Developing “PEP”: A Personalized, Web-Supported Energy Conservation Education Program for People on Chronic Dialysis Therapy with Fatigue

by

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A thesis submitted in conformity with the requirements for the degree of Doctor of Philosophy
Rehabilitation Sciences Institute
University of Toronto

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Abstract

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2018

Background: Fatigue is a common and disabling symptom experienced by people with end-stage renal disease on chronic dialysis therapy (CDT). Energy conservation education (ECE) is an approach to fatigue management that provides people with energy-saving strategies, to reduce their fatigue and improve their life participation. ECE has yet to be trialed in the CDT population.

Objective: To explore the potential for energy conservation education to improve fatigue and life participation outcomes in people on CDT.

Methods: A three-step process was undertaken: 1. A scoping review was conducted to investigate what is known about energy conservation education in people with chronic diseases who experience fatigue. 2. The World Health Organization framework was used to develop an ECE program, tailored specifically to meet the needs of people on CDT. Feedback on the program was collected via key informant interviews and usability testing, to inform program revisions. 3. Preliminary efficacy testing was conducted using a mixed-methods sequential
explanatory design, including a single-case, tri-phasic, time-series study with four replications, and qualitative post-intervention interviews. **Results:** The majority of evidence on ECE in people with chronic diseases focused on a specific, group-based ECE program in people with MS. There was a dearth of evidence to demonstrate positive effects of ECE on life participation outcomes across chronic disease populations, and a lack of programs that would be feasible for people on CDT. A personalized, web-supported ECE program (The “PEP” Program) was therefore created to meet the CDT population’s key needs. Key informant interviews suggested the program was perceived positively, and usability testing found people on CDT could complete the program independently. Efficacy testing revealed consistently positive changes in fatigue and life participation associated with the program in three of five participants, while all participants reported experiencing benefits during the qualitative interviews.

**Conclusion:** The PEP program has the potential to improve fatigue-related outcomes in people on CDT. Further robust testing of the program is warranted.
Acknowledgments

Someone once said that it takes a village to finish a PhD, and my journey throughout the past five years has confirmed the absolute truth of that sentiment. Luckily, I have been surrounded by a village of the most helpful, generous, kind, intelligent, insightful and all-around wonderful people, without whom none of this would have been possible.

To my two powerful, inspiring, and brilliant co-supervisors – Helene Polatajko and Vanita Jassal - how lucky can one PhD student possibly get? Helene, I was counting my blessings when you agreed to be part of my PhD journey, because of your incredible track record of professional success as an occupational therapy innovator and educator. Not only have I had the benefit of your intellectual mentorship, but also your kindness, benevolence, flexibility, and unwavering dedication to your students. Words cannot express my deep gratitude for your support, and your friendship. Vanita, this is yet another wonderful and unexpected development in my career that I can attribute to your dedicated, passionate, and selfless support. Since we first met at UHN seven years ago, you have pushed me to explore the boundaries of my limits and venture beyond them, all while providing the perfect amount of encouragement, guidance, space, and assistance to ensure I could be successful. You are the living definition of what it means to be a mentor, and I doubt I will ever be able to repay the deep debt of gratitude I have for you.

To my Program Advisory Committee member, Sara McEwen, who has provided me with thoughtful, insightful wisdom and experience at so many key points throughout my PhD journey. Thank you for your commitment to my learning, and for the considerate contributions that have helped to make this thesis come together.

To my brilliant labmates at the Rehabilitation Sciences Institute, who have shared their friendship, advice, and expertise with me during these past years: Adina Houldin, Katherine Stewart, Christie Welch, Samantha Seaton, and so many others. To Jane Davis, who has always made herself available to impart her seemingly limitless knowledge about research and occupational therapy. To Margaret McGrath-Chong, who has been an incredible friend and research mentor at UHN since I first started my career in research.

A special thank you to the participants of my research studies, for your enthusiasm, flexibility, and generous contributions of time, input, and insight. None of this would have been possible
without your kind and helpful involvement. To the countless others that have also provided me with resources, support and assistance at RSI and UHN during my project - you have been absolutely instrumental to its success.

Finally, to my incredible family. My parents, John and Maureen – you instilled in me the importance of studying, working hard, and persevering from a young age, and those lessons have gotten me to where I am today. Dad, you have always been an example of how to approach a career with the utmost integrity, dedication, reasonability, and professionalism. Mom, you will always be my ultimate female role model – strong, brilliant, passionate, and 100% committed.
To my wonderful sister, Keara, who has stood by me through thick and thin, providing me with a loyal and supportive friendship I can count on no matter what may come.

And to my amazing husband, Raphael, who has done everything he possibly could to help me accomplish my dreams: flexed when I needed flexibility; accommodated when I needed accommodation; provided space when I needed space; lifted me up when I needed support; and made countless, daily sacrifices for my benefit.

Words cannot express my gratitude, appreciation, and love for you all.
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<td>ABI</td>
<td>Acquired Brain Injury</td>
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<td>CAPD</td>
<td>Continual Assisted Peritoneal Dialysis</td>
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<td>CDT</td>
<td>Chronic Dialysis Therapy</td>
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<td>CFS</td>
<td>Chronic Fatigue Syndrome</td>
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<td>CKD</td>
<td>Chronic Kidney Disease</td>
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<td>CO-OP</td>
<td>Cognitive Orientation to daily Occupational Performance</td>
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<td>COPD</td>
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<td>DPA</td>
<td>Dynamic Performance Analysis</td>
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<td>ECE</td>
<td>Energy Conservation Education</td>
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<td>eGFR</td>
<td>Estimated Glomerular Filtration Rate</td>
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<td>EPO</td>
<td>Erythropoietin</td>
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<tr>
<td>ESA</td>
<td>Erythropoeitin Stimulating Agent</td>
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<td>ESRD</td>
<td>End-Stage Renal Disease</td>
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<td>GPDC</td>
<td>Goal-Plan-Do-Check</td>
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<td>HD</td>
<td>Hemodialysis</td>
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<td>HHD</td>
<td>Home Hemodialysis</td>
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<td>HRQoL</td>
<td>Health-Related Quality of Life</td>
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<td>ICHD</td>
<td>In-Center Hemodialysis</td>
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<td>PD</td>
<td>Peritoneal Dialysis</td>
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<td>PDF</td>
<td>Post-Dialysis Fatigue</td>
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<td>PEP</td>
<td>Personal Energy Planning</td>
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<td>PG-BPS</td>
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<td>PPS</td>
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<td>Abbreviation</td>
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<td>RCT</td>
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<td>RRT</td>
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<td>SWOT</td>
<td>Strengths, Weaknesses, Opportunities, Threats</td>
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<td>TTM</td>
<td>Transtheoretical Model</td>
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Chapter 1:
Introduction and Thesis Overview
Chapter 1: Introduction & Thesis Overview

End-stage renal disease (ESRD) is a serious chronic condition associated with high healthcare costs (H. Lee et al., 2002; Loubeau, Loubeau, & Jantzen, 2001; United States Renal Data System, 2017), high morbidity and mortality (Lozano et al., 2012; United States Renal Data System, 2015; Wolfe et al., 1999), and low quality of life (Fukuhara et al., 2003; Merkus et al., 1997; Wyld, Morton, Hayen, Howard, & Webster, 2012). The most common form of treatment for ESRD is chronic dialysis therapy (CDT), which requires the recipient to undergo regular, frequent dialysis sessions, either in hospital or at their home. People with ESRD on CDT often experience a number of disease-related complications, including frailty (Johansen, Chertow, Jin, & Kutner, 2007), cognitive impairment (Murray et al., 2006; O’Lone et al., 2016), and psychosocial disorders such as depression and anxiety (Hedayati, Bosworth, Kuchibhatla, Kimmel, & Szczech, 2006), all of which negatively impact their quality of life. One of the more negative facets of living with ESRD on CDT, according to people with the disease, is fatigue. An estimated seven in 10 people on CDT experience fatigue (Murtagh, Addington-Hall, & Higginson, 2007), and it has frequently been ranked among the top concerns of people on CDT (Manns et al., 2014; Weisbord et al., 2007). Unfortunately, fatigue is a poorly-understood, multifactorial symptom of ESRD (Astroth, Russell, & Welch, 2013; Bossola, Vulpio, & Tazza, 2011; Jhamb, Weisbord, Steel, & Unruh, 2008), and treatment options are limited. Fatigue management is a high-priority for people with ESRD on CDT: a recent Canadian study found that people on CDT ranked fatigue as being in their top-three priorities for ESRD research (Manns et al., 2014), and another recent international study found that people on CDT identified the negative impact of fatigue on their life participation as being their most concerning consequence (Ju et al., 2018). Collectively, these findings highlight the need to develop novel approaches that can support people on CDT with day-to-day fatigue management.

Energy conservation education (ECE) is an approach to fatigue management found in the general literature. ECE aims to provide people with strategies (eg. organizing the environment, changing body positioning, prioritizing) that will reduce their energy expenditure during everyday activities, thereby minimizing their fatigue and improving their life participation (Mathiowetz, Matuska, & Murphy, 2001). ECE is often used by rehabilitation professionals working with chronic disease populations who experience fatigue, such as multiple sclerosis, cancer, and chronic obstructive pulmonary disease, but has yet to be investigated as a fatigue management
approach for the CDT population. Furthermore, the literature on ECE in people with other chronic diseases has not been comprehensively explored.

The overarching objective of the multi-staged work reported in this manuscript-style thesis, was to explore the potential for ECE to improve fatigue-related outcomes for people on CDT. The work began with a review of background information on chronic kidney disease, fatigue, and energy conservation education, presented in Chapter 2. Next, a scoping review was conducted to investigate what is known about energy conservation education in chronic disease populations who experience fatigue. This work, presented in Chapter 3 (Manuscript 1), was undertaken to identify the populations in which ECE has been studied, the characteristics of energy conservation education programs that have been tested, and findings that have been reported about their impact on fatigue and life participation outcomes. The scoping review guidelines of Arksey and O’Malley (2005), which outline a five-stage process involving systematic literature searching, data extraction and synthesis, were followed. A comprehensive search of seven relevant online databases and hand-searching of relevant journals was undertaken by the first author to identify literature on ECE, and study eligibility was assessed according to pre-established criteria by the first author, with validation from a second reviewer. Data from the eligible studies were extracted into a Microsoft Excel spreadsheet, and were collated using descriptive and narrative syntheses.

Informed by the results of the scoping review, the development of a new ECE program for people on CDT was then undertaken. For this work, presented in Chapter 4 (Manuscript 2), the World Health Organization’s (2014) six-step framework on health education planning was used to guide program development. The process began with a literature-based Strengths, Weaknesses, Opportunities and Threats (SWOT) needs assessment, informed by the findings from scoping review (Chapter 3), to assess the need to develop a new energy conservation education program for the CDT population. The results of the SWOT analysis suggested a new program was needed, and informed the goals and objectives for the new program. Evidence-informed design strategies were researched and applied to develop the draft program. Next, the draft version was presented to four key informants, chosen to bring a broad range of expertise to the evaluation. Semi-structured qualitative interviews were conducted, to gather their impressions of the program, and their suggestions for improvement. Usability testing was also conducted with five people on CDT, purposively selected to represent typical dialysis user
characteristics, to assess if they could use the program as intended and identify further design revisions to be made. This process indicated the program had potential, and identified a number of changes to be made, resulting in the test version of the program.

The final stage of the work presented in this thesis, was the preliminary exploration of the potential for the new ECE program (“The PEP Program”) to effect change in fatigue and life participation in people on CDT. This work, reported in Chapter 5 (Manuscript 3), involved preliminary efficacy testing of the program with five people on CDT. A mixed-methods, sequential explanatory design (Tashakkori, Teddlie, & Teddlie, 2003) was used, which included a single-case, time-series experiment with four replications, and follow-up qualitative interviews with study participants. The five participants were purposively selected to represent various facets of the CDT population on key characteristics (age, gender and dialysis modality). The primary outcomes examined were fatigue, life participation, and self-efficacy. The study participants initially underwent a three- to four-week baseline observation period, during which fatigue and life participation outcomes were assessed weekly. Participants then began the six- to eight-week “PEP” program, throughout which the weekly assessments of fatigue and life participation outcomes were continued. The single-case data were analyzed using both visual analysis and the Tau-U statistic, to identify patterns of change in the study outcomes associated with the intervention. Thematic coding was used to analyze the qualitative interview data.

Finally, an overview of the findings from this multi-staged work is provided in Chapter 6, with an outline of the methodological strengths and weaknesses of the work, and a discussion of implications and directions for future research.
Chapter 2:
Background Literature Review
Chapter 2: Background Literature Review

2.1 The global burden of chronic kidney disease

Kidneys perform a number of key functions in the body that are critical for human health and survival. These functions include controlling fluid and electrolyte balance; removing toxins and metabolic end-products; and contributing to the function of several hormones such as erythropoietin, renin and angiotensin, and the Vitamin D axis. Disease affecting the kidneys is often progressive, and can be present undetected for several years. The term chronic kidney disease (CKD) describes a chronic progressive, multi-staged disorder, which is associated in the later stages with a decline in renal function characterized by a reduced glomerular filtration rate (<60 ml/min/1.73m²), and often protein or albumin in the urine (Levey et al., 2005). CKD has become a growing global health concern in recent years (Atkins, 2005; Jha et al., 2013), because of an accelerating incidence rate driven largely by factors such as the aging population, and increasing prevalence of cardiovascular disease and diabetes (Jha et al., 2013). Estimates suggest that approximately 13% of the global population now meet the criteria for CKD (Hill et al., 2016). CKD is also an increasingly prevalent cause of mortality, moving from 27th to 18th on the list of causes of total number of worldwide deaths between 1990 and 2010 (Lozano et al., 2012).

Stage 5 CKD, which is typically referred to as end-stage renal disease (ESRD), is the most severe category of CKD. ESRD is defined as an estimated Glomerular Filtration Rate (eGFR) of <15 ml/min/1.73m² (Levey et al., 2005), and is an imminently life-threatening condition that is typically associated with the use of renal replacement therapy (RRT) as a life-sustaining measure. There are two primary forms of RRT: kidney transplantation, and chronic dialysis therapy (CDT). According to an estimate from 2010, 2.6 million people receive RRT worldwide, with the number needing RRT estimated to be almost double (Liyanage et al., 2015). Kidney transplantation is considered the optimal form of RRT, as it offers better survival (Wolfe et al., 1999), lower morbidity, and superior quality of life outcomes (Purnell et al., 2013; Wyld et al., 2012) compared to CDT. However, as the demand for donor kidneys outweighs the supply in most parts of the world, including Canada, more than half of Canadians who have ESRD rely on routine, chronic dialysis therapy as their primary ESRD treatment (Canadian Institute of Health Information, 2017).
2.2 Chronic dialysis therapy

CDT performs some of the most critical functions of the kidneys, such as removing metabolic waste products from the bloodstream, balancing fluid and electrolyte levels, and controlling blood pressure. Estimates suggest that 284 per million people worldwide are currently treated with CDT (Thomas et al., 2015). There are two different modalities of dialysis therapy: hemodialysis, and peritoneal dialysis.

Hemodialysis (HD) removes uremic waste products and fluid from the bloodstream through a process of diffusion and osmosis, where the blood is filtered through a semi-permeable membrane located in an external hemodialysis machine. People on chronic hemodialysis typically undergo dialysis in a setting with the assistance of specially trained nurses and technicians (ie. “In-center hemodialysis, or ICHD), on average three times per week for 4-5 hours per session. People on ICHD typically follow a consistent weekly hemodialysis schedule: dialyzing either on Mondays, Wednesdays, and Fridays, or, Tuesdays, Thursdays and Saturdays, and typically either during a morning, afternoon, evening, or overnight “shift”. More than 75% of people on CDT in Canada undergo ICHD (Canadian Institute of Health Information, 2017). Hemodialysis can also be performed at home, however, by the patient or a personal caregiver, within a self-care model of dialysis referred to as “home hemodialysis”. People on home hemodialysis typically first undergo an extensive training period to learn how to administer hemodialysis to themselves, and are then provided with recommendations as to the frequency and duration for their home dialysis. Home hemodialysis is undertaken by approximately 5% of people on CDT in Canada (Canadian Institute of Health Information, 2017).

In peritoneal dialysis (PD), uremic waste products and excess fluids are removed from the body, using the natural filter-like properties of the abdominal lining. This lining, termed the peritoneal membrane, already exists in the person’s abdomen and acts a semipermeable filtering mechanism. Within this model of dialysis, a special sterile solution called dialysate, is regularly instilled into the peritoneal cavity, via a permanent, surgically-placed catheter. Fluids are exchanged on average 3-5 times daily, using a 30-minute process that is often performed by the person on CDT themselves. Between exchanges, waste products and excess fluids pass from the bloodstream through the peritoneal membrane into the dialysate, via a process of diffusion and osmosis. Unlike hemodialysis, peritoneal dialysis is typically performed in the home setting.
Exchanges can either be done manually by the person on CDT (termed “continuous automated peritoneal dialysis”, or CAPD), or using a machine to perform the exchanges, often at night (termed “continuous cycler peritoneal dialysis”, or CCPD). Peritoneal dialysis is the modality of choice for 15% of people on CDT in Canada (Canadian Institute of Health Information, 2017).

2.3 Quality of life and life participation on chronic dialysis therapy

Dialysis therapy has greatly prolonged the life expectancy of people diagnosed with ESRD, and provided hope to many individuals affected by the disease. However, despite experiencing a prolonged survival, people maintained on CDT long-term often experience poor physical and psychosocial outcomes (Jassal & Watson, 2010; Kliger & Finkelstein, 2009), and have difficulty with engaging in valued day-to-day activities (ie., life participation). Health-related quality of life (HRQoL), defined as “a multi-dimensional concept that includes domains related to physical, mental, emotional, and social functioning” (Office of Disease Prevention & Health Promotion, n.d.), is typically low among people on CDT (Fukuhara et al., 2003; Merkus et al., 1997; Pagels, Söderkvist, Medin, Hylander, & Heiwe, 2012). For example, data from the international Dialysis Outcomes and Practice Patterns Study (DOPPS) indicated that HRQoL among 7 378 people on CDT was significantly lower than that of population-based norms, across the continents of Europe, Japan, and the USA (Fukuhara et al., 2003). A central facet of quality-of-life is the ability to engage in valued, day-to-day activities (ie., life participation). People on CDT often fall into the category of “high needs, high cost” people, which has been defined by Hayes and colleagues (2016) as people who have three or more chronic diseases and a functional limitation in their ability to care for themselves or perform routine daily tasks. Multiple qualitative studies have identified the negative effect of CDT on daily activities, such as home responsibilities and social engagement, as being a key theme of the experience of people on CDT (Clarkson & Robinson, 2010; Harwood, Wilson, Locking-Cusolito, White, & Spittal, 2005; Y. White & Grenyer, 1999). Quantitative studies have similarly found that people on CDT experience high rates of disability in self-care and work activities (Cook & Jassal, 2008; Jassal et al., 2016; Jassal, Chiu, & Hladunewich, 2009; Kurella Tamura et al., 2009; Kutner, Brogan, & Fielding, 1991). For example, Jassal and colleagues (2016) found that only 36% of 7226 people on hemodialysis were able to perform 13 self-care tasks without any assistance. Several studies have also reported a loss of employment among working-age people on CDT after dialysis initiation.
People on CDT experience multiple disease-related physical and psychosocial sequelae, which may contribute to their poor quality of life and life participation. One study estimates that 70% of people on hemodialysis meet Fried and colleagues’ (2001) established criteria for frailty (at least three of weakness, impaired mobility, weight loss, inactivity, and fatigue) (Johansen, Chertow, Jin, & Kutner, 2007). Seven in 10 people on CDT have also been found to exhibit moderate to severe cognitive impairment, according to a comprehensive neuropsychological test battery (Murray et al., 2006), while a recent systematic review found that people on hemodialysis experience impaired orientation, attention, and executive function, compared to the general population (O’Lone et al., 2016). People on CDT also experience a heavy burden of symptoms: for example, a systematic review of symptom prevalence studies found that 45% of people on CDT experience chronic pain, 33% have nausea, and 28% have depression (Murtagh et al., 2007). Yet another major challenge of living on CDT is managing its intensive, day-to-day health management tasks. The responsibilities of a person on CDT typically include attending (or performing) frequent, routine dialysis sessions; monitoring and recording blood pressure daily; managing multiple medications; and adhering to strict diet and fluid intake guidelines. Illness intrusiveness, which is the degree to which an illness and its associated treatments interfere with normal life activities, has also been found to be associated with poorer psychosocial outcomes in the CDT population (Devins et al., 1983, 1990, 1993)

Among the many challenges faced by people on CDT, the symptom of fatigue is consistently ranked as one of their top concerns. Fatigue is the most common symptom experienced by people on CDT (Murtagh et al., 2007; Weisbord et al., 2007), and is often identified as being a top stressor of living with ESRD (Baldree, Murphy, & Powers, 1982; Juergensen et al., 2006; Lok, 1996; Mok & Tam, 2001; Weisbord et al., 2007). Fatigue is associated with a variety of negative outcomes in people on CDT; for example, it is an independent predictor of poor physical and mental quality of life (Davison & Jhangri, 2010; Wang et al., 2014), and is correlated with increased morbidity and mortality (Bossola et al., 2011; Jhamb et al., 2011). People on CDT have identified the negative impact of fatigue on their life participation as being among its most important consequences (Ju et al., 2018). This was recently highlighted in a study
by Ju and colleagues (2018), for which an international consensus workshop was held with 15 people on CDT/caregivers and 42 health professionals from nine countries, to discuss the development of a core outcome measure for ESRD fatigue. All of the people on CDT who participated in the workshop agreed that fatigue played a vital role in their ability to participate in activities and tasks (Ju et al., 2018). This finding is consistent with what has been reported in other qualitative studies on fatigue, where people on CDT have described the limiting effect of fatigue on their self-care, productivity, and leisure activities (Al-Arabi, 2006; Hagren, Pettersen, Severinsson, Lützén, & Clyne, 2005; Heiwe, Clyne, & Dahlgren, 2003; Heiwe & Dahlgren, 2004; B.-O. Lee, Lin, Chaboyer, Chiang, & Hung, 2007; Yngman-Uhlin, Friedrichsen, Gustavsson, Fernström, & Edéll-Gustafsson, 2010). For example, Heiwe and colleagues (2003) previously reported that people on hemodialysis perceived fatigue as being the most limiting factor with respect to their overall physical and functional capacity. One person on CDT was quoted as saying “… it’s a kind of tiredness that you wouldn’t wish on your worst enemy … when you can’t read, you’re too tired to watch the telly, you’re too tired to do anything, because your brain is so tired like all of you … it feels like you’re kind of hollow inside … like it’s only a kind of shell that’s functioning” (Heiwe et al., 2003, p. 173). In Ju and colleagues’ (2018) study, both people on CDT and health professionals agreed that “the ability to participate in life activities was the fundamental goal of treatment, because it symbolized some indicator of being able to live a life without being confined by the disease. Other dimensions of fatigue, such as post-dialysis fatigue and muscle weakness, were considered mediators that contributed to the end goal of life participation” (Ju et al., 2018, p. 108). Collectively, these studies highlight the need to better understand fatigue, and explore ways to optimize its day-to-day management, in the CDT population.

2.4 Defining fatigue

The definition of fatigue, according to the Merriam-Webster dictionary, is an “extreme tiredness resulting from mental or physical exertion or illness” (Merriam-Webster, n.d.-a). This definition identifies the hallmark quality of fatigue, which is a subjective feeling of tiredness. It also specifies that fatigue is commonly experienced by people after periods of extensive exertion. However, fatigue in the healthcare literature typically refers to an abnormal degree of fatigue, experienced by people with illness. To differentiate disease-related fatigue from usual fatigue, some refer to it as chronic, or pathological fatigue. Jason and colleagues (2010) explain that
pathological fatigue “is experienced in many people with chronic illness, and with a greater intensity and longer duration” and that it typically causes “severe impairments to an individual’s functional activity and quality of life” (Jason et al., 2010, p. 327). Pathological fatigue is typically also said to have an unpleasant or unwanted quality. For example, Ream and Richardson (1996) describe fatigue as a “subjective, unpleasant symptom which incorporates total body feeling ranging from tiredness to exhaustion” (Ream & Richardson, 1996, p. 520).

Fatigue shares its core quality of tiredness with several other symptoms, such as sleepiness, lethargy, and malaise. However, there are conceptual distinctions between them. Whereas the hallmark quality of fatigue is tiredness, sleepiness involves both a feeling of tiredness and difficulty staying awake. Shen, Barbara and Shapiro (2006) explain that sleepiness is specifically caused by an alteration or imbalance in sleep/wake mechanisms. Lethargy, meanwhile, is defined as “the quality or state of being lazy, sluggish, or indifferent” (Merriam-Webster, n.d.-b), and unlike fatigue, is characterized by a lack of enthusiasm or motivation in addition to tiredness. Malaise is defined by Merriam Webster as “an indefinite feeling of debility or lack of health often indicative of or accompanying the onset of an illness” ((Merriam-Webster, n.d.-c), and refers to a more general feeling of unwellness that may include, but not be limited to, tiredness.

The majority of the healthcare literature on fatigue refers primarily to the physical, bodily tiredness described above. However, other types of fatigue have also been described that reflect a specific location, quality, timing, or other characteristic. For example, mental fatigue refers to “a transient decrease in maximal cognitive performance resulting from prolonged periods of cognitive activity, that can manifest as somnolence, lethargy, or directed attention fatigue” (Van Cutsem et al., 2017, p. 1569). Emotional fatigue has been described as a feeling of being emotionally overextended and exhausted by one's work (Wright & Cropanzano, 1998), and is akin to the concept of burnout. Exertional fatigue describes an “increased sense of effort in relation to a task” (Macdonald, Fearn, Jibani, & Marcora, 2012), and often relates to the phenomenon of muscle fatigue, which is “an exercise-induced reduction in the ability of muscle to produce force or power whether or not the task can be sustained” (Enoka & Duchateau, 2008, p. 12). A common distinction is that between central versus peripheral fatigue, the former being mediated by central nervous system mechanisms, and the latter resulting from decreased response in the neuromuscular system after central activation (Chaudhuri & Behan, 2004). There
has also been discussion in the nephrology literature of “post-dialysis” fatigue, a type of fatigue that describes the tiredness and general malaise people on hemodialysis often experience following a hemodialysis treatment session (Sklar, Riesen, Silber, Ahmed, & Ali, 1996).

2.5 Fatigue in people with ESRD on CDT

Fatigue is a widespread experience in the CDT population. A systematic review by Murtagh and colleagues (2007) found that the reported prevalence of fatigue in people on CDT ranged from 42-89%, with the mean weighted prevalence being 70%. The Dialysis Outcomes and Practice Patterns Study (DOPPS), which studied a large, international sample of people on hemodialysis, reported that mean scores on the SF-36 vitality scale in people on hemodialysis ranged between 40 and 50 across age groups (Mapes et al., 2004). These scores were lower than the mean scores reported across age groups from population-based normative data in Canada, which were above 60 (Hopman et al., 2000). In addition to physical fatigue, people on CDT also appear to experience the various types of fatigue discussed above. For example, Karakan and colleagues (2011) found that the majority of people on CDT reported experiencing moderate to severe levels of cognitive and emotional fatigue on a multidimensional fatigue scale, while in a qualitative study, Lee and colleagues (2007) similarly found that people on CDT described experiencing physical, cognitive and emotional aspects of fatigue in their day-to-day lives. Although exertional fatigue has not been directly studied people on CDT, Johansen and colleagues (2005) report that people on CDT experience threefold greater muscle fatigue (defined as a fall in their maximal voluntary contraction) than controls during exercise, indicating that they fatigue more easily on exertion. This aligns with a large body of qualitative literature, in which it has been described that people on CDT experience fatigue when attempting to engage in their day-to-day activities (Al-Arabi, 2006; Hagren et al., 2005; Heiwe et al., 2003; Heiwe & Dahlgren, 2004; Yngman-Uhlin et al., 2010). Post-dialysis fatigue, meanwhile, is estimated to be experienced by half of people on ICHD (Sklar et al., 1996).

With respect to its natural history, higher rates of fatigue are seen in people with mid-stage CKD compared to normative samples (Mujais et al., 2009; Pagels et al., 2012; Perlman et al., 2005), which suggests that fatigue may originate in earlier stages of CKD. For example, Perlman (2005) found that people with CKD Stages 3 and 4 had lower vitality scores on the SF-36 than healthy-matched peers. Similarly, Pagels and colleagues (2012) found that people with Stage 2-3 CKD
had a higher prevalence of fatigue than healthy controls. Fatigue also appears to worsen with the progression of CKD; Mujais and colleagues (2009) found that vitality levels across the stages of CKD were highest in people with Stage 3 CKD, and lowest in people with ESRD. The progression of fatigue in people with ESRD after they initiate CDT is unclear, due to a general dearth of longitudinal studies. Ossareh and colleagues (2003) reported that the prevalence of fatigue increased from 55% to 67% in people on PD over the year following dialysis initiation, possibly indicating a worsening of fatigue after dialysis initiation. However, a prospective study by Bossola and colleagues (2017) reported that fatigue typically remained stable over the period of one year, in a sample of people already established on hemodialysis.

Most of the literature on fatigue in people on CDT is based on studies of the ICHD population. In people on ICHD, fatigue also appears to fluctuate diurnally: a study by Abdel-Kader and colleagues (2014) that used ecological momentary assessment of fatigue throughout people’s day-to-day lives, found that people on ICHD experienced greater fatigue on dialysis days compared to non-dialysis days, which was similarly reported by Delgado and colleagues (2012). Fatigue has also been found to worsen later in the day in the hemodialysis population (Abdel-Kader et al., 2014). Relatively less is known about fatigue in the PD and HHD populations. Available literature suggests fatigue is also common in people on PD. For example, Merkus and colleagues (1997) reported equal fatigue levels among people on HD and PD, with both groups experiencing greater fatigue compared to a normative sample. Ossareh and colleagues (Ossareh et al., 2003) similarly reported that fatigue is common in people on PD, with 67% of people on PD having been found to complain of fatigue at their last clinical visit based on a clinical chart review. There is a dearth of literature on fatigue in the home hemodialysis population. One study by Watanabe and colleagues (2014) found that vitality scores were higher among people on HHD compared to people on ICHD in Japan, suggesting they may be less prone to fatigue than other CDT groups. However, this has yet to be confirmed in other studies.

The literature is fairly consistent that fatigue is greater among people on CDT who are older (Artom, Moss-Morris, Caskey, & Chilcot, 2014). There is conflicting evidence regarding the relationship between gender and fatigue; some, but not all, studies have found fatigue to be more common among women on CDT (Artom et al., 2014). With respect to geography, the DOPPS study found that fatigue was reported more commonly in European and American dialysis centres, compared to Japanese centres (Mapes et al., 2004). Some literature has also suggested
that Caucasians with ESRD are more likely to experience fatigue compared to other races (Artom et al., 2014). Social and situational factors including education, and marital and employment status have also been associated with fatigue in people on CDT. For example, Karadag and colleagues (2013) found that more education was associated with higher fatigue levels, while multiple studies have reported associations between unemployment and greater fatigue (Jhamb et al., 2011; Karadag et al., 2013; Liu, 2006). Married people on CDT have also been found to generally report more fatigue compared to single people (Akin, Mendi, Ozturk, Cinper, & Durna, 2014; Bonner, Wellard, & Calatabiano, 2010), although whether this may be a function of older age is unclear.

2.6 Proposed mechanisms of fatigue in people on CDT

Pathological fatigue is generally discussed as being a complex, multifactorial symptom. Such symptoms, according to the middle-range theory of unpleasant symptoms, can be influenced by physiologic, psychological, and/or situational factors (Lenz, Pugh, Milligan, Gift, & Suppe, 1997).

Physiologic symptom factors are defined as “normally functioning bodily systems; the existence of any pathology, including the occurrence of trauma; and the individual's level of energy (reflecting baseline nutritional balance and hydration level)” (Lenz et al., 1997, p. 15). Johansen (2005) specifies that the physiologic mechanisms which may contribute to pathological fatigue in general include central activation failure, impaired neuromuscular propagation, impairment of contractile function, and altered muscle metabolism. A number of physiologic factors may contribute to fatigue in people on CDT. Uremia is a clinical syndrome that develops in parallel with the deterioration of renal function, and is associated with fluid, electrolyte and hormone imbalances and metabolic abnormalities (Medscape, n.d.). Uremic syndrome is often said to be characterized by symptoms of fatigue, weakness, and malaise, and may lead to protein and energy malnutrition, nausea, and loss of appetite, which can contribute to fatigue (Artom et al., 2014). However, markers of uremic syndrome, such as albumin, creatinine, Kt/V, urea reduction ratio, phosphate, and calcium, have been inconsistently correlated with fatigue in the renal literature (Artom et al., 2014). Anemia is a deficiency in red blood cells or blood hemoglobin levels that is a typical complication of ESRD (Locatelli et al., 2004), and is characterized by
fatigue symptoms. Inflammation has also been recently identified as a potential biological mechanism of fatigue in people on CDT. Increased levels of interleukin-1b (IL-1b) and IL-6, which are biomarkers of inflammation, have been documented in several chronic disease populations in whom fatigue is common (Rohleder, Aringer, & Boentert, 2012). In people on CDT, IL-6 levels have been found to significantly associated with fatigue after controlling for confounding factors (Bossola, Di Stasio, Giungi, Rosa, & Tazza, 2015). Physical comorbidity is another potential contributing physiologic factor to the fatigue experienced by people on CDT. Chronic kidney disease rarely occurs in isolation, as an estimated 86% of people with advanced CKD have at least one comorbidity (Gullion, Keith, Nichols, & Smith, 2006), the most common being hypertension, cardiac disease and diabetes. Several studies have found significant associations between fatigue and the number of comorbidities in people on CDT (Bossola et al., 2011).

Psychological symptom factors include “the individual's mental state or mood, affective reaction to illness, and degree of uncertainty and knowledge about the symptoms and their possible meaning” (Lenz et al., 1997, p. 15). Concomitant psychological disorders that are linked to fatigue are common in the CDT population. For example, approximately 25% of people on long-term dialysis are estimated to have clinical depression (Palmer et al., 2013), and the correlation between depression and fatigue has been well-established in both the renal and non-renal literature (Farragher and colleagues, 2017). People on CDT also experience high rates of sleep disorders, such as sleep apnea; insomnia; restless legs syndrome; and impaired sleep initiation, maintenance, and adequacy; which are associated with fatigue or overlapping symptoms (eg. sleepiness) in people on CDT (Artom et al., 2014). Sedentary behaviour may also contribute to fatigue in people on CDT. People on CDT have been found to be less physically active than a control group of sedentary adults without kidney disease (Johansen, 2007), and sedentary behaviour has been linked to fatigue in ESRD people (Brunier & Graydon, 1993; Gordon, Doyle, & Johansen, 2011), although the directionality of this relationship is unclear.

Situational symptom factors refer to “aspects of the social and physical environment that may affect the individual's experience and reporting of symptoms” (Lenz et al., 1997, p. 15). Undergoing routine dialysis therapy is a prominent situational factor which may contribute to fatigue in people on CDT. Just over half of people on in-center hemodialysis report experiencing post-dialysis fatigue (Sklar et al., 1996); 41% of people on CDT say it takes two to six hours to
recover from a dialysis session, while 27% say it takes more than six hours (Rayner et al., 2014). The mechanisms underlying postdialysis fatigue are still poorly-understood, although excessive ultrafiltration, rapid osmolar flux (Gorden et al., 2011), and repeated episodes of myocardial ischaemia during hemodialysis (Dubin et al., 2013) have been proposed as potential mechanisms. People on CDT may also experience excessive exertional fatigue (i.e. the fatigue experienced in relation to a task), due to the extensive number of health management tasks they must routinely complete in addition to their usual day-to-day activities. For example, people on CDT must regularly attend dialysis sessions and hospital appointments; monitor their blood pressure and fluid intake; and specially prepare meals, using techniques targeted at limiting potassium or phosphate intake such as double boiling potatoes, or extra rinsing meats.

2.7 Clinical approaches to fatigue management in people on CDT

Evidence-based interventions to mitigate fatigue in people on CDT are currently limited. Erythropoietin stimulating agents (ESAs) are one well-studied approach, that target the deficiency in erythropoietin that causes anemia in people on CDT. A systematic review by Johansen and colleagues (2012) found that ESAs were associated with a mean 35% reduction in fatigue among people with baseline hemoglobin levels <10 g/dL, when a correction to >10 g/dL was achieved. The DOPPS study also found that anemia is inconsistently managed across treatment settings internationally (Pisoni et al., 2004), which suggests that improved knowledge translation and training on the use of ESA therapy may positively affect fatigue in people on CDT in some parts of the world. However, the primary limitation of ESAs is that they do not address the multiple other purported mechanisms of fatigue in people on CDT beyond anemia. Exercise training is another well-studied approach in the CDT population, which aims to improve physical fitness levels by engaging people in structured and/or routine physical exercise. A review by Johansen (2007) found extensive literature to support that aerobic exercise training increases the exercise capacity of people on CDT. Astroth and colleagues (2013), meanwhile, identified a number of studies, of varying levels of evidence, that reported positive effects of exercise training on subjective fatigue in people on CDT. However, there are various documented limitations to exercise training as a fatigue intervention for people on CDT, such as lack of motivation, fear of adverse consequences, and insufficient staff expertise (Delgado & Johansen, 2012; Jhamb et al., 2016; Kontos et al., 2007; Painter, Clark, & Olausson, 2014).
These barriers have hindered the use of exercise training in the CDT clinical context. The improved exercise capacity after exercise training in people on CDT has also not been found to match age-adjusted normative levels (Johansen, 2007), suggesting that people on CDT would still experience higher levels of fatigue than normal even after undergoing exercise training.

A number of other approaches have also been proposed for managing fatigue in the CDT population. Interventions targeting improved sleep quality, such as cognitive-behavioral therapy (CBT) and individualized behavioural approaches, have been reported to have positive effects on fatigue (Chen et al., 2008, 2011) in people on CDT who have sleep disorders. Acupressure is another approach, grounded in Eastern medicine, that has been explored in two studies of people on CDT and reported to have some positive effects on fatigue (Cho & Tsay, 2004; Tsay, 2004), although their potential mechanism of action is unclear. Interventions for depression, such as antidepressant medications and cognitive-behavioural therapy, have also been discussed as being potentially important for fatigue management in the ESRD population (Farragher, Polatajko, & Jassal, 2017). Antidepressant medications are often ineffective at directly ameliorating depression-related, according to literature from non-renal populations (Fava et al., 2014; Menza, Marin, & Opper, 2003); however, they may help to counteract secondary fatigue related to inactivity that can occur with low mood and anhedonia. Cognitive-behavioural therapy has also been studied as a fatigue management approach in other chronic disease populations, and shown to have positive effects on fatigue perceptions and quality of life (Sandler et al., 2017; van den Akker et al., 2017), and thus may warrant exploration in people on CDT as a secondary coping mechanism for fatigue.

### 2.8 Energy conservation education

Energy conservation education (ECE) is an approach to fatigue management that has been used in several other chronic disease populations, including multiple sclerosis, cancer, and chronic fatigue syndrome. Packer and colleagues (2005) describe the goal of ECE as being to promote “optimum use of available energy to fit the unique needs of each individual” (Packer, Brink, & Sauriol, 1995, p. 2). The underlying theory of ECE is that exertional fatigue, and its limiting effects on life participation, can be minimized in people with pathological fatigue by decreasing the amount of energy they expend during their day-to-day activities. Engaging in day-to-day activities can lead to exertional fatigue because activities are comprised of a set of movements
and/or cognitive processes, which each use energy. Energy is required to achieve the muscular contractions that enable purposeful body movements, such as standing, lifting, reaching, or walking. Factors such as the force required, the number and types of muscles recruited, and the speed at which an activity is performed, can affect the amount of energy expended during movement. It is also widely accepted that the brain utilizes glucose during neural activity (Bell, Willson, Wilman, Dave, & Silverstone, 2006), suggesting that energy is also expended during cognitive processing. People with chronic illnesses, who often have reduced energy capacities, are therefore more likely to fatigue while attempting to engage in their valued, day-to-day activities.

The energy conservation approach is based on the notion that identifying and reducing the energy-draining steps of an activity, can reduce the exertional fatigue experienced during day-to-day activities and thereby improve life participation. The energy required to engage in a given activity can be identified by considering the movements and cognitive processes it involves, and the finding ways to reduce them. For example, if the amount of energy expended to read a book equals that required for the arm, forearm and hand muscles to hold the book and turn the pages, and the brain to process the content, energy could be saved by instead placing the book on a table. Packer and colleagues

| 1. Change body position for activities |
| 2. Plan the day to balance rest and work |
| 3. Modify frequency or outcome standards |
| 4. Include rest periods in the day for at least 1 hour |
| 5. Adjust priorities |
| 6. Simplify activities |
| 7. Communicate needs for assistance |
| 8. Rest during longer activities |
| 9. Change location of equipment/supplies |
| 10. Delegate part or all of an activity |
| 11. Eliminate part or all of an activity |
| 12. Identify and change incorrect work heights |
| 13. Change the time of day of an activity |
| 14. Use adapted equipment |

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Table 2.1: Energy conservation strategies from Packer and colleagues’ “Managing Fatigue” Program
(1995) have outlined fourteen fundamental energy conservation strategies, included in their ECE program, that can be used to reduce the energy expended during an activity (Table 2.1). Examples of strategies include simplifying an activity; prioritizing; using energy-efficient body postures; or asking for assistance.

ECE appears as though it could be a good fit for the CDT population. Laboratory studies have supported the notion that using energy conservation strategies can reduce both physiological energy expenditure, and perceived exertion, during day-to-day tasks. For example, Velloso and colleagues (2006) demonstrated that energy conservation strategy use was associated with reduced energy expenditure and shortness of breath during four prespecified self-care tasks (grooming, putting on shoes, retrieving food on high shelves, and retrieving food on low shelves), in people with moderate to severe COPD. Ip and colleagues (2006), similarly, found that the use of energy conservation strategies was associated with a reduction in physiological energy expenditure for younger study participants, and reduced perceived exertion for older study participants, when they completed three self-care tasks (grocery organization, handwashing laundry, and hanging laundry). People on CDT seem to be particularly good candidates for ECE, as they have a marked mismatch between their reduced energy capacities (Johansen, 1999; Johansen et al., 2005; Kopple, Storer, & Casburi, 2005), and the many health management activities they must routinely perform in addition to their usual day-to-day tasks. However, ECE has never been empirically investigated in the CDT population. Furthermore, the literature on energy conservation education and its effects on pertinent fatigue-related outcomes, such as life participation, in other chronic disease populations has never been systematically synthesized, apart from a systematic review that focused only on the Multiple Sclerosis population. The review reported small positive effects of ECE on fatigue, and insufficient evidence to draw conclusions about life participation (Blikman, 2013). Exploring what is known about ECE in people with other chronic diseases would help to inform future directions for ECE research in the CDT population. The next chapter of the thesis therefore outlines a scoping review, that was undertaken to investigate more broadly what is known about ECE in people with chronic diseases.
Chapter 3:
Energy Conservation Education for Adults with Chronic Diseases: A Scoping Review

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Target Journal for Submission: Archives of Physical Medicine & Rehabilitation
Chapter 3: Energy Conservation Education for Adults with Chronic Diseases: A Scoping Review

3.1 Abstract

**Background:** Fatigue is a highly common symptom of illness, and is often persistent and disabling among individuals living with chronic diseases. Energy conservation education (ECE) aims to teach people to use energy-conserving strategies, such as planning ahead, balancing activity with rest, using assistive tools, and simplifying activities, to manage day-to-day fatigue. No review to date has explored the full body of evidence that exists on ECE in adults with chronic diseases.

**Objective:** To describe what is known about energy conservation education for adults with chronic diseases.

**Methods:** We used scoping review methodology, as outlined by Arksey and O’Malley (2005), to guide this review. We searched seven electronic databases, and reference lists of seminal articles, for relevant articles. The first author then assessed the identified articles for eligibility, with validation from a second reviewer for a subset of articles. We extracted data about study populations, program design, and study outcomes from eligible articles, and summarized them descriptively. Finally, we grouped findings on ECE according to the chronic disease population studied, and described them narratively.

**Results & Conclusions:** Forty-one articles were included in this review. They collectively reveal that ECE has been studied in seven different chronic disease populations, including multiple sclerosis, cancer, and chronic fatigue syndrome. Nineteen distinct ECE programs have been studied, which were predominantly face-to-face and included more than seven hours of intervention time. Multiple articles reported positive outcomes associated with a specific face-to-face, group-based ECE program in MS people. Beyond this program with people with MS, the evidence on ECE was more limited and equivocal. Future research should investigate the effectiveness of ECE in chronic disease populations who experience fatigue beyond MS, using robust study methodologies and evidence-informed program design. The effect of ECE on occupational engagement should also be further studied.
3.2 Introduction

Fatigue is one of the most common symptoms of illness; an estimated 25% of people who visit a primary healthcare provider present with fatigue (Kroenke, Wood, Mangelsdorff, Meier, & Powell, 1988). Fatigue is defined as “an uncommon, abnormal or extreme whole bodily tiredness, disproportionate or unrelated to activity or exertion”, and is particularly prevalent in populations with chronic or long-term illnesses. For example, 59-100% of people with cancer (Weis, 2011), 29-77% of post-stroke survivors (Acciarresi, Bogousslavsky, & Paciaroni, 2014) 75% of people with multiple sclerosis (MS) (Braley & Chervin, 2010), 70% of people with advanced kidney disease (Murtagh et al., 2007), and 69-88% of people with heart failure (Fini & de Almeida Lopes Monteiro da Cruz, 2009) are estimated to experience abnormal levels of fatigue. Across populations, fatigue is a nonspecific and poorly-understood symptom that can have a complex array of contributing factors, and effective medical treatments are often limited. Fatigue is reported to be a highly concerning and problematic symptom for people with chronic diseases (Curt et al., 2000; Fisk, Pontefract, Ritvo, Archibald, & Murray, 1994; Manns et al., 2014), that interferes with their ability to engage in everyday activities of importance (ie., their occupational engagement) (Jones et al., 2016; Ju et al., 2018; Mandliya et al., 2016; Mollaoglu, Fertelli, & Tuncay, 2011) and diminishes their quality of life (Amato et al., 2001; J. S. Anderson & Ferrans, 1997; Curt, 2000). As the prevalence of chronic illness continues to increase globally, investigating approaches that can support people in living with fatigue more successfully should be a high-priority for rehabilitation.

Energy conservation education (ECE) is an approach that teaches people to use energy-saving strategies during day-to-day occupations, to minimize their fatigue and improve their occupational engagement (Mathiowetz et al., 2001). Examples of energy-saving strategies include prioritizing, simplifying, pacing, using energy-efficient body postures, and using energy-saving tools (Matuska, Mathiowetz, & Finlayson, 2007). ECE has been in the literature for over 50 years (eg. (Whitehouse, 1963), and its mechanism of action (reducing fatigue by decreasing day-to-day energy expenditure) is widely applicable, which suggests it has the potential to benefit many chronic disease populations. Laboratory studies have also confirmed the efficacy of energy conservation strategy use for reducing energy expenditure and perceived exertion (Ip et al., 2006; Velloso & Jardim, 2006). However, the literature on energy conservation education as a rehabilitative intervention for adults with chronic diseases has not yet been well-summarized,
apart from one systematic review published in 2013 that focused exclusively on quantitative evidence from the multiple sclerosis population (Blikman et al., 2013). It remains unknown whether ECE has been formally studied in other chronic disease populations, what the characteristics of ECE programs are, and what findings have been reported about their impact on fatigue, occupational engagement, and quality of life. This information would help to inform the clinical practice of rehabilitation professionals working with chronic disease populations, and guide future research in the area. The overall purpose of this scoping review was therefore to identify and describe the literature on ECE in adults with chronic diseases.

3.3 Methods

We used scoping review methodology, as described by Arksey and O’Malley (2005), to conduct this review. Scoping review methodology is used to summarize the extent, range and nature of research activity in a research area, for the purpose of collating knowledge and/or identifying evidence gaps (Arksey & O’Malley, 2005; Colquhoun et al., 2014; Rumrill, Fitzgerald, & Merchant, 2010). Scoping reviews are a useful approach to knowledge synthesis in disciplines or research areas where there are insufficient randomized controlled trials to undertake a systematic review. Arksey and O’Malley (2005)’s five, iterative scoping review stages were implemented, and are used to structure this paper.

3.3.1 Stage 1: Identify the research question(s)

The overarching research question of this review was: What is known about ECE in adults with chronic diseases? Specific questions of interest were:

1. In which chronic disease populations has ECE been studied?
2. What are the characteristics of the ECE programs that have been described in the literature?
3. What findings have been reported regarding the impact of ECE on fatigue, occupations, and quality of life?
4. What other findings have been reported on ECE; eg. regarding its feasibility and acceptability, or mediators or moderators of its effects?
3.3.2 Stage 2: Identify relevant studies

The primary author constructed the search strategy in collaboration with an experienced information specialist. Background literature was reviewed to develop the following list of search terms related to ECE: energy conservation, fatigue management, adaptive pacing, work simplification, and energy envelope. The subject heading, title, abstract, and keyword fields were searched in seven electronic literature databases (Medline, Embase, Pubmed, Cochrane database of systematic reviews, CENTRAL, CINAHL, and PsycInfo). Details of the search strategy used for Medline are provided in Appendix A, as an example of the approach used. The primary author also reviewed reference lists of seminal articles, to identify missed literature from the electronic search.

3.3.3 Stage 3: Select studies

The information specialist imported the results from the electronic search into Endnote reference management software, and removed duplicate articles. Filters were then applied to eliminate extraneous articles that were captured due to conceptual overlap (ie. environmental energy conservation). Two screeners reviewed a sample (10%) of the results according to the study inclusion/exclusion criteria, and discussed their findings, to validate the screening process. The primary author then screened the remaining abstracts and, if necessary, full-text articles, to determine their eligibility. We used the following inclusion/exclusion criteria to select articles:

3.3.3.1 Inclusion criteria

Any full-text, peer-reviewed primary article which reported on ECE, in which:

- Participants were aged ≥18 years and had a chronic disease (defined as a disease lasting >3 months, in accordance with the U.S. National Center for Health Statistics) and
- The main focus of the program was education regarding energy conservation, planning, and/or prioritization during everyday activities, and
- The article was available in English

3.3.3.2 Exclusion criteria

- The article did not provide findings on energy conservation education, or
- ECE was combined with another fatigue management approach (eg. CBT, exercise), or
- Participants were <18 years of age or had no chronic disease, or
● The article was not peer-reviewed, or
● The result was an abstract, conference proceeding, or review article

3.3.4 Stage 4: Chart the data

We used a Microsoft Excel data sheet to document and organize the study data from the eligible articles. Data extracted were:

● Publication characteristics (ie., title, authors, year, journal)
● Study characteristics (ie., location, research question, research design, sample size, outcome measures)
● Sample characteristics (ie. clinical condition, mean age, gender, additional unique characteristics of the sample)
● ECE program characteristics (ie. length, mode, format)
● Primary findings reported in the studies (consistent with scoping review methodology, no critical appraisal was undertaken)

3.3.5 Stage 5: Collate, summarize and report results

We described characteristics of the included articles narratively, and synthesized them using frequencies or percentages where relevant. We similarly described ECE program characteristics narratively, and synthesized them using frequencies and percentages. We listed the clinical populations in which ECE had been studied, and reported the number of articles addressing each population. We then used a narrative approach to summarize the findings on ECE for each clinical population. As the literature was particularly extensive on the MS population, findings in this population were further grouped according to the specific ECE program investigated.

3.4 Results

The search strategy generated 6,243 possible items. After we removed duplicate and screened articles for eligibility (Figure 3.1), we identified 41 primary articles that were eligible for the review (Table 3.1).
3.4.1 Description of the literature

Seventeen (41%) articles were published within the last five years (2013-2017). The majority of articles described studies conducted in the USA (67%); however, studies were also conducted in the UK (8 studies), Australia (3 studies), Austria (1 study), Iran (1 study), the Netherlands (1 study), and Sweden (1 study). The most common study designs were RCTs (9 studies), pilot

Figure 3.1: PRISMA Flow Diagram of Study Selection
Table 3.1: Characteristics of ECE articles included in review

<table>
<thead>
<tr>
<th>Disease Group</th>
<th>Study Year</th>
<th>First Author</th>
<th>Study Design</th>
<th>Sample Size</th>
<th>Additional Sample Characteristics</th>
<th>Mean Age</th>
<th>% Female</th>
<th>Energy Conservation Program Used (see Table 3.2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acquired Brain Injury</td>
<td>2015</td>
<td>Boehm</td>
<td>Case study</td>
<td>1</td>
<td>Post-stroke</td>
<td>71</td>
<td>0</td>
<td>Finlayson et al.</td>
</tr>
<tr>
<td></td>
<td>2017</td>
<td>Raina</td>
<td>Pilot study</td>
<td>41</td>
<td>Mild to severe traumatic brain injury, &gt;6 months post-injury</td>
<td>NR</td>
<td>45</td>
<td>Raina et al.</td>
</tr>
<tr>
<td>Cancer</td>
<td>2002</td>
<td>Barsevick</td>
<td>Pilot study</td>
<td>80</td>
<td>Initiating chemotherapy or radiation therapy</td>
<td>NR</td>
<td>NR</td>
<td>Barsevick et al.</td>
</tr>
<tr>
<td></td>
<td>2004</td>
<td>Barsevick</td>
<td>RCT</td>
<td>396</td>
<td>Initiating chemotherapy or radiation therapy</td>
<td>56</td>
<td>85</td>
<td>Barsevick et al.</td>
</tr>
<tr>
<td></td>
<td>2006</td>
<td>Yuen</td>
<td>Pilot study</td>
<td>12</td>
<td>Previously underwent radiation therapy</td>
<td>55</td>
<td>42</td>
<td>Yuen et al.</td>
</tr>
<tr>
<td></td>
<td>2017</td>
<td>Sadeghi</td>
<td>RCT</td>
<td>135</td>
<td>Starting treatment for breast cancer</td>
<td>55.7</td>
<td>100</td>
<td>Sadeghi et al.</td>
</tr>
<tr>
<td>Cardiac disease</td>
<td>2017</td>
<td>Norberg</td>
<td>Mixed methods</td>
<td>5 pts; 2 OTs</td>
<td>People with cardiac disease &amp; OTs who administered program</td>
<td>80</td>
<td>40</td>
<td>Norberg et al.</td>
</tr>
<tr>
<td></td>
<td>2016</td>
<td>Kim</td>
<td>Pilot study</td>
<td>18</td>
<td>&gt;3 months post- cardiac arrest</td>
<td>53.2</td>
<td>44</td>
<td>Kim et al.</td>
</tr>
<tr>
<td></td>
<td>2017</td>
<td>Kim</td>
<td>Qualitative</td>
<td>18</td>
<td>See Kim (2016)</td>
<td>53.2</td>
<td>44</td>
<td>Kim et al.</td>
</tr>
<tr>
<td>CFS</td>
<td>2004</td>
<td>McDermott</td>
<td>Quasi-experiment</td>
<td>98</td>
<td>Consecutive new CFS clinic people</td>
<td>39</td>
<td>69</td>
<td>McDermott et al.</td>
</tr>
<tr>
<td></td>
<td>2011</td>
<td>White</td>
<td>RCT</td>
<td>641</td>
<td>Independent in most everyday activities</td>
<td>38</td>
<td>77</td>
<td>White et al.</td>
</tr>
<tr>
<td></td>
<td>2016</td>
<td>Friedburg</td>
<td>RCT</td>
<td>137</td>
<td>Aged 18-65</td>
<td>~45</td>
<td>88</td>
<td>Friedburg et al.</td>
</tr>
<tr>
<td></td>
<td>2016</td>
<td>Wiltshire</td>
<td>Re-analysis</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Wiltshire</td>
</tr>
<tr>
<td>Disease Group</td>
<td>Study Year</td>
<td>First Author</td>
<td>Study Design</td>
<td>Sample Size</td>
<td>Additional Sample Characteristics</td>
<td>Mean Age</td>
<td>% Female</td>
<td>Energy Conservation Program Used (see Table 3.2)</td>
</tr>
<tr>
<td>---------------</td>
<td>------------</td>
<td>--------------</td>
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<td>-------------</td>
<td>----------------------------------</td>
<td>----------</td>
<td>----------</td>
<td>------------------------------------------------</td>
</tr>
<tr>
<td>Multiple sclerosis</td>
<td>2001</td>
<td>Mathiowetz</td>
<td>Pilot study</td>
<td>54</td>
<td>Community-dwelling volunteers</td>
<td>50</td>
<td>67</td>
<td>Packer et al.</td>
</tr>
<tr>
<td></td>
<td>2003</td>
<td>Vanage</td>
<td>Quasi-experiment</td>
<td>37</td>
<td>Receiving community-based rehab &amp; significant disability</td>
<td>56</td>
<td>81</td>
<td>Vanage et al.</td>
</tr>
<tr>
<td></td>
<td>2005</td>
<td>Finlayson</td>
<td>Pilot study</td>
<td>29</td>
<td>Community-dwelling volunteers</td>
<td>47</td>
<td>83</td>
<td>Packer et al.</td>
</tr>
<tr>
<td></td>
<td>2005</td>
<td>Mathiowetz</td>
<td>RCT</td>
<td>169</td>
<td>Community-dwelling volunteers</td>
<td>48</td>
<td>83</td>
<td>Packer et al.</td>
</tr>
<tr>
<td></td>
<td>2006</td>
<td>Mathiowetz</td>
<td>Follow-up survey</td>
<td>140</td>
<td>See Mathiowetz (2005)</td>
<td>49</td>
<td>83</td>
<td>Packer et al.</td>
</tr>
<tr>
<td></td>
<td>2007</td>
<td>Holberg</td>
<td>Qualitative</td>
<td>8</td>
<td>See Finlayson (2005)</td>
<td>46</td>
<td>88</td>
<td>Finlayson et al.</td>
</tr>
<tr>
<td></td>
<td>2007</td>
<td>Finlayson</td>
<td>Subgroup analysis</td>
<td>169</td>
<td>See Mathiowetz (2011)</td>
<td>48</td>
<td>83</td>
<td>Finlayson et al.</td>
</tr>
<tr>
<td></td>
<td>2008</td>
<td>Sauter</td>
<td>Quasi-experiment</td>
<td>32</td>
<td>Attending MS outpatient clinic</td>
<td>NR</td>
<td>NR</td>
<td>Sauter et al.</td>
</tr>
<tr>
<td></td>
<td>2009</td>
<td>Ghahari</td>
<td>Pilot study</td>
<td>5</td>
<td>Community-dwelling volunteers with internet access</td>
<td>NR</td>
<td>NR</td>
<td>Ghahari et al.</td>
</tr>
<tr>
<td></td>
<td>2010</td>
<td>Gharari</td>
<td>RCT</td>
<td>95</td>
<td>Community-dwelling volunteers with internet access</td>
<td>50</td>
<td>81</td>
<td>Ghahari et al.</td>
</tr>
<tr>
<td></td>
<td>2011</td>
<td>Finlayson</td>
<td>RCT</td>
<td>190</td>
<td>Community-dwelling volunteers</td>
<td>56</td>
<td>79</td>
<td>Finlayson et al.</td>
</tr>
<tr>
<td></td>
<td>2012</td>
<td>Ghahari</td>
<td>Quasi-experiment</td>
<td>115</td>
<td>Community-dwelling volunteers with internet access</td>
<td>NR</td>
<td>NR</td>
<td>Ghahari et al.</td>
</tr>
<tr>
<td></td>
<td>2012</td>
<td>Preissner</td>
<td>Subgroup analysis</td>
<td>181</td>
<td>See Finlayson (2011)</td>
<td>56</td>
<td>79</td>
<td>Finlayson et al.</td>
</tr>
<tr>
<td>Disease Group</td>
<td>Study Year</td>
<td>First Author</td>
<td>Study Design</td>
<td>Sample Size</td>
<td>Additional Sample Characteristics</td>
<td>Mean Age</td>
<td>% Female</td>
<td>Energy Conservation Program Used (see Table 3.2)</td>
</tr>
<tr>
<td>--------------------</td>
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<td>-------------</td>
<td>---------------------------------------------------------------------------------------------------</td>
<td>----------</td>
<td>----------</td>
<td>-----------------------------------------------</td>
</tr>
<tr>
<td>Post-polio sequelae</td>
<td>1991</td>
<td>Young</td>
<td>Quasi-experiment</td>
<td>35</td>
<td>Outpatient OT patients</td>
<td>55</td>
<td>66</td>
<td>Young et al.</td>
</tr>
<tr>
<td>Rheumatoid Arthritis</td>
<td>1987</td>
<td>Barry</td>
<td>Quasi-experiment</td>
<td>55</td>
<td>Outpatient clinic patients</td>
<td>57</td>
<td>60</td>
<td>Barry et al.</td>
</tr>
<tr>
<td></td>
<td>1987</td>
<td>Furst</td>
<td>RCT</td>
<td>28</td>
<td>RA &gt;1 year, not currently hospitalized</td>
<td>55</td>
<td>89</td>
<td>Furst et al.</td>
</tr>
<tr>
<td>Energy Conservation Program Used (see Table 3.2)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*NR = not reported
studies (8 studies), and quasi-experiments (7 studies) (Table 3.1). Other study designs included subgroup analyses (4 studies), qualitative studies (3 studies), long-term follow-up studies (4 studies), follow-up surveys (3 studies), mixed-methods studies (1 study), study re-analyses (1 study), and case studies (1 study). Twenty-six studies reported on the efficacy or effectiveness of ECE (Table 3.3). The most common dependent variables explored were fatigue (20 studies), fatigue impact (13 studies) and quality of life or its subdomains (12 studies). Other dependent variables that were investigated were occupational engagement (10 studies), energy conservation strategy use (7 studies), self-efficacy (7 studies), and fatigue-related knowledge (4 studies).

3.4.2 Clinical populations studied

Just over half of the included studies (22 of 41) focused exclusively or primarily on the multiple sclerosis (MS) population. The remainder focused on six different populations: chronic fatigue syndrome (7 studies), cancer (4 studies), cardiac disease (3 studies), rheumatoid arthritis (2 studies), acquired brain injury (2 studies), and post-polio syndrome (1 study).

3.4.3 Characteristics of the ECE programs

The literature on ECE described nineteen different ECE programs (see Table 3.2 for their characteristics). Seven programs were versions of Packer and colleagues’ (1995) “Managing Fatigue: A Six-Week Course in Energy Conservation” program. The “Managing Fatigue” program is a protocolized, face-to-face, group-based ECE, with a total of ~9 hours of ECE provided. Its adaptations included a teleconference-based version, a web-supported version, and two individually-delivered versions. The “Managing Fatigue” program and/or its adaptations were used for all 22 of the MS studies on ECE, but only one ECE study outside of the MS population.

The remaining 12 ECE programs, used in the 18 other studies of ECE in different clinical populations, were all distinct. Six programs used a face-to-face modality, while the other six used different delivery modes, such as telephone, computer, audio CDs, a self-guided workbook, or mixed-modalities. Eight of the programs were delivered individually, and four were group-based. Total reported program lengths ranged from one to twelve hours, with the median being 7.5 hours and the majority (82%) being more than five hours.
Table 3.2: Design characteristics of ECE programs described in the literature

<table>
<thead>
<tr>
<th>Program Described By</th>
<th>Supporting theory</th>
<th>Delivery Model</th>
<th>Format</th>
<th>Sessions</th>
<th>Total approx. length</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Managing Fatigue</strong> or adaptations</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Packer et al. (original)</td>
<td></td>
<td>Face to face</td>
<td>Group (n = 8-10)</td>
<td>6 sessions x 1.5-2 hrs</td>
<td>9 hours</td>
</tr>
<tr>
<td>Sauter et al. (adaptation)</td>
<td>Self-efficacy theory</td>
<td>Face to face</td>
<td>Group (n = 6-8)</td>
<td>6 sessions x 2 hrs</td>
<td>12 hours</td>
</tr>
<tr>
<td>Van Heest et al. (adaptation)</td>
<td></td>
<td>Face to face</td>
<td>Individual</td>
<td>6 sessions x 1.5 hrs</td>
<td>9 hours</td>
</tr>
<tr>
<td>Blikman et al. (adaptation)</td>
<td></td>
<td>Face to face</td>
<td>Individual</td>
<td>12 sessions</td>
<td>Not stated</td>
</tr>
<tr>
<td>Finlayson et al. (adaptation)</td>
<td></td>
<td>Teleconference</td>
<td>Group</td>
<td>7 sessions x 45 mins</td>
<td>5h 15 mins</td>
</tr>
<tr>
<td>Ghahari et al. (adaptation)</td>
<td></td>
<td>Computer</td>
<td>Group</td>
<td>7 sessions x 1 hr</td>
<td>7 hours</td>
</tr>
<tr>
<td>Jalon et al. (adaptation)</td>
<td></td>
<td>Face to face</td>
<td>Group</td>
<td>5 sessions x 2 hrs</td>
<td>10 hours</td>
</tr>
<tr>
<td>Barry et al.</td>
<td>NR</td>
<td>Face to face</td>
<td>Individual</td>
<td>1 session x 1 hr</td>
<td>1hr</td>
</tr>
<tr>
<td>Barsevick et al.</td>
<td>Common-sense model of illness</td>
<td>Telephone</td>
<td>Individual</td>
<td>3 sessions (30, 15, 15 mins)</td>
<td>1hr</td>
</tr>
<tr>
<td>Friedburg et al.</td>
<td>NR</td>
<td>Audio CDs &amp; booklets</td>
<td>Individual</td>
<td>12 weeks</td>
<td>NR</td>
</tr>
<tr>
<td>Furst et al.</td>
<td>NR</td>
<td>Face to face</td>
<td>Group</td>
<td>6 sessions x 1.5 hrs</td>
<td>9 hours</td>
</tr>
<tr>
<td>Kim et al.</td>
<td>Problem solving therapy</td>
<td>Telephone</td>
<td>Individual</td>
<td>Up to 8 sessions x 45 mins</td>
<td>6 hours</td>
</tr>
<tr>
<td>McDermott et al.</td>
<td>NR</td>
<td>Face to face</td>
<td>Group</td>
<td>6 sessions x 2 hrs</td>
<td>12 hours</td>
</tr>
<tr>
<td>Norberg et al.</td>
<td>Occupational therapy intervention process</td>
<td>Tailored for each client</td>
<td>Individual</td>
<td>Tailored for each client</td>
<td>Varied</td>
</tr>
<tr>
<td>Raina et al.</td>
<td>Problem-solving therapy</td>
<td>Computer</td>
<td>Individual</td>
<td>12 sessions x 30 mins</td>
<td>6 hours</td>
</tr>
<tr>
<td>Sadeghi et al.</td>
<td>NR</td>
<td>Face to face</td>
<td>Group (n = 6-8)</td>
<td>5 sessions x 1.5 hrs</td>
<td>7.5 hours</td>
</tr>
<tr>
<td>White et al.</td>
<td>NR</td>
<td>Face to face</td>
<td>Individual</td>
<td>12-15 sessions x 50 mins</td>
<td>10-12 hours</td>
</tr>
<tr>
<td>Young et al.</td>
<td>NR</td>
<td>Face to face</td>
<td>Group (3-4)</td>
<td>3-4 sessions x 2 hrs</td>
<td>6-8 hours</td>
</tr>
<tr>
<td>Yuen et al.</td>
<td>NR</td>
<td>Face to face + telephone</td>
<td>Individual</td>
<td>1 session x 1-2 hrs + 3 follow-up calls</td>
<td>2-3 hours</td>
</tr>
</tbody>
</table>

*NR = not reported
3.4.4 Review of reported findings on energy conservation education

3.4.4.1 Multiple sclerosis

3.4.4.1.1 The “Managing Fatigue” program

Seven studies investigated the face-to-face, group-based “Managing Fatigue” program (Packer et al., 1995) in people with MS (Table 3.1). Mathiowetz and colleagues (2001) conducted a pilot RCT including 54 community-dwelling volunteers with MS, and reported that the “Managing Fatigue” participants experienced significantly greater improvements in fatigue, fatigue impact, and some quality of life domains compared to an active control. The ECE participants also used more energy-conserving strategies, and reported greater self-efficacy (Mathiowetz et al., 2001). Mathiowetz and colleagues (2005) conducted a randomized controlled trial (RCT) with 169 volunteers with MS, and found that, consistent with the pilot RCT, the “Managing Fatigue” participants were less fatigued, and experienced greater gains in fatigue impact, some domains of quality of life, self-efficacy, and use of energy-conserving strategies, compared to a wait-list control. Improvements were still seen six weeks (Mathiowetz et al., 2005) and one-year post-intervention (Mathiowetz, Matuska, Finlayson, Luo, & Chen, 2007). Mathiowetz and Busch (2006) administered post-study program evaluations and reported that the “Managing Fatigue” program was well-regarded among participants, receiving a mean overall value rating of six out of seven. Core concepts such as budgeting/banking energy, and the social aspect of the group intervention, were the most highly-rated aspects of the program. Lower-rated aspects included aspects of the intervention format (eg. completing homework assignments), and specific course topics (eg. activity stations and ergonomics) (Mathiowetz & Busch, 2006). Matuska and colleagues (2007) reported that all 14 of the ECE strategies taught in the program were adopted by at least half of the participants after the course. Participants perceived the strategies of taking rest breaks, delegating tasks, and modifying priorities to be the most useful ECE strategies (Matuska et al., 2007). Finlayson and colleagues (2007) reported there was no interaction between participants’ baseline cognitive status and their change in vitality scores after the program, although poorer cognitive functioning was associated with poorer post-intervention quiz performance and less reported energy conservation strategy use. Lamb and colleagues (2005), meanwhile, reported that participants who missed ≥1 treatment session, receiving self-study modules instead, experienced comparable positive outcomes to those who attended all sessions.
3.4.4.1.2 Teleconference-based adaptation

Seven studies investigated an adaptation of the “Managing Fatigue” program, delivered by teleconferencing, in people with MS. Finlayson and colleagues (2005) conducted an uncontrolled pilot study, involving 29 volunteers with MS, and reported that participants experienced significant improvements in fatigue impact, fatigue severity, and some domains of quality of life. Finlayson and colleagues (2011) conducted an RCT, including 190 volunteers with MS, and similarly found that the teleconference-based program was associated with significantly greater improvements in fatigue impact, compared to a wait-list control. These gains were reportedly maintained at 6 months post-intervention. However, they reported no differences between groups in self-efficacy, fatigue severity, or quality of life, at immediate or long-term follow-up (Finlayson et al., 2011). In a follow-up study, Asano and colleagues (2015) reported that participants achieved approximately half of the activity-related goals they had set at the beginning of the program, with short-term goals being more frequently achieved than mid-term or long-term goals. However, outcome information was only available for 60% of the goals originally set by study participants. Holberg and Finlayson (2007) conducted a qualitative follow-up study, and reported that factors such as disease progression, level of disability, predictability of fatigue, concurrent symptoms, cognitive status, and physical and social environment affected participants’ use of the program information. However, they reported that participants felt the program had changed their perspective on fatigue, and enabled them to feel more in control of their lives (Holberg & Finlayson, 2007). Finlayson, Preissner and Cho (2012) conducted secondary analyses of the data, and reported that older age was associated with less improvement in self-efficacy and fatigue impact, and lower functional status was associated with less improvement in mental health. They also reported that the type and nature of comorbidities affected outcomes. For example, people with diabetes experienced more gradual improvements during and after the program compared to non-diabetics, and people with rheumatoid arthritis (RA) were less likely to maintain initial benefits gained from the program (Finlayson, Preissner, & Cho, 2013). Dunleavy, Preissner and Finlayson (2013) conducted a retrospective study of clinical chart notes, and reported that the occupational therapists providing the teleconference-based ECEP perceived it to be generally feasible and beneficial, although they identified several aspects of the phone-based delivery (eg. managing time, adhering to the treatment protocol, managing the group process) as challenging.
3.4.4.1.3 Internet-based adaptation

Three studies examined an internet-based adaptation of the “Managing Fatigue” program in the MS population. Ghahari, Packer and Passmore (2009) conducted a pilot trial involving 5 people with MS, and reported that the web-supported program was associated with improvements in fatigue impact, performance of activities of daily living, and quality of life compared to baseline. Ghahari, Packer and Passmore (2010) conducted a three-arm RCT (n=95) involving people who had a progressive neurological condition, and reported the web-supported ECEP had no significant effects on fatigue impact, performance of activities of daily living, or quality of life, compared to an information-only control and a no-intervention control. Ghahari and Packer (2012) conducted a secondary analysis, comparing the RCT data to a non-equivalent group who received the original face-to-face “Managing Fatigue” protocol, and reported that the face-to-face program was associated with the greatest improvements in the primary outcome of fatigue impact.

3.4.4.1.4 One-to-one adaptations

Two studies examined 1:1 adaptations of the “Managing Fatigue” program among MS people. Blikman and colleagues (2017) conducted an RCT involving 76 individuals with MS, and reported that the 1:1 “Managing Fatigue” program had no significant effect on fatigue or participation outcomes, compared to an information-only control. Van Heest, Mogush and Mathiowetz (2017) conducted a quasi-experimental study (n=49) involving predominantly people with MS (78%), and reported that their 1:1 program adaptation was associated with improvements in the majority of the study outcomes (including fatigue and self-efficacy).

3.4.4.1.5 Other adaptations

Three studies examined other adaptations of the “Managing Fatigue” course in people with MS. Vanage, Gilbertson and Mathiowetz (2003) conducted an RCT examining a version of the “Managing Fatigue” program for people with progressive MS, who had a lower baseline functional status, and reported the program was associated with significant improvements in fatigue impact compared to control. They also reported that the gains made were maintained at eight weeks post-intervention (Vanage et al., 2003). García Jalón and colleagues (2013) examined an ECE program informed by several other ECE programs, including the “Managing Fatigue” program, and reported no differences in self-efficacy, fatigue severity, or depressive
### Table 3.3: Reported outcomes associated with ECE

<table>
<thead>
<tr>
<th>Population</th>
<th>Abbreviated Study Citation</th>
<th>Control</th>
<th>Reported Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Fatigue Impact</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Total</td>
</tr>
<tr>
<td>Multiple sclerosis</td>
<td>Mathiowetz, 2001</td>
<td>Support group</td>
<td>Fatigue</td>
</tr>
<tr>
<td></td>
<td>Vanage, 2003</td>
<td>Support group</td>
<td>Fatigue</td>
</tr>
<tr>
<td></td>
<td>Mathiowetz, 2005</td>
<td>Wait-list</td>
<td>Fatigue</td>
</tr>
<tr>
<td></td>
<td>Finlayson, 2005</td>
<td>None</td>
<td>Fatigue</td>
</tr>
<tr>
<td></td>
<td>Sauter, 2008</td>
<td>None</td>
<td>Fatigue</td>
</tr>
<tr>
<td></td>
<td>Ghahari, 2009</td>
<td>None</td>
<td>Fatigue</td>
</tr>
<tr>
<td></td>
<td>Ghahari, 2010</td>
<td>Standard care</td>
<td>Fatigue</td>
</tr>
<tr>
<td></td>
<td>Finlayson, 2011</td>
<td>Wait-list</td>
<td>Fatigue</td>
</tr>
<tr>
<td></td>
<td>Jalon, 2013</td>
<td>Support group</td>
<td>Fatigue</td>
</tr>
<tr>
<td></td>
<td>Asano, 2015</td>
<td>N/A</td>
<td>Fatigue</td>
</tr>
<tr>
<td></td>
<td>Blikman, 2017</td>
<td>Information-only</td>
<td>Fatigue</td>
</tr>
<tr>
<td>Cancer</td>
<td>Barsevick, 2002</td>
<td>Standard care</td>
<td>Fatigue</td>
</tr>
<tr>
<td></td>
<td>Barsevick, 2004</td>
<td>Support group</td>
<td>Fatigue</td>
</tr>
<tr>
<td></td>
<td>Yuen, 2006</td>
<td>None</td>
<td>Fatigue</td>
</tr>
<tr>
<td></td>
<td>Sadeghi, 2016</td>
<td>Standard care</td>
<td>Fatigue</td>
</tr>
<tr>
<td>Cardiac disease</td>
<td>Norberg, 2017</td>
<td>None</td>
<td>Fatigue</td>
</tr>
<tr>
<td></td>
<td>Kim, 2016</td>
<td>None</td>
<td>Fatigue</td>
</tr>
<tr>
<td>Rheumatoid Arthritis</td>
<td>Furst, 1987</td>
<td>Existing ECEP</td>
<td>Fatigue</td>
</tr>
<tr>
<td>Post-polio</td>
<td>Young, 1991</td>
<td>None</td>
<td>Fatigue</td>
</tr>
<tr>
<td>Acquired brain injury</td>
<td>Boehm, 2015</td>
<td>None</td>
<td>Fatigue</td>
</tr>
<tr>
<td></td>
<td>Raina, 2016</td>
<td>Health education</td>
<td>Fatigue</td>
</tr>
<tr>
<td>CFS</td>
<td>McDermott, 2004</td>
<td>None</td>
<td>Fatigue</td>
</tr>
<tr>
<td></td>
<td>White, 2011</td>
<td>Standard care</td>
<td>Fatigue</td>
</tr>
<tr>
<td></td>
<td>Friedburg, 2015</td>
<td>Standard care</td>
<td>Fatigue</td>
</tr>
<tr>
<td>Chronic condition</td>
<td>Van Heest, 2017</td>
<td>None</td>
<td>Fatigue</td>
</tr>
</tbody>
</table>

Legend:  | favours ECE; | no difference between ECE & control; | not assessed
symptoms in the ECE group compared to control, with the exception of the cognitive subscale of the Fatigue Impact Scale. Sauter and colleagues (2008) conducted an uncontrolled study of 32 people to examine a German-language adaptation of the program, and reported it was associated with improvement in fatigue impact, but not fatigue, at 3 months and 9 months post-intervention.

### 3.4.4.2 Chronic fatigue syndrome

Seven studies explored ECE in chronic fatigue syndrome (CFS). White and colleagues (2011) conducted an RCT involving 641 people with CFS to compare ECE to cognitive behavioural therapy (CBT), graded exercise therapy (GET), and a standard care control. They found an extensive, individually-delivered ECE had no effect on the primary outcomes (fatigue or physical performance) or secondary outcomes (mental health, participation) compared to the standard care control, and was less effective than CBT and GET (P. White et al., 2011). Dougall and colleagues (2014) conducted a follow-up study and found that people allocated to ECE or standard care were more likely to experience a post-intervention decline in physical functioning, compared to the CBT and GET participants, while White and colleagues (2013) found that ECE participants were less likely to recover from CFS. There was no difference in rates of serious adverse events reported among the treatment groups (Dougall et al., 2014). Wilshire and colleagues (2017) conducted a re-analysis of the RCT data to explore the study results according to the original RCT protocol, and found that when the original protocol was used, the recovery rate from CFS was in fact no better for the CBT or GET treatment groups compared to ECE or usual care (Wilshire et al., 2017). Sharpe and colleagues (2015) conducted a long-term follow up study at 2.5 years post-intervention, and found no difference in fatigue and physical functioning between the four treatment groups, although participants in the ECE and standard-care groups more frequently participated in alternative treatments (CBT or GET) after the original study ended.

McDermott and colleagues (2004) undertook a uncontrolled, retrospective study to examine return-to-work activities in 98 people with CFS who participated in a clinical, group-based ECE program. They reported 56% of program participants had undergone work training or acquired new full-time, part-time or volunteer work at 18 months post-intervention, while 19% continued with their previous employment (McDermott et al., 2004). Sixty-six percent of participants were reported to have an increase in their feelings of vitality, compared to baseline. Friedberg and
colleagues (2016) conducted an RCT studying ECE among a sample of 137 CFS people who had a high level of disability at baseline, and reported that two versions of an ECE self-management program (a “high tech” and “low-tech” version) were associated with significant reductions in fatigue severity and depression scores compared to usual care. However, self-care independence, activity levels, and anxiety did not change significantly in the ECE groups compared to control (Friedberg et al., 2016). The positive effects on fatigue and depression were also not reported to be maintained at long-term follow-up.

3.4.4.3 Cancer

Four studies examined ECE programs in people with cancer. Barsevick and colleagues (2002) undertook a pilot study of a brief, telephone-based ECEP with 80 cancer people initiating chemotherapy or radiation therapy, and reported that the program was feasible, acceptable, and associated with reductions in fatigue compared to a non-equivalent control. Barsevick and colleagues (2004) conducted an RCT, comparing the same ECE to a support group control with a sample of 396 cancer people initiating chemotherapy or radiation therapy, and reported that the ECE group adopted more energy conservation strategies post-intervention and experienced significantly less fatigue compared to control; however, the effect sizes were reported to be very small. No improvement was reported in the people’ participation in activities of daily living (Barsevick et al., 2004). Yuen, Mitcham and Morgan (2006) conducted a pilot study comparing a different ECE program to a standard-care control with 12 cancer survivors in the post-treatment stage of their illness, and reported that only the sensory dimension of fatigue demonstrated positive outcomes, while general, physical and cognitive fatigue were unaffected (Yuen et al., 2006). Meanwhile, Sadeghi, Gozali and Tabrizi (2016) undertook an RCT (n=135) comparing a group-based ECE program to a usual-care control in women with breast cancer, and reported that multiple types of fatigue improved significantly in the ECE group compared to control, as did several indicators of healthy living (eg. physical activity, nutrition, stress management).

3.4.4.4 Cardiac disease

Kim and colleagues (2016) tested a telephone-based ECE program for cardiac arrest survivors, that used an individualized, problem-solving approach to ECE training. They involved eighteen participants in a quasi-experimental trial of the program, and found it to be feasible and associated with improvements in fatigue impact, fatigue and participation (Kim et al., 2016).
Planning ahead, pacing oneself, and delegating activities were reported to be the most commonly-used energy conservation strategies by participants, and household tasks, leisure activities and grocery shopping were the most common occupations targeted during the program (Kim et al., 2017). Norberg and colleagues (2017) conducted a mixed-methods study (n=5) of a different, individualized ECE program for people with chronic heart failure, and reported that participants adopted energy conservation strategies after participating in the ECEP, but fatigue and depression-related outcomes were mixed. The occupational therapists who administered the ECEP were reported to appreciate its thoroughness, but questioned the feasibility of using the extensive program in routine clinical practice (Norberg et al., 2017).

### 3.4.4.5 Acquired brain injury

Raina and colleagues (2016) undertook a pilot RCT of an internet-based ECE program with 41 people living with a traumatic brain injury, and reported that the ECE program, which used a problem-solving approach, was feasible and associated with small to moderate-sized improvements in fatigue impact and fatigue. Meanwhile, Boehm, Muehlberg and Stube (2015) studied an individually-delivered, teleconference-based adaptation of the “Managing Fatigue” program in a case study of a 70-year-old person living post-stroke, and reported that it was associated with a decrease in physical, cognitive and social fatigue impact. However, minimal change was reported to occur in the participant’s performance of, and satisfaction with, three self-identified occupational goals (Boehm et al., 2015).

### 3.4.4.6 Rheumatoid arthritis

Barry and colleagues (1994) conducted an uncontrolled, pre-post study, and reported that people with rheumatoid arthritis (RA) were able to identify energy conservation strategies more successfully after participating in one hour of individually-delivered ECE. Furst and colleagues (1987) undertook a pilot study involving 28 people with RA to compare a formally-developed, group-based ECE program to usual occupational therapy care, and reported that the ECE program was associated with greater increases in physical activity levels, and balance between rest and activity, at 3 months post-intervention. However, no differences were reported in other study outcomes such as pain, fatigue, psychosocial adjustment to illness, knowledge, or independence in activities of daily living (Furst et al., 1987).
3.4.4.7 Post-polio syndrome

Young and colleagues (1991) conducted a retrospective study investigating a clinical, group-based ECE program in a sample of 35 people with post-polio syndrome, and reported that participants’ knowledge about their disease, use of energy-conserving behaviours, and fatigue ratings improved after the program.

3.5 Discussion

Our study is the first to comprehensively identify and describe the literature on ECE in adults with chronic diseases. We found ECE has been studied in seven chronic disease populations: MS, cancer, CFS, cardiac disease, acquired brain injury, RA, and post-polio syndrome. Multiple approaches to ECE have been examined, but the literature was most extensive on a six-session, face-to-face, group-based program entitled “Managing Fatigue: A Six-Week Course in Energy Conservation” (Packer et al., 1995), studied almost exclusively in the MS population. The program was said to be feasible with this population, and both quantitative and qualitative studies reported it had various positive effects on participants, such as reducing the impact of fatigue on their physical, cognitive and psychosocial functioning and improving their self-efficacy (Finlayson et al., 2011; Mathiowetz et al., 2005). Participants also reported that they valued the social aspect of the program (Mathiowetz & Busch, 2006), and that they energy conservation strategies they learned were novel and effective (Mathiowetz & Busch, 2006; Matuska et al., 2007). The consistency of these positive findings indicate the “Managing Fatigue” program is a beneficial treatment option for people with MS who experience fatigue, and may warrant investigation in other chronic disease populations for whom its program format would be feasible.

A potential limitation of the “Managing Fatigue” program is its face-to-face, group-based design, which may be inaccessible or inconvenient for people with barriers to attending a health facility. Several adaptations of “Managing Fatigue” were created to be more accessible, such as a teleconference-based adaptation, a web-supported adaptation, and individualized adaptations, but were reportedly associated with more mixed results. Beyond the “Managing Fatigue” program, a number of remotely-delivered and individualized ECE programs were studied in other populations that were said to be associated with positive outcomes; however, the literature was still preliminary. Further robust research into accessible and/or individualized ECE programs is
therefore needed. In the general literature, e-health education programs have been found to be effective (Buntin, Burke, Hoaglin, & Blumenthal, 2011; Krebs, Prochaska, & Rossi, 2010; Morrison, Yardley, Powell, & Michie, 2012). Design components that have been identified as important include social interaction or social references, tailoring, contact with the intervention, and self-management features (Morrison et al., 2012). Individually-delivered interventions, meanwhile, can offer tailoring towards individual needs, preferences, and goals, which is associated with better health education outcomes (Lustria et al., 2013), and which may therefore be beneficial for ECE program design.

Despite the positive reported effects of the “Managing Fatigue” program on fatigue outcomes, there were also a limited number of studies that investigated its effects on occupational engagement. ECE is an approach to fatigue management that uniquely focuses on occupational engagement, which is an important consequence of fatigue for people with chronic diseases (Curt et al., 2000; Fisk, Pontefract, et al., 1994; Ju et al., 2018). The reported findings that were available did not support a strong effect on occupational engagement; for example, Asano and colleagues (2015) reported that people’s life goals were infrequently achieved after the “Managing Fatigue” program. They subsequently proposed, in their discussion of findings, that adding a goal management component to the “Managing Fatigue” program might facilitate the attainment of participants’ life participation goals (Asano, Berg, Johnson, Turpin, & Finlayson, 2015). A functional goal-focused approach to rehabilitation has generally been associated with positive occupational engagement outcomes in multiple populations, such as traumatic brain injury (Dawson et al., 2009), developmental coordination disorder (Smits-Engelsman et al., 2013), and stroke (Polatajko, McEwen, Ryan, & Baum, 2012). It offers several advantages over traditional education approaches, including a client-centered consideration of individual participant needs and situations (Polatajko et al., 2001), which allows for targeted intervention tailoring. There were more recent ECE programs identified in this review that did include a goal-focused component; however, they require further study to ascertain their effects on occupational engagement. In general, ECE studies should routinely include personalized measures of occupational engagement or performance, such as the Canadian Occupational Performance Measure (Law et al., 1990), Activity Card Sort (Gustafsson et al., 2014), or Performance Quality Rating Scale (Martini, Rios, Polatajko, Wolf, & McEwen, 2015), to measure its effect on participation in occupations that are meaningful to the participant.
Beyond the “Managing Fatigue” program in the MS population, the reported findings on ECE in other chronic disease populations were either conflicting, or preliminary. It is unclear whether the conflicting findings were attributable to study variations in ECE program, sample, and/or design. For example, in people with cancer, two controlled studies reported that ECE had little to no effect on outcomes such as fatigue and physical function (Barsevick et al., 2004; Yuen et al., 2006), yet another RCT reported ECE had a positive effect on fatigue (Sadeghi et al., 2016). The length of the ECE programs used varied greatly between the studies, as did the timing of the introduction of the intervention, both which could have affected study outcomes. In people with CFS, a large RCT showed no effect of an extensive, individually-delivered ECE program compared to standard care, on fatigue, physical performance, participation and mental health (P. White et al., 2011). This finding could be related to the longstanding ambiguity of the underlying nature of CFS, which has been discussed as being a psychological disorder that therefore may not respond to ECE. However, the scientific rigor of the PACE trial has also been questioned since its publication (Wilshire et al., 2017), as mid-study protocol changes were subsequently reported to have inflated the effects of two active control arms (CBT and graded exercise). Other preliminary studies have, by contrast, reported that ECE has positive effects on people with CFS (Friedberg et al., 2016; McDermott et al., 2004). Further research on ECE in both the cancer and CFS populations, using well-designed ECE programs and robust study methodologies, is therefore needed.

The reported findings on ECE in other chronic disease populations (eg. rheumatoid arthritis, post-polio syndrome, cardiac disease, acquired brain injury) were predominantly positive, but preliminary. Further robust research on ECE in these populations is therefore warranted. We also found no studies of ECE in chronic disease populations such as kidney disease or chronic obstructive pulmonary disease, who also experience a high burden of fatigue (Mollaoglu et al., 2011; Murtagh et al., 2007). Given the benefits of ECE that have been demonstrated in the MS population, research should be undertaken to explore the potential for ECE to improve fatigue-related outcomes in these populations.

The strengths of this review include the comprehensive literature search that was conducted by trained professionals; the broad examination of the evidence on ECEs across clinical populations; and the systematic approach used to identify and describe the evidence. Its limitations include the exclusion of non-English studies, which may limit the generalizability of
the findings; and, limitations inherent to a scoping review, such as a lack of consideration of evidence quality, which may mean that quality-based evidence gaps were not identified.

3.6 Conclusion

Multiple studies support the “Managing Fatigue” ECE program as an effective approach in the MS population. Preliminary evidence on ECE is also promising in acquired brain injury, post-polio, and cardiac disease, justifying the need for further robust trials in these populations. Evidence on ECE is currently conflicting in cancer and CFS, and thus further well-designed research is also warranted for clarification. Investigation into ECE in other chronic disease populations with a high burden of fatigue, such as COPD and kidney disease, is needed. Future ECE trials should aim to use evidence-informed programs, and measure occupational engagement. Flexible and convenient program delivery formats, such as self-guided, individualized, or telehealth programs, should also be further investigated.
Chapter 4:  
Developing PEP”: A Personalized, Web-supported Energy Conservation Education Program for Adults on Chronic Dialysis Therapy

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Target Journal for Submission: American Journal of Occupational Therapy
Chapter 4: Developing “PEP”: A Personalized, Web-supported Energy Conservation Education Program for Adults on Chronic Dialysis Therapy

4.1 Abstract

**Background:** Fatigue is one of the most common and disabling symptoms experienced by people with end-stage renal disease (ESRD) on chronic dialysis therapy (CDT). Energy conservation education (ECE) is an approach to fatigue management that has demonstrated some positive effects in other chronic disease populations, but has yet to be explored for its potential for the CDT population. **Objectives:** To explore whether an ECE program exists to meet the needs of adults on CDT; to develop a new ECE program tailored for the CDT population, if needed; and to carry out preliminary evaluation of the program. **Methods:** We followed the World Health Organization’s framework for health education planning to guide the intervention development process. We addressed *Stage 1, engaging and understanding the population*, through an examination of recent CDT studies that included a patient engagement component. We accomplished *Stage 2, assessing the needs and assets of the priority population*, using a literature-informed Strengths, Weaknesses, Opportunities and Threats (SWOT) analysis. We then identified the highest-priority results of the SWOT, and transformed them into program goals and objectives, meeting *Stage 3, developing program goals and objectives*. We accomplished *Stage 4, planning an intervention*, in three substages: a. Initial program development; b. Key informant feedback; and c. Usability testing. We completed Stage 4a by consulting relevant literature to select theory and evidence-based educational approaches, and then engaged key expert informants in semi-structured interviews about the new program during *Stage 4b*. We accomplished Stage 4c using performance- and questionnaire-based usability testing with people on CDT. **Results and Conclusions:** We identified needs that could be addressed by ECE in the CDT population through the SWOT analysis. As there was no existing ECE program that met these needs, we developed a new program. The three goals we identified from the SWOT for the new program were that it would 1. improve life participation; 2. be feasible for people on CDT; and 3. use theory and evidence from the ECE and health education literature. The resulting new ECE program combines an established personalized, goal-based, problem solving approach (CO-OP) with traditional didactic ECE methods that are delivered via three brief, novel web modules. The feedback provided by key informants on the program was
positive, while a number of program modifications were recommended, of which 26 were implemented. Usability testing revealed the majority of the program was usable by people on CDT with various characteristics, while minimal support was required for people with little to no computer literacy. Further research should investigate the effects of the program on fatigue-related outcomes in people on CDT.
4.2 Introduction

Fatigue is among the most common and limiting experiences of people with end-stage renal disease (ESRD) treated with chronic dialysis therapy (CDT) (Ju et al., 2018; Manns et al., 2014; Murtagh et al., 2007; Weisbord et al., 2007). Fatigue has been defined as an “unusual, abnormal or excessive whole-body tiredness, disproportionate to or unrelated to activity or exertion”. It has been estimated that approximately 70% of people on chronic dialysis experience fatigue (Murtagh et al., 2007). Fatigue is a complex, nonspecific symptom that, in end-stage renal disease (ESRD), is associated with a multitude of factors, such as anemia, inflammation, depression and sleep disorders (Artom et al., 2014; Bossola et al., 2011; Jhamb et al., 2008). Evidence-based treatment options for fatigue in people with ESRD are currently limited (Artom et al., 2014). Erythropoietin stimulating agents (ESAs) are the most well-established approach to fatigue management for people on CDT, and have been found to reduce fatigue by 35% in people on CDT with severe forms of anemia (Johansen et al., 2012a). However, ESAs do not address the multiple other factors that contribute to fatigue in ESRD beyond anemia. Exercise training is another widely-researched approach in people with ESRD, that has been associated with an increased energy capacity and a reduction in subjective fatigue in people on CDT (Astroth et al., 2013; Johansen, 2007). However, there are a number of longstanding barriers to the use of exercise training with people on CDT, such as insufficient dialysis staff expertise, and low motivation or energy among people on CDT (Delgado & Johansen, 2012; Kontos et al., 2007; Painter et al., 2014), that have proven challenging to overcome in the ESRD community to date.

Fatigue is associated with a range of negative outcomes in the CDT population (Davison & Jhangri, 2010; Jhamb et al., 2011; Wang et al., 2014), with the most prominent, according to people on CDT themselves, being its negative impact on their ability to participate in daily activities (Ju et al., 2018). In a recent Canadian research-priority setting exercise, people on dialysis identified fatigue as being among their top-three research priorities (Manns et al., 2014), underscoring the need to investigate novel approaches to minimize fatigue and its impact on life participation for this population.

Energy conservation education (ECE) is an approach to fatigue management which has been reported to have positive effects on fatigue outcomes in other chronic disease populations,
including multiple sclerosis, cardiac disease, and acquired brain injury (Farragher, Jassal, McEwen & Polatajko, unpublished). The overall goal of ECE approach is to promote “optimum use of available energy to fit the unique needs of each individual” (Packer et al., 1995, p. 2). People are taught to use a range of energy conservation strategies during everyday activities, to reduce fatigue and improve life participation. Examples of energy conservation strategies include combining steps of an activity, using assistive tools, avoiding inefficient body postures, and reorganizing activity stations. Energy conservation education is theoretically a good fit for the CDT population, given that multiple studies have shown the exercise capacity of people on CDT is reduced, and they fatigue more easily during activity (K. L. Johansen, 2007; Kirsten L. Johansen et al., 2005). In addition, people on CDT also have extra health-related activities they must routinely complete in addition to their usual day-to-day tasks, such as going to dialysis; monitoring blood pressure, fluid intake and diet; and attending frequent hospital appointments; which may exacerbate their fatigue. However, despite its potential to improve fatigue-related outcomes in people on CDT, ECE has never been formally investigated in the CDT population (Farragher et al., unpublished). Our primary objective was therefore to investigate the potential of an energy conservation approach in the CDT population.

### 4.3 Methods

We used the six-stage WHO framework for health education planning (World Health Organization, 2014) to inform our intervention exploration and development process (Figure 4.1). Stages 1–4 are reported here; stages 5–6 are reported in a separate publication (Farragher, Polatajko, McEwen & Jassal, unpublished).

We addressed *Stage 1, engaging and understanding the population*, through an examination of recent studies that included a patient engagement component, and that explored their experiences and/or needs related to CDT and fatigue.

We undertook *Stage 2, assessing the needs and assets of the population*, by conducting a SWOT analysis to identify the strengths, weaknesses, opportunities and threats to ECE among people on CDT. The primary sources we consulted to inform the SWOT analysis were: a recent scoping review of energy conservation education literature in other chronic disease populations (Farragher et al., unpublished); published nephrology literature; and the nephrologist on our development team, who has 15 years of experience working in a large, academic hospital setting.
We addressed **Stage 3, developing program goals and objectives**, by having the primary research team (two academic OTs, one nephrologist and one academic PT) discuss the findings from the SWOT analysis, to identify the highest priority needs and reformulate them into goal and objective statements.

We undertook **Stage 4, planning an intervention**, in three substages: 4a. Initial program development, 4b. Key informant feedback, and 4c. Usability testing.

We accomplished **Stage 4a, initial program development**, using an iterative, multi-staged process. Guided by the program goals and objectives, we reviewed relevant background literature to inform theory or evidence-based strategies that could be incorporated into the new energy conservation program. We then designed the program, with multiple revision and moderations made during the process, until the research team reached consensus that the program would meet its goals and objectives.

We accomplished **Stage 4b, key informant feedback**, by conducting semi-structured interviews with two CKD people, one CDT clinician, and one health education specialist, to gather their perspectives on the strengths and limitations of the program modules and recommendations for modifications. We chose the informants purposively to provide a range of expertise regarding the program content and design, and for desired characteristics such as insightfulness, discernment,
and enthusiasm to participate. We showed each key informant each of the three program computer modules over three separate sessions, and then interviewed them using a semi-structured guide (Appendix B). The first author audio-recorded and transcribed all interviews, and then read the transcriptions to get a general sense of the content. The first author then coded the content into one of two broad categories: program strength, or program weakness/recommendation for change. The first author then created more specific codes, that described the type of strength and/or weakness. Next, the research team met to review the information and decide on actions. Recommended modifications were implemented unless they were conflicting between informants, or deemed to be unnecessary or infeasible by the research team.

We undertook *Stage 4c, usability testing*, with intended users to assess the usability of the program, and identify usability barriers to address with further design modifications. We recruited participants from the dialysis units at an academic hospital in Toronto. We identified prospective participants using purposive sampling, to represent varying levels of functional abilities and computer literacy of the CDT population. Participants were required to be over 18 years of age, and to have adequate visual function and English comprehension to complete study activities. We conducted both a performance-based assessment, in which the user was observed engaging with the program technology, and a user satisfaction questionnaire. We provided each participant with the program workbook, gave them a brief orientation to the program and workbook, and then asked them to access and complete each of the program’s computer modules independently. The first author observed participants while they completed each module task, documented their progress through the modules, noted the need for cues or assistance, and documented any observed or reported barriers to completion. Analysis of these observations consisted of tabulating the percentage of module tasks that participants were able to complete independently. Barriers to independent completion were also listed. Once the modules were completed, the first author administered the System Usability Scale (SUS) (Jordan, Thomas, McClelland, & Weerdmeester, 1996). The SUS asked participants to rate their satisfaction and the ease of use of the technology on ten, four-point Likert-scale questions. The SUS is a widely-used measure of system usability in healthcare, with strong reliability and validity across various populations and interventions (Bangor, Kortum, & Miller, 2008). We summed scores on the SUS
and then multiplied by 2.5, to generate a total usability score out of 100, with higher scores representing better usability. We also calculated the median score on the SUS.

We completed Stage 5, implementing the intervention, and Stage 6, evaluating the importance of the intervention, with a small group of participants. These data are reported in a separate publication (Farragher, in preparation).

4.4 Results

4.4.1 Stage 1: Engaging and understanding the priority population

We found people on CDT were recently engaged in two studies that explored their top uncertainties and priorities for research into CDT. The first was a study conducted in Canada, where Manns and colleagues (2014) undertook a two-staged consensus-building process. In the first stage, they distributed a survey to a sample of people on CDT from across Canada, to identify the research uncertainties of people on CDT. They then held a consensus workshop with a steering committee, involving 11 people, to select the top ten uncertainties. They found that fatigue and its management were among the top three research priorities of people on CDT (Manns et al., 2014). The second study was an international consensus-building workshop conducted by Ju and colleagues (2018) to discuss the development and implementation of a core outcome measure for fatigue in the CDT population. Fifteen people on CDT/caregivers and 42 healthcare professionals participated in the discussion. One of their core findings, was that the impact of fatigue on the life participation of people on CDT was the most salient aspect of fatigue to address (Ju et al., 2018). These two studies provided justification to further explore ECE for the CDT population, as it is an approach that targets the impact on fatigue on life participation.

4.4.2 Stage 2: Assessing the needs and assets of the priority population

The SWOT analysis, presented in Figure 4.2, revealed a number of strengths and opportunities (eg. evidence of positive effects of ECE on fatigue in other chronic disease populations; increased focus on quality of life and symptom management in nephrology). However, there were also a number of weaknesses and threats identified (eg. lack of evidence for improving life
participation; limited time among people on CDT to participate in an ECE program). Collectively, the results suggested that an ECE program could be beneficial for people on CDT, but that it would need to be designed to meet the specific needs of the CDT population.

**Figure 4.2: SWOT analysis of energy conservation education for people on CDT**

- **Strengths**
  - Has been associated with positive fatigue-related outcomes in other chronic disease populations, such as Multiple Sclerosis
  - Well-positioned to target life participation outcomes
  - Theoretical basis suggests it can be useful regardless of the underlying fatigue aetiology provided it has a physical origin, which is true for people on CDT
  - Common ECE strategies from existing programs have been found to be useful and effective

- **Weaknesses**
  - Limited evidence that existing programs improve life participation
  - Most ECE programs are time-consuming, involving on average 7 hours of patient education
  - Most evidence-based ECE programs are delivered in-person, which is inaccessible to people with barriers to attending a health facility
  - Existing programs not designed to meet specific user characteristics (e.g., visual impairment, cognitive impairment)

- **Opportunities**
  - Increased focus on addressing patient-reported outcomes such as fatigue in the nephrology community
  - People on CDT identify fatigue management as a top research priority, suggesting interest in a new fatigue management approach
  - People on CDT report some maladaptive fatigue management strategies that could be amenable to change via energy conservation education
  - People on dialysis have benefitted from self-management interventions in previous studies
  - Found to be beneficial for people with characteristics common to the dialysis population (e.g., older age, cognitive impairment, comorbidity)

- **Threats**
  - People on CDT spend extensive time on health-related activities & may be unable to commit extra time for ECE
  - Many existing programs use formats (e.g., group-based, face-to-face) that may be inconvenient for people on CDT
  - Therapist-facilitated design of existing programs may be unfeasible, given the limited rehabilitation staffing on dialysis units
  - Energy expenditure issues which may be important to people on dialysis, such as the extensive energy spent on dialysis-related care, are not addressed
4.4.3 Stage 3: Developing program goals and objectives

The highest-priority needs we identified from the SWOT analysis were for an ECE program that would be feasible for people on CDT, and would positively affect their life participation. These needs informed the following program development goals and objectives:

1. The new ECE program will incorporate a theory or evidence-based approach to facilitating life participation
2. The new ECE program will be feasible in the dialysis clinical context, as follows:
   a. The program will require less time to complete than existing evidence-based energy conservation education programs (ideally less than five hours)
   b. The program will require less time than existing programs for clinicians to administer (ideally less than three hours per participant)
   c. The program will be amenable to completion at flexible and convenient times and locations for people (e.g., from home; during dialysis sessions)
   d. The program will be usable by people with common ESRD characteristics (i.e., older age, visual impairments, cognitive impairments)
3. The ECE program design will build on the evidence and theories from the existing ECE and health education literature

4.4.3.1 4a: Initial program development

4.4.3.1.1 Program Goal 1: Improving the life participation of people on CDT

We first undertook to identify an intervention approach, that would facilitate people’s use of energy conservation strategies to address their life participation goals. We identified the Cognitive Orientation to Occupational Performance (CO-OP) as a promising option. CO-OP can be described as a personalized, goal-based, problem solving (PG-BPS) approach. One of its primary goals is to facilitate client-centered, functional skill acquisition (Polatajko et al., 2001). The CO-OP approach is grounded in dynamic systems theories, such as the Canadian Model of Occupational Performance and Engagement (CMOP-E) (Townsend & Polatajko, 2007), which posit that the performance of functional skills, or tasks, depends on an idiosyncratic interaction between the person’s skills and abilities, the environment they are in, and the task they are performing (Townsend & Polatajko, 2007). A client-centered, top-down approach, focusing
directly on three client-chosen functional goals, therefore forms the basis of CO-OP. For each chosen goal, the therapist and participant collaboratively undertake a process of dynamic performance analysis (DPA) in the therapeutic setting, during which the participant is observed attempting to perform his/her target goal skill or task. Out of the DPA, the therapist and participant identify where the participant’s performance is breaking down, and generate personalized strategies, or plans, to address the performance breakdown(s). The participant then enacts these strategies and checks to see if they work, in an iterative fashion, until an optimal performance solution is found. Features are also embedded in CO-OP to help the participant generalize the progress they make in therapy to other contexts (ie. real-world settings) and transfer their progress to other goals (Houldin, McEwen, Howell, & Polatajko, 2018; Polatajko et al., 2001). For example, the therapist and client apply a global problem-solving strategy (goal-plan-do-check) consistently during CO-OP to frame the problem-solving process, which the participant can then apply independently to problem-solve around other potential performance problems. The therapist also uses a guided discovery approach throughout CO-OP, to further encourage the participant’s independence in discovering performance breakdowns and solutions (Missiuna, Mandich, Polatajko, & Malloy-Miller, 2001; Polatajko et al., 2001).

CO-OP has never been specifically tested for addressing fatigue-related performance breakdowns. However, it has strong evidence of effectiveness at improving life participation for a variety of other functions (eg. motor-based, organizational) in other clinical populations, such as stroke (Polatajko et al., 2012), developmental coordination disorder (Smits-Engelsman et al., 2013), and traumatic brain injury (Dawson et al., 2009; Ng, Polatajko, Marziali, Hunt, & Dawson, 2013). CO-OP’s general focus on strategy-based skill acquisition (Polatajko et al., 2001) aligns well with the strategy-focused approach of ECE. CO-OP builds on existing ECE programs by using a personalized approach to energy conservation strategy selection, which we reasoned may generate energy conservation strategies that are more relevant to the individual’s own life participation goals. The components used to promote generalization and transfer in CO-OP (eg. guided discovery, metacognitive strategy use) may also increase the likelihood of people on CDT achieving positive real-world outcomes (ie. better life participation) after ECE, providing them with the self-efficacy to independently problem-solve around fatigue problems that arise in their lives. Houldin and colleagues (n.d.) have found that increased self-efficacy is a mediator of successful generalization and transfer after CO-OP.
4.4.3.1.2 Program Goal 2: Maximizing program feasibility for the CDT population

Although a CO-OP approach had potential to improve life participation outcomes after ECE, its typical twelve-session model did not match the feasibility objectives for the CDT population. Further, CO-OP has no specific educational component, while all ECE programs do. We therefore decided to precede the CO-OP component of the intervention with a brief, didactic-style education section about energy conservation, informed by the content from existing energy conservation programs. Gaining declarative (ie. knowledge-based) information about a skill to be learned is proposed by many to be the first stage in skill acquisition (J. R. Anderson, 1982; Fitts & Posner, 1967), is consistent with CO-OP’s pre-requisite of having a general understanding of the skill to be performed, and is also consistent with the 'supplementing task knowledge' strategy often used in CO-OP to accelerate skill acquisition (Polatajko et al., 2001). We reasoned that providing this evidence-informed information a priori would enable clients to apply energy conservation principles and develop appropriate plans more easily during CO-OP, thus accelerating their learning process. We decided to deliver the didactic component of the program via a series of online modules, that people could access and complete independently at their own convenience. Web and mobile-based approaches have been effectively used for various behaviour change objectives (Wantland, Portillo, Holzemer, Slaughter, & McGhee, 2004), and have been found to be feasible and acceptable in the CKD population (Diamantidis et al., 2015; Ong et al., 2016). A partially self-administered, web-supported model would also reduce the time needed for clinicians to administer the program.

We used a number of design strategies to enhance the usability of the computer modules for people with common dialysis user characteristics, such as visual impairments and cognitive impairments. All graphics and text we used were large in size, and we used bright colours and strong contrast, to increase module visibility. We also used simple analogies throughout the modules to promote comprehension of the content for individuals with cognitive impairments, and employed extensive repetition of key concepts to accommodate learning or memory impairments. The instructions for accessing the computer modules provided in the program workbook were also simple and detailed, to accommodate people with little to no computer literacy.
We made further modifications to CO-OP to align it with the ECE program feasibility objectives. First, although CO-OP is typically administered in-person by a therapist, we had to be flexible with its administration so it could be completed in-person during dialysis, over the web, or via telephone, according to participant preference. Web-administered CO-OP has been used previously by Ng and colleagues (2013), and found to be feasible and associated with improvements in participants’ goals. The revised mode of delivery for CO-OP, combined with the complex nature of people’s fatigue-related goals (e.g., having enough energy to go grocery shopping), also meant that participants could not be directly observed attempting to perform their target functional activity for the DPA process. As DPA is a crucial component of CO-OP for problem-solving and generating strategies, we decided to instead elicit detailed descriptions of people’s typical performance of their functional goal using visualization and question probing. Question probing and verbal descriptions of task performance were used for DPA successfully by Ng and colleagues (2013) in their web-administered CO-OP study. The complex goals and mode of delivery also meant it was typically not possible for the client to immediately try strategies generated from the DPA, as is typically done in CO-OP. Since trying the strategy is a key part of the learning process for CO-OP, we instead asked participants to “Do” their plans in between CO-OP sessions, and then reviewed the success of the plans during a “Check” at their next session to determine whether further DPA and planning were needed.

4.4.3.1.3 Program Goal 3: Using evidence and theories from existing ECE and health education literature

We created the PEP Program module content using energy conservation literature and health education literature, while also incorporating information from nephrology and movement science literature. We included general information on kidney disease-related fatigue, such as its prevalence and potential causes, and outlined aspects of everyday activities that can affect energy expenditure, such as movement, speed, and body positioning. We included content to promote participants’ readiness to change their behaviours; for example, we briefly addressed the pros and cons of continuing with current energy expenditure patterns to ready participants for change, consistent with the principle of decisional balance from the Transtheoretical Model (Prochaska, DiClemente, & Norcross, 1993). We then presented core energy conservation strategies from Packer and colleagues’ (1995) evidence-based “Managing Fatigue: A Six Week Course in Energy Conservation” program, with an emphasis on those that had specifically been found to be
effective. For example, we used the analogy of “budgeting” energy from the “Managing Fatigue” program extensively to explain much of the content, as this comparison was identified as particularly helpful and beneficial by the “Managing Fatigue” program participants (Mathiowetz & Busch, 2006). We also included the fourteen energy conservation strategies from the “Managing Fatigue”, as they were all reported to be useful and beneficial by people from the MS literature (Matuska et al., 2007). However, for brevity we consolidated and condensed the strategies into seven key energy-saving strategies (eliminate, simplify, tools, organize, assistance, reposition, and slow down). A brief description of each strategy was provided along with one or two illustrative examples, and a mnemonic (E-STOARS) was presented to promote their retention.

The web module design was inspired by the style of whiteboard animation, which is “the process by which an author physically draws and records an illustrated story using a whiteboard- or whiteboard like surface- and marker pens” (Whiteboard Animation Studio, n.d.), frequently aided with narration by script. We achieved a whiteboard animation effect using Microsoft Powerpoint, by animating simple pictures and diagrams against a plain white background and adding a narrative overlay to create a video-like experience. The design of the web modules was also informed by Morrison and colleagues’ (2012) four components of effective e-health interventions: contact with the intervention, tailoring, self-management, and social supports. Contact with the intervention was achieved by engaging users with a number of reflective and practice activities, embedded throughout the modules. We accomplished tailoring and self-management features with a novel, personalized prioritization exercise, termed “the Energy Inventory”, that set the stage for the goal-based CO-OP portion of the intervention. Further information about the Energy Inventory is provided in Appendix C. Although there were no direct social interactions included in the modules, they featured an animated protagonist who was a person on CDT, and was intended to be relatable for the target population. We also created a participant workbook to accompany the modules, which included key program information, activity worksheets, and detailed, step-by-step instructions on how to access the online educational modules.
4.4.3.1.4 The PEP (Personal Energy Planning) Program

The PEP program (Table 4.1) is a two-part energy conservation education program, that is uniquely tailored for the CDT population. Part 1 of the program involves two educational web modules which last approximately 20 minutes each. The modules introduce participants to the basic concepts and principles needed to practice energy conservation, including information about fatigue, energy expenditure, and energy-saving strategies. The modules are designed to be user-friendly, and are available for people to complete independently over the Internet. The PEP module slides and audio transcripts for Module 1 are provided in Appendix D, to demonstrate the approach.

Part 2 of the program uses a modified version of the Cognitive Orientation to Occupational Performance (CO-OP) approach (Missiuna et al., 2001), to facilitate participants’ application of the energy conservation strategies to achieve their own life participation goals. Participants complete a third computer module which briefly explains the fundamentals of CO-OP, and then work directly with a trained clinician over four to six sessions to create and test personal energy plans for three personal life participation goals. Participants are also provided with a supplementary workbook to guide and track their progress in the PEP program.

Table 4.1: Overview of the PEP (Personal Energy Planning) Program

<table>
<thead>
<tr>
<th>PART 1: “LEARNING ABOUT PEP”</th>
<th>PART 2: “CREATING YOUR PEP”</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Web Module 1: Energy priorities</strong></td>
<td><strong>Web Module 2: Cutting energy costs</strong></td>
</tr>
<tr>
<td>-Reviews information on fatigue, energy, dialysis and activity</td>
<td>-Explores how to balance energy budget</td>
</tr>
<tr>
<td>-Introduces concept of energy budgeting</td>
<td>-Explains how to break down energy costs</td>
</tr>
<tr>
<td>-Asks people to consider their energy priorities during Energy Inventory</td>
<td>-Outlines 7 key energy-saving strategies</td>
</tr>
</tbody>
</table>

|
4.4.3.2 4b: Key Informant Feedback & Program Modifications

The four key informants we interviewed after initial program development were two people with CKD, one clinician with experience working with people on CDT, and one health education technology specialist. Their characteristics are described in Table 4.2. The informants’ impressions of the modules were overall positive; all identified several strengths and also a few weaknesses and recommendations for change, which are summarized below, as are the modifications made based on the feedback. A full account of participants’ feedback about the program is provided in Appendix E.

Table 4.2: Key Informant Characteristics

<table>
<thead>
<tr>
<th>Informant 1</th>
<th>Informant 2</th>
<th>Clinician Informant</th>
<th>Health Education Technology Specialist</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Male</td>
<td>• Female</td>
<td>• Female</td>
<td>• Female</td>
</tr>
<tr>
<td>• 52 years old</td>
<td>• 56 years old</td>
<td>• PD nurse coordinator</td>
<td>• Prior experience designing</td>
</tr>
<tr>
<td>• Stage 3 CKD</td>
<td>• On ICHD for 2.5 years</td>
<td>• Large, academic dialysis center</td>
<td>technology-based health education</td>
</tr>
<tr>
<td>• Employed full-time</td>
<td>• Retired</td>
<td>• &gt;10 years experience</td>
<td>programs</td>
</tr>
<tr>
<td>• High comfort with computers</td>
<td>• Living in supported care residence</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Moderate comfort with computers</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

4.4.3.2.1 Program strengths

All four informants considered the modules to accomplish many of their intended objectives. The informants all described the program’s core approach of budgeting energy as a way of managing fatigue to be novel, relevant, and relatable. The informants with CKD expressed that the modules raised their awareness about their own energy spending, and the need to prioritize and consider their everyday activities in more detail. The informants all saw the energy-saving strategies outlined in the modules as being valuable. They identified the personalized approach used in the program to be another strength, and both informants with CKD could identify personal energy goals they would work on in Part 2 of the program. The informants expressed that the program design was engaging and effective. All informants felt that the length and pace of the modules was suitable, as was their visual design. All informants also described the examples and activities
incorporated into the modules, as being relevant and relatable. Overall, the informants judged the PEP program to be important, and saw it as filling a gap in care provided to this population. The informants with CKD indicated that they would recommend the program to other people with CKD on dialysis.

4.4.3.2.2 Weaknesses and recommendations

The key informants identified several minor critiques and recommendations about the program content during the interviews. The two informants with CKD and the health education specialist felt it would be helpful to clarify ways to increase one’s energy beyond pacing with rest breaks. The informant with Stage 3 CKD also expressed he was not yet at the stage where he was ready to cut down on his energy expenditure if it meant changing activities he valued, and wished the

| Table 4.3: Program Modifications Implemented based on Key Informant Interviews |
|---|---|
| 1. Explain other ways to build energy besides resting |
| 2. Emphasize shrinking of the energy tank in relevant slides |
| 3. Improve explanation of why to use Goal-Plan-Do-Check |
| 4. The explanation of what happens in module 3 is misleading, makes person think they will make PEPs in that module |
| 5. Grocery shopping example should also include considering where items are in the store and grouping them |
| 6. Clarify how the approach would practically be used, i.e., that making an actual list will only help to learn how to do it implicitly |
| 7. Time of day also affects energy, independently of occupation |
| 8. Clarify how mental energy costs work, especially during physical rest |
| 9. The beginning section of Module 1 was a bit too negative |
| 10. De-emphasize strategies that require money, which may not be feasible for some |
| 11. Clarify what a health-related activity is in Inventory |
| 12. Clarify what click to continue button means for the activities |
| 13. Energy cuts on the slide for Module 3 were not visible enough |
| 14. Change wording of “when you’re ON dialysis” to when you’re LIVING with dialysis in introduction |
| 15. Too much jargon in flow chart, remove “computer module” and replace with picture |
| 16. Use white lettering to label full energy tank to improve contrast |
| 17. The green colour might not be good for colour blindness or contrast |
| 18. Delay the appearance of “click to continue” |
| 19. Fix typo in simplify example slide |
| 20. Differentiate visual appearance of buttons from callouts, eg. fill them in |
| 21. Make visual speech bubbles consistent with narration |
| 22. Visually differentiate example character (Jim) from other character in Module 3 |
| 23. Simplify slide is too busy |
| 24. Click to continue not pausing in Module 1 activity |
| 25. Audio issues, eg. narration cutting out |
program spent more time addressing the mental recalibration required to accept his growing personal limitations. Two of the key informants felt that there was conflicting information about whether low-energy activities and/or mental activities drain versus refresh energy, while two informants suggested providing information on how to communicate with family about needing greater assistance from them. The informants also expressed that they found some of the module content was overexplained at times; however, there was general ambivalence about this issue, because they also appreciated its clarify and simplicity. Finally, the nurse informant wondered whether people would be able to complete the computer modules independently due to their burden of health-related impairments, and also wondered about the clinical feasibility of Part 2 of the program, which requires a healthcare provider to work 1:1 with the participant for four to six half-hour sessions.

4.4.3.2.3 Program modifications

Based on the key informant feedback, a total of 60 possible program modifications were identified, and 25 were implemented (Table 4.3).

4.4.3.3 4c. Usability testing

We recruited five people on CDT to participate in usability testing of the program modules (Table 4.4). One participant was subsequently found to be unable to use the computer provided for the testing due to physical limitations, and therefore did not complete the performance-based assessment or the System Usability Scale.

<table>
<thead>
<tr>
<th>Table 4.4: Participant characteristics from PEP usability testing</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>P1</strong></td>
</tr>
<tr>
<td>Age group</td>
</tr>
<tr>
<td>Gender</td>
</tr>
<tr>
<td>Modality</td>
</tr>
<tr>
<td>Computer use</td>
</tr>
</tbody>
</table>
Table 4.5 outlines a listing of the usability issues encountered by the participants. Among these, the most common barriers encountered were related to computer literacy (e.g. uncertainty about how to access the PEP computer modules online, and challenges completing the drag-and-drop sorting task from the Energy Inventory activity). All participants were consistently able to perform tasks such as navigating and completing the reflective exercises in the workbook, and interacting with the onscreen buttons to restart the modules after activity breaks. We carefully considered all usability barriers, and where possible, addressed the identified issues with program design changes (Table 4.5). As can be seen, a few barriers could not be overcome with design modifications.

Table 4.5: PEP program usability barriers and corresponding program modifications

<table>
<thead>
<tr>
<th>Usability Barrier(s)</th>
<th># of participants</th>
<th>Resulting Program Modifications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unable to use computer mouse (motor control deficits)</td>
<td>1</td>
<td><strong>Stipulation:</strong> Ability to manipulate computer (mouse, keyboard) required for independent program use</td>
</tr>
<tr>
<td>Unsure how to locate web browser and enter web address to access modules</td>
<td>2</td>
<td><strong>Change:</strong> Web links to modules provided directly on desktop and/or provided via email</td>
</tr>
<tr>
<td>Difficulty clicking and dragging for EI activity</td>
<td>2</td>
<td><strong>Change:</strong> Additional click-and-drag instructions added to module</td>
</tr>
<tr>
<td>Difficulty reading text for Energy Inventory</td>
<td>1</td>
<td>None (unable to change)</td>
</tr>
<tr>
<td>Did not know how to double-click mouse</td>
<td>1</td>
<td><strong>Stipulation:</strong> Some initial support may be required for people unfamiliar with basic computer operations</td>
</tr>
</tbody>
</table>

The median score on the SUS was 93.75 (range 82.5 - 95) (Figure 4.3). Two participants “strongly agreed” that they would recommend the PEP program to other people on dialysis in response to an additional follow-up question, while the other two participants “agreed”.
4.5 Discussion

The Personal Energy Planning program is a novel, personalized, web-supported energy conservation education program for adults on chronic dialysis therapy with fatigue. The development of the program was guided by a health education planning framework (World Health Organization, 2014), and driven by the findings of a population-specific needs assessment. The needs assessment suggested an ECE program was needed for people on CDT that would improve their life participation; be feasible in the dialysis clinical context; and build on theory and evidence from the existing ECE and health education literature. The resulting program combines an established personalized, goal-focused intervention (CO-OP) (Missiuna et al., 2001), with a series of educational modules about energy conservation that are informed by evidence-based ECE and health education principles, and are accessible to people via the internet. Preliminary feedback from key patient, clinician and health education informants was positive with respect to program content and design, while usability testing suggested the program modules were usable by people on CDT with a variety of levels of computer literacy. We addressed several recommended or observed issues, identified during the key informant interviews and usability testing, with design revisions.
The preliminary findings from the key informant interviews and usability testing are promising, regarding the potential of the PEP program to fill an important gap in the care provided to people with ESRD. At present, there are a dearth of evidence-based approaches to help people with ESRD with day-to-day fatigue management, despite it being a prominent concern within this population (Ju et al., 2018; Manns et al., 2014). Erythropoietin (EPO) and exercise training are currently the two primary approaches to managing fatigue for people on CDT, but each have limitations; EPO only addresses one contributing factor of fatigue in people on CDT, while exercise training requires substantial participant and clinician time and energy. The PEP program is a novel approach to fatigue management for people on CDT, which may offer advantages over these approaches: it theoretically can be used irrespective of the person’s underlying fatigue aetiology, and has been designed to minimize the demands on people’s time and energy. The ECE approach has also been found to be effective in other chronic disease populations, such as multiple sclerosis (Finlayson et al., 2011; Mathiowetz et al., 2005), which further supports its potential in the CDT population. The positive program feedback provided by key informants suggests that efficacy testing, to assess the PEP program’s impact on fatigue-related outcomes in people on CDT, is now warranted.

The PEP program incorporated both novel and well-established ECE components into its design, and the key informant interviews highlighted a number of possible program strengths. In general, informants expressed that the energy conservation approach was a novel and seemingly helpful way to manage fatigue, which supports the justification for further exploring ECE in the CDT population. The informants all expressed that the modules were engaging and interesting, which may relate to the inclusion of specific design features (eg. tailoring, self-management) that have been associated with more effective e-health programs (Morrison, 2012). Both informants with CKD said that they appreciated the program’s acknowledgement of their physical fatigue, feedback that could reflect the lack of attention often paid to symptoms in CDT clinical practice (Weisbord et al., 2007), or, an assumption that fatigue in people on CDT is primarily related to psychological disorders. The informants with CKD also provided positive feedback about the program’s personalized approach, which supports the rationale behind incorporating the personalized, goal-based, problem-solving CO-OP approach into the program. The CO-OP approach aligns with other frameworks (eg. problem-solving training) that have been used in other recent energy conservation programs, for which preliminary findings have been positive.
with respect to people’s life participation outcomes (Kim et al., 2017; Raina et al., 2016). Life participation has recently been identified by people on CDT as being their highest-priority fatigue-related outcome (Ju et al., 2018). As such, exploring the efficacy of the PEP program for improving the life participation of people on CDT will be a top priority for the next phase of program research.

The positive usability data collected on the PEP program web modules also support its potential to be a convenient tool for both people on CDT and clinicians, as people can complete portions of the program without clinician assistance, and at times and locations of their choosing. This data builds on other literature, which has shown e-health technology may be a feasible and advantageous way to administer care to people with CKD (Weisbord et al., 2007). For example, Ong and colleagues (2016) recently reported strong feasibility data for the use of a tailored, health management smartphone application among people with pre-dialysis CKD, even among people with no prior experience using a smartphone. We used a user-centered approach to designing the modules, proactively identifying and addressing potential usability barriers (e.g., visual and cognitive impairments) that could arise in the CDT population with design solutions such as large text, use of colour contrast, and simple explanations of key concepts. Our results suggest that common impairments in the CDT population, which may be viewed as preclusive for the use of technology-based tools, can be overcome with sound design. Additional adaptations may be required for people with certain impairments, however, such as motor-based impairments that prevent physical manipulation of the technology.

Despite the positive preliminary findings about the PEP program, our key informants highlighted a number of potential program limitations that should be monitored in future studies. Although we designed the PEP program to minimize the time required for administration, our clinician informant suggested there may still be a lack of clinical resources on dialysis units to implement the program successfully. Patient-reported outcomes have become an increasing priority in nephrology; however, there are still often limited clinical resources allocated to staff, such as rehabilitation therapists, who may be able to improve quality of life outcomes such as life participation (Farragher, 2017). If the PEP program is found to be efficacious in future robust studies, a reconsideration of clinical resource allocation, combined with targeted knowledge translation strategies, would likely be required to achieve successful clinical implementation of the program. Another observation was that, despite the benefits of a program that was simple and
easy-to-use, the key informants wondered if the modules moved too slowly to optimally engage and interest participants. This feedback could be related to the highly-selected sample of dialysis stakeholders we involved for the key informant interviews. These people were purposively chosen to provide insights, reflections and feedback about the program; however, they also may not have had the level of cognitive impairment typically seen within the CKD and dialysis populations. Alternatively, this feedback may reflect that people on CDT are already familiar with some of the program content and energy conservation strategies discussed. People with MS, who completed a different ECE program, were similarly found to familiar with some of the energy conservation strategies covered in the program prior to completing it (Matuska et al., 2007). However, they nevertheless reported it to be beneficial, stating that they used a wider variety of strategies, and used them more often, after participating in the program. It is possible that people on CDT who complete the entire PEP program in the next phase of research may realize the value of the EC strategy ideas provided in Part 1, as they work to identify and develop new, personalized EC strategies for themselves in Part 2 of the program. Future studies on the PEP program should nevertheless monitor patient engagement with the modules, to assess the need to revise the program content and/or delivery.

In conclusion, the PEP program is a novel interactive, web-supported, energy conservation education program that has been designed to be feasible in the dialysis clinical context, and effective at improving life participation outcomes. Future research should address program development stages 5 and 6, by assessing the efficacy of the program at improving the target outcomes of life participation and fatigue in the CDT population.
Chapter 5:
Exploring the Efficacy of the PEP Program for Improving Life Participation and Reducing Fatigue in Adults on Chronic Dialysis Therapy

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Target Journal for Submission: Nephrology Dialysis Transplantation
Chapter 5: Exploring the Efficacy of the PEP Program for Reducing Fatigue and Improving Life Participation in Adults on Chronic Dialysis Therapy

5.1 Abstract

Background: Fatigue is a common and difficult-to-treat symptom of renal disease, that interferes with people’s abilities to participate in meaningful daily activities (ie., life participation). The PEP program is a personalized, web-supported energy conservation education (ECE) program recently developed to reduce fatigue and improve life participation in adults on chronic dialysis therapy (CDT), but its efficacy has yet to be explored. Primary Objective: To explore if the PEP program is associated with improvements in life participation and fatigue-related outcomes in adults on CDT with fatigue. Methods: We used a mixed-methods, sequential explanatory study design, including a single-case, time-series experiment with four replications, and follow-up qualitative interviews. We recruited study participants who were on CDT, and who were purposively selected to represent typical dialysis user characteristics. We administered measures of life participation (created for this study) and fatigue (Fatigue Severity Scale) repeatedly at weekly intervals, before and after study participants began the PEP program. These time series measures were cross-validated with other validated measures of life participation (COPM) and fatigue (Modified Fatigue Impact Scale, SF-36 vitality scale), as well as post-intervention interviews examining people’s experiences and perceptions of the program. We analyzed the data using visual analysis and the Tau-U for the time series data, examined pre-to-post changes for the quasi-experimental data, and used thematic analysis for the qualitative interviews. Results and Conclusions: We recruited five people on CDT (3 IHD, 1 PD, 1 HHD) to participate in the study. Three participants demonstrated a positive response to the program across multiple measures of fatigue and life participation, with effect sizes ranging from small to moderate. The remaining two participants demonstrated an inconsistent response, or no response, to the program. All participants expressed that the program had benefitted them in the qualitative follow-up interview, with the most commonly identified benefit being that it made their lives or day-to-day activities easier. The format of the program was also said to be feasible and convenient by the participants. These findings suggest the PEP program has potential to improve
important fatigue-related outcomes on CDT. Further clinical trials to examine program efficacy are therefore warranted.

5.2 Introduction

Reported by an estimated 70% of people on chronic dialysis therapy (CDT) (Murtagh et al., 2007), fatigue is one of the most common and concerning symptoms experienced by the CDT population (Ju et al., 2018; Manns et al., 2014; Weisbord et al., 2007). Defined as an “unusual, abnormal or excessive whole-body tiredness, disproportionate to or unrelated to activity or exertion” (Piper, 1993, p. 285), fatigue affects all aspects of life participation for people on CDT. Due to its complex, multifactorial nature, evidence-based targeted treatment approaches for fatigue are limited (Artom et al., 2014). Recently, Farragher and colleagues (Chapter 4) proposed the adoption of an energy conservation education approach to address this problem. Energy conservation education (ECE) has been reported to be efficacious in a number of clinical populations who experience fatigue, including multiple sclerosis (Finlayson et al., 2011; Mathiowetz et al., 2005), rheumatoid arthritis (Furst et al., 1987), and cardiac disease (Kim et al., 2017; Norberg et al., 2017). This approach teaches individuals to use strategies, such as simplifying activities, using energy-efficient postures, and prioritizing, that will reduce energy expenditure during everyday activities and thereby minimize fatigue. We reasoned that energy conservation may be a particularly good fit for individuals on CDT, given that they are prone to exertional fatigue (Johansen, 1999; Macdonald et al., 2012) and have extensive treatment-related activities they must routinely spend energy on, such as attending dialysis sessions, managing medications, and monitoring weight and blood pressure. However, after an examination of existing ECE approaches (Chapter 3), we concluded that a new approach to ECE, specifically designed to meet the unique needs of the CDT population, was necessary (Chapter 4).

We therefore developed a new web-supported, personalized ECE program (the PEP Program) for people on CDT, with input from key stakeholders, that is designed to be feasible and to improve fatigue and life participation outcomes. The program draws on established energy conservation strategies from other evidence-based energy conservation programs, and incorporates a personalized, goal-based-problem solving component to enable personalized solutions to solve the individual’s specific life participation challenges. The program is brief, remotely accessible, and partially self-administered, to maximize delivery convenience and minimize clinician load.
Preliminary assessments of the program’s web-supported modules by four key informants (two people with CKD, one dialysis nurse and one health education designer) were positive, as were the findings from usability testing with people on CDT (Chapter 4) Accordingly, in this study we set out to evaluate the potential of the PEP to affect change in fatigue and life participation among individuals on CDT.

5.3 Research Questions

1. Is participating in the PEP program associated with changes in life participation and fatigue-related outcomes (including fatigue, fatigue impact, and fatigue management self-efficacy) in people on CDT?

2. Is participating in the PEP program associated with increased fatigue-related knowledge and/or energy budgeting strategy use in people on CDT?

3. What are people on CDT’s perceptions and experiences of the PEP program and its impact on their lives, and what program modifications do they recommend?

5.4 Methods

5.4.1 Design

We used a mixed-methods, sequential explanatory study design (Ivankova and colleagues, 2006). This design includes a quantitative study phase, followed by a qualitative phase to help explain and elaborate on the quantitative findings. The quantitative design we used was a single-case study design, supported by a quasi-experimental, pre-post design, to allow for cross-validation of study results across multiple measures. The single-case methodology we employed was a triphasic, time-series design, with four replications. The three study phases constituted a three- or four-week baseline observation period (Phase A); Part 1 of the PEP program (Phase B1); and Part 2 of the PEP program (Phase B2). The first author conducted observational assessments weekly (±3 days) with each participant throughout the three phases. For the quasi-experimental, pre-post design, the first author administered standardized assessments at the start of the baseline period, and after the last intervention session. The qualitative component of the study comprised a semi-structured interview, conducted by the first author after all other assessments had been completed.
5.4.2 Participants

We recruited participants from a large, academic, hospital-based dialysis center in Toronto, Canada. The clinical care teams identified individuals on CDT who had chronic fatigue, and who were likely to be willing to participate in the study procedures. Study posters were also used to recruit participants. We applied purposive sampling during the study recruitment, to maximize the representation of the target population on key variables of age, gender, and dialysis modality. Prospective participants were approached about the study by the first author to assess their interest in the study. Interested individuals underwent further assessment of their study eligibility for the following criteria:

5.4.2.1 Inclusion criteria

1. Aged ≥18 years
2. On chronic dialysis therapy for ≥3 months at time of recruitment
3. Self-identifies as having problems with fatigue
4. Otherwise able and willing to provide informed consent

5.4.2.2 Exclusion criteria

1. Significant visual impairment (unable to read the text in the intervention video and workbook)
2. Scores >3 on PHQ-2 depression screening tool*
3. Plans to change RRT modality within 3 months of recruitment
4. Inadequate written and verbal English comprehension (Grade six or higher)

The first author underwent a comprehensive informed consent process with eligible individuals. Baseline demographic, clinical, and laboratory information about the participants were then collected through participant interview, and/or reference to the clinical chart. The study was approved by the Research Ethics Board.

5.4.3 Intervention: The “PEP” (Personal Energy Planning) Program

The PEP program has previously been described in detail (Chapter 4). In brief, the “PEP” (Personal Energy Planning) program is designed to provide clients on dialysis with personalized training in energy conservation strategy use. The program consists of two parts, and is delivered over six to eight weekly sessions lasting 20-40 minutes each. Part 1 of the program involves two
online educational modules, that introduce participants to the fundamental concepts and strategies needed to practice energy conservation. Part 2 includes four to six individualized sessions with a therapist or clinician, to help participants develop their own personalized energy conservation plans that address their life participation goals. Participants can complete the program from their preferred location: at the hospital during dialysis, from home, or from another remote-based location.

For this study, the first author assisted participants who opted to complete the PEP program during hemodialysis, to watch the Part 1 computer modules in the dialysis unit on a provided laptop. These participants also completed the individualized sessions of Part 2 in-person, with the first author, during their dialysis sessions. Participants who chose to complete the program remotely (ie. from home) were first oriented to the program and its workbook during a single in-person session with the first author. They then completed the modules independently from home, using the workbook instructions as a guide. They completed the individualized sessions of Part 2 via phone with the first author.

5.4.4 Measurement

The measures used for the study are provided in Appendix F.

5.4.4.1 Life participation

For the single-case study component, we assessed life participation weekly throughout the study using three questions created for the study. We created the three questions to address a gap in available assessments that were brief, and that captured the impact of fatigue on people’s participation in personally relevant activities. The three questions asked participants to rate, on a scale of 1-10, how well they managed their fatigue during the past week; how often they had the energy to do the things they needed to do during the past week; and how often they had the energy to do the things they wanted to do during the past week. A score of one indicated poor fatigue management or insufficient energy, while a score of 10 indicated optimal fatigue management or always having sufficient energy. We averaged scores from the three items, to create a summary score out of 10. To cross-validate the findings from these novel measures, we also assessed participant-perceived performance of three specific life participation goals before and after Part 2 of the program, using the Canadian Occupational Performance Measure (COPM) (Law et al., 1990). The COPM asks individuals to rate, on a 10-point Likert scale, their current
perceived performance on a self-chosen goal and their satisfaction with that performance. A score of 1 indicates poor performance or satisfaction, while 10 indicates optimal performance or satisfaction. The COPM has been found to be a valid, reliable, clinically useful and responsive outcome measure in multiple disease populations (Carswell, 2004).

5.4.4.2 Life participation satisfaction

For the single-case study component, we assessed life participation satisfaction using one question created for this study, which was patterned after the COPM’s (Law et al., 1990) assessment of satisfaction on specific life participation goals. The question asked participants to rate, on a scale of one to 10, how satisfied they were with their fatigue management. A score of one indicated low satisfaction, while a score of 10 indicated optimal satisfaction. For the quasi-experimental component, we assessed participants’ satisfaction with their performance on three specific occupational goals before and after Part 2 of the intervention, using the satisfaction rating of the COPM (Law et al., 1990). Having rated performance on a self-chosen goal (see above), the participants were asked to rate, on a 10-point Likert scale, their current perceived satisfaction with their performance.

5.4.4.3 Fatigue

For the single-case study component, we assessed fatigue weekly using the fatigue severity scale (FSS) (Krupp, LaRocca, Muir-Nash, & Steinberg, 1989). The FSS is a nine-item scale that asks individuals to rate, on a Likert scale from one to seven, the severity of their fatigue and its impact on their life during the past week. Individual item scores are averaged to create a summary score out of 7. The FSS is a valid, reliable and responsive measure (Flachenecker et al., 2002; Learmonth et al., 2013) that has previously been used in the CDT population (Farragher et al., 2017). For the quasi-experimental component, we cross-validated the FSS with two additional fatigue measures, the SF-36 Vitality Scale (Ware & Sherbourne, 1992) and the Modified Fatigue Impact Scale (Ritvo et al., 1997), administered before and after each phase of the study. The SF-36 Vitality scale includes four questions that ask individuals to rate, on a six-point scale, their energy levels during the past four weeks. The SF-36 vitality scale is a well-validated measure (McHorney, Ware, & Raczek, 1993; Ware, 2000), that is commonly used to assess fatigue in the renal population. The MFIS is a 21-item scale that asks individuals to rate, on a Likert scale from zero to five, the impact of fatigue on various facets of their functioning during the past four
weeks. The Fatigue Impact Scale has frequently been used as an outcome measure, in energy conservation education studies involving other chronic disease populations (Farragher et al., unpublished).

5.4.4.4 Fatigue management self-efficacy

For the single-case component, we assessed self-efficacy for managing fatigue using one question created for this study, patterned after Bandura’s (2006) method for measuring self-efficacy for a particular skill or task. The item asked the participant to rate his/her present confidence in his/her ability to manage fatigue, on a scale of one to 10. A score of one indicated no confidence in one’s ability to manage fatigue, while 10 indicated full confidence.

5.4.4.5 Energy budgeting strategy use

We assessed energy budgeting strategy use using an 11-item questionnaire created for this study. The questionnaire asked participants to rate, on a five-point scale, how often they used each of 11 energy budgeting strategies within the past week. A score of one indicated that the strategy was never used, while a score of five indicated that the strategy was used regularly. We averaged the scores for each item to create a total summary score of energy budgeting strategy use.

5.4.4.6 Energy conservation knowledge

We assessed energy conservation knowledge using two knowledge assessments created for the study, which participants were asked to complete before and after Part 1 of the PEP program. The assessments constituted 10 multiple choice questions, that measured participants learning of the key concepts from each of the two computer modules of Part 1 of the PEP program.

5.4.4.7 Post-intervention interview

The first author conducted a semi-structured interview, lasting 20-30 minutes, with each participant one to two weeks after their final intervention session after all other measures had been administered. The interview was conducted in the hemodialysis unit for P1 and P2, and over the phone for P3, P4, and P5. Participants were asked about their subjective perceptions of the PEP program and its impact on their lives, inconsistencies from the quantitative data, and recommended program changes (see Appendix G for interview guide).
5.4.5 Data analysis

We analyzed the single-case, time-series data using a combination of visual analysis, and the Tau-U statistic. Visual analysis is considered the cornerstone of studies that employ a single case, time-series design. The guidelines provided by Lane and Gast (2014) informed the visual analysis approach:

1. **Graphing:** Data for each variable were graphed on an interrupted time-series scatterplot, and labelled according to study phase (A, B1, or B2)

2. **Within-phase analysis:** Data within each of the three study phases were analyzed to determine the following:
   a. Level, which is the mean value of the data points within a phase
   b. Trend direction, which is the direction (rapidly deteriorating, deteriorating, no-change, improving, or rapidly improving) of the data points across the phase

3. **Between-phase analysis:** Data from the baseline and intervention phases were compared, to identify changes in trend direction and/or level that occurred between phases.

We supported the visual analysis with statistical analysis, in keeping with recommendations from several single-case study design guidelines (Brossart, Vannest, Davis, & Patience, 2014; Single-case intervention research, 2014). We chose the Tau-U statistic for the statistical analysis because of its relatively high degree of power to detect an effect with a small number of datapoints, and its capability to correct for trends in the baseline phase (Parker, Vannest, Davis, & Sauber, 2011). The Tau-U is also robust against autocorrelation (ie., serial correlation between observations as a function of the time lag between them), thus eliminating the need to test for autocorrelation in these data. We calculated the Tau-U statistic (Parker et al., 2011) to compare the Phase A (baseline) data to the Phase B2 (goal management training) data. A Tau-U value between 0 and .65 indicates a small effect size, while .65-.92 is a moderate effect size, and >.92 is a large effect size. Due to the preliminary, exploratory nature of this study, p-values were not calculated.

We did not perform statistical analyses for the quasi-experimental data, given the small number of data points. Rather, we reported the pre-post data as absolute values, and calculated changes between phases by subtracting the participants’ baseline score from their post-intervention score.
We interpreted the scores according to minimal clinically important differences reported from previous literature, where available.

For the qualitative interview data, the first author audio-recorded and transcribed the qualitative interview data, and then read the transcripts to get a general sense of the content. The first author then coded the transcriptions in cycles, as recommended by Saldana (2018). In the first coding cycle, descriptive codes were created for meaningful units of data that were close to the original data. The second coding cycle involved extrapolating from the first-cycle codes to form broader descriptive categories, and in the third coding cycle, further abstraction was conducted to create key themes.

5.5 Results

Five people on CDT were recruited to participate in the study. Four people on CDT were invited by the clinical staff, based on the presence of longstanding fatigue and a perceived openness to completing the study activities. The remaining participant (P3) volunteered to participate, after having seen a study advertisement poster. Participant characteristics are outlined in Table 5.1. To preserve anonymity, some data (e.g., age) are not reported as absolute values. All five participants completed the 3 computer modules of the program, and then underwent four to seven individualized goal training sessions with the study therapist, which lasted a median of 24 minutes (range, 7-48). The median total time spent working with the therapist per participant was two hours, 11 minutes (range 1 hour, 32 minutes to 3 hours, 25 minutes). Three people (P1, P2 and P3) completed the PEP program at the hospital during their regular hemodialysis sessions, while P4 and P5 completed the program remotely from home.
Table 5.1: Participant characteristics from PEP efficacy study

<table>
<thead>
<tr>
<th></th>
<th>P1</th>
<th>P2</th>
<th>P3</th>
<th>P4</th>
<th>P5</th>
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</thead>
<tbody>
<tr>
<td>Age group</td>
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<td>60-69</td>
<td>20-29</td>
<td>40-49</td>
<td>50-59</td>
</tr>
<tr>
<td>Gender</td>
<td>M</td>
<td>F</td>
<td>M</td>
<td>M</td>
<td>M</td>
</tr>
<tr>
<td>Dialysis duration (yrs)</td>
<td>2</td>
<td>8</td>
<td>1</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
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<td>ICHD</td>
<td>ICHD</td>
<td>Home HD</td>
<td>CAPD</td>
</tr>
<tr>
<td>Independent in basic ADLs</td>
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<td>Y</td>
<td>Y</td>
<td>Y</td>
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<tr>
<td>Lives alone</td>
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<td>N</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Computer use</td>
<td>Never</td>
<td>Never</td>
<td>Daily</td>
<td>Daily</td>
<td>Daily</td>
</tr>
</tbody>
</table>

5.5.1 Quantitative results

Single-case, time series scatterplots for P1 are provided in Figure 5.1, and the time series results for the remaining participants are described in Table 5.2 (See Appendix H for remaining participants’ scatterplots). Pre- and post-intervention data for the COPM are provided in Table 5.3, while Table 5.4 presents pre- and post-intervention data for the FIS, SF-36 Vitality Scale, knowledge questionnaires, and energy budgeting strategy use.

5.5.1.1 Life participation

Three participants (P1, P3 and P4) demonstrated improvements in life participation associated with the intervention. The effect sizes were small for P1 and P3, and moderate for P4, according to the Tau-U analysis of the time-series data (Table 5.2). P1 and P4 also experienced clinically significant performance improvements for all three of their life participation goals on the COPM (Table 5.3), while P3 improved on two out of three goals. Two participants (P2 and P5) demonstrated no improvement in life participation, on either the time-series data or the COPM performance ratings.
Figure 5.1: Interrupted time-series scatterplots for P1

- **Mean life participation score (10)**
  - X-axis: Weekly session (± 3 days)
  - Y-axis: Mean life participation score (10)

- **Satisfaction (10)**
  - X-axis: Weekly session (± 3 days)
  - Y-axis: Satisfaction (10)

- **Fatigue Scale (7)**
  - X-axis: Weekly session (± 3 days)
  - Y-axis: Fatigue Scale (7)

- **Self-efficacy (10)**
  - X-axis: Weekly session (± 3 days)
  - Y-axis: Self-efficacy (10)
5.5.1.2  Life participation satisfaction

Three participants (P1, P3 and P4) displayed improvement in life participation satisfaction associated with the intervention. P3’s effect size was small and P1 and P4’s effect sizes were moderate, according to the Tau-U. These three also demonstrated clinically significant changes in self-rated satisfaction; P1 and P4 for all three of their life participation goals on the COPM, and P3 for two out of three goals. Two participants (P2 and P5) demonstrated no improvement in life participation satisfaction, on either the time-series analysis or the COPM satisfaction rating.

5.5.1.3  Fatigue

Four participants (P1, P2, P3 and P4) demonstrated improvement in fatigue on the FSS associated with the intervention, according to the time-series analysis. P1 and P3’s effect sizes were small, while P2 and P4’s effect sizes were moderate according to the Tau-U. All except P1 also demonstrated clinically significant improvements on the SF-36 vitality scale and the FIS, from pre- to post-intervention (Table 5.4). P5 demonstrated no positive changes in fatigue on any outcomes.

5.5.1.4  Fatigue management self-efficacy

Three participants (P1, P3 and P4) demonstrated improvement in self-efficacy associated with the intervention, according to the time-series analysis. P1 and P3’s effect sizes were small, and P4’s effect size was moderate (n=1), according to the Tau-U. P2 and P5 demonstrated no positive change in self-efficacy.

5.5.1.5  Energy budgeting knowledge & strategy Use:

The median score on both knowledge questionnaires at pre-intervention was eight out of 10; post-intervention improvement was only observed for P3. Three participants (P3, P4, & P5) demonstrated moderate-sized increases in their energy budgeting strategy use, according to the Tau-U, between the baseline phase and the second intervention phase. P1 demonstrated small-sized improvements.
Table 5.2: Visual analysis and Tau-U results for single-case, time-series data

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<td><strong>Life participation</strong></td>
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</tr>
<tr>
<td>P1</td>
<td>Trend</td>
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</tr>
<tr>
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<td>Level</td>
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<tr>
<td>P2</td>
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<td>↓</td>
<td>→</td>
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<td>Level</td>
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<td>4.75</td>
<td></td>
</tr>
<tr>
<td>P3</td>
<td>Trend</td>
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<td>↑</td>
<td>↑</td>
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<tr>
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<td>↑</td>
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<td>P2</td>
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<td>→</td>
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</tr>
<tr>
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<td>Trend</td>
<td>↗</td>
<td>→</td>
<td>↑</td>
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<tr>
<td></td>
<td>Level</td>
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<td>P4</td>
<td>Trend</td>
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<td>↓</td>
<td>↑</td>
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<td>P5</td>
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<td>↓</td>
<td>↑</td>
<td>-.14</td>
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<td></td>
<td>Level</td>
<td>3.67</td>
<td>6.50</td>
<td>3.75</td>
<td></td>
</tr>
</tbody>
</table>

*↓ = rapid deterioration; ↘ = deterioration; → = no-change; ↗ = improvement; ↑ = rapid improvement*
5.5.2 Qualitative findings

5.5.2.1 Program benefits

The participants were unanimous in expressing that the program had helped them to manage their fatigue more effectively. A common sentiment was that the program had, in some way, made life easier. P3 stated that the program made him feel “more energized”, while P2, P3 and P5 shared that the program had enabled them to cope with their daily tasks more easily. For example, P3 stated:

“I’ve been using it daily, to help with my daily activities at home and outside, and at dialysis, too.”

Table 5.3: Changes on Canadian Occupational Performance Measure (COPM) after PEP

<table>
<thead>
<tr>
<th>PT</th>
<th>GOAL</th>
<th>PERFORMANCE (/10)</th>
<th>SATISFACTION (/10)</th>
<th>IMPORTANCE (/10)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Pre</td>
<td>Post</td>
<td>Change</td>
</tr>
<tr>
<td>1</td>
<td>a. Getting dressed</td>
<td>5</td>
<td>8</td>
<td>+3*</td>
</tr>
<tr>
<td></td>
<td>b. Showering</td>
<td>5</td>
<td>8</td>
<td>+3*</td>
</tr>
<tr>
<td></td>
<td>c. Walking dog</td>
<td>1</td>
<td>5</td>
<td>+4*</td>
</tr>
<tr>
<td>2</td>
<td>a. Housekeeping</td>
<td>5</td>
<td>5</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>b. Exercising</td>
<td>4</td>
<td>4</td>
<td>-</td>
</tr>
<tr>
<td>3</td>
<td>a. Health mgmt</td>
<td>1</td>
<td>5</td>
<td>+4*</td>
</tr>
<tr>
<td></td>
<td>b. Reading</td>
<td>7</td>
<td>9</td>
<td>+2*</td>
</tr>
<tr>
<td></td>
<td>c. Meal preparation</td>
<td>6</td>
<td>7</td>
<td>+1</td>
</tr>
<tr>
<td>4</td>
<td>a. Meal preparation</td>
<td>2</td>
<td>8</td>
<td>+6*</td>
</tr>
<tr>
<td></td>
<td>b. Housekeeping</td>
<td>2</td>
<td>6</td>
<td>+4*</td>
</tr>
<tr>
<td></td>
<td>c. Exercising</td>
<td>1</td>
<td>7</td>
<td>+6*</td>
</tr>
<tr>
<td>5</td>
<td>a. Meal preparation</td>
<td>6</td>
<td>7</td>
<td>+1</td>
</tr>
<tr>
<td></td>
<td>b. Leisure shopping</td>
<td>5</td>
<td>6</td>
<td>+1</td>
</tr>
<tr>
<td></td>
<td>c. Laundry</td>
<td>6</td>
<td>6</td>
<td>-</td>
</tr>
</tbody>
</table>

*Denotes clinically significant change (≥ +2 points)

Note: COPM scores are based on client self-ratings

P4 expressed that the program had reminded him of what was possible for his life. He particularly valued that the program had changed his sense of independence:
“Well, it was good for the fact that it allowed me to be a bit more independent...and it gave me hope...that I could actually do things, if I were to manage my other activities, and my other plans....” (P4)

Table 5.4: Changes in energy conservation knowledge, SF-36 vitality scale, Modified Fatigue Impact Scale, and energy budgeting strategy use after the PEP program

<table>
<thead>
<tr>
<th>Knowledge Quiz 1 (/10)</th>
<th>Knowledge Quiz 2 (/10)</th>
<th>SF3-36 Vitality Scale (/100)</th>
<th>Modified Fatigue Impact Scale (/84)</th>
<th>EC Strategy Use (Mean value /5)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Pre</strong></td>
<td><strong>Post</strong></td>
<td><strong>Change</strong></td>
<td><strong>Pre</strong></td>
<td><strong>Post</strong></td>
</tr>
<tr>
<td>P1</td>
<td>9</td>
<td>10</td>
<td>+1</td>
<td>8</td>
</tr>
<tr>
<td>P2</td>
<td>8</td>
<td>8</td>
<td>-</td>
<td>8</td>
</tr>
<tr>
<td>P3</td>
<td>4</td>
<td>9</td>
<td>+5</td>
<td>3</td>
</tr>
<tr>
<td>P4</td>
<td>8</td>
<td>9</td>
<td>+1</td>
<td>8</td>
</tr>
<tr>
<td>P5</td>
<td>9</td>
<td>9</td>
<td>-</td>
<td>9</td>
</tr>
</tbody>
</table>

*Denotes clinically significant change

P1, P2 and P4 expressed that the program had “opened their eyes” and helped them to think more carefully about how they were spending their energy. For example, P1 stated:

“Before we started this, I didn’t realize I had these problems. But you opened my eyes to it all.”

P2 similarly described how the program had helped her to attend more closely to her methods of completing activities:

“It helped me to be more sharp, more alert, thinking, “oh – I should do it this way”. So you always – you go back to it. And you apply what you’ve learned”

The participants all expressed that the program had helped them to generate new ideas and strategies for completing their day-to-day tasks. P4 expressed that he was already familiar with
most of the strategies covered in the program, but that the program had reminded him about the strategies, and motivated him to use them. All participants described instances where they had used the energy budgeting strategies to address the goals they set in therapy in their everyday lives. They also provided examples of when they had applied the strategies to work on goals that were not directly addressed in therapy. For example, P4 described how energy conservation principles such as simplifying and pacing had enabled him to visit the local zoo to take photographs, and P1 shared that he transferred the strategy of being more organized before getting dressed, to also make shopping and other excursions easier:

“If I’m going shopping now or I have to go to a few different places, I just try to organize it so there’s a route, right – not wasting energy”.

In general, all of the participants stated that they would recommend the program to other people on dialysis. P1 felt the program should be completed by everyone on dialysis:

“I kinda think everyone in here should go through this. I think it would help everybody. I’m glad I did it”.

5.5.2.2 Weaknesses and recommendations

The participants identified few weaknesses and had few recommendations about the PEP program. Indeed, when asked, P1 and P2 stated that they had no suggested improvements or recommendations they would make to the program. P3 suggested offering the program in a group-based format, because he would have liked the opportunity to learn from his peers. P4 expressed the importance of being motivated in order to benefit from the program, and wondered whether this could somehow be facilitated in the program for others on CDT. P4 also recommended that the program modules be made available on a tablet, to increase portability and convenience. P5, meanwhile, felt that financial budgeting was not a perfect analogy to use to explain how one should manage their energy, and that discrepancies between the two should be further clarified. He also expressed that the way fatigue was described in the videos did not align with his experience of sometimes gaining energy and momentum by engaging in tasks, and felt this should be further clarified as well.
5.5.2.3 Delivery mode

The mode used to deliver the program was well-received, and said to be convenient by all participants. P1 and P2, who completed the program sessions while on in-hospital hemodialysis, expressed that they preferred doing it on dialysis rather than during their own time, and that it helped to pass the time during dialysis. For example, P2 stated:

“I think it’s perfect to do it here, because, what do you do with the four hours? You know, at least you have this to look forward to! So it’s very good.”

P3, however, expressed that he found the dialysis unit to be noisy and distracting, and that he would have preferred to do the sessions outside of dialysis if it were feasible for him. P4 and P5, who completed the program on their own with weekly phone contact, both endorsed the phone-based format. P4 expressed that the phone-based delivery was convenient because it meant he didn’t have to come to the hospital for sessions. P5, however, shared that he would have been willing to coming to the hospital for the program sessions if necessary. P2 and P5 also shared that they liked how the weekly intervals between program sessions gave them time to think about and reflect on strategies throughout the week.

5.5.2.4 Web modules

All participants felt that the web modules were an important part of the program, and all expressed that the computer-based delivery was acceptable and easy to use. P1, P3, P4 and P5 all shared that they found the modules were simple and understandable. P3 and P4 shared that they found the combined audio-visual delivery of the information to be effective. P1 and P5 further stated that they found the pace of the modules good; P5 expressed that he liked that they gave him enough time to absorb the information. P3 expressed that he had “learned a lot” from the modules; however, P4 expressed that the modules moved too slowly for him at times. Participants’ viewpoints were conflicting about whether they used the information from the modules when engaging in the personalized goal-based problem solving part of the program.

5.5.2.5 Personalized goal-based problem solving

The participants all expressed that they valued the personalized goal-based problem solving part of the intervention. For example, P4 and P5 expressed that they liked the program’s focus on their personal goals, while P2 expressed that she preferred the “personalized” section of the
program to the computer modules, because it was easier to use the personalized information. P3, however, found it challenging to try to imagine himself doing tasks for the purpose of exploring his performance breakdowns, because every time he performed the task was different. He felt it would have been easier to problem-solve while he was actually doing the task in question. P1 and P4 expressed that the guidance provided by the therapist during the PG-BPS was helpful for generating new strategies. The participants’ experiences with the Goal-Plan-Do-Check (GPDC) problem-solving strategy were disparate. P5 expressed strongly that he believed the GPDC process was a good way to approach problem-solving, and P3 shared that he was still using GPDC in his day-to-day life. However, P1 and P4 did not recall using the GPDC strategy at all.

5.5.2.6 Inconsistencies between qualitative and quantitative Findings

The positive qualitative reports on the PEP program from P2 and P5 were found to be inconsistent with their negative quantitative outcomes. As such, P2 and P5 were asked to provide further insight into their experiences with the program. Upon further probing, P2 seemed conflicted about her experience with the program. She repeatedly emphasized that the program had benefitted her. However, she also shared that she felt she was “in a rut”, and that it was not necessarily the responsibility of the program to change that. She talked about the need to be motivated to change, and that because she lived alone, her current activity patterns were adequate for her. She also stated that what she really needed to solve her fatigue was “a new kidney”. Generally, she expressed during the interview that the program may not benefit everybody. However, she also repeatedly emphasized that she felt the program had benefitted her personally. P5, meanwhile, confirmed that he did feel had benefitted from the program, and stated that it had helped him to be able to “do more things.”

5.6 Discussion

This is the first study to explore the efficacy of an energy conservation education program, the “PEP” program, for changing fatigue and life participation outcomes in adults on CDT. Quantitative findings on the effects of the program were mixed: three participants demonstrated a consistently positive response to the program, across multiple measures of fatigue and life participation, while two demonstrated an inconsistent or no response. However, qualitative findings indicated that all of the participants identified benefits of participating in the program, with the most common reported benefit being that it had made their lives and/or their daily
activities easier. The format of the program was also largely said to be feasible and convenient by the participants. These findings provide preliminary, proof-of-principle evidence that the PEP program has the potential to fill the current gap in interventions targeting fatigue, and its impact on life participation, in people on CDT.

At present, there is a widely-recognized dearth of clinical interventions that can be used to address fatigue in people on CDT (Artom et al., 2014). Despite the longstanding use of ECE to target fatigue in other chronic disease populations, and evidence of positive effects (Farragher, unpublished), ECE had never been studied as a fatigue management intervention for the CDT population prior to this study. The improvements seen in fatigue and self-efficacy associated with the PEP program, are consistent with other results on ECE in different chronic disease populations, such as MS (Finlayson et al., 2011; Holberg & Finlayson, 2007; Mathiowetz et al., 2005; Matuska et al., 2007; Vanage et al., 2003). However, the positive changes observed in life participation are relatively novel for ECE research (Farragher, unpublished). The approach to personalized goal-based problem solving (CO-OP) used in the PEP program, was included to strengthen the effect of ECE on this outcome, given CO-OP’s strong evidence for improving life participation in other disease populations (Dawson et al., 2009; Ng et al., 2013; Polatajko et al., 2012; Smits-Engelsman et al., 2013). However, CO-OP had yet to be studied in the CDT population prior to this study, and yet to ever be applied to address fatigue with energy conservation strategies. The positive changes in life participation observed in three participants are consistent with other recent preliminary studies (Kim et al., 2017; Raina et al., 2016), which have similarly employed a goal-based approach to ECE. Collectively, these studies suggest that a personalized, goal-focused approach to ECE might be optimal for improving life participation outcomes in people with fatigue, although further, more rigorous investigations are needed to confirm these preliminary findings.

Although positive life participation outcomes were achieved in three participants in this study, their effect sizes were small to moderate according to the time-series analyses. The CO-OP approach has previously been associated with larger effects on life participation outcomes (Dawson et al., 2009; Polatajko et al., 2012). In this study we used a modified version of CO-OP, which was created to be more feasible for individuals on CDT, and better suited to address fatigue-related problems. CO-OP is normally studied as a protocolized intervention, and several intervention components are believed to mediate its effects. These include the use of dynamic
performance analysis to identify individual’s specific performance breakdowns of their goal activity, and an iterative process of generating, trying, and revising plans to address the breakdowns (Missiuna et al., 2001). The modifications we made to CO-OP included reducing the number of sessions provided; using a revised approach to dynamic performance analysis that relied on visualizing, rather than actually performing, the target goal; and trying, or “doing”, plans outside of therapeutic sessions, instead of during therapy. Reports from the qualitative interviews suggested that these changes may have attenuated CO-OP’s effectiveness; for example, one participant expressed that the process of analyzing his performance using visualization was difficult and frustrating at times, and two participants did not retain the metacognitive goal-plan-do-check strategy that is believed to be key for promoting generalization and transfer of strategy use after CO-OP (Houldin et al., 2018). Further consideration of how the core elements of CO-OP could be reinforced within the PEP program may therefore be required. However, the measures used to assess life participation for the time-series studies were also specifically created for this study, and thus lacked thorough psychometric testing to support their validity and reliability. There is currently an international effort underway to create a validated measure of the impact of fatigue on life participation in the CDT population (Ju et al., 2018), which may prove to be a valuable outcome tool to assess life participation outcomes in future studies of the PEP program.

Despite the positive changes in life participation, fatigue and self-efficacy seen for three of the study participants, two participants did not show consistent signs of improvement in the study outcomes associated with the program. It is unclear why these participants may not have responded to the program. In the follow-up qualitative interviews, one of the participants emphasized that the program had impacted him positively. The other participant, however, seemed ambivalent about the program. The main program benefit she reported was an increased awareness of the activities she could be doing. Yet, she still did not feel the need to change her routines, and spoke of being in a “rut” that the program was not designed to address. The Transtheoretical model (TTM) of readiness for behaviour change (Prochaska et al., 1993) may help to explain her response. According to the TTM, people who are at a pre-contemplative stage of behaviour change are often unaware that their behavior is problematic or produces negative consequences, and do not intend to take action in the foreseeable future (Prochaska et al., 1993). Another participant similarly spoke of the need to be motivated to reap the benefits of the
program, during his follow-up qualitative interview. A different approach, grounded in the TTM, might therefore be needed to encourage readiness for behaviour change in such people on CDT who are at not yet ready for to change their fatigue management behaviours (eg. an increased consideration of the pros and cons of their current methods for managing fatigue.)

The results of this study suggest there is potential for the PEP program to positively affect people on CDT who experience fatigue. However, although the median program administration time of just over two hours was far less than other energy conservation programs described in the literature, it may still be more than what clinicians already working in CDT care are able to commit to a program of this nature. There are also often a dearth of rehabilitation specialists working in CDT clinical settings who would be qualified to administer this program, which is ideally designed to be administered by an occupational therapist. Given that other CDT clinicians (eg. nurses) have previously expressed a lack of comfort with providing rehabilitation-focused interventions to people (Painter, Carlson, Carey, Myll, & Paul, 2004; Painter et al., 2014), further consideration of the need for more rehabilitation professionals on CDT multidisciplinary teams may be needed, particularly if such individuals could help people with CKD with the high-priority task of fatigue management.

This study had a number of strengths. Among them were the use of a single-case, time-series design, which is a cost-effective way to generate preliminary data about an intervention (Kratochwill & Levin, 2015). The use of multiple assessments of the dependent variable throughout the study phases, also served to decrease the risk of spurious findings arising from measurement error at a single timepoint. We also used methods to triangulate the exploratory study findings, such as including multiple measures of the primary study outcomes, and interviewing participants after the study to further confirm and clarify the quantitative study findings. Study limitations included those inherent to an early exploratory study. The first author both conducted the study assessments and administered the intervention, which means it is possible that a social desirability effect may have biased participants to report greater benefit associated with the program than they experienced. All participants were recruited from a common dialysis center in Toronto, Canada, which may mean the study findings are not generalizable to the broader CDT population. There was also no long-term follow up conducted as part of this study, which means is it unknown whether people maintained the improvements they made during the study.
In conclusion, this study provides preliminary evidence that the PEP program may be associated with positive fatigue-related outcomes, including life participation, in adults on CDT. Further, more rigorous efficacy testing of the PEP program is thus warranted.
Chapter 6:
Summary of Findings, Discussion, and
Methodological Strengths and Limitations
Chapter 6: Summary of Findings, Discussion, and Methodological Strengths and Limitations

6.1 Introduction

This thesis sought to explore the potential for energy conservation education (ECE) to improve fatigue and life participation outcomes in the chronic dialysis therapy (CDT) population. A multi-staged project was undertaken to address the three objectives: 1. To explore what was known about energy conservation education in adults with chronic diseases; 2. To develop an ECE program for people on CDT that would be feasible, improve their life participation, and use sound education and design principles, and 3. To conduct preliminary efficacy testing to explore if the ECE program was associated with improvements in fatigue and life participation in people on CDT. In the following chapter, a summary of the findings as they relate to each objective is presented. The main strengths and limitations of the research are outlined, and the findings and their implications are discussed. Directions for future research are also discussed throughout the chapter.

6.2 Summary of Findings

The first study of this thesis (Chapter 3) was an investigation into what was known about energy conservation education, in chronic disease populations who experience fatigue. The specific objectives were to describe the chronic disease populations in which ECE had been studied; the characteristics of the ECE programs in the literature; and the findings that had been reported regarding the impact of ECE on fatigue and life participation. Through the scoping study, literature on ECE was identified for seven different chronic disease populations: MS, cancer, CFS, cardiac disease, acquired brain injury, RA, and post-polio syndrome. Numerous qualitative and quantitative studies reported positive findings on a 10-12 hour, face-to-face, group-based ECE program entitled “Managing Fatigue: A Six-Week Course in Energy Conservation” (Packer et al., 1995) in the MS population. There were, however, a lack of studies to demonstrate the “Managing Fatigue” program’s effect on life participation outcomes, and adaptations of the program, including a web-supported version and an individualized version, also reported less consistent positive findings. In the six other chronic disease populations, the reported findings on ECE were mixed, and largely preliminary. A heterogeneous set of 19 different ECE programs were identified throughout the literature. The most common program design was face-to-face
delivery with more than five hours of total education time, and half of the programs were group-based. There was also no ECE research in some clinical populations, such as chronic kidney disease or chronic obstructive pulmonary disease, who experience fatigue.

In the next stage of the thesis (Chapter 4), a new ECE program for the CDT population was developed, applying the WHO (2014) framework for health education planning to guide the development process. The CDT population’s needs and assets were identified using a literature-based Strengths, Weaknesses, Opportunities and Threats (SWOT) analysis, which revealed there was no existing ECE program that would meet the needs of adults on CDT of improved life participation, and feasibility in their clinical context and situation. The goals of improved life participation and feasibility in the dialysis clinical context were then set for the new ECE program. The literature was consulted to identify theory and/or evidence-based approaches that would meet the goals of the program, and the Cognitive Orientation to Occupational Performance (CO-OP) (Missiuna et al., 2001) was identified as a promising, personalized goal-focused problem-solving approach, to facilitate energy conservation strategy training. The CO-OP intervention was subsequently adapted to suit the dialysis clinical context, and clients’ energy-related challenges. Two complementary educational web modules were also designed, which provide people on CDT with a concise and convenient method to gain relevant background information on energy conservation prior to CO-OP. The resulting “PEP” program is a two-part, personalized, web-supported ECE program, which combines web-supported educational modules with personalized, goal-based problem solving to facilitate life participation goal attainment via the use of EC strategies. After initial program development, semi-structured qualitative interviews conducted with four selected key CDT informants (two people with CKD, one clinician, and one health education specialist) revealed that their perceptions of the program were positive. For example, they expressed that the program modules were novel, useful, and engaging. They also provided a number of recommended program modifications, of which 26 were implemented. Usability testing undertaken with five people on CDT, which incorporated both performance-based and subjective assessments, also suggested the program was largely usable by people with a variety of levels of computer literacy.

Finally, the efficacy of the PEP program for improving fatigue and life participation outcomes in people on CDT was explored (Chapter 5). A mixed-methods, sequential explanatory study design was used (Ivankova, Creswell, & Stick, 2006), that included a single-case, time-series
experiment with four replications, and follow-up qualitative interviews with program participants. The five study participants were all on CDT, and were purposively selected to represent typical dialysis user characteristics including age, gender and dialysis modality. Three participants demonstrated a positive response to the program across multiple quantitative measures of fatigue, self-efficacy, and life participation, while the remaining two participants demonstrated an inconsistent response, or no response. The post-intervention qualitative interviews indicated that all five participants felt the program had benefitted them, with the most commonly-reported benefit being that it made their lives and/or their daily activities easier. The format of the program was also largely said to be feasible and convenient by the participants.

6.3 Discussion and Implications

This thesis has produced the first evidence that ECE has the potential to improve fatigue and life participation outcomes in people on CDT. These findings, while preliminary, are nevertheless important given recent evidence showing that fatigue and its impact on life participation are highly important to people on CDT (Ju et al., 2018; Manns et al., 2014). Currently, there are few evidence-based treatment options for addressing fatigue that clinicians can use with the CDT population (Artom et al., 2014). Furthermore, the treatments that are available pose significant challenges, such as excessive specificity and/or infeasibility, which have been discussed in previous chapters. Energy conservation education is a non-specific approach to fatigue management, that can benefit people on CDT with varying fatigue aetiologies (Farragher et al., unpublished, and can require less time or energy investment from participants than existing approaches. The single-case study participants reported experiencing various benefits from the PEP program, and confirmed in qualitative interviews that the program was easy-to-use and suitable for their needs. These findings justify the need for more research to be conducted on the “PEP” program, using a larger sample of patients and robust trial methodology (ie. control, blinding, randomization), to further understand its effects on fatigue and life participation in people on CDT.

Outside of the renal population, much of the ECE research to date has focused on a specific face-to-face, group-based ECE program, “Managing Fatigue: A Six-Week Course in Energy Conservation” (Packer et al., 1995), in the MS population. The considerable body of evidence to support this program speaks to the potential of ECE for chronic disease populations more
broadly, in whom fatigue is pervasive and highly problematic, and justifies the need for robust randomized trials of ECE in other chronic disease populations. However, despite its strong evidence for people with MS, the “Managing Fatigue” program has never been studied outside of the MS population. It is possible that, as was true for the CDT population, a program which requires such extensive participant commitment may not be feasible or convenient for other chronic disease populations, or may not meet the need for a program that facilitates people’s life participation goals. The PEP program included novel design components to address these limitations, as they were anticipated to be major potential barriers to program uptake in the CDT population. Among the most prominent was the addition of a CO-OP-informed approach, which is an established personalized, goal-based problem-solving intervention, with strong evidence for facilitating life participation improvements in other chronic disease populations (Dawson et al., 2009; McEwen, Polatajko, Huijbregts, & Ryan, 2009; Ng et al., 2013; Polatajko et al., 2012; Smits-Engelsman et al., 2013). Simultaneously, other ECE programs have emerged in the literature that also use a more personalized, goal-focused approach to ECE (Kim et al., 2017; Raina et al., 2016). CO-OP shares similarities with these approaches, such as its top-down, client-centered approach, and the incorporation of problem-solving training. However, it also has unique features (eg. dynamic performance analysis and guided discovery) that are believed to help promote generalization and transfer of strategy use to untrained tasks and contexts (Houldin et al., 2018). Positive quantitative improvements in both general and goal-specific life participation were observed in three people after the PEP program, and all five participants qualitatively reported that the program helped them cope with day-to-day activities. This preliminary evidence supports the potential of a CO-OP approach to ECE for improving life participation outcomes in people on CDT with fatigue. Participants also qualitatively described instances of using energy conservation strategies after the program for life goals that were not directly addressed in therapy, which provides early supporting evidence that the PEP program may facilitate generalization and transfer of ECE strategy use to untrained tasks and contexts. These findings justify the need for further investigation into the effects of the PEP program on generalization and transfer in people on CDT. Given its potential strengths in this area, adaptation and testing of the PEP program for other chronic disease populations who experience fatigue may also be warranted for future research.
The PEP program was designed to be feasible and convenient for people on CDT, via the use of web-supported educational modules to teach clients about ECE. e-Health designs have been found to be effective in other areas of health education research, but have scarcely been shown to be effective for delivering ECE (Chapter 3). A variety of sources were consulted during the design of the PEP program modules. Literature that identified important components of e-Health and ECE interventions, and literature on chronic kidney disease and movement science principles, were used to inform module content and design. A novel, whiteboard animation-style design was also incorporated into PEP. Preliminary evidence suggested that people found the style of the modules to be engaging and interesting. This may reflect the broader potential of whiteboard animation design to enhance the delivery of health education, as it has recently become a popular medium for delivering information in popular culture, but has scarcely been tested in the health education domain. Participants also reported gaining novel and useful information from the modules. However, the true effects of the modules on study outcomes remain unclear, based on the single-case study data. Participants’ scores on the knowledge questionnaires designed to assess their learning demonstrated a ceiling effect at baseline. This could mean that participants already knew the information from the modules, or, that the questionnaires did not adequately capture their learning. There were a limited number of datapoints available during the module phase of the intervention to reliably assess changes in the other study outcomes (life participation, fatigue, self-efficacy, and energy conservation strategy use) associated with the modules. Future studies on the PEP program should thus re-evaluate the learning assessments to ensure they match the learning objectives of the modules, and include a larger number of study participants, to clarify the role of the modules in participants’ outcomes.

Although CO-OP principles were used in the PEP program to facilitate life participation, a number of modifications were made to the original CO-OP protocol to increase its feasibility in the CDT population. For example, a modified approach to dynamic performance analysis (DPA) that asked people to visualize performing their target activity, rather than actually performing it, was used to identify performance breakdowns. Clients were also asked to try, or “do”, energy conservation plans outside of therapy sessions, rather than trying the plan immediately during therapy. Although positive effects on life participation were reported after the PEP program, the improvements appeared to be relatively modest compared to what has been reported in other CO-OP literature (Dawson et al., 2009; McEwen et al., 2009). Given that DPA and the iterative
process of acting out GPDC are both seen as key features of the CO-OP approach, further consideration may need to be given to how to better simulate these CO-OP components in the PEP program. For example, clients may be able to video-record their activity performance using a device like a Go-pro for use in the DPA, rather than using visualization. A further training period to consolidate the GPDC process may also help to strengthen this component of CO-OP during PEP.

Despite the positive preliminary findings on the PEP program in three of five participants on CDT, the nonresponse to the program seen in two people on CDT with fatigue also warrants consideration. The only differences observed in their characteristics, compared to those for whom the program was effective, were their female gender and PD dialysis modality, respectively, which therefore may warrant exploration in larger studies of PEP. However, during the post-intervention qualitative interviews, participants also spoke of needing motivation to change to reap the benefits of the PEP program. Possible reasons for a lack of motivation to change may be that people have come to accept their fatigue, or that they do not view their fatigue management behaviours as being problematic. According to the Transtheoretical Model (TTM) of readiness for behaviour change (Prochaska et al., 1993), these people may be at an earlier, pre-contemplative stage of readiness to change. A different approach might thus be needed to ready people who do not yet feel ready or motivated to use ECE strategies, such as a more extensive consideration of the pros and cons of their current methods for managing fatigue, as is specified by the TMM. Such a component could be incorporated directly into the PEP program in the future, or, used to precede the program for people with whom it might be beneficial.

Although the PEP program was designed to offer greater feasibility than existing ECE programs in the CDT clinical context, its feasibility also remains an area for further consideration. ECE is an approach most commonly administered by rehabilitation professionals. Furthermore, the CO-OP approach that is included in the PEP program typically requires clinical training for administration. There are typically few rehabilitation staff who work on CDT units, and other CDT clinicians (eg. nurses) have previously expressed a lack of comfort with providing rehabilitation-focused interventions (eg. exercise training) to people on CDT (Painter et al., 2004, 2014). The PEP program was designed to require less program administration time than other ECE programs, in an attempt to accommodate the limited staffing that may be available for
its administration. The PEP program efficacy study did reveal the median program administration time to be relatively brief, at just over two hours in total. However, this may still be more than what clinicians currently working in CDT care are able to commit to a program of this nature. Further consideration of staff resources, and how they may be adjusted to facilitate the use of the PEP program in clinical practice, may therefore be needed, if the PEP program is found to be efficacious in more robust, controlled trials.

6.4 Methodological Strengths and Limitations

The first study of this thesis employed a scoping review approach to explore the literature on ECE in adults with chronic diseases. Scoping reviews are useful when there is insufficient evidence on an intervention to conduct a full systematic review, which was found to be the case for ECE. Scoping review methodology can identify gaps in literature where there is an absence of evidence, or where the available evidence is clearly at a preliminary stage. The gold-standard scoping review guidelines used for the review on ECE (Arksey and O’Malley, 2005) outline a comprehensive and systematic approach to examining the literature. The literature search strategy we used was co-constructed by an experienced librarian with expertise in rehabilitation, and a systematic process using pre-established eligibility criteria and data extraction sheets was used to select relevant studies and extract data. These steps increased the likelihood that a comprehensive and nonbiased review of the ECE literature was achieved. Furthermore, the use of a scoping review approach enabled us to synthesize both qualitative and quantitative findings on ECE, providing an integrative overview of the literature for knowledge users to inform their clinical and/or research work. However, one of the primary limitations of scoping review methodology is that breadth is prioritized over depth; thus, a critical appraisal of the quality of included studies is not typically performed. Additional quality-related evidence gaps may therefore exist in the ECE literature, which were not identified by our review. Given the advancements in ECE literature that have taken place in recent years, sufficient literature may soon become available to answer more focused questions about the effects of ECE in different chronic disease populations, using systematic review methodology. Another limitation of the scoping review was the exclusion of non-English articles, which may limit the generalizability of the findings to non-English-speaking locations.
To develop the new ECE intervention for people on CDT, the WHO framework for planning a health education intervention was used. Health education planning models are used for “planning, implementing and evaluating health education programmes and for providing a framework on which to build a plan” (World Health Organization, 2014, p. 21), and help to promote effective decision-making (Bartholomew, Parcel, & Kok, 1998). A Strengths, Weaknesses, Opportunities and Threats (SWOT) analysis, which is an established, evidence-based needs assessment tool (Nixon & Helms, 2010), was used to systematically examine the needs of the CDT population regarding an ECE program. Relevant literature was consulted to inform the selection of intervention approaches and strategies to include in the program, which is recommended by prominent intervention planning models such as the Intervention Mapping approach (Bartholomew et al., 1998). People with CKD and other key informants were also engaged during the intervention development process, which is increasingly recognized as an important factor in creating better-quality healthcare (Carman et al., 2013). However, limited time and resources meant it was not possible to engage the full range of CKD stakeholders during the intervention development process. Our initial program development team, key informants, and usability study participants were therefore all based out of one common health center in Toronto, which may mean their perspectives and experiences do not fully represent those of people on CDT or stakeholders from other locations. The key informants interviewed about the program were also a selected group, chosen for possessing characteristics such as insightfulness and enthusiasm. Thus, it is possible their perspectives may not represent the average target user of the PEP program. To test the program’s usability, a small sample size of five people on CDT was also used. Although five usability tests is accepted by many to be adequate to uncover ~80% of a system’s usability problems (Virzi, 1992), and our participants were purposely selected to represent the most important and potentially impactful characteristics, involving a larger sample of people with CDT would nevertheless have provided more comprehensive program usability information in the target population. Finally, despite our efforts to use best-available methods to develop a feasible ECE intervention for people on CDT, it still requires time from a trained rehabilitation clinician, which is not available in some dialysis contexts. Collectively, these limitations mean the PEP program may require adaptation to be used with some people on CDT and/or in some other clinical settings, where patient and/or clinical needs and resources are different.
Finally, a single-case, time-series design was used to explore the efficacy of the PEP program, which is considered an efficient and robust way to generate preliminary data about an intervention (Dallery, Cassidy, & Raiff, 2013; Kratochwill & Levin, 2015). The multiple measurements taken of the dependent variables during each study phase make single-case, time-series methodology more robust than a pre-post design, as they decrease the risk of random measurement error that may occur at a single assessment timepoint (Dallery et al., 2013). We also performed four replications of the single-case study to increase our confidence in the findings, and used people on CDT who were sampled purposively to represent a variety of patient characteristics to maximize the generalizability of study findings. Additionally, a number of triangulation methods were used to cross-validate the exploratory study findings: we incorporated multiple measures of the primary study outcomes, and interviewed participants after the study to further confirm and clarify the findings from the quantitative measures. However, although the time-series design provided superior validity to a pre-post design, the risk of excessive participant questionnaire burden ultimately led us to only conduct a minimally-acceptable three baseline assessments to establish their pre-intervention status for the study outcomes. More assessments taken during the baseline phase would have further decreased the risk of spurious findings, and provided more statistical power to detect changes between the baseline and intervention study phases. The exploratory nature of the study also meant that the first author was responsible for performing multiple study duties, including both conducting the study assessments and administering the intervention. This overlap may have increased the risk of a social desirability effect biasing participants to report greater benefit associated with the program than they actually experienced. Furthermore, control groups and randomization were not used for this preliminary exploration, which means there is a risk that other factors (eg. the placebo effect) might explain improvements in study outcomes observed at the time of intervention. All participants were also recruited from a common dialysis center in Toronto, Canada, which may mean the study findings are not generalizable to the broader CDT population. Finally, there was no long-term follow up conducted for this study, which means that maintenance of gains made from the program is unknown. Collectively, these limitations warrant the need for a larger trial of the PEP program, using a larger, more representative sample and methodologies to further minimize the risk of bias affecting study outcomes.
6.5 Conclusion

In conclusion, this thesis has shown that an energy conservation education program, tailored to meet the needs of people on CDT, has the potential to improve fatigue and life participation in the CDT population. Further robust testing of the program’s efficacy in people on CDT is therefore warranted.
References


https://doi.org/10.22034/APJCP.2016.17.10.4783


Appendices

Appendix A: Medline Search Strategy for Scoping Review

Database: Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) <1946 to Present>

Search Strategy:

1. (energy adj2 conserv*).tw,kw. (2990)
2. ((energy or fatigu*) adj2 manag*).tw,kw. (1010)
3. (energy adj2 sav*).tw,kw. (1879)
4. work simpl*.tw,kw. (113)
5. adaptive pac*.tw,kw. (208)
6. (energy adj2 behav*).tw,kw. (731)
7. energy envelop*.tw,kw. (25)
8. 1 or 2 or 3 or 4 or 5 or 6 (6774)
9. exp Health Education/ (142577)
10. ed.fs. (232040)
11. educat*.tw,kw. (425621)
12. train*.tw,kw. (365220)
13. program*.tw,kw. (631057)
14. course*.tw,kw. (493711)
15. treatment*.tw,kw. (3345346)
16. 9 or 10 or 11 or 12 or 13 or 14 or 15 (4830963)
17. 8 and 16 (1450)
18. exp animals/ not (exp animals/ and exp humans/) (4171020)
19. 17 not 18 (1260)
20. (exp child/ or exp infant/) not ((exp child/ or exp infant/) and exp adult/) (1437836)
21. 19 not 20 (1223)
22. 8 not 18 (5483)
23. 22 not 20 (5361)
24. limit 23 to "therapy (maximizes sensitivity)" (555)
25. comparative study/ (1719040)
26. evaluation studies/ (211332)
27. meta-analysis/ (60194)
28. multicenter study/ (191797)
29. exp clinical trial/ (719497)
30. 25 or 26 or 27 or 28 or 29 (2539582)
31. 23 and 30 (542)
32. 21 or 24 or 31 (1709)
33. limit 32 to english language (1637)
Appendix B: Semi-Structured Interview Guide for Key Informants

ORIENTATION

- Thank you for participating
- One of the big issues people with kidney disease seem to face is fatigue
- The modules you will be viewing are part of a program called the PEP program that’s been designed to help people on dialysis better manage their fatigue
- Program has 2 parts
- The first part is 3 computer modules that people can work through themselves
- This is the part we’ll be looking for your feedback on
- Modules last between 10-20 mins each
- After I’ll ask some questions about what you think about different aspects of the module
- Any comments, opinions or suggestions you have are helpful
- Questions?

MODULE 1

1. What are your overall thoughts or impressions about the module you just completed? (Feel free to tell me things you liked and most importantly, things you didn’t like.)

2. Do you think people with kidney disease would find what they learned in this module useful or helpful?

3. What did you think about this whole idea of energy budgeting?

4. Were any parts of the module not well-explained or difficult to follow?

5. Was there anything you wanted to hear more about or thought was missing?

6. What did you think about the pace of the module – were there any parts that went too fast, or too slow? (Pull up slides if necessary)

7. What did you think of the visual aspect of the module?
   a. Were there any images or slides that were confusing or difficult to see?

8. You completed a few activities during this session. The first asked you to reflect on how much energy would be in your tank, and how much activity or resting you had done today. What did you think about the image of the fuel tank in general, and what did you think about this activity?

9. The second exercise asked you to consider two self-care, work and leisure activities you found important, and why they were important to you (flip to the slide as necessary). What did you think about this activity?
10. At one point a balance scale was introduced, showing the discrepancy between the energy a person may have, and the energy required for what they need to do. What did you think about this image?

11. You also completed an energy inventory exercise during this session. What were your thoughts about that activity?

In summary:

12. What are the most valuable things you learned or would take away from the module?

13. Do you think people with kidney disease would be interested enough in what they learned in this module to complete the next module on their own?

14. If you could change anything about this module, what would you change?

15. Is there anything else you want to tell me that I forgot to ask you about?

**MODULE 2**

“Now I’m going to ask you some questions about your opinion of the session you just completed. Please feel free to be honest with your feedback.”

1. What are your overall thoughts or impressions about the module you just completed? (Feel free to tell me things you liked and most importantly, things you didn’t like.)

2. Do you think people with kidney disease would find what they learned in this module useful or helpful?

3. What did you think about the whole idea of activities having energy ‘costs’?
   a. Did it make sense?
   b. Is it helpful to think of your activities in this way?
   c. Did it make sense what affects the energy costs of an activity?

4. What do you think about the 7 energy saving ideas? (ESTOARS)
   a. Did you think they were helpful?
   b. Were there any you particularly liked, or didn’t like? (Could you please explain/tell me more?)

5. There were several practice exercises in this module. What did you think about them? (Return to exercises if necessary)

6. Were any parts of the module not well-explained or difficult to follow?
7. Was there anything you wanted to hear more about or thought was missing?

8. What did you think about the length and the pace of the module – were there any parts that went too fast, or too slow? (Pull up slides if necessary)

9. What did you think of the visual aspect of the module?
   a. Were there any images or slides that were confusing or difficult to see?

In summary:

10. What are the most valuable things you learned or would take away from the module?

11. Do you think people with kidney disease would be interested enough in what they learned in this module to complete the next module on their own?

12. If you could change anything about this module, what would you change?

13. Is there anything else you want to tell me that I forgot to ask you about?

**MODULE 3**

“Now I’m going to ask you some questions about your opinion of the session you just completed. Please feel free to be honest with your feedback.”

1. What are your overall thoughts or impressions about the module you just completed? (Feel free to tell me things you liked and most importantly, things you didn’t like)

2. Do you think people with kidney disease would find what they learned in this module useful or helpful?

3. What did you think about using a problem-solving system like goal plan do check to practice energy budgeting?
   a. Was GPDC explained well? Was anything confusing?
   b. Did it seem like it could be helpful or useful?

4. What did you think of the example of using GPDC and energy budgeting with Jim the dialysis patient?
   a. Did it make sense? Was anything unclear?

5. Were any parts of the module not well-explained or difficult to follow?

6. Was there anything you wanted to hear more about or thought was missing?
7. What did you think about the length and the pace of the module – were there any parts that went too fast, or too slow? (Pull up slides if necessary)

8. What did you think of the visual aspect of the module?
   a. Were there any images or slides that were confusing or difficult to see?

In summary:

9. What are the most valuable things you learned or would take away from the module?

10. Do you think people with kidney disease would be interested enough in what they learned in this module to complete the next module on their own?

11. If you could change anything about this module, what would you change?

12. Is there anything else you want to tell me that I forgot to ask you about?
Appendix C: Energy Inventory Development Process

The “Energy Inventory” activity from the PEP program was adapted from the Activity Card Sort (ACS), which is a validated assessment used by occupational therapists to assess an individual’s participation in instrumental, social, and leisure activities. The ACS presents patients with a set of 80 physical cards, each depicting one common activity of day-to-day living (eg. going to a restaurant; cleaning the house). Patients are then asked to sort the cards into one of five participation categories: “not done prior to illness/injury”; “continued to do during illness/injury”; “given up due to illness/injury”; “beginning to do again”; and “new activity since illness/injury”.

The goal of the energy inventory was to increase clients’ awareness of their energy spending habits, consider activities that they might be spending too much energy on, and identify activities they wished to allocate more energy towards. As such, the sorting categories from the ACS were condensed and modified to focus specifically on energy spending, as follows: “I spend enough energy on it”, “I wish to spend more energy on it”, and “I don’t want or need to spend energy on it”. As the set of activities included in the ACS were derived from a sample of older adults in the 1980’s, we also updated the activity set to reflect a broader and more current occupational repertoire, using activities from the Australian Adult ACS, which were derived from a more recent, broad patient sample. We also reduced the total number of activities from 80 to 55 to make the Inventory briefer, using a systematic selection process that took into account the importance rank of the activity from the original paper, and the perceived relevance of the activity to current-day life. After making the final modifications to the activity set, we transferred it to an online website, via an external card-sorting web platform, so that it could be completed online with the other PEP web module content.
<table>
<thead>
<tr>
<th>#</th>
<th>ORIGINAL ACS ACTIVITY</th>
<th>ACS VERSION</th>
<th>ROUND 1 CHANGE</th>
<th>REVISED ACTIVITY</th>
<th>ROUND 2 CHANGE</th>
<th>FINAL ENERGY INVENTORY ACTIVITY</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Bathing/showering</td>
<td>N/A</td>
<td>Add</td>
<td>Bathing/showering</td>
<td>None</td>
<td>Bathing/showering</td>
</tr>
<tr>
<td>2</td>
<td>Beauty therapy (hairdresser, barber shop, spas)</td>
<td>Both</td>
<td>Reword</td>
<td>Beauty care</td>
<td>None</td>
<td>Beauty care</td>
</tr>
<tr>
<td>3</td>
<td>Caregiving</td>
<td>18-64</td>
<td>None</td>
<td>Caregiving</td>
<td>None</td>
<td>Caregiving (other than children)</td>
</tr>
<tr>
<td>4</td>
<td>Caring for and interacting with pets/animals</td>
<td>Both</td>
<td>Reword</td>
<td>Caring for pets/animals</td>
<td>None</td>
<td>Caring for pets/animals</td>
</tr>
<tr>
<td>5</td>
<td>Gardening</td>
<td>Both</td>
<td>Combine</td>
<td>Caring for plants (indoor/outdoor)</td>
<td>None</td>
<td>Caring for plants (indoor/outdoor)</td>
</tr>
<tr>
<td>6</td>
<td>Parenting activities</td>
<td>Both</td>
<td>None</td>
<td>Child care</td>
<td>None</td>
<td>Child care</td>
</tr>
<tr>
<td>7</td>
<td>Communicating via skype/phone/email</td>
<td>Both</td>
<td>Expand</td>
<td>Communicating via phone/text/internet/letter</td>
<td>None</td>
<td>Communicating via phone/text/internet/letter</td>
</tr>
<tr>
<td>8</td>
<td>Cooking as a hobby</td>
<td>Both</td>
<td>None</td>
<td>Cooking as a hobby</td>
<td>None</td>
<td>Cooking as a hobby</td>
</tr>
<tr>
<td>9</td>
<td>Handwork/crafts</td>
<td>Both</td>
<td>Combine</td>
<td>Handwork/crafts/creative writing</td>
<td>None</td>
<td>Crafts/handwork/creative writing</td>
</tr>
<tr>
<td>10</td>
<td>Dancing (ballet, contemporary)</td>
<td>Both</td>
<td>None</td>
<td>Dancing (ballet, contemporary)</td>
<td>None</td>
<td>Dancing</td>
</tr>
<tr>
<td>11</td>
<td>Exercising (eg. walking, aerobics, gym, running, jogging, stretching)</td>
<td>Both</td>
<td>Reword</td>
<td>Deliberate exercising (eg. walking, jogging, gym activities)</td>
<td>None</td>
<td>Deliberate exercise (eg. walking, jogging, gym activities)</td>
</tr>
<tr>
<td>12</td>
<td>Taking a road trip/driving for leisure</td>
<td>18-64</td>
<td>Reword</td>
<td>Driving for leisure</td>
<td>None</td>
<td>Driving for leisure</td>
</tr>
<tr>
<td></td>
<td>Activity Description</td>
<td>Gender</td>
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</tr>
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<td>---------------------------------------------------------------</td>
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</tr>
<tr>
<td>13.</td>
<td>Driving (necessary)</td>
<td>Both</td>
<td>Combine</td>
<td>Driving/using public transportation</td>
<td>None</td>
<td>Driving/using public transportation</td>
</tr>
<tr>
<td>14.</td>
<td>Employment-related activities</td>
<td>18-64</td>
<td>None</td>
<td>Employment-related activities</td>
<td>None</td>
<td>Employment-related activities</td>
</tr>
<tr>
<td>15.</td>
<td>Entertaining at home</td>
<td>Both</td>
<td>None</td>
<td>Entertaining at home</td>
<td>None</td>
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</tr>
<tr>
<td>16.</td>
<td>Food/drink preparation</td>
<td>Both</td>
<td>Reword</td>
<td>Preparing food/dinks</td>
<td>None</td>
<td>Food preparation/clean-up</td>
</tr>
<tr>
<td>17.</td>
<td>Putting clothes on/off</td>
<td>N/A</td>
<td>Add</td>
<td>Putting clothes on/off</td>
<td>None</td>
<td>Getting dressed/undressed</td>
</tr>
<tr>
<td>18.</td>
<td>Going out for meals/drinks</td>
<td>Both</td>
<td>None</td>
<td>Going out for meals/drinks</td>
<td>None</td>
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</tr>
<tr>
<td>19.</td>
<td>Going to a movie/concert/performance</td>
<td>Both</td>
<td>None</td>
<td>Going to a movie/concert/performance</td>
<td>None</td>
<td>Going to a movie/concert/performance</td>
</tr>
<tr>
<td>20.</td>
<td>Going to mass events (eg. fairs, street festivals, dances, fireworks)</td>
<td>18-64</td>
<td>Combine</td>
<td>Going to public events (eg. festivals, fairs)</td>
<td>None</td>
<td>Going to public events (eg. festivals, fairs)</td>
</tr>
<tr>
<td>21.</td>
<td>Preventative health-related activities</td>
<td>18-64</td>
<td>Reword</td>
<td>Health-related activities</td>
<td>None</td>
<td>Health-related activities</td>
</tr>
<tr>
<td>22.</td>
<td>Heavy household chores (vacuuming, changing the sheets)</td>
<td>Both</td>
<td>Reword</td>
<td>Heavy household chores (vacuuming, scrubbing)</td>
<td>None</td>
<td>Heavy household chores (eg. vacuuming, scrubbing)</td>
</tr>
<tr>
<td>23.</td>
<td>Home/yard/pool maintenance</td>
<td>Both</td>
<td>Reword</td>
<td>Home/yard maintenance</td>
<td>None</td>
<td>Home/yard maintenance</td>
</tr>
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<td>24.</td>
<td>Individual sports</td>
<td>18-64</td>
<td>Combine</td>
<td>Individual sports (eg. tennis, bowling)</td>
<td>None</td>
<td>Individual sports (eg. golf, tennis, bowling, skiing)</td>
</tr>
<tr>
<td>25.</td>
<td>Home decorating/renovating</td>
<td>Both</td>
<td>Reword</td>
<td>Interior decorating</td>
<td>None</td>
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<tr>
<td>26.</td>
<td>Laundry/clothes care</td>
<td>Both</td>
<td>None</td>
<td>Laundry/clothes care</td>
<td>None</td>
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<td>Action</td>
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</tr>
<tr>
<td>27.</td>
<td>Light household chores (dusting, tidying, taking rubbish out, making bed)</td>
<td>Both</td>
<td>Reword</td>
<td>Light household chores (dusting, tidying, making bed)</td>
<td>None</td>
<td>None</td>
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<tr>
<td>28.</td>
<td>Listening to radio/music/mp3/ipod</td>
<td>Both</td>
<td>Reword</td>
<td>Listening to music</td>
<td>None</td>
<td>None</td>
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<tr>
<td>29.</td>
<td>Money management/paying bills</td>
<td>Both</td>
<td>Reword</td>
<td>Money management</td>
<td>None</td>
<td>None</td>
</tr>
<tr>
<td>30.</td>
<td>Music (performing, singing, composing)</td>
<td>Both</td>
<td>Reword</td>
<td>Performing or composing music</td>
<td>None</td>
<td>None</td>
</tr>
<tr>
<td>31.</td>
<td>Photography</td>
<td>Both</td>
<td>None</td>
<td>Photography</td>
<td>None</td>
<td>Photography</td>
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<tr>
<td>32.</td>
<td>Pilates/yoga/tai-chi</td>
<td>18-64</td>
<td>None</td>
<td>Pilates/yoga/tai-chi</td>
<td>None</td>
<td>Pilates/yoga/tai-chi</td>
</tr>
<tr>
<td>33.</td>
<td>Word/brain games</td>
<td>Both</td>
<td>Combine</td>
<td>Puzzles and brain games</td>
<td>None</td>
<td>Puzzles and brain games</td>
</tr>
<tr>
<td>34.</td>
<td>Reading newspapers/magazines/books</td>
<td>Both</td>
<td>Reword</td>
<td>Reading newspapers/magazines/other</td>
<td>None</td>
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<td>35.</td>
<td>Religious activities</td>
<td>Both</td>
<td>None</td>
<td>Religious or spiritual activities</td>
<td>None</td>
<td>Religious or spiritual activities</td>
</tr>
<tr>
<td>36.</td>
<td>Restful outdoor activities (sitting outside, looking at nature)</td>
<td>18-64</td>
<td>None</td>
<td>Restful outdoor activities (sitting outside, looking at nature)</td>
<td>None</td>
<td>Restful outdoor activities (eg. sitting outside, looking at nature)</td>
</tr>
<tr>
<td>37.</td>
<td>Intimate activities</td>
<td>Both</td>
<td>None</td>
<td>Romantic activities</td>
<td>None</td>
<td>Romantic activities</td>
</tr>
<tr>
<td>38.</td>
<td>Recreational shopping</td>
<td>Both</td>
<td>None</td>
<td>Shopping for enjoyment</td>
<td>None</td>
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</tr>
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<td>Age</td>
<td>Gender</td>
<td>Details</td>
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<tr>
<td>39</td>
<td>Purchasing goods</td>
<td>Both</td>
<td>None</td>
<td>Shopping for goods (groceries, items)</td>
<td>None</td>
<td>None</td>
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<td>40</td>
<td>Socializing at a club/party</td>
<td>Both</td>
<td>None</td>
<td>Socializing at a party/club</td>
<td>None</td>
<td>None</td>
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<td>41</td>
<td>Special interest group/club/course</td>
<td>18-64</td>
<td>None</td>
<td>Special interest group/club/course</td>
<td>None</td>
<td>None</td>
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<td>42</td>
<td>Education-related activities</td>
<td>Both</td>
<td>None</td>
<td>Studying &amp; educational activities</td>
<td>None</td>
<td>None</td>
</tr>
<tr>
<td>43</td>
<td>Table games (chess, cards, board games)</td>
<td>Both</td>
<td>None</td>
<td>Table games (cards, board games)</td>
<td>None</td>
<td>None</td>
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<tr>
<td>44</td>
<td>Team sports</td>
<td>18-64</td>
<td>None</td>
<td>Team sports (eg. baseball, soccer)</td>
<td>None</td>
<td>None</td>
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<tr>
<td>45</td>
<td>Thinking/reflecting/resting</td>
<td>Both</td>
<td>None</td>
<td>Thinking/reflecting/resting</td>
<td>None</td>
<td>None</td>
</tr>
<tr>
<td>46</td>
<td>Going on a holiday/traveling</td>
<td>Both</td>
<td>None</td>
<td>Traveling</td>
<td>None</td>
<td>None</td>
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<tr>
<td>47</td>
<td>Using the internet (locating, researching, surfing, downloading, uploading)</td>
<td>Both</td>
<td>None</td>
<td>Using the internet</td>
<td>None</td>
<td>None</td>
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<tr>
<td>48</td>
<td>Using the toilet</td>
<td>N/A</td>
<td>Add</td>
<td>Using the toilet</td>
<td>None</td>
<td>None</td>
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<tr>
<td>49</td>
<td>Car/boat/bike maintenance/repairs</td>
<td>Both</td>
<td>None</td>
<td>Vehicle maintenance/repairs</td>
<td>None</td>
<td>None</td>
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<td>50</td>
<td>Gaming</td>
<td>18-64</td>
<td>None</td>
<td>Video/computer games</td>
<td>None</td>
<td>None</td>
</tr>
<tr>
<td>51</td>
<td>Visiting family/neighbours/friends</td>
<td>Both</td>
<td>None</td>
<td>Visiting family/neighbours/friends</td>
<td>None</td>
<td>None</td>
</tr>
<tr>
<td>52</td>
<td>Going to zoo/park/gardens/theme park</td>
<td>18-64</td>
<td>None</td>
<td>Visiting public attractions (eg. park, picnic, museum, library)</td>
<td>None</td>
<td>None</td>
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<tr>
<td>53</td>
<td>Volunteer work</td>
<td>Both</td>
<td>None</td>
<td>Volunteer work</td>
<td>None</td>
<td>None</td>
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<tr>
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<td>Age Limit</td>
<td>Action</td>
<td>Time</td>
<td>Activity</td>
<td>Age Limit</td>
</tr>
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<tr>
<td>54.</td>
<td>Washing/grooming</td>
<td>N/A</td>
<td>Add</td>
<td>Washing/grooming</td>
<td>None</td>
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<tr>
<td>55.</td>
<td>Watching TV shows/movies/DVDs</td>
<td>Both</td>
<td>None</td>
<td>Watching TV/movies</td>
<td>None</td>
<td>Watching TV/movies</td>
</tr>
<tr>
<td>56.</td>
<td>Water sports</td>
<td>Both</td>
<td>None</td>
<td>Water activities (eg. swimming, boating)</td>
<td>None</td>
<td>Water activities (eg. swimming, boating)</td>
</tr>
<tr>
<td>57.</td>
<td>Train/plane/bird/animal watching</td>
<td>Both</td>
<td>None</td>
<td>Yard or outdoor activities (bird watching, frisbee, kite)</td>
<td>None</td>
<td>Yard or outdoor activities (eg. bird watching, hiking, frisbee, fishing)</td>
</tr>
<tr>
<td>58.</td>
<td>Attending family gatherings/events</td>
<td>Both</td>
<td>None</td>
<td>Attending family gatherings</td>
<td>Combine</td>
<td>Attending family gatherings</td>
</tr>
<tr>
<td>59.</td>
<td>Attending spectator sports</td>
<td>Both</td>
<td>None</td>
<td>Attending spectator sports</td>
<td>Combine</td>
<td>Attending spectator sports</td>
</tr>
<tr>
<td>60.</td>
<td>Clean up after food and drink preparation/meal</td>
<td>Both</td>
<td>None</td>
<td>Clean up after food preparation</td>
<td>Combine</td>
<td>Clean up after food preparation</td>
</tr>
<tr>
<td>61.</td>
<td>Fine arts</td>
<td>Both</td>
<td>None</td>
<td>Fine arts</td>
<td>Combine</td>
<td>Fine arts</td>
</tr>
<tr>
<td>62.</td>
<td>Fishing</td>
<td>Both</td>
<td>Combine</td>
<td>Fishing</td>
<td>Combine</td>
<td>Fishing</td>
</tr>
<tr>
<td>63.</td>
<td>Gambling (bingo, poker, keno)</td>
<td>18-64</td>
<td>None</td>
<td>Gambling</td>
<td>Combine</td>
<td>Gambling</td>
</tr>
<tr>
<td>64.</td>
<td>Golf</td>
<td>Both</td>
<td>None</td>
<td>Golf</td>
<td>Combine</td>
<td>Golf</td>
</tr>
<tr>
<td>65.</td>
<td>Hiking/bush walking/beach walking</td>
<td>Both</td>
<td>None</td>
<td>Walking/hiking for pleasure</td>
<td>Combine</td>
<td>Walking/hiking for pleasure</td>
</tr>
<tr>
<td>66.</td>
<td>Wheel sports</td>
<td>Both</td>
<td>None</td>
<td>Wheel activities (eg. biking, skateboarding, roller blading)</td>
<td>Combine</td>
<td>Wheel activities (eg. biking, skateboarding, roller blading)</td>
</tr>
<tr>
<td>67.</td>
<td>Winter sports</td>
<td>18-64</td>
<td>None</td>
<td>Winter sports</td>
<td>Combine</td>
<td>Winter sports</td>
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<tr>
<td>68.</td>
<td>Yard games</td>
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<td>69.</td>
<td>Social network via internet</td>
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<td>Combine</td>
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<td>70.</td>
<td>Clothes making</td>
<td>Both</td>
<td>Combine</td>
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<td>Activity</td>
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<tr>
<td>71.</td>
<td>Using public transport</td>
<td>18-64</td>
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<tr>
<td>72.</td>
<td>Flower arranging</td>
<td>65+</td>
<td>Combine</td>
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<tr>
<td>73.</td>
<td>Going to exhibition/museum/library/street gallery</td>
<td>Both</td>
<td>Combine</td>
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<tr>
<td>74.</td>
<td>Literature (writing a book/poetry)</td>
<td>Both</td>
<td>Combine</td>
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<tr>
<td>75.</td>
<td>Managing financial investments</td>
<td>Both</td>
<td>Combine</td>
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<tr>
<td>76.</td>
<td>Camping</td>
<td>65+</td>
<td>Combine</td>
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<tr>
<td>77.</td>
<td>Frisbee/kite/boomerang/hackysak</td>
<td>18-64</td>
<td>Combine</td>
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<tr>
<td>78.</td>
<td>Spiritual/meditation activities</td>
<td>18-64</td>
<td>Combine</td>
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<tr>
<td>79.</td>
<td>Going to picnic/bbq</td>
<td>Both</td>
<td>Combine</td>
<td></td>
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<tr>
<td>80.</td>
<td>Doing favours/helping out</td>
<td>18-64</td>
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<tr>
<td>81.</td>
<td>Motor sports (motorbikes, etc)</td>
<td>18-64</td>
<td>Delete</td>
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<tr>
<td>82.</td>
<td>Doing up old cars/bikes/equipment</td>
<td>18-64</td>
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<td>83.</td>
<td>Horseback riding</td>
<td>65+</td>
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<td>84.</td>
<td>Making furniture</td>
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<td>Mending</td>
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<td>86.</td>
<td>Model building/operating</td>
<td>18-64</td>
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<td></td>
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<td>Wine/beermaking</td>
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<td>65+</td>
<td>Combine</td>
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<tr>
<td>92</td>
<td>Bowling/lawn bowls/cricket</td>
<td>Both</td>
<td>Combine</td>
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<tr>
<td>93</td>
<td>Tennis/badminton/squash/etable tennis</td>
<td>Both</td>
<td>Combine</td>
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<td>94</td>
<td>Swimming/water polo</td>
<td>Both</td>
<td>Combine</td>
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<td>Researching family history</td>
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<td>Getting gas</td>
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</tbody>
</table>
Hi there, and welcome to the CLICK PEP program – CLICK Personal Energy Planning CLICK for People on dialysis with fatigue. CLICK... CLICK

For today’s session, you’ll need your CLICK pep workbook, CLICK a pen or pencil, and CLICK about 20 minutes. Go ahead and gather any materials you need, and click the button onscreen whenever you’re ready to keep going. CLICK x 2
*Living with kidney disease and being on dialysis can be a challenging experience. Kidney failure can affect the body and mind in different ways, and for many, it can create some uncomfortable symptoms.

For example, 3 in 10 people on dialysis say they experience nausea, 4 in 10 have trouble breathing, 5 in 10 report feeling pain, and 6 in 10 have difficulty with itchiness.

*However, one of the most common and troubling symptoms people on dialysis experience is fatigue. 7 out of 10 people on dialysis have difficulty with fatigue.
Fatigue stops me from doing what I want and need to do…

*And many say that it CLICK stops them from doing what they want or need to do in their lives. CLICK

If you can relate to this, CLICK the PEP Program may be helpful for you. CLICK

The PEP program is designed to help you learn CLICK how to make the most of the energy you have, so that fatigue doesn’t interfere with what’s important to you so much. CLICK

*The PEP program is divided into two parts. In CLICK Part 1, we explain an approach to managing fatigue called “PEP”, or PERSONAL ENERGY PLANNING, during CLICK 2 computer modules that you can complete yourself over the internet. CLICK Today’s module will explore how energy fuels everything you do, and how budgeting your energy can be a way to accomplish your priorities in spite of having fatigue. The CLICK second session will give you some ideas about how to cut your energy costs to bring your energy budget into balance.
In part 2 of the PEP program, we’ll focus on creating your personal energy plans. After completing a third computer module about how to put personal energy planning into action, you’ll work on your own goals during several one-on-one sessions with a specific member of your healthcare team known as your PEP partner. The name of your PEP partner and the dates and locations of your appointments are listed on page 7 of your PEP workbook. We recommend that you try to complete the 3 computer modules of PEP at some point before you meet with your PEP partner.

Your PEP workbook also contains other information you may need as you work through the PEP program.
You can pause and restart these modules anytime by pressing the pause/play button at the bottom of your screen. You can repeat a section by pressing the “repeat” button, or skip over something you may have heard before by hitting “skip”. There are also buttons to change the volume, and make the module bigger on your screen.

Now that we’re done orienting, let’s get started with Session 1.

You may or may not have thought about this before, but your body is a lot like a power plant—it’s constantly making energy that you use to do all the things you do in your day to day life.
Slide 14

*Every time you CLICK move, you’re using a bit of CLICK energy... CLICK

Slide 15

Even when you CLICK think, you use CLICK energy as your brain works to process what it’s thinking about. CLICK

Slide 16

Just about everything you do requires CLICK energy, and you have a limited CLICK amount of it to use at any given time CLICK. Imagine this fuel tank was beside you all the time holding your energy, so you could watch your energy levels change throughout the day. CLICK
After a night’s rest, your CLICK energy tank would probably be close to full. But once your day started, you would start to use energy when you CLICK stood up CLICK

Walked to the washroom, washed up, CLICK

Headed to the closet, got your clothes out, and got dressed CLICK
And then went to the kitchen to prepare your breakfast. CLICK

If you keep on using up your energy, eventually you CLICK run out. Your body lets you know this by causing you to feel CLICK fatigue. CLICK

This is so you know it’s time to stop and rest CLICK, so your body can replenish your energy again. CLICK x 2
Other things can also affect your energy levels, like whether you follow your diet, and how much exercise you get. But for the PEP program, we’re focusing on the different things you do throughout your days, and how much you rest.

You may not be in the habit of thinking about it, but you make choices about how to spend your energy all the time, when you decide what to do. Most people spend their energy on a combination of self care activities- which includes things like showering, getting dressed, and eating – work activities – which could be things you do at a job, or work you do around the house like cooking, laundry and grocery shopping – and leisure activities, which are fun or relaxing things you do like reading, playing an instrument, playing games, or visiting with friends. Different types of activities are important to us for different reasons – they may make us feel independent, helpful, or like we’re enjoying life.
Let’s pause to give you the chance to reflect on your own situation. What are 2 activities from each group – self care, work, and leisure - that are important to you, and what is it that makes them important?

Open your PEP workbook to page 8 and jot down your thoughts there. When you’re finished, CLICK click the button on the screen to continue with the session.

CLICK

Let’s pause to give you the chance to reflect on your own situation. What are 2 activities from each group – self care, work, and leisure - that are important to you, and what is it that makes them important?

Jot down your thoughts in your PEP workbook on page 9. When you’re finished, CLICK click the button on the screen to continue with the session. CLICK x 2
Kidney disease can affect the body’s ability to create and use energy for different reasons. For example, anemia means your body has hard time getting oxygen to its cells, which it needs for energy. There may be an imbalance of nutrients and fluids in your body, which are important sources of energy. Your body may be slightly inflamed trying to get rid of the toxins in its system, which can use up energy. You may have a hard time refreshing your energy during sleep because of symptoms like restless legs or pain. And you may also be spending some energy on worrying because of the stress that comes with the disease. Even dialysis itself tends to leave many people feeling drained. Because of these things, you may have noticed that you seem to have less energy to do the things that you would normally do. You might think of yourself as having a fuel tank that’s a little smaller than it used to be.

When you start dialysis, you also have extra activities you have to spend your energy on – like going to your dialysis sessions, setting up your machine at home, or managing your medications and diet. When you think of it this way, it makes sense that you’re running out of energy trying to keep up with your normal activities.
You have an energy imbalance – where the amount of energy you have doesn’t match all of the things there are to do. CLICK x 2

Some people respond by putting dialysis and self-care activities first no matter what, since they can’t really be missed. CLICK
Slide 32

This may CLICK bring things back into balance. CLICK x 2

Slide 33

Slide 34

But it probably also means giving up things that are personally important, because CLICK work and CLICK leisure add a certain kind of value to our lives CLICK
Another way some people might respond is to conserve as much energy as possible by avoiding activities that use a lot of energy.

But this also means giving up things that are important...

And it can also create...
A different type of energy imbalance

Because when you don’t use the energy you have, your body starts to produce even less of it.

But there is another way to address this energy imbalance.
And that’s by using energy budgeting

You’re probably familiar with budgeting when it comes to money. All of us have a certain amount of money to spend, which we could call our budget - and different things we want or need to buy with it.

Someone has a “balanced budget” when they have enough money to buy the things they want or need.
The smaller our budget is, the more helpful it is to be careful and strategic about what we spend it on.

We have to take a close look at what our priorities really are, and find creative ways to cut costs that aren't necessary from our budget in order to keep it balanced.
Examples of money-saving ideas could be making CLICK coffee at home, using CLICK public transit instead of buying a car, or waiting to buy your favourite shoes until they’re on CLICK sale.

During the PEP Program CLICK

We’re going to take a similar approach to CLICK budgeting your energy CLICK
Today, we’ll take a close look at what your energy priorities are, and then starting next session, consider creative ways you can cut your energy costs.

To bring your energy budget back into balance without missing out on things that are important to you.

*So let’s consider your energy priorities now by having you take an Energy Inventory. Note that the following instructions can also be found on page 10 of your PEP workbook. After these instructions...
A CLICK button will appear onscreen to take you to the Energy inventory website. CLICK

There, you’ll find a CLICK list of activities on the left side of the screen, and CLICK three categories on the right side of the screen that the activities may fall into for you.

The first category is CLICK I have enough energy for it – these would be the activities you generally have enough energy to do without too much trouble. The second category is CLICK I want or need more energy for it, and these are the activities you wish you had MORE energy to do. CLICK The third category is CLICK I don’t do it and that’s fine, which are activities that you don’t tend to want or need to do. CLICK
Choose 5 you want or need to work on the most. Write them down in your PEP workbook on page 11.

*Sort the activities into the right categories by clicking and holding the activity with the mouse button, dragging it over to the right box, and then dropping it under the category title by releasing the mouse button. CLICK x 3. Be sure to drag the activity into the CLICK dark grey part of the category box, rather than the light grey part. CLICK

When you’re finished, take a moment to look over the activities you have enough energy for. This is where you’re currently choosing to spend your energy. Then, go over the activities you want or need more energy for and choose 5 that you’d like to work on the most. Write them down in your PEP workbook on page 11, because we’ll revisit them later on in the PEP program CLICK

Also, remember to click the CLICK button on the top right-hand side of the screen when you’re finished the activity to make sure it gets saved. CLICK
*Enjoy completing your energy inventory, and we'll see you back here again soon for module 2 of the PEP Program, when we'll look more closely at how to cut your energy costs. CLICK
Appendix E: Full Account of Key Informant Interview Findings

Program Strengths

The informants’ overall impressions of the modules were generally positive, and largely supported that the modules successfully accomplished many of their intended objectives. The patient informants expressed that the modules validated their lived experience of fatigue, and its impact on their everyday activities. They both identified the information about the causes of fatigue in kidney disease as being at least somewhat new, and helpful to hear. One patient appreciated that the program had confirmed his fatigue was not merely psychosomatic in nature:

“That’s the big gain, is that yes, this, the reality of it is I only have so much energy, it’s not just in my head, I’m not reacting to this from an emotional psychosomatic way – I am tired - and so this whole thing validates that, which is huge.”

The patient informants expressed that the modules raised their awareness about their own energy spending, and the need to make active choices about what activities to engage in. The two patient informants communicated that the modules, and the energy inventory in particular, helped them to reflect on and identify their activity-related priorities, as described by the patient on dialysis:

“The things I discovered about myself already are helping me, just to see my priorities… I see where this is going, and I’m really excited about this.”

The patient informants also described that the modules enabled them to recognize and break down their own energy costs in more detail than what they otherwise would have been doing:

“It just breaks down something that people can all just lump together. Ok, I don’t have the energy to do everything, so I have to cut some things out - I mean, that’s no problem. But here, if you really look at it and break it down further, then all of these things can start adding up.”

The program’s core approach of budgeting energy as a way of managing fatigue was described as novel, relevant, and relatable by all informants. This was exemplified by the CKD Stage 3 patient:

“I thought it was good – because it was going directly to a key question for me, which is, how much energy do I have? And am I out of bounds thinking that I have to, uh, budget – for lack of a
better word – and this whole idea of having to rethink how much energy you have all the time, for me anyway, is pretty new.”

The CKD patient informant further expressed that the overall approach of planning ahead, and anticipating versus reacting to challenges, was a valuable way to approach his fatigue. The content provided about the energy-saving strategies was seen as valuable by all informants. Although the nurse and the CKD informant anticipated that some patients on dialysis may already be familiar with the strategies, they expressed that it was nevertheless beneficial because it provided a methodology, or framework, that could be used to apply the appropriate strategies. The CKD patient also described how the modules were encouraging him to take action in response to his fatigue:

“I’m thinking about it a lot more concretely, instead of just, going around in a big circle – yeah I’d love to take guitar lessons, but I don’t know if I have the energy, and yes I want to take guitar lessons, but... and then it’s like okay, not next week....whereas really it has to be, do it, and budget, so that you can do it.”

The personalized aspect of the program was identified as another strength by the dialysis patient, who conveyed that she appreciated how the program allowed her to focus on what was important to her. The patient informants could both readily identify personal energy goals they would want to work on in Part 2 of the program.

With respect to design, the key informants expressed that the modules were generally well-designed, engaging and interesting. The health education consultant expressed that the program had good flow, and the length and pace of the modules was said to be suitable by all key informants. The visual design of the modules was said to be strong by all informants, who spoke specifically about the clarity and effective illustration of the concepts being explained. Some of the visual imagery in particular, such as the energy tank used to depict one’s energy capacity and the stick-figure protagonist used to demonstrate key concepts, were endorsed by multiple key informants, and said to make the underlying concepts concrete and relatable. The spare design and ample white space used in the slides was also identified as a visual design strength by two of the key informants, including the health education specialist:
“It felt like intentionally spare design that’s meant to allow somebody a lot of mental freedom to put themselves in there or not. I felt like I wasn’t forced to imagine something in particular”

Two of the key informants also expressed that that the narration used in the modules was effective and used the right tone.

The examples and activities incorporated into the modules were described by all informants as being relevant and relatable for the patient population. The health education specialist expressed that she felt the examples would encourage participants to think creatively:

“Those were great examples, and they really made me think in a way - I think it would encourage some creative thinking for people that they may not have thought of.”

In general, the program design was praised for its overall clarity and simplicity. The nurse informant felt the simplicity of the modules was particularly beneficial for patients using the modules who may have cognitive impairments.

Overall, the PEP program was said to be needed by the key informants, and was seen as filling a gap in care provided to this population. The patient informants endorsed that they would recommend the program to other patients with CKD on dialysis. Two of the informants also expressed that they felt caregivers would benefit from seeing the modules, to validate the experiences of their loved ones and/or to learn about the intervention approach. Both patient informants endorsed that they benefited from the modules enough to want to continue onto Part 2 of the program, as exemplified by the dialysis patient informant:

“I’m ready to use a PEP partner! I really would like to [go to the next step], I think it’s a good program. I need the help.”

Program Weaknesses and Recommendations

A number of critiques and recommendations about the program content were identified by the key informants during the interviews. For example, both the CKD patients and the health education specialist felt that it would be helpful to clarify whether there were ways to increase one’s energy besides just taking rest breaks, which is the strategy that is emphasized in the program. The Stage 3 CKD patient also expressed that he was not necessarily yet at the stage
where he was ready to cut his energy costs, if that meant sacrificing or changing activities he valued. As such, he wished the program spent more time addressing the mental recalibration required to accept his growing personal limitations, as he felt that this was the issue he was most struggling with. Two of the key informants felt that there was conflicting information about whether low-energy activities and/or mental activities drain versus refresh energy, and suggested clarifying this point. Two informants also suggested providing information on how to communicate with family about the need for their assistance to complete activities. One informant identified the monetary cost of some of the energy-saving strategy examples as being a potential barrier for some patients, while another wondered about the long-term feasibility of having to write down energy plans while engaging in the goal management process outlined in Part 2 of the program.

The informants all also expressed that they found some of the content to be overexplained at times. However, there was ambivalence about this issue across informants, because they also appreciated its clarify and simplicity and struggled to identify how specifically they would alter the modules to address this issue. The CKD patient informant further expressed that even if some patients found parts of the modules too slow, he believed the overall content would nevertheless be valuable for anyone:

“I think I would anticipate that anybody, at any level of education, would get something out of this.”

Despite the simplicity and user-friendliness of the program design, the nurse informant also still wondered about the feasibility of some patients completing the computer modules independently due to their burden of health-related impairments. She also wondered about the feasibility of Part 2 of the program, which requires a healthcare provider to work 1:1 with the patient for several half-hour sessions (4-6). The nurse informant felt that Part 2 of the program would be important to ensuring the patients would implement the strategies learned in Part 1, but was unsure who on the healthcare team would have the time or knowledge to work with the patients. She suggested that allied health members of the team such as the social worker may be able to administer the program, or, that units may need to hire an occupational therapist to administer the program. A number of minor modifications to several visual images, slide transitions, and narrative
components were also recommended by the key informants. Several technical issues were also identified during the sessions, such as audio skipping and buttons not working.

Following the key informant interviews, the research team met to discuss the comments and recommendations put forth by the key informants. A total of 60 recommended modifications were derived from the participant comments, and 25 were implemented. Recommended modifications that were conflicting between informants, that were held by a minority of informants, or that were deemed to be infeasible, were not implemented.
Appendix F: Outcome Measures for PEP Efficacy Study

**FATIGUE SEVERITY SCALE (FSS)**

Please circle the number between 1 and 7 which you feel best fits the following statements. This refers to your usual way of life within the last week. 1 indicates “strongly disagree” and 7 indicates “strongly agree.”

<table>
<thead>
<tr>
<th>Read and circle a number.</th>
<th>Strongly Disagree</th>
<th>→</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. My motivation is lower when I am fatigued.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Exercise brings on my fatigue.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. I am easily fatigued.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Fatigue interferes with my physical functioning.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Fatigue causes frequent problems for me.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. My fatigue prevents sustained physical functioning.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Fatigue interferes with carrying out certain duties and responsibilities.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Fatigue is among my most disabling symptoms.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Fatigue interferes with my work, family, or social life.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Modified Fatigue Impact Scale (MFIS)

Following is a list of statements that describe the effects of fatigue. Please read each statement carefully, circle the one number that best indicates how often fatigue has affected you in this way during the past 4 weeks. Please answer every question. If you are not sure which answer to select, choose the one answer that comes closest to describing you. Ask the interviewer to explain any words or phrases that you do not understand.

Because of my fatigue during the past 4 weeks...

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>I have been less alert.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2</td>
<td>I have had difficulty paying attention for long periods of time.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3</td>
<td>I have been unable to think clearly.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4</td>
<td>I have been clumsy and uncoordinated.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5</td>
<td>I have been forgetful.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6</td>
<td>I have had to pace myself in my physical activities.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7</td>
<td>I have been less motivated to do anything that requires physical effort.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8</td>
<td>I have been less motivated to participate in social activities.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9</td>
<td>I have been limited in my ability to do things away from home.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10</td>
<td>I have trouble maintaining physical effort for long periods.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11</td>
<td>I have had difficulty making decisions.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>12</td>
<td>I have been less motivated to do anything that requires thinking</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>13</td>
<td>My muscles have felt weak</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>14</td>
<td>I have been physically uncomfortable.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>15</td>
<td>I have had trouble finishing tasks that require thinking.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>16</td>
<td>I have had difficulty organizing my thoughts when doing things at home or at work.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
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<td>---</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. I have been less able to complete tasks that require physical effort.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>18. My thinking has been slowed down.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>19. I have had trouble concentrating.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>20. I have limited my physical activities.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>21. I have needed to rest more often or for longer periods.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
</tbody>
</table>
These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...

<table>
<thead>
<tr>
<th>All of the time</th>
<th>Most of the time</th>
<th>Some of the time</th>
<th>A little of the time</th>
<th>None of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
</tr>
</tbody>
</table>

a. Did you feel full of life? □ □ □ □ □

b. Did you have a lot of energy? □ □ □ □ □

c. Did you feel worn out? □ □ □ □ □

d. Did you feel tired? □ □ □ □ □
WEEKLY ENERGY QUESTIONNAIRE

1. On a scale of 1-10, how well do you manage your fatigue?

Not well

1  2  3  4  5  6  7  8  9  10

Extremely well

at all

2. On a scale of 1-10, how satisfied are you with your fatigue management?

Not at all

1  2  3  4  5  6  7  8  9  10

Totally satisfied

satisfied

3. On a scale of 1-10, how often do you have the energy to do the things you need to do?

Never

1  2  3  4  5  6  7  8  9  10

Always

4. On a scale of 1-10, how often do you have the energy to do the things you want to do?

Never

1  2  3  4  5  6  7  8  9  10

Always
5. On a scale of 1-10, how confident are you that you can keep the fatigue caused by your disease from interfering with the things you want or need to do?

| Not at all confident | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 Totally confident |

6. How often in the past week did you:

<table>
<thead>
<tr>
<th>Action</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Regularly</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Notice that you were spending energy</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b. Think about how much energy an activity or action costs</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c. Question whether what you were doing was worth your energy</td>
<td></td>
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<td>d. Eliminate an activity to save energy</td>
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<td>e. Simplify an activity to save energy</td>
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<td>f. Use tools to save energy</td>
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<td>g. Stop and organize to save energy</td>
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<td>h. Ask for assistance to save energy</td>
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<td>i. Reposition yourself to save energy</td>
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<td>j. Slow down to save energy</td>
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<td>k. Deliberately pace your energy spending</td>
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DID THE PEP PROGRAM TEACH ME WHAT I NEED TO KNOW?

MODULE 1

This is **not** a test of your abilities – it’s a test of how well the PEP program works! These questions will tell the researchers if the PEP program modules teach you what they’re supposed to teach you. So just do your best and circle the answer that you think is right. If you don’t know something, just take your best guess!

1. What is the most common symptom people with kidney disease on dialysis say they have?
   a. Pain
   b. Fatigue
   c. Nausea
   d. Itching

2. Our bodies make energy that we use to accomplish things throughout the day. Which of the following uses energy?
   a. Putting on clothes in the morning
   b. Thinking about what groceries to buy
   c. Preparing breakfast
   d. All of the above

3. The main types of activities that most people do in their lives could be grouped into three categories. What are they?
   a. Sports, housework, and sleeping
   b. Running, sitting, and walking
   c. Self-care, work, and leisure
   d. Reading, playing an instrument, and visiting family and friends
4. How does kidney disease affect the body’s ability to create and use energy?

   a. It can make it harder for the body to get oxygen to its cells
   b. It can make it difficult to get a good night’s sleep
   c. It can create an imbalance of nutrients and fluids in the body
   d. All of the above

5. Many people use **budgeting** as a way to manage their money. Budgeting typically includes:

   a. Prioritizing the things you want and need
   b. Spending your money until there’s none left
   c. Buying things you like when you see them
   d. Buying only things you absolutely need

6. Budgeting also usually includes finding creative ways to cut your costs. Which of the following would be an example of a **cost-cutting** strategy?

   a. Taking an extra job to make more money
   b. Getting another credit card to buy the big-screen TV you’ve always wanted
   c. Cooking more meals at home instead of eating at restaurants
   d. Asking a friend to lend you some cash until your next payday

7. Which of the following is **usually** true about your **energy levels**?

   a. My energy level is not affected by what I do
   b. As I do more things during a day, my energy level will get **lower**
   c. As I do more things during a day, my energy level will get **higher**
   d. None of the above
8. What is the main goal of the PEP Program?

   a. Help you make the most of the energy you have
   b. Make your itching go away
   c. Help bring your energy levels back to normal
   d. Help with your pain

9. Which of the following is probably the most effective strategy for living well with kidney disease-related fatigue?

   a. Avoid all activities that use a lot of energy
   b. Use your energy only on self-care activities
   c. Reserve energy to do the things that matter to you
   d. Let family and friends take over most of your usual activities

10. Energy budgeting is one approach to managing fatigue. Energy budgeting involves:

    a. Doing what you feel like doing, until you feel exhausted
    b. Doing what other people expect you to do, until you feel tired
    c. Conserving as much energy as possible by doing very little
    d. Prioritizing and cutting your energy costs where you can
DID THE PEP PROGRAM TEACH ME WHAT I NEED TO KNOW?

MODULE 2

This is not a test of your abilities – it’s a test of how well the PEP program works! These questions will tell the researchers if the PEP program modules teach you what they’re supposed to teach you. So just do your best and circle the answer that you think is right. If you don’t know something, just take your best guess!

1. Having a balanced energy budget means there is enough energy to do the things you want or need to do. What are two important steps involved in balance your energy budget?
   
   a. Prioritizing, and cutting energy costs
   b. Cutting energy costs, and reducing energy levels
   c. Prioritizing, and increasing energy costs
   d. Prioritizing, and reducing energy levels

2. There are many different actions that can “cost” energy. Which of the following is an action that costs energy?
   
   a. Standing
   b. Thinking
   c. Lifting something
   d. All of the above

3. Activities that include more actions, tend to cost more energy. Which of the following activities would probably cost the most energy?
   
   a. Watching a movie
   b. Cooking dinner for the family
c. Getting dressed in the morning
d. Reading a novel

4. There are many different ways to save energy, which can be summarized using the 7 energy-saving strategies. What are they?

   a. Eliminate, Simplify, Tools, Organize, Assistance, Reposition, and Slow down
   b. Reposition, Organize, Assistance, Slow down, Tools, Yes to everything, and Simplify
   c. Simplify, Tools, Organize, Reposition, Innovate, Educate, and Slow down
   d. Organize, Reposition, Slow down, Innovate, Eliminate, Simplify, and Try again

5. One strategy that can be used to save energy is eliminating an activity. When is eliminating an activity a good energy-saving strategy?

   a. When it’s an activity you don’t really want or need to do
   b. When it’s an activity you do want or need to do, but it may cost some energy
   c. When it’s an activity that doesn’t cost much energy
   d. None of the above

6. Another strategy that can be used to save energy is simplifying an activity. What are two ways an activity can be simplified?

   a. Combining steps of the activity, or cutting out steps of the activity
   b. Scaling back the activity, or doing the activity more quickly
   c. Combining steps of the activity, or adding steps to the activity
d. Doing the activity more quickly, or adding steps to the activity

7. Another strategy that can be used to save energy is organizing. What is the best example of using organization to save energy?

   a. Storing household items that you use frequently in the garage
   b. Storing your cleaning products close to where you use them
   c. Storing your heaviest kitchen items on the highest shelves
   d. Saving your receipts after you go grocery shopping

8. Many different tools exist that can allow you to save energy. Which of the following is the best example of a tool that would help you save energy?

   a. A coffee cup
   b. A watering can
   c. An electric toothbrush
   d. A door

9. Some body positions we use throughout a day cost more energy than others. Which of the following body positions would likely cost the most energy?

   a. Sitting in a chair
   b. Squatting down in a crouched position
   c. Lying on your back
   d. Standing upright with comfortable shoes on

10. Besides cutting your energy costs, what is another important way to keep your energy budget balanced?

    a. Reduce your energy level
    b. Pace your spending
    c. Spend more energy
d. Slow down your saving
Appendix G: Semi-structured Interview Guide for PEP Efficacy Study

Preamble  Thank you very much for doing this. I would like to hear about your experience with the PEP program today – just any thoughts you have about it – things you liked, things you didn’t like, things that worked, things that didn’t work. Feel free to be completely open and honest. Your name will not be used when I report on this session, so go ahead and speak your mind.

General Perceptions
- Can you begin by telling me about your experience with the PEP program? What did you think about it?
- What are some of the things that you liked about the PEP program?
- What did you not like, or what would you have done differently?

Part 1: Modules
- The PEP program began with three computer modules that provided some information about fatigue, kidney disease, and how to budget your energy to manage your fatigue. Can you tell me about your experience with the PEP program computer modules? What did you think about them?
  - What did you learn from the modules?
  - Did you find what you learned from the modules helpful for when you started to work on your own fatigue management? Why or why not?
  - Did you like having the information delivered to you by a computer? Was it problematic in any way?
  - Was there anything you would change about the modules of the PEP program?

Part 2: CO-OP
- Can you tell me about your experience working on your own goals during the PEP program? What did you think about that part of the program?
  - What did you like about it?
  - What did you not like about it?
    - What did you think about the process of using goal-plan-do-check while we worked on your goals? Did you find that helpful?
    - Were some of the concepts from the computer modules (eg. the energy-saving strategies or the energy budgeting idea) helpful?

Location:
- How did you feel about doing the PEP program sessions while you were on dialysis (from home)? What did you like about it, what did you not like about it?

Fatigue management:
- Do you feel that the PEP program has helped you to better manage your fatigue?
  - How? What do you think didn’t quite hit the mark?
o Would you say you use more energy-saving strategies now than you did before the program?
o What else is different about how you manage your fatigue now, compared to before?
o Have you been able to use the skills you learned in the PEP program in aspects of your life that we didn’t directly work on together?
  - a) Can you give me an example?

Revisiting Overall Perceptions

- Reflecting on the strengths and limitations of the program, would you recommend the PEP program to other people on dialysis who have fatigue?
- Is there anything else you would like to tell me about the PEP program?
- Is there anything we have missed in this discussion today?
Appendix H: Time-Series Scatterplots for P2, P3, P4 and P5

Participant 2:
Participant 3:
Participant 4:

- Life participation
- Life participation satisfaction
- Fatigue
- Self-efficacy
Participant 5: