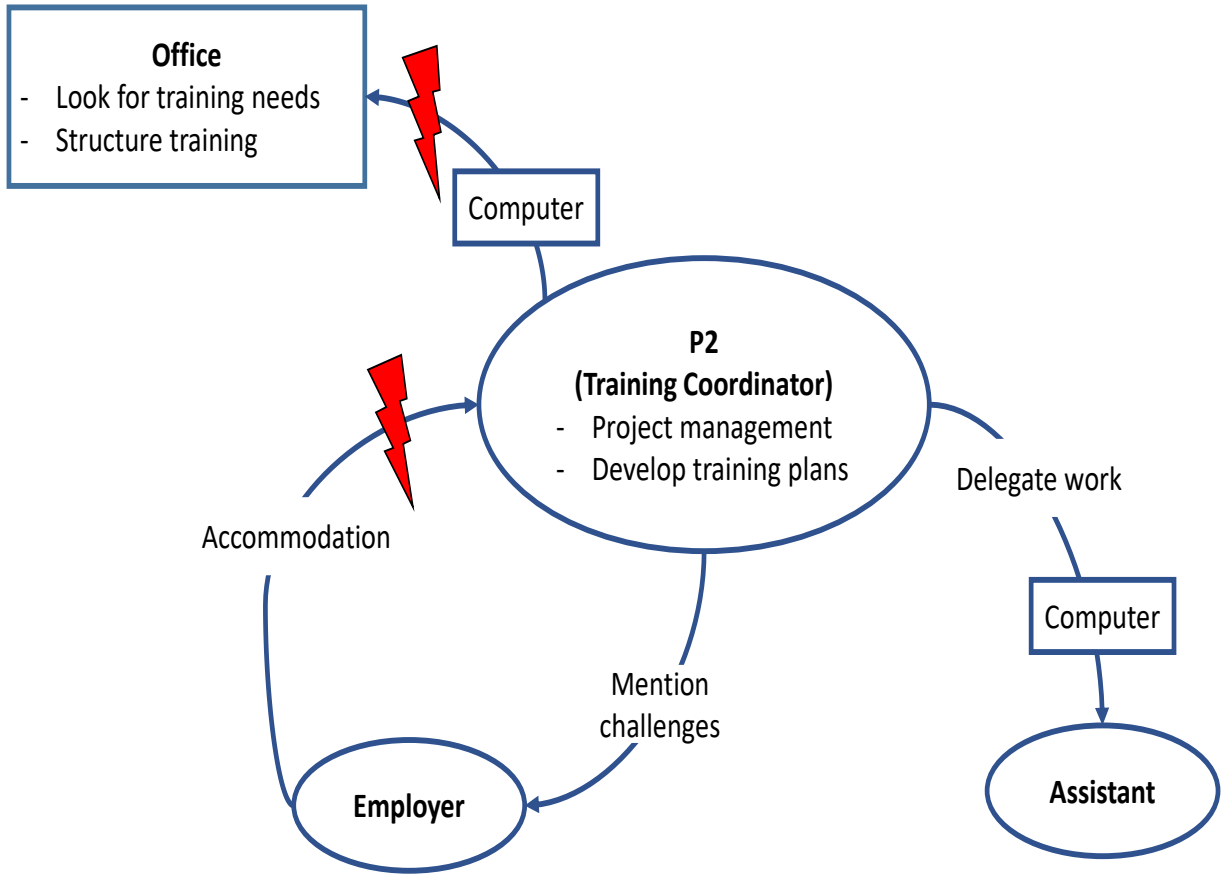


Figure 4.3: Work-flow model for P2

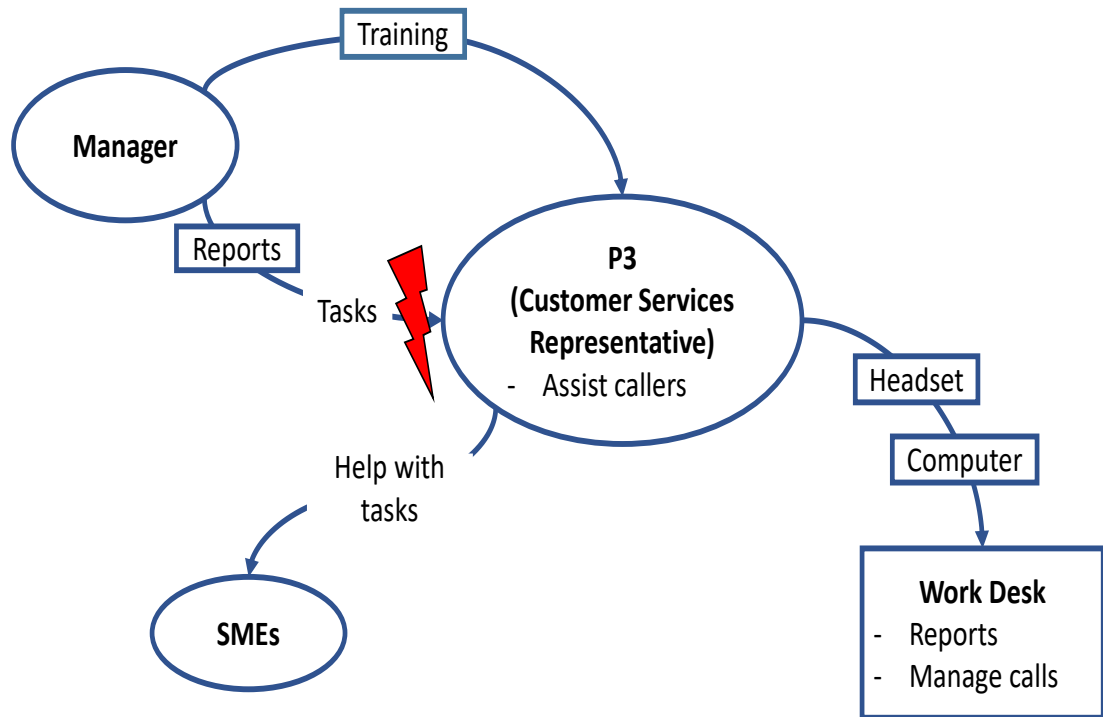


Figure 4.4: Work-flow model for P3

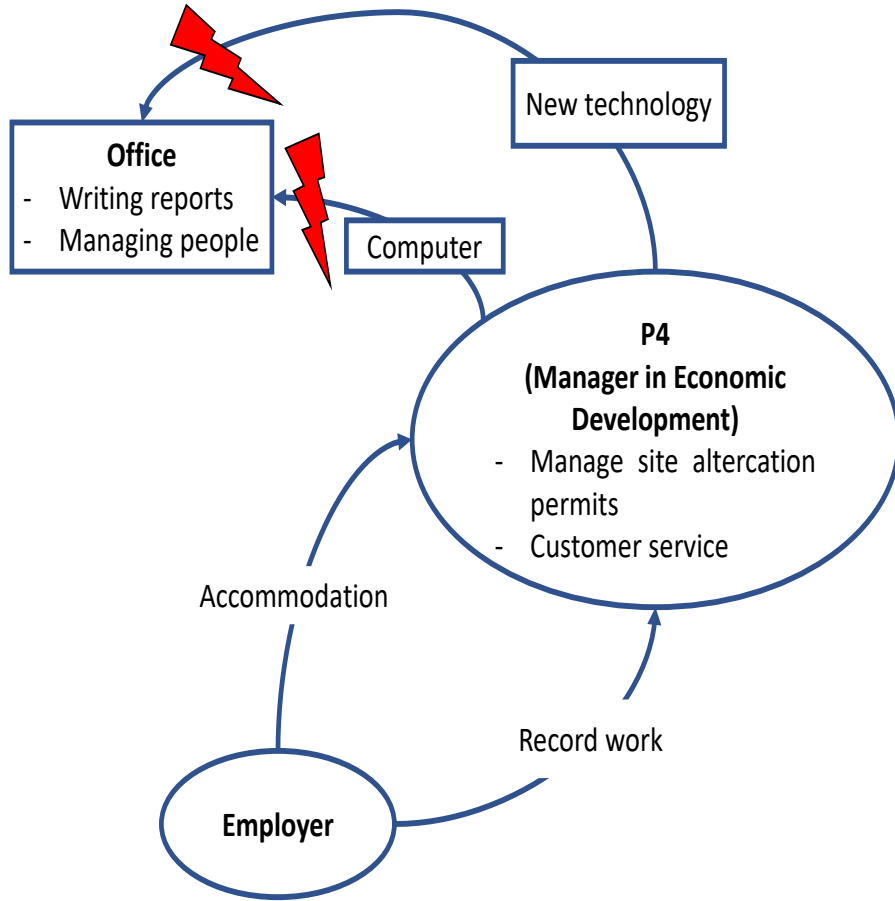


Figure 4.5: Work-flow model for P4

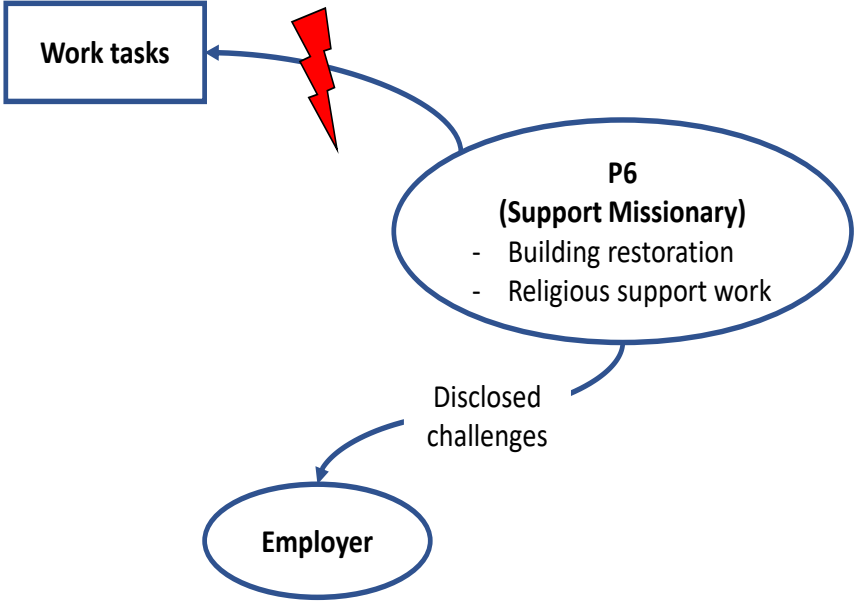


Figure 4.6: Work-flow model for P6

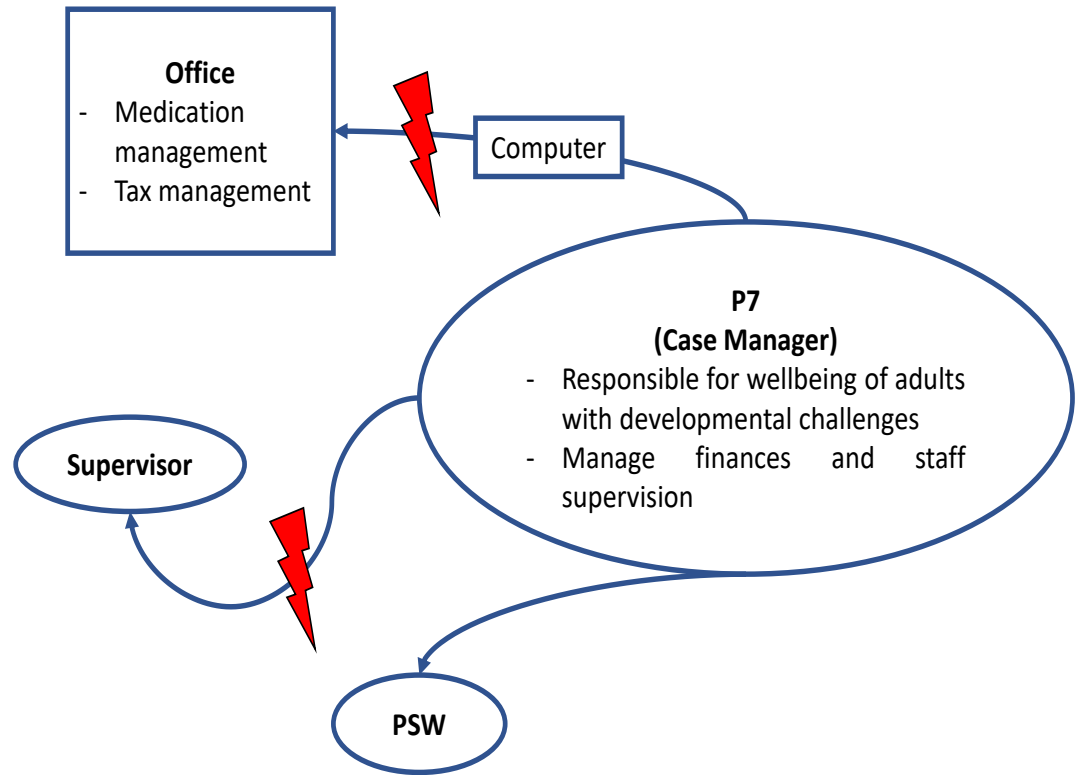


Figure 4.7: Work-flow model for P7

4.3.2 Discussion

All work in this world involves other people to some extent [10]. From this representation, problems or pressure points of individuals are identified in what context they occur.

The work-flow model can be used to contextualize a participant's vocation. It is important to note that the work-flow model for each participant was constructed based on the participant's recollection of their vocation, which may or may not be a true representation

of their vocation. Some of the pressure points that are not clear just by looking at the models are discussed in the earlier section (thematic analysis) and in the following section (cognitive support requirements and macrocognitive activities).

The work-flow model captured challenges of people with MCI/EOD that were not necessarily a theme, but a personal experience at work. The work-flow model aided in visualizing how people worked, who they communicated with, and what artifacts or tools they used to get work done. The work-flow model captures the pressure points of each participant and represents their corresponding flow of work. These pressure points do not influence the identification of cognitive support requirements, however, this does aid in identifying the challenges of the participants in their daily routine of work through the pressure points.

4.4 Phase 4 - Decision Support Requirements: Cognitive Support Requirements and Macrocognitive Activities

Cognitive Support Requirement

Cognitive support requirements are heuristics used in this thesis to understand the cognitive elements that need support for people with MCI/EOD and understand the work context. The term *decision requirements* is used broadly in the decision-centered design literature to include a range of complex cognitive activities [66]. For clarity, the more descriptive term *cognitive support requirements* is used in this thesis [89]. These cognitive support requirements and complex macrocognitive activities (described below) are identified to inform the design criteria for technologies for people with MCI/EOD.

Cognitive support requirements can be difficult to identify and represent. Key judgments and decisions are often subtle, not open to observation, and require interpretation [72].

Macroognitive Activity

A general finding from the area of HF research has been to describe and understand decision making and cognitive tasks in real-world environments, a higher level of analysis and descriptions is required than is typically described in cognitive psychology. This level has been termed as “macrognition”. Furthermore, the post-hoc method of organizing the data using the macrocognitive framework has helped design teams maintain a focus on user needs. The macrocognitive framework has allowed designers to anticipate implications of individual barriers and aspects of cognitive work not specified initially [89].

The CTA-DCD approach is intended to explicitly acknowledge that people need support for cognitive tasks in real-world environments and provides the means to articulate the related macrocognitive activities that must be supported. Researchers and domain practitioners have identified macrocognition functions that characterize work in complex domains. These functions provide a broad conceptual lens to aid description and thematic analysis of overwhelming, messy, interrelated observational and interview data from cognitive field research [103].

Some of the macrocognitive activities and descriptions of cognitive tasks that underpin the CTA-DCD approach include sensemaking, re-planning/adaption, maintaining common ground, detecting problems, managing uncertainty, managing attention, naturalistic decision making, and coordinating(as depicted in Figure 4.8). For the scope of this thesis research and the goal of the CTA-DCD approach is to support the articulation, analysis, and understanding of these activities, such that the appropriate choice of design of technologies can be recommended [57].

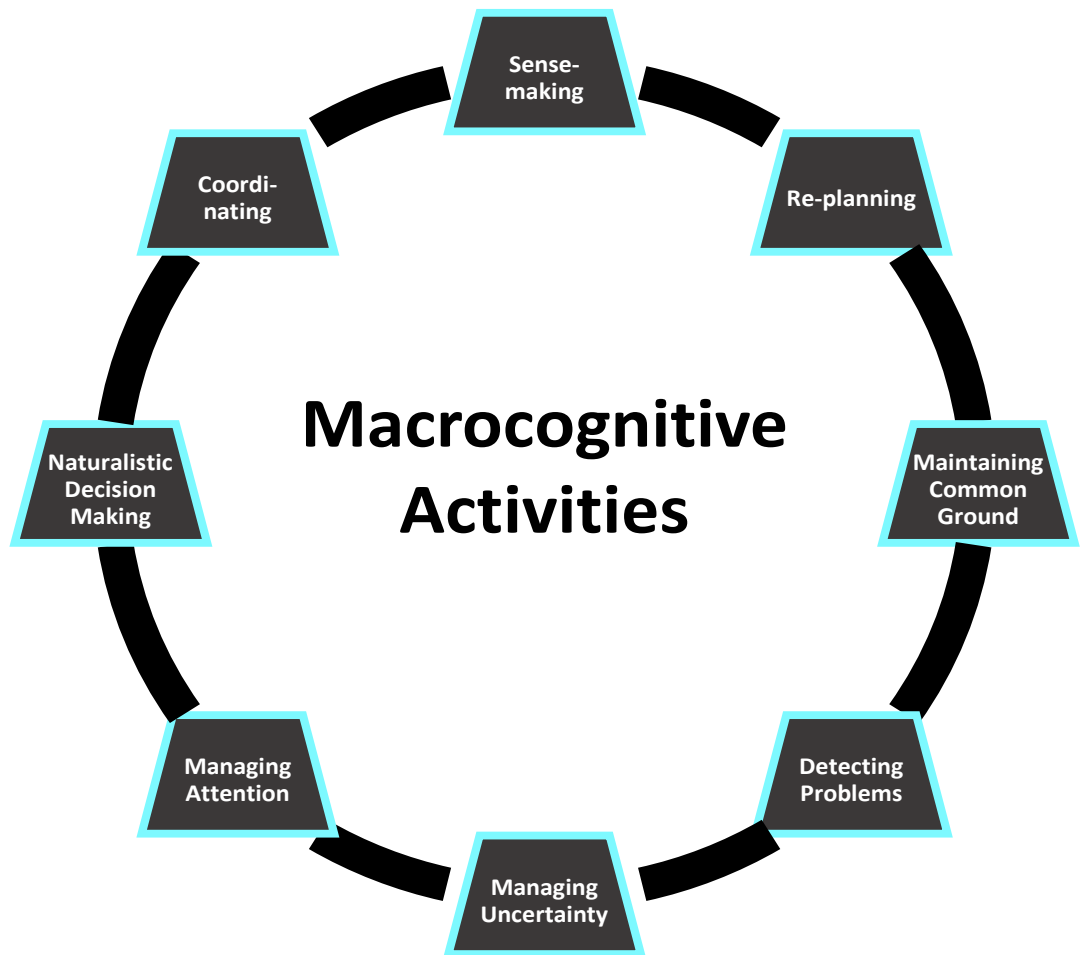


Figure 4.8: The macrocognition process (Recreated from [73]) with all supporting functions as macrocognitive activities

4.4.1 Results

Cognitive Support Requirements

The cognitive support requirements were identified using deductive thematic analysis, where the data was explored for the cognitively challenging aspects of work. The data was looked at with pre-existing codes (e.g. cognitively challenging work) and were correspondingly assigned to multiple quotes. The pre-existing codes were derived from related literature on cognitive support requirements [89, 79, 57]. Table 4.4 describes the six identified cognitive support requirements and their description.

Confusion with work tasks is the first identified cognitive support requirement. P1 had problems with initiating and completing tasks. For example,

“And then I go and do something completely different from what I just decided I was gonna do” [P1].

Memory problems is the second identified cognitive support requirement. P1 had problems with remembering tasks to complete. P2 describes using timers to remind her of tasks to complete. P6 had challenges with disorientation while driving and completing work tasks. P7 had forgotten one of her client’s medication.

“its the challenge in my brain that is (pause) you know, Im wrestling in my head trying to, you know, okay, this is what I gotta do, this is Cause its starting to slip away” [P1].

“It [timers] was to help me with my next task. Like, to get me, to get me from my focus (sigh) I dont know how to describe it. Lets, um, work on that game, and Im so entrenched in this now its like I dont know of anything else going on, and then I would set the timer. There were times the timer would go off and I didnt even remember what it was for, but I just knew it was for something” [P2].

“Well my wife had said shed seen symptoms for a couple years that I had not. Some little things that Reactions, uh, a little disorientation driving, more emotional. Just subtle things. My daughter also acknowledged them to the point where, well it could maybe start to affect safety. Thirty-five feet up on a clay roof working away might not be as good a place [P6].

“I mean it was a common thing to make a med error like that but I had never made one in twelve years” [P7].

Problem with restructuring is the third identified cognitive support requirement. P1 had problems with reorganizing tasks, if they went out of the planned structure.

“...and if it goes outside of that logical way, now its a challenge for me to figure that out. It can be a challenge for me. Its just like okay if I, instead of doing this way, and I do this way, how do I bring myself back around to this way?” [P1].

Inability to concentrate is the fourth identified cognitive support requirement. P2 had problems with concentration on daily tasks at work which she could complete before. P5 (caregiver) mentioned P4’s inability to concentrate. P7 mentioned experiences with feeling of stress.

“I couldnt concentrate. I was in the office and I was just, I, I had nothing. I couldnt process what was happening, um. My anxiety was through the roof, um. My doctor started to explain to me, um, that That was then another start to another whole big bad crash that as time went on, I just, I just kept getting worse and worse” [P2].

“He was having trouble with his concentration, but um And he told me he got called into a couple of meetings, right?” [P5]

...it [challenges at work] had to do with process, you know. My, um This was something that became really evident, is that my executive functioning, right, the process of step one, step two, step three. And I was also (inaudible) and I mean, lots of thoughts were (inaudible) and thats also, that ability comes from your executive functioning, its one step, two step, you know. And, um, I was halfway through a book and I couldnt, I just couldnt do it anymore. I had to keep ripping it or I was doing it all wrong and it just, you know, so. Ive lost that, um, which I really, really enjoyed. [P7].

Learning new tasks is the fifth identified cognitive support requirement. P3 mentioned challenges with learning new programs at work.

“...it took a while for it to kind of sink in. At first it just, I just felt like I may be stupid or something like that. Um, and so this, not ignoring it but just I was angry (laughter). And um one of the things that I couldnt do was learn new programs like (inaudible 6:13) which I always loved. I used to love a challenge. But I couldnt retain it so I cant, you know, couldnt take calls on um There was some short small ones that I had done since then but some of the big, um, bigger programs I cant, I dont” [P3].

Processing large amounts of information is the sixth identified cognitive support requirement.

“Well I guess there was some things where I was told I would have to go for the training and I resist. At first they did, like I went for a few, a couple of them, and then I, um, just wasn't working for me and I had to get my union involved. Where I mean my doctors reports have always said that its hard for me to retain new, and especially large, amounts of information.” [P3].

Table 4.4: Cognitive support requirements

Cognitive Support Requirement	Description
Confusion with work tasks	Challenging in Initiating and completing different tasks, different from what was initially planned.
Memory problems	Need for writing everything down, tasks slipping away, disorientation during tasks.
Problems with restructuring	Trouble with reorganizing tasks if they are not completed in a specific order. Challenging if the tasks go outside of the “logical way”
Inability to concentrate	Inability to process and initiate tasks at work, challenges with day-to-day tasks, feelings of stress and anxiety.
Learning new tasks	Inability to retain new programs related to work tasks.
Large amounts of information	Inability to retain new information, especially large amounts of information.

Macroognitive Activities

The macroognitive activities are identified from [73] (Figure 4.8) discussed in the previous subsection. The identified cognitive support requirements are broadened to their corresponding macroognitive activity, based on their definition of the activity. This is done to seek design recommendations used in HF literature that support corresponding

Table 4.5: Linking cognitive support requirements to macrocognitive activities and general design implications

Cognitive Support Requirement	Macrocognitive Activity	General Design Implications
Confusion with work tasks, learning new programs	Sensemaking	Instruction options
Problems with restructuring	(Re-) Planning/Adapting	System supporting planning
Inability to concentrate, large amounts of information, memory problems	Managing attention	Display important, information, reminder prompts.

macrocognitive activities and see how they relate to literature discussing features and functionalities in technology for people with dementia, in general.

The first macrocognitive activity is **sensemaking**, defined as the deliberate effort to understand events and is typically triggered by unexpected changes or surprises that make a decision maker doubt their prior understanding [59]. Sensemaking is one of a number of macrocognitive activities that needs to be supported by design. Some tasks are more focused on assessing situations and sensemaking and therefore DCD is driven by the sensemaking challenges. A significant barrier or the cognitive support requirement to sensemaking were confusion with work tasks and learning new programs.

Re-planning and adapting is the second macrocognitive activity. [92] describes the metrics for re-planning and adaption including but not limited to low barriers in re-planning, not using existing information appropriately, and dissemination of new plan. Problems with restructuring tasks were a significant barrier or cognitive support requirement to re-planning and adaption.

The third macrocognitive activity is **managing attention**. The challenges of concentrating during work tasks, processing large amounts of information and memory problems reflect the challenges of managing attention [90] to multiple participants in different occupations.

4.4.2 Discussion

Table 4.5 shows how the characterization of the macrocognitive work broadened from cognitive support requirements to general design implications, such as instructions and reminder prompts. This table illustrates the value of decision-centered design in keeping the macrocognitive activities in the foreground throughout to requirement gathering for the purposes of technology design; namely, by looking at how different design decisions have supported the different macrocognitive activities. This is valuable because the likelihood of the resulting tool or technology that will in fact support the end-user in managing cognitive complexity, critical to their work, will increase [89].

It is important to note that the cognitive support requirements are specific to the vocation of the person with MCI/EOD. For example, P3's inability to learn new tasks is specific to her vocation's requirement to do so. Similarly, P1's challenges with restructuring work tasks were due to the way work orders were arranged at his vocation.

The start of the challenges at vocation for most participants were minor difficulties at work, like forgetting tasks, being overwhelmed with work tasks. Other studies have also reported similar slow changes at work [101, 37]. In one case (P4), the time-frame from diagnosis of EOD to transition out of work was relatively quick, when compared to other participants. This may be due to the nature of the diagnosis and the participant's unique challenges. Some participants noticed the change in their function of work but did not think it was a sign of anything serious [20].

The cognitive support requirements and decision strategies are the drivers of the design concept solutions. Often design concepts fall out of, or emerge from, the CTA and the cognitive support requirements analysis, even though these are not necessarily specific objectives of the CTA itself. Sometimes the expertise and creativity of the design team are required to envision potential solutions to support these tough cognitive activities. Sometimes, new technologies are required to recommend to solve the design problem, and in other cases, the findings drive research to solve problems that currently are beyond the technologies and human skills that exist [57].

4.5 Phase 5 - Design Recommendations: Design Concepts

As mentioned earlier, the design concepts (as seen in Figure 4.5) are derived from HF and designing for dementia literature to support the corresponding macrocognitive activities. Other design factors will play into the design process, including HF guidelines, ergonomic issues, organizational design issues, and standards and guidelines from other disciplines, but these recommendations are grown from the goal of supporting the key decision requirements of people with MCI/EOD at work [57].

4.5.1 Discussion

The rationale for identifying cognitive support requirements is to use them to guide the design process. The process of transforming decision requirements into design recommendations is a critical one. In this pilot work, this was done by looking at what designs are recommended to support the corresponding macrocognitive activities and see if they are logical in the study context. The design implications for this research are focused on technology design to assist people with MCI/EOD with managing work tasks related to cognitively challenging work or the cognitive support requirements.

The design features recommended are derived from literature covering the design of technologies [68, 67] for people with MCI/EOD. The design features were chosen to support the macrocognitive activities such as sensemaking, re-planning/adapting, and managing attention.

The design of a new system should support the sensemaking macrocognitive activity; this could be done through features like an instruction guide that can be used to avoid confusion with a system. [68] makes use of an instruction feature in a system to help guide people with dementia to find different apps. Other features could be a time-based display of the history of tasks completed. This feature has been deployed in HF healthcare research to support sensemaking [89].

Features supporting planning and restructuring of tasks in an intuitive way is the second

design implication. [68]’s study, for example, highlights that design of tools or apps should have an emphasis on a user-friendly way to update tools (eg. mobile apps).

Participants in this research also mentioned challenges with retaining large amounts of information, along with memory challenges and inability to concentrate at work tasks. Thus only useful information should be displayed in the design of a system for people with MCI/EOD at work. Features like reminder prompts can also be utilized in a system to support the managing attention macrocognitive activity.

4.6 Phase 6 - Design Validation: Verify If Designs Work

Validation of the recommended designs can be done with low to high-fidelity prototypes and are out of the scope of this thesis.

4.6.1 Discussion

Validation of designs mentioned in Table 4.5 can be done through different usability tests, however, due to time limitations this was out of the scope of this thesis. When this is done in future research, it is important to consider the participant’s vocation context and how that may change from participant to participant. For example, the usability test for P1 whose vocation involves driving and lifting work will look very different than the usability test for P2, whose vocation context involves an office space with a desk.

4.7 Chapter Summary

This chapter piloted the CTA-DCD model to systematically elicit, analyze, and represent the needs, artifact interaction, cognitive support requirements of people with MCI/EOD at work. The design decisions were then recommended with the goal of supporting the cognitively challenging tasks for people with MCI/EOD at work.

To answer the first question guiding the chapter: The CTA-DCD model's strength and validity are in its a systematic approach to elicit the cognitively challenging tasks at work. It is especially applicable for designing technology for people with MCI/EOD because of its focus on recommending designs with the goal of supporting the cognitively challenging aspects of vocation, which can get increasingly difficult with time for people with MCI/EOD [37].

To answer the sub-questions of the second overarching question guiding this chapter: The themes from unmet needs and challenges for people with MCI/EOD are:

1. Accommodations made / not made
2. Challenges that were not cognitive related

The themes from the tools/technology/artifact interaction that people with MCI/EOD use at work are:

1. Strategies for managing symptoms
2. Strategies and solutions that may work

The six cognitive support requirements identified are:

1. Confusion with work tasks
2. Memory problems
3. Problems with restructuring
4. Inability to concentrate
5. Learning new tasks
6. Large amounts of information

The three broad macrocognitive activities are:

1. Sensemaking
2. Re-planning/adapting
3. Managing attention

The three design recommendations to support the macrocognitive activities are:

1. Having instruction options
2. System functions supporting planning
3. Display of important/relevant information and reminder prompts.

Chapter 5

Overall Discussion

This thesis presents the CTA-DCD as a systematic framework to elicit the needs of people with MCI/EOD with the intent of technology design. The unmet needs, challenges, and technology use of people with MCI/EOD in the workplace were highlighted.

P1's quote stands out and perhaps best describes most participants' experience in the study:

Every day is different. Some days are great, some days are different [P1].

It is important to note that each participant's experience was specific to their vocation environment and diagnosis. For example, P4's challenges with speech were very different from P7's more memory-related problems at work. The implications in design of technology with adaptable interfaces and machine learning will be discussed later in this chapter.

As discussed in earlier (in [chapter 4](#)), cognitive support requirements in this thesis's context are the heuristics used to understand the cognitive elements that need support for people with MCI/EOD and understand the work context. The design of a system to support people with MCI/EOD's challenging tasks at work should support the broader categorization of cognitive support requirements or in other words, the macrocognitive activities. The design of technology to support cognitively challenging tasks can also apply to late-onset dementia. However, the context of the tasks that technology would be supporting would be more in the home or assisted-living context.

Certain aspects of CTA were modified to fit the context of the problem space. For example, conventionally, CTA methods use data representation (third phase of CTA) like abstraction hierarchy; however, the data representation phase in CTA in this thesis makes use of the work-flow model [10] from contextual design. This is done to contextualize the participant's vocation and is hence used over abstraction hierarchy.

CTA-DCD methods have not been used to explore the requirements for technology design for people with MCI/EOD. The goal of CTA-DCD is to provide design recommendations that supports the identified cognitively challenging aspects of work. This is especially important for people with MCI/EOD because cognitively challenging tasks at work are changing constantly.

An aspect that worked well with piloting the CTA-DCD model was identifying the cognitive support requirements through deductive thematic analysis. The CTA-DCD model presented the opportunity to see how previous designs of technology have supported various macrocognitive activities and how it matches with current technology designs for people with cognitive impairment or dementia. The CTA-DCD model also aids in contextualizing the participants' vocation. This is especially important given the lack of ethnographic observation.

Aspects of linking different cognitive support requirements to their corresponding macrocognitive activities were difficult. This was due to the broad definition of different macrocognitive activities and how one macrocognitive activity may potentially include multiple cognitive support requirements. While the broad definition of the macrocognitive activities gives room for flexibility for technology design to support them, there needs to be more research on what design features are used and how they support the macrocognitive activities, outside of the traditional contexts like the military [55]. More diversity in the types of occupation under observation will enrich the use of macrocognition in design research, as a consequence.

Significant tension in design research concerns the generalization relevance issue: the problem of theorizing beyond local context but losing relevance; or diving into local context but losing broader applicability [71]. Local context at this level is typically case-based nature, focusing on individual problems and unique situations. In this thesis, the

generalization-relevance issue was faced with focus groups and one-on-one interviews. The first set of interviews raised the problem of generalizing the participants' needs to all scenarios. Participant comments were included to enrich the descriptions of their challenges and demographics were presented to offer background information.

5.1 Design Implications

Given how diverse the occupations were in this study and in related literature, the platform that the design features recommended in [chapter 4](#) sit on can be vocation-specific or unique. For example, machine learning algorithms supporting adaptable interfaces to the person's unique occupation could be potentially a way to support a broader population of MCI/EOD currently in vocation. Machine learning could also be an important way to improve user experience. Adaptive user interface (UI) patterns are of growing importance in designing new technologies [148]. These could be used to support MCI/EOD at work by having an adaptable interface or platform, specific to the vocation. For example, having vocation-tailored interfaces to support the cognitively challenging tasks could use adaptable UIs.

The absence of the employer/co-worker's perspective has implications on design as well. Feelings of social isolation and stigma for people with MCI/EOD at work have been documented in other studies [37]. Involving employers/co-workers in the design of technology for their co-workers/employees with MCI/EOD, may result in a more functional and collaborative tool.

5.2 Applications of CTA-DCD Model

The CTA-DCD model introduced in [chapter 3](#) could be used in various different domains. CTA and DCD methods have already been used in healthcare [65] and military [55] spaces. With this thesis, it has been applied in the MCI/EOD space. This thesis has a focus on the general definition of occupation to include paid work, as seen in the participant demographic (see [chapter 4](#)). The model can be used in various different work-contexts

however. The Canadian Model of Occupational Performance and Engagement (CMOP-E) classified occupation into three categories referred to as occupational purposes which are; self-care, productivity and leisure. This model can be potentially used to break down tasks and decision requirements of all three occupation classifications. Furthermore, this thesis research could be used for other populations with disabilities and at different ages in the workplace as well as other contexts.

5.3 Limitations and considerations

This research is not without limitations. While it is aligned with other studies in this field (i.e., designing technology for people with dementia), the sample sizes are modest, with six people with MCI/EOD and one caregiver interviewed. In addition, the perspective of the employer/co-worker along with an ethnographic observation is missing, which is crucial in the design of technologies in the context of vocation. Furthermore, the study is limited by the chosen methodological approach. In the focus groups and one-on-one interviews, participants were asked to recall previous events and describe their challenges. Due to the nature of MCI/EOD, participants' recall of the events may be inaccurate.

This thesis research pilots the CTA-DCD model with a challenging design population and has shown good results; however, this is one population in one context. The CTA-DCD must be evaluated over other applications to gain a better understanding of its strengths and weaknesses as well as to verify its usefulness in a range of situations.

Strengths of this thesis include the in-depth interviews with participants and putting forward a systematic framework to understand the needs of people in different occupations (according to the occupation model [69]), not just the vocational context of people with MCI/EOD. A Key strength of this thesis is that it is a first from a technology design perspective to develop technologies for people with MCI/EOD at work.

As mentioned earlier in this thesis, MCI and EOD are different. This thesis follows the MCI/EOD throughout to generally depict people with memory deficits, which is a limitation of this thesis. This may have impacted the data analysis and conclusions as the design recommendations for technology creation may work for people with MCI at this

stage, however, it may not work for them over the period of time, as MCI may or may not lead to dementia [45]. This also ties into adaptable interfaces and machine learning potentially tackling this problem. It may also be helpful to classify different MCI diagnoses into amnesic MCI (where memory loss is more prevalent) and non-amnesic MCI (where organization, planning, and reasoning may be affected) [19].

Any system designed to assist people with MCI/EOD with their challenging tasks should also support the identified cognitive support requirements and their corresponding macrocognitive activities, in a broader sense. As discussed earlier section, keeping macrocognitive activities in the foreground is valuable because the likelihood of the resulting tool or technology that will in fact support the end-user, (people with MCI/EOD in this case) in managing cognitive complexity, critical to their work, will increase [89].

This can be reaffirmed through usability tests of a prototype involving the design recommendations. For example, in this pilot work the the design decisions were systematically recommended by process of identifying the cognitive support requirements and macrocognitive activities.

It is important to note that Table 4.5 represents a somewhat sanitized and simplified version of linkages, as individual design features may support more than one cognitive support requirement or macrocognitive activity [89]. While this may potentially give a wider range of technology design opportunities, in terms of design recommendations, there needs to be more research in technology usability and acceptance for people with MCI/EOD.

Chapter 6

Conclusion

6.1 Summary

This thesis puts forward the CTA-DCD model, as well as investigated the unmet needs, challenges, and technology design requirements of people with MCI/EOD at work. The results from the exploratory study illustrate the complexity of work for people with MCI/EOD and the uniqueness of their challenges depended on their vocation. This thesis describes exploring the requirements for technology design for people with MCI/EOD at work.

6.1.1 Key Findings

1. The CTA-DCD model can be used to identify design decisions for developing technology to support people with MCI/EOD at work.
2. We can understand the unmet needs of people with MCI/EOD at work through different elicitation methods from the CTA-DCD model, a cognitive systems engineering approach.

6.2 Future Work

The validation Phase (i.e., Phase 6) for the CTA-DCD model and understanding how well the design recommendations work need to be carried out through usability tests of a prototype, which is out of scope of this thesis, but is the focus of future research.

Participatory design workshops are currently being carried out with people with MCI/EOD to contextualize the workplace more and elicit design cues from their everyday technology use through interactive activities.

The thesis contributes to the design and development of the MCI@Work digital tool, that will potentially assist employees with MCI/EOD and their employers to collaboratively identify the challenges and strategies needed to be addressed for the employee to continue to work, if that is what they want.

6.3 Final Remarks

The overall aim of this thesis was to better understand the needs for technology design for people with MCI/EOD at work. The findings point to different cognitively challenging tasks and their corresponding design requirement.

While this research was done with people with MCI and EOD by grouping them, in practice there are considerations for each group, and indeed for each individual.

The CTA-DCD methods can be used to identify design decisions for developing technology to support people with MCI/EOD at work. We can understand the unmet needs of people with MCI/EOD at work through user-centered design approaches like focus groups and one-on-one interviews.

As described previously, there is lack of technology design approaches for people with MCI/EOD. This thesis contributes to the piloting and analytical phases of a cognitive systems engineering and user-centered design approach. This thesis and work is a first-step towards designing technology to support choice for people with MCI/EOD - a choice to continue to work or transition out in a more respectful way.

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APPENDICES

Appendix A

Technology use

Technology use at work		
Codes: Artifact, technology, co-workers, self-initiated strategies		
Artifact/technology	Description	
Car/Truck	Drive to parks (work task)	P1
Work-order	Task description	
Daily Schedule	Write park name	
Notes	Prev day's work and emergency notes	
GPS (Satellite link)	Car routes and navigation	
Report	Log traffic problems	
Cellphone (work)	Call supervisor	
Cellphone (personal)	Take pictures of damage, email, Waze app, Groovy Notes app, look up park names, Google calendar	
Co-worker	Tension among co-workers, help from one co-worker	
Computer	Email	P2
To-do lists and daybook	Plan everyday tasks	
Blackberry	Work phone (given by employer)	
Assistant's help	With technology	
Desktop and laptop	Set timers, e-learning	
Timers	Reminder	

Work phone	Calling (work task)	P3
Computer	Writing up reports	
Headset	Answer calls (work task)	
iPhone	Text, email, e-newspaper, facetime	
Subject matter experts	Seek help with work tasks	
Computer	Reports, notes, email	P4
Binder	Notes	
Post-its	Notes	P5, P6
Computer	Manage finances (work task)	
Paper	Notes	
Smartphone	Calendar, reminders	
Appointment book	Keep track of work tasks	
iPad	not specified	
Assistant's help	With work tasks	

Appendix B

Screening Questionnaire

SCREENING QUESTIONNAIRE

1. Have you been diagnosed with early onset dementia or mild cognitive impairment?
Yes No **If no, skip to Question 6.*
2. Were you diagnosed with early onset dementia or mild cognitive impairment while employed?
Yes No
3. Are you currently employed?
Yes No
4. If yes, part time or full time?
part time / full time
5. Have you been employed within the last 12 months?
Yes No
6. Are you a friend, family member, or co-worker of someone has been diagnosed with early onset dementia or mild cognitive impairment?
Yes No
7. Are you an employer who has worked with someone who has been diagnosed with early onset dementia or mild cognitive impairment?
Yes No
8. Do you Influence company policies and work adjustments for those affected by early onset dementia or mild cognitive impairment?
Yes No

*Researcher to verify capacity to consent and ability to speak and understand English

Appendix C

Demographic Form (MCI/EOD)

Office use ONLY PCODE SCODE ACODE LCODE

Date

MM DD YYYY

Demographic Questionnaire

1. Gender Identity:
 - Male
 - Female
 - Other (please specify): _____
2. Age: _____
3. Please describe your living situation:
 - Living alone
 - Cohabiting
4. Living environment:
 - Urban area
 - Rural area
 - Suburb
 - Inner city
 - Other (please specify): _____
5. Do you have a driver's license?
 - Yes
 - No
6. Do you receive support in daily life?
 - Yes
 - No
 - Daily supports not needed
7. What is the highest level of education you obtained?
 - No formal schooling
 - Some elementary school
 - Completed elementary school (Finished grade 8)
 - Obtained high-school/GED diploma
 - Obtained college/undergraduate University degree
 - Obtained masters or doctoral degree
8. Which ethnicity best describes you?
 - First Nations, Métis, Inuit/Aboriginal
 - Asian
 - South Asian
 - African American/Black
 - Caucasian/White
 - Hispanic/Latino/Latin American
 - Middle Eastern
 - Multiracial/Mixed
 - Other (please specify): _____
9. Please give the approximate month and year of your diagnosis with dementia/MCI:

_____ (month) _____ (year)
10. Are you currently employed?
 - Yes
 - No
11. Please indicate the type of employment
 - Unemployed
 - Retired
 - Sick leave
 - Permanent, full time
 - Temporary/contract, full time
 - Part time
 - Self-employed
 - Other (please specify): _____
12. Has your employment schedule (i.e. full-time vs part-time or reduced hours) changed since your diagnosis of dementia/MCI?
 - Not applicable
 - Yes, now part-time
 - Yes, reduced hours
 - No changes
 - Other (please specify): _____
13. If you are **not currently employed**, is it due to your diagnosis of dementia/MCI?
 - Not applicable, I am employed
 - Yes
 - No
14. If you are **not currently employed**, when was the last time you worked?

_____ (month) _____ (year)
15. What is your current job title? *(If you are not employed at the moment, what was your last job title?)*

16. Please list/describe two main tasks associated with your job *(If you are not employed at the moment, list two main tasks you completed at the last position you held):*
 1. _____
 2. _____

Appendix D

Demographic Form (Caregiver)

Office use ONLY	PCODE	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	SCODE	<input type="text"/>	<input type="text"/>	<input type="text"/>	ACODE	<input type="text"/>	<input type="text"/>	LCODE	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
		Date	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>								
			MM	DD	YYYY												

Demographic Questionnaire ~PS~

Questions about yourself

1. Gender Identity:
 - Male
 - Female
 - Other (please specify): _____

2. Age: _____

3. Please select your relationship with the person in your life with dementia/mild cognitive impairment (MCI):
 - Spouse of person with dementia/MCI
 - Child of person with dementia/MCI
 - Close friend of person with dementia/MCI
 - Other (please specify): _____

4. Which ethnicity best describes you?
 - First Nations, Métis, Inuit/Aboriginal
 - Asian
 - South Asian
 - African American/Black
 - Caucasian/White
 - Hispanic/Latino/Latin American
 - Middle Eastern
 - Multiracial/Mixed
 - Other (please specify): _____

5. What is the highest level of education **you** obtained?
 - Some elementary school
 - Completed elementary school (Finished grade 8)
 - Obtained high-school/GED diploma
 - Obtained college/undergraduate University degree
 - Obtained masters or doctoral degree

Questions about the person with dementia/MCI in your life

6. Please list, to the best of your recollection, when the person with dementia/MCI received their diagnosis:

(month) (year)

7. Was the person with dementia/MCI employed at the time of their diagnosis?
 - Yes
 - No

8. If the person with dementia/MCI was employed at the time of diagnosis, how long did they continue working post-diagnosis?
 - Not applicable, they are employed presently
 - Less than 6 months
 - 6 - 12 months
 - More than 12 months, please specify: _____

(PLEASE TURN OVER)

9. What employment position did/does the person with dementia/MCI hold at the time of their diagnosis? *(Please describe, to the best of your ability, what their job was/is and what it entails/entailed)*

Appendix E

Consent Form (MCI/EOD)



Focus Group Consent Form – Persons with Cognitive Impairments

Research Project Title: Dementia or mild cognitive impairment: at work in progress (MCI@work)

Funding: CIHR, JPI - MYBL

Principal Investigator: Dr. Jennifer Boger, University of Waterloo; Dr. Arlene Astell, Ontario Shores

Co Investigator: Dr. Parminder Flora, Ontario Shores

Research Investigator: Karan Shastri, University of Waterloo, Sheida Marashi, University of Waterloo.

You are being invited to take part in a research project, and thus it is important for you to understand why the research is being done and what it will involve. Please take time to carefully read the following information and to decide whether or not you wish to take part. Please read this form carefully. If anything is unclear or if you would like more information, please contact the researchers listed at the end of this document.

What is the purpose of the research study?

We are inviting you to participate in a focus group session aimed at exploring the types of challenges and solutions people diagnosed with early dementia or mild cognitive impairment (MCI) have while receiving this diagnosis in the context of continuing to be employed. We are looking to understand the type of learning approaches and problem-solving strategies each person develops in order to adapt and manage working with cognitive impairment. We are also interested in learning about the regulations and policies available at different companies for persons with cognitive impairments. As well, we will explore the role of technology in providing assistance to persons with MCI/dementia in order to continue a meaningful employment. Each session will be led by a member of our research team who will audio and/or video-record the interactions for future evaluation.

Why am I being asked to participate?

You are being invited to voluntarily participate in this project because you have been recently diagnosed with early stage MCI/dementia. For this study, we are hoping to recruit approximately 48 individuals who have been recently diagnosed with early stage MCI/dementia or who are supporting someone who has been recently diagnosed.

Do I have to participate?

It is completely up to you to decide whether you wish to take part in this research. If you do decide to take part, you will be asked to sign this consent form and you will receive a copy to keep. Even if you do consent now, you can withdraw from the study at any time without any consequence. However, certain information collected prior to withdrawal, such as audio/video recordings, will be retained and cannot be withdrawn once collected.

What do I have to do to participate?

You will be scheduled to participate in a focus group session with other participants who have a diagnosis of MCI/dementia or are supporting someone with a diagnosis. The group session will consist of no more than six participants plus one or two research team members. You will be asked to participate in only one focus group session, lasting approximately 1.5 to 2 hours. The session will be audio and/or video-recorded in order to evaluate the interactions happening in the group. You will also be asked to complete a demographic questionnaire including general personal information about you. If you do not wish to answer certain questions, you may choose to leave them blank. To complete the questionnaire will take approximately 5-7 minutes.

What are the possible disadvantages or risks of taking part?

The risk of you experiencing any disadvantages by taking part in this research is low. As a possible disadvantage, you may find it challenging to share your experience in a group format and/or you may find the questions on the questionnaire uncomfortable to answer. Researchers may use small clips of the video-recordings in academic presentations for educational or illustrative purposes, which could put you at risk of being identified. However, at the end of this document, your permission will be asked for video-clips of you to be shared outside of the immediate research team; to which you may agree or disagree without affecting your study participation.

What are the possible benefits of taking part?

Your participation in this research may benefit others in the future.

Will I be compensated for taking part?

You will not be compensated for participating in the study.

Will I be reimbursed for any expenses that I incur?

You will be eligible to receive reimbursement for transportation or parking expenses incurred while for taking part in the focus group.

What if I want to withdraw from the study?

Your well-being is our top priority. Your participation in this study is voluntary. You may decide not to participate in this study, or to leave the study at any time. You may let the researcher know at any time if you no longer wish to participate. There are no consequences for doing so. At the same time, if you withdraw after you have been audio and/or video-recorded in a session, it will be impossible to remove your image and voice from the recordings. Similarly, you may withdraw the information you provided on the demographics questionnaire. However, depending on your withdrawal time, if your data has been mixed with others and sent to be presented on or published we would not be able to remove it. If you have any questions, or wish to withdraw from the study, **please contact:** Dr. Parminder Flora (Co-Investigator) at florap@ontarioshores.ca or (905)430-4055 ext 6663.

Will my participation in this project be kept confidential?

The information collected from you during the course of this research will be kept confidential within the research team at Ontario Shores and the University of Waterloo and not shared with anyone outside the team. Your confidentiality will be protected to the extent permitted by the law.

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

You will be audio and/or video recorded during your participation in the focus group, in order to review and analyze the recordings for the project. The recordings are an important part of the research, as they allow the research team to capture all nuances of the interactions, which may include demonstrations of physical or environmental adjustments which are important to see. At the same time, if you do not wish to be viewed on camera, you may ask to be seated outside of the camera's visual range but you will need to remain within a reasonable audible range, so that we may capture your contributions.

Who will have access to the data and where will it be held?

All data will be held securely at Ontario Shores under the supervision of the Principal Investigator, the immediate research team and the Research Ethics Board. Your data may also be shared with our research team for this study at the University of Waterloo. All data will be stored for seven years after the completion of the project.

What will happen to the results of the research project?

When we are finished collecting data for this project we will write a report about what was learned. This report will not include your name or that you were in the study. The report aims to develop a wholesome and inclusive picture about the challenges faced by people with MCI/dementia while they continue their employment.

Who may I contact if I have questions about the study?

If you have any questions or concerns, or would like to speak to the research team for any reason, please contact:

Dr. Jennifer Boger, Principal Investigator, at jboger@uwaterloo.ca

Dr. Arlene Astell, Principal Investigator, at (905) 430-4055 ext. 6750 or astella@ontarioshores.ca

Dr. Parminder Flora, Co-Investigator, at florap@ontarioshores.ca or (905) 430-4055 ext 6663

If you wish to discuss your rights as a participant or any ethical issues in the research, please contact: **Ms. Natascha Kozlowski**, Research Ethics Board Chair at (905) 668-5881 ext. 6996.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE# 40051). If you have questions for the Committee contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca.



MCI@work – Focus Group Consent Form

- I confirm that I have read and understood the above information explaining the research study and what is being asked of me.
- I have had the opportunity to ask questions and have had acceptable responses to my questions.
- I understand that my participation is voluntary and I am free to withdraw at any time without giving a reason and without there being any consequences.
- I understand that I will be audio and/or video-recorded while participating in the study.
- I understand that my personal health information (e.g. diagnosis) will be accessed and kept confidential within the research team and the Research Ethics Board for seven years after the study.
- I understand that I am not waiving any of my legal rights by signing this form.

Please respond to the statements below. Note that whether you agree or disagree with one or both statements below, it will not affect your participation in this study.

1. I agree to allow members of the research team to use video recorded clips of me in future academic presentations for illustrative or educational purposes.
 Yes No
2. I agree to allow members of the research team to use data collected for this study to be used in future research.
 Yes No

Signatures

_____	_____	_____
Participant First & Last Name	Date (mm/dd/yyyy)	Signature

_____	_____	_____
Person Obtaining Consent	Date (mm/dd/yyyy)	Signature

To be signed and dated in presence of the participant, and copy of the signed form to be given to the participant.

Appendix F

Consent Form (Caregiver)



Focus Group Consent Form – Personal Support

Research Project Title: Dementia or mild cognitive impairment: at work in progress (MCI@work)

Funding: CIHR, JPI - MYBL

Principal Investigator: : Dr. Jennifer Boger, University of Waterloo; Dr. Arlene Astell, Ontario Shores Centre for Mental Health Sciences

Co Investigator: Dr. Parminder Flora, Ontario Shores

Research Investigator: Karan Shastri, University of Waterloo, Sheida Marashi, University of Waterloo.

You are being invited to take part in a research project, and thus it is important for you to understand why the research is being done and what it will involve. Please take time to carefully read the following information and to decide whether or not you wish to take part. Please read this form carefully. If anything is unclear or if you would like more information, please contact the researchers listed at the end of this document.

What is the purpose of the research study?

We are inviting you to participate in a focus group session aimed at exploring the types of challenges and solutions people diagnosed with early dementia or mild cognitive impairment (MCI) have while receiving this diagnosis in the context of continuing to be employed. We are looking to understand the type of learning approaches and problem-solving strategies each person develops in order to adapt and manage working with cognitive impairment. We are also interested in learning about the regulations and policies available at different companies for persons with cognitive impairments. As well, we will explore the role of technology in providing assistance to persons with MCI/dementia in order to continue a meaningful employment. Each session will be led by a member of our research team who will audio and/or video-record the interactions for future evaluation.

Why am I being asked to participate?

You are being invited to voluntarily participate in this project because you are a nominated personal support (e.g., family member or a close friend) of someone who has been recently diagnosed with early stage MCI/dementia. For this study, we are hoping to recruit approximately 48 individuals who have been recently diagnosed with early stage MCI/dementia or who are supporting someone who has been recently diagnosed.

Do I have to participate?

It is completely up to you to decide whether you wish to take part in this research. If you do decide to take part, you will be asked to sign this consent form and you will receive a copy to keep. Even if you do consent now, you can withdraw from the study at any time without any consequence. However, certain information collected prior to withdrawal, such as audio/video recordings, will be retained and cannot be withdrawn once collected.

What do I have to do to participate?

You will be scheduled to participate in a focus group session with other participants who have a diagnosis of MCI/dementia or are supporting someone with a diagnosis. The group session will consist of no more than six participants plus one or two research team members. You will be asked to participate in only one focus group session, lasting approximately 1.5 to 2 hours. The session will be audio and/or video-recorded in order to evaluate the interactions happening in the group. You will also be asked to complete a demographic questionnaire including general personal information about you. If you do not wish to answer certain questions, you may choose to leave them blank. To complete the questionnaire will take approximately 5-7 minutes.

What are the possible disadvantages or risks of taking part?

The risk of you experiencing any disadvantages by taking part in this research is low. As a possible disadvantage, you may find it challenging to share your experience in a group format and/or you may find the questions on the questionnaire uncomfortable to answer. Researchers may use small clips of the video-recordings in academic presentations for educational or illustrative purposes, which could put you at risk of being identified. However, at the end of this document, your permission will be asked for video-clips of you to be shared outside of the immediate research team; to which you may agree or disagree without affecting your study participation.

What are the possible benefits of taking part?

Your participation in this research may benefit others in the future.

Will I be compensated for taking part?

You will not be compensated for participating in the study.

Will I be reimbursed for any expenses that I incur?

You will be eligible to receive reimbursement for transportation or parking expenses incurred while for taking part in the focus group.

What if I want to withdraw from the study?

Your well-being is our top priority. Your participation in this study is voluntary. You may decide not to participate in this study, or to leave the study at any time. You may let the researcher know at any time if you no longer wish to participate. There are no consequences for doing so. At the same time, if you withdraw after you have been audio and/or video-recorded in a session, it will be impossible to remove your image and voice from the recordings. Similarly, you may withdraw the information you provided on the demographics questionnaire. However, depending on your withdrawal time, if your data has been mixed with others and sent to be presented on or published we would not be able to remove it. If you have any questions, or wish to withdraw from the study, **please contact:** Dr. Parminder Flora (Co-Investigator) at florap@ontarioshores.ca or (905)430-4055 ext 6663.

Will my participation in this project be kept confidential?



The information collected from you during the course of this research will be kept confidential within the research team at Ontario Shores and the University of Waterloo and not shared with anyone outside the team. Your confidentiality will be protected to the extent permitted by the law.

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

You will be audio and/or video recorded during your participation in the focus group, in order to review and analyze the recordings for the project. The recordings are an important part of the research, as they allow the research team to capture all nuances of the interactions, which may include demonstrations of physical or environmental adjustments which are important to see. At the same time, if you do not wish to be viewed on camera, you may ask to be seated outside of the camera's visual range but you will need to remain within a reasonable audible range, so that we may capture your contributions.

Who will have access to the data and where will it be held?

All data will be held securely at Ontario Shores under the supervision of the Principal Investigator, the immediate research team and the Research Ethics Board. Your data may also be shared with our research team for this study at the University of Waterloo. All data will be stored for seven years after the completion of the project.

What will happen to the results of the research project?

When we are finished collecting data for this project we will write a report about what was learned. This report will not include your name or that you were in the study. The report aims to develop a wholesome and inclusive picture about the challenges faced by people with MCI/dementia while they continue their employment.

Who may I contact if I have questions about the study?

If you have any questions or concerns, or would like to speak to the research team for any reason, please contact:

Dr. Jennifer Boger, Principal Investigator, at jboger@uwaterloo.ca

Dr. Arlene Astell, Principal Investigator, at (905) 430-4055 ext. 6750 or astella@ontarioshores.ca

Dr. Parminder Flora, Co-Investigator, at florap@ontarioshores.ca or (905)430-4055 ext 6663

If you wish to discuss your rights as a participant or any ethical issues in the research, please contact: **Ms. Natascha Kozłowski**, Research Ethics Board Chair at (905) 668-5881 ext. 6996.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE# 40051). If you have questions for the Committee contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca.



MCI@work – Focus Group Consent Form

- I confirm that I have read and understood the above information explaining the research study and what is being asked of me.
- I have had the opportunity to ask questions and have had acceptable responses to my questions.
- I understand that my participation is voluntary and I am free to withdraw at any time without giving a reason and without there being any consequences.
- I understand that I will be audio and/or video-recorded while participating in the study.
- I understand that my personal health information (e.g. diagnosis) will be accessed and kept confidential within the research team and the Research Ethics Board for seven years after the study.
- I understand that I am not waiving any of my legal rights by signing this form.

Please respond to the statements below. Note that whether you agree or disagree with one or both statements below, it will not affect your participation in this study.

1. I agree to allow members of the research team to use video recorded clips of me in future academic presentations for illustrative or educational purposes.
 Yes No
2. I agree to allow members of the research team to use data collected for this study to be used in future research.
 Yes No

Signatures

Participant First & Last Name	Date (mm/dd/yyyy)	Signature

Person Obtaining Consent	Date (mm/dd/yyyy)	Signature

To be signed and dated in presence of the participant, and copy of the signed form to be given to the participant.

Appendix G

Focus Group Guide

Semi-Structured Focus Group Guide – PCI/PS/WS

SESSION OPENING: Thank you for being here today. My name is (Researcher name[s]). The purpose of this focus group is to learn about your experiences with early stage dementia or Mild Cognitive Impairment (MCI) in the context of continuing to be employed. Today we will be asking you a series of questions in a group format. We would like to understand your experience with early stage dementia or MCI in the workplace and various aspects of the experience including (i) the experience at the onset of dementia/MCI, including possible workplace adjustments; (ii) the possible role of technology in adapting to and managing cognitive impairment in the work environment; (iii) learning approaches and problem-solving strategies employed when adapting to and managing cognitive impairment in the work environment; (iv) the role of regulations and policies in supporting or hindering continued work and/or transition from work; and (v) the impact of a dementia/MCI diagnosis on an individual, their families, and their place of employment. We will audio and/or video-record the interactions so that we can accurately capture and recall the information that is shared.

There are some guidelines that will help us as we move through the session. It would be helpful if we could talk one at a time. We will be recording and taking notes within the session so please speak in turn and simply give a signal if you would like a turn to speak. Please turn off your cell phone ringers so that we can focus on the session. Finally, one point on confidentiality. Because of the group setting that we are sharing in, we are all relying on one another to protect confidentiality of everyone sharing today. Please do not share anything that was discussed here today outside of this group.

Just a reminder that this session will be video recorded and transcribed. No identifying information such as your name will be transcribed. In order to further protect your privacy, please avoid saying your name or sharing any personal identifying information during the interview. Are there any questions?

Confirm informed consent is obtained, outline procedures, and begin recording.

QUESTIONS FOR PCI/PS/WS (adapt wording/delivery as needed):

1. Please describe your general experience at work once you were diagnosed with early onset dementia or MCI.
2. What were some of your greatest challenges?
3. Please tell me about any work adjustments that were made at work following the diagnosis.
4. Please tell me about the impact of the diagnosis on you and your work/the individual you support.
5. Please describe any learning approaches and problem solving strategies that you used to adapt to and manage cognitive impairment in the work environment.
 - a. Please describe the strategies that you used to adapt to and manage cognitive impairment in the work environment.
 - b. Who suggested these strategies?
 - c. Please describe the strategies that were suggested by the organization for the individual

- d. Please describe how where the individual and/or organization learned about the strategies
 - e. If you could do it again, is there anything that you would do differently?
 - f.
6. Please tell me about any policies or regulations that impacted your experience at work.
 - a. Existing policies that impacted your work
 - b. Policies that would have been helpful had they been available
 7. Please describe any technology and/or tools that you used to support your work.
 - a. Who selected these?
 - b. How did they find out about it?
 - c. What worked well?
 - d. What didn't work well?
 - e. What devices or technology do you use (or feel comfortable using) in your day-to-day life?
8. If the you have transitioned out of the organization, please describe the steps that were taken
 - a. How did the transition happen?
 - b. What was the time frame?
 - c. How was it supported?
 - d. Whose choice was it?
 - e. Did policy (corporate or government) play any role?

ADDITIONAL QUESTIONS FOR PS/WS:

9. Please describe your general experience in supporting someone who was diagnosed with early onset dementia or MCI while working.
10. What were the major supportive care needs of the individual that you support?

SESSION CLOSING: Thank you for taking part today. Are there any final questions?

Appendix H

Study Poster



Invitation to Participate in a Research Study on Early Onset Dementia and Mild Cognitive Impairments

Have you or someone you know recently been diagnosed with early onset dementia or mild cognitive impairment?

Researchers at Ontario Shores and University of Waterloo are conducting a **focus group** to understand the experiences of people who develop early onset dementia or mild cognitive impairments while in the workforce. You will be asked to take part in one focus group for approximately 1.5-2 hours.

You are invited to participate if you:

- Were recently diagnosed with early onset dementia or mild cognitive impairment **and** are currently working or recently retired, OR
- Are a family member, friend, or co-worker of someone who was recently diagnosed and is participating in the study, **and** have been approved by them to take part, OR
- Are an employer and have worked with someone who has been diagnosed with early onset dementia or mild cognitive impairment, OR
- Influence company policies and work adjustments for those affected by early onset dementia or mild cognitive impairment

You will be eligible to receive reimbursement for transportation or parking expenses incurred while for taking part in the focus group.

For more details, please contact Dr. Parminder Flora (Study Co-Investigator):

(905)430-4055 ext 6663 | florap@ontarioshores.ca

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