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Anne R. Ordway

The Broader Impact of Disability Research:
Aligning Public Policy with the Experiences of People with Disabilities and Healthcare
Providers

Anne R. Ordway

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Reading Committee:

Kurt L. Johnson, Chair

Dagmar Amtmann

Jennifer S. Pitonyak

Program Authorized to Offer Degree:

Rehabilitation Science

University of Washington

Abstract

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Anne R. Ordway

Chair of the Supervisory Committee:
Professor Kurt L. Johnson
Rehabilitation Medicine

The general purpose of this three-article dissertation is to investigate public policy issues salient to people with disabilities, their families, and healthcare providers. The studies in this dissertation are united by a conceptual framework and applied policy research methods. The first article in this dissertation, “The Relationship between Psychological Assets and Employment in Individuals with Physical Disabilities,” was designed as a secondary analysis of existing data. Using cross-sectional survey data collected as part of the Rehabilitation Research and Training Center on Healthy Aging and Physical Disability, the purpose of this study was to determine the relative importance of resilience and self-efficacy in explaining employment status for people with physical disabilities after controlling for sociodemographic and disease covariates. Data were analyzed using multiple logistic regression with sequential predictor entry. Results indicate that resilience but not self-efficacy was uniquely predictive of employment status. We found in this study preliminary evidence to suggest that rehabilitation professionals should consider the importance of a client’s psychological resources with respect to employment.

The second article in this dissertation, “Durable Medical Equipment Reuse and Recycling: Uncovering Hidden Opportunities for Reducing Medical Waste,” was designed as a basic interpretive qualitative study. The purpose of this study was to investigate the phenomenon of durable medical equipment (DME) reuse and recycling in the context of a healthcare delivery system as a first step in understanding how hospitals manage DME waste and how healthcare providers conceive of their role in preventing DME waste. The findings for this study include descriptions of the process for patients to acquire both new and used DME and environmental sustainability practices for reducing DME waste generated by hospitals. The third and final article in this dissertation, “The Experience of Homecare Providers and Beneficiaries with Enhanced Training Requirements in Washington State,” was also designed as a basic interpretive qualitative study. This study was conducted as the first phase in a potential multiphase study to develop a battery of self-report instruments for evaluating consumers’ satisfaction with their homecare and for assessing health-related quality of life outcomes presumed to improve with quality caregiving. We used exploratory research to identify domains relevant to a new homecare aide training and certification program that was mandated by Washington State Initiative 1163. The findings for this study include a description of the components of person-centered delivery of care and an assessment of the homecare aide training from the perspective of some consumers and homecare aides in Washington State.

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Chapter 1. GENERAL INTRODUCTION

1.1 RELATIONSHIP BETWEEN RESEARCH AND POLICYMAKING

As of late, academic researchers and government decision-makers have been exploring ways to more closely align research and policy. More than just a buzzword, evidence-based policymaking denotes a process where information and systematic analysis are used to resolve a policy problem (Cartwright & Hardie, 2012). There is considerable debate in the literature on the definition of evidence with respect to policy, what constitutes evidence, and how evidence is used to improve the policy process and/or outputs (see Oliver, Lorenc, & Innvaer, 2014, for a review of the literature on evidence-based policy). Despite these ambiguities, it is in general acceptance that policymaking should be driven by information as opposed to ideology, power, or privilege and rigor as opposed to guesswork.

Although research evidence is only one type of information used in policymaking (Hämäläinen, Aro, Lau, Chereches, & Syed, 2015), academic researchers play an important role in the policymaking process. Government decision-makers and the public value independent research and analysis as supplements to the knowledge and skills within government (Kraft & Furlong, 2010). As such, government entities as well as community-based organizations often partner with academic institutions and leverage their resources to foster better-informed policymaking. Additionally, it is not uncommon for funders as part of a grant application to require that researchers engage with policy stakeholders or to encourage policy communication in addition to the typical strategies for disseminating research findings. Therefore, more academic researchers are orienting their research in policy-informing ways.

Hanushek's (1990) description of what he termed the "policy research market" provides a framework for considering the different types of research and how each can inform policymaking. This framework also serves as a way to organize and unify the three independent studies that comprise this dissertation. First, disciplinary research is conducted by academic researchers, in Hanushek's words, to "seek truth" through scientific methods regardless of whether the knowledge is relevant or useful in some immediate way. Disciplinary research might relate to potential public policies, but the pursuit of policy issues per se is not the intent of the researcher. The disciplinary researcher is characterized by expertise in a specific domain but not by expertise in policy. Criticism that academic research is not relevant to immediate policy problems (Prewitt, Schwandt, & Straf, 2012) is likely in reference to disciplinary research. A noted exception might be systematic reviews and meta-analyses, which aim to identify, evaluate, and summarize the findings of all the relevant individual studies on a specific issue and are often used to inform policy (Davis, Mengersen, Bennett, & Mazerolle, 2014).

Next is policy research which, according to Hanushek, is similar to disciplinary research in that it gives weight to rigorous analyses and standards of evidence. However, the objective of this type of research is to respond directly to a policy issue and extend a decision-maker's capacity for judgment. The research findings might include a recommended course of action. Policy researchers typically think of their research agendas in terms of policy relevance. A criticism of policy research is that the researcher's need for methodological precision and comprehensive analysis is often not compatible with the decision-maker's need for the immediate use of the results (Prewitt, Schwandt, & Straf, 2012).

Finally, Hanushek named a third type of research, policy analysis, that is linked directly to the policy process. While policy analysis might employ some of the same methods of

disciplinary and policy research, policy analysis typically has a short timeframe both in its formulation and utility and is client-oriented in that its usefulness is determined by a managerial decision-maker in the policy process (Kraft & Furlong, 2010). Also, unlike disciplinary and policy research, policy analysis tends to be reactive rather than proactive, which means it is often deployed in the evaluation of policies or programs after they have been implemented. The policy analyst, therefore, is generally situated closer to the political action than the disciplinary or policy researcher.

Hanushek described the relationship between these different types of research as an “informational hierarchy.” Briefly, disciplinary research from which come theories and models sets the stage for policy research. The approaches and particularly the findings of policy research can become data for policy analysis. Finally, in policy analysis, research findings are frequently translated into the specifics of policy. The current focus on evidence-based policymaking, however, might blur the boundaries between these categories. Policy and even disciplinary researchers are attempting to improve the policy relevance and uptake of their work by becoming more politically astute, by responding to current policy issues, and by presenting their research outputs in a format that has more utility to decision-makers. Hence, in light of this movement toward evidence-based policymaking the relationship between these types of research and, consequently, the policy research market might be thought of as a continuum rather than a discrete hierarchy (see Figure 1.1).

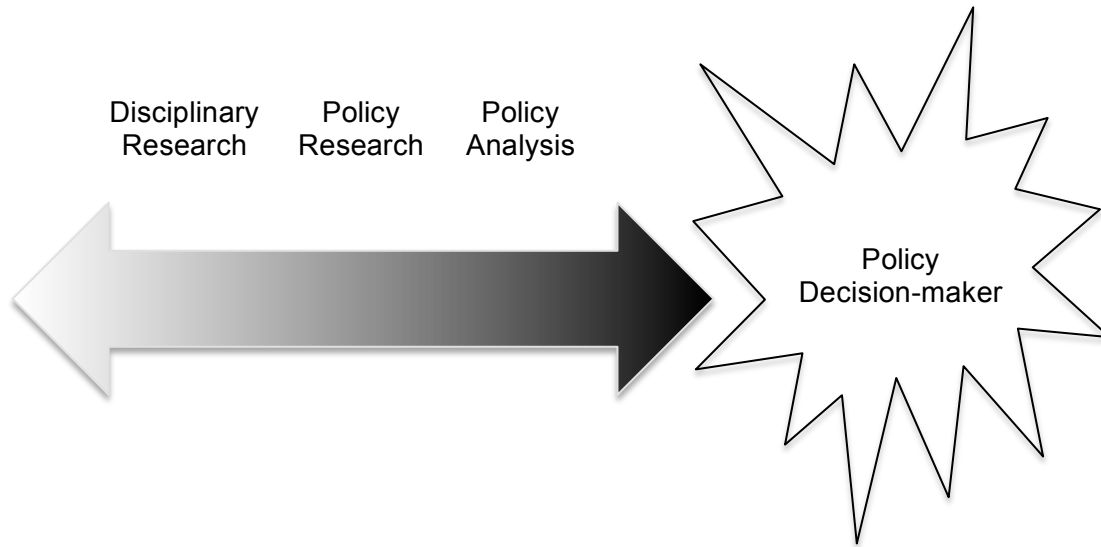


Figure 1.1. Relationship between three types of policy research and the policy decision maker. The informational hierarchy as described by Hanushek (1990) is redefined as a continuum.

1.2 APPLIED POLICY RESEARCH METHODS

Despite ambiguity in the literature on the methodological commitments to evidence-based policy, there should not be a prescriptive account of methods for policy research. Reliance on a few mainstay designs will likely result in insufficient evidence to address policy problems. Ultimately, the choice of research methods should be linked to the question of interest. In this dissertation, I use what are collectively known as applied policy research methods to address the research questions for each of my studies. Applied policy research is distinguished from basic or theoretical research through its requirements to meet specific information needs and its potential for actionable outcomes (Ritchie & Spencer, 1994). Quantitative research methods are typically favored in applied policy research; however, qualitative research methods are being used with more frequency as a standalone approach. I describe some of the merits of both qualitative and quantitative research methods for applied policy research.

For researchers in the social and applied sciences, there is a clear (but debated) hierarchy of evidence. For example, according to the hierarchy of evidence, quantitative experimental evidence (i.e., from randomized controlled trials) is considered high-quality evidence whereas observational data is low-quality evidence (Dijkers, Murphy, & Krellman, 2012). Academic researchers involved in evidence-based policymaking have adhered, for the most part, to this hierarchy, which might explain why qualitative research methods as a source of information have been undervalued and underutilized in applied policy research. At one time, the use of qualitative research methods was seen as acceptable only if it was confined to a developmental role for quantitative methods of inquiry. Increasingly, however, qualitative research methods are used independently in policy research.

Sallee and Flood (2012) identified what they consider the three strengths of qualitative research methods to inform policy. First, a hallmark of qualitative research methods is a focus on the context in which the phenomenon under study occurs. Policy choices themselves are context dependent. Qualitative methods, therefore, can be used to facilitate the researcher's and decision-maker's understandings of the potential real world implications of the policy (Nolen & Talbert, 2011). The second advantage of qualitative research methods is the researcher makes use of an emergent design. The researcher can respond to changes and capture what is meaningful from the perspective of the research respondents. This speaks to policy relevance. Third, all qualitative research is descriptive by nature. As such, the researcher can capture stories that are readily understandable and accessible to those outside the academic community including decision-makers, who may use the stories as rhetorical devices when advocating for a particular policy position. Another notable strength of qualitative research not mentioned by Sallee and Flood is the co-creation of data between the respondent and researcher. Termed

“knowledge brokerage” in evidence-based policy, this is not a new concept in the traditions of qualitative research. As it relates to evidence-based policymaking, knowledge brokerage is perceived as a more democratic and potentially useful exchange of information (Oliver, Lorenc, & Innvaer, 2014).

Conversely, the secondary analysis of quantitative data is a common method used in applied policy research. Simply put, this approach involves the analysis of data that was collected for some other purpose than the one currently being considered. Cheng and Phillips (2014) described two general approaches for analyzing extant data: the research question-driven approach and the data-driven approach. According to the authors, in the research question approach, the researcher formulates a question or an a priori hypothesis and then looks for a suitable dataset to address the question. In the data-driven approach, the researcher examines variables in an available dataset and decides what questions can be answered. The merits of secondary analysis of quantitative data are quite obvious and require little explanation. This approach is low cost, requires less time for the researcher to collect data, and avoids duplication of effort by making use of available data.

1.3 SUMMARY OF STUDIES

The general purpose of this three-article dissertation is to investigate public policy issues salient to people with disabilities, their families, and healthcare providers. Each study in this dissertation fits somewhere in Hanushek’s framework and was conducted using applied policy research methods. The first article in the dissertation, “The Relationship between Psychological Assets and Employment in Individuals with Physical Disabilities,” was designed as a secondary analysis of existing data. Using cross-sectional survey data collected as part of the Rehabilitation Research and Training Center (RRTC) on Healthy Aging and Physical Disability,

the purpose of this study was to determine the relative importance of resilience and self-efficacy in explaining employment status for people with physical disabilities after controlling for sociodemographic and disease covariates. Data were analyzed using multiple logistic regression with sequential predictor entry. This study was conducted as an initial step in identifying individuals who may benefit from interventions to strengthen their psychological assets with regard to employment. As such, it is considered disciplinary research. The study findings have some implications for policy; however, more evidence is needed to confirm and extend these findings.

The second article in the dissertation, “Durable Medical Equipment Reuse and Recycling: Uncovering Hidden Opportunities for Reducing Medical Waste,” was designed as a basic interpretive qualitative study. The purpose of this study was to investigate the phenomenon of durable medical equipment (DME) reuse and recycling in the context of a healthcare delivery system as a first step in understanding how hospitals manage DME waste and how healthcare providers conceive of their role in preventing DME waste. The findings include descriptions of the process for patients to acquire both new and used DME and environmental sustainability practices for reducing DME waste generated by hospitals. This study was conceived as policy research and addresses issues regarding patient access to healthcare services and supports and environmental sustainability in healthcare. We identify the potential barriers and facilitators to a hospital-based DME reuse program and discuss the fostering of professional and organizational behaviors to support DME reuse and recycling initiatives.

The third and final article in the dissertation, “The Experience of Homecare Providers and Beneficiaries with Enhanced Training Requirements in Washington State,” was also designed as a basic interpretive qualitative study. This study was conducted as the first phase in

a potential multiphase study to develop a battery of self-report instruments for evaluating consumers' satisfaction with their homecare and for assessing health-related quality of life outcomes presumed to improve with quality caregiving. This study uses exploratory research to identify domains relevant to a new homecare aide training and certification program that was mandated by Washington State Initiative 1163. The findings include a description of the components of person-centered delivery of care and an assessment of the homecare aide training from the perspective of some consumers and homecare aides in Washington State. This study was initially conceived as policy research and addresses issues regarding Medicaid Home- and Community-Based Services waiver programs and state policy innovations. Although we were not tasked with a formative evaluation of the new homecare aide training, we provide a snapshot of how respondents experienced the training and their perspectives on how best to modify or revise the training. Therefore, in consideration of this evaluative component, this study might be situated between policy research and policy analysis on the continuum (see Figure 1.2).

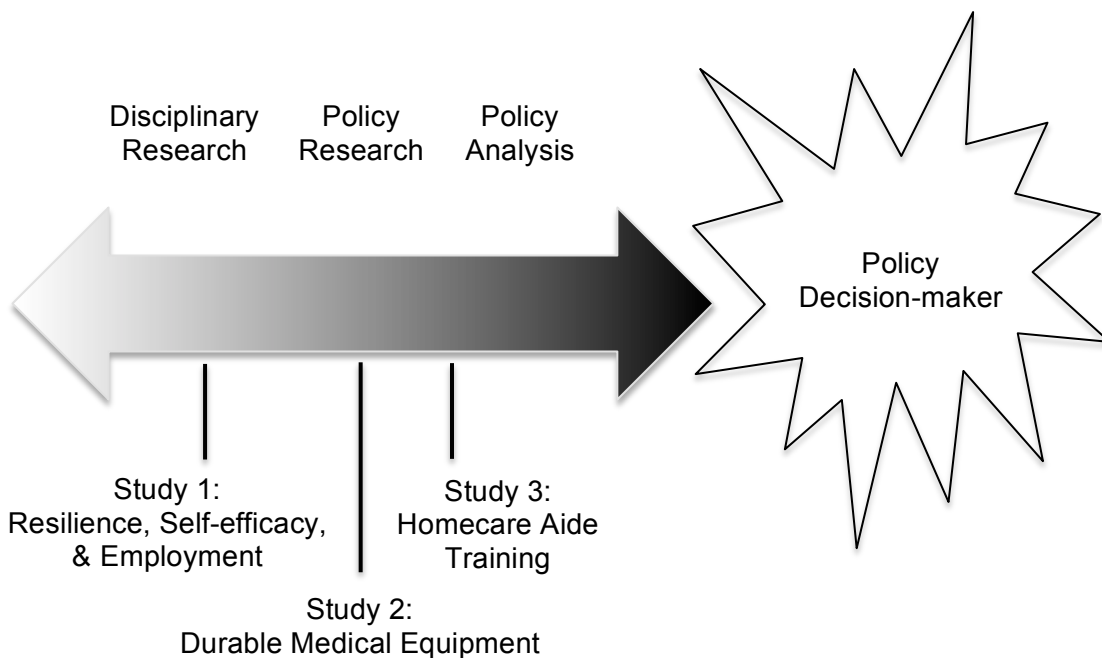


Figure 1.2. Location of the three studies in this dissertation on the policy research continuum.

1.4 FLOW OF DISSERTATION

This is a three-article dissertation that incorporates the independent studies format. Following the brief introduction and overview in chapter one, chapters two through four are comprised of three complete articles in various stages of preparation and submission to peer-reviewed journals. Each article contains an introduction, background, methods, findings, discussion, conclusion, and reference list. In accordance with requirements of the PhD Program in Rehabilitation Science at the University of Washington, each article is accompanied by a plain language summary in the form of a policy memo (see Appendices A, B, and C). Policy memos are unlike academic research in that the main purpose is to provide a brief analysis on a policy issue and recommendations for action, and they are directed toward a specific policy stakeholder. The policy memos are not a direct translation of each research study, however, but an extrapolation of the findings to a related policy issue.

Chapter 2. THE RELATIONSHIP BETWEEN PSYCHOLOGICAL ASSETS AND EMPLOYMENT IN INDIVIDUALS WITH PHYSICAL DISABILITIES

2.1 ABSTRACT

The objective of this study was to determine the relative importance of resilience and self-efficacy in explaining employment status for people with physical disabilities when other sociodemographic and disease variables were also examined. A multiple logistic regression with sequential predictor entry was used to predict employment status. This study draws from extant data collected as part of the Rehabilitation Research and Training Center on Healthy Aging and Physical Disability, a longitudinal survey project exploring factors associated with participation for individuals aging with physical disabilities. Participants were individuals 18 to 65 years of age with a diagnosis of multiple sclerosis, muscular dystrophy, post-polio syndrome, or spinal cord injury ($N = 919$). Results indicate that resilience but not self-efficacy was uniquely predictive of employment status. We found in this study preliminary evidence to suggest that rehabilitation professionals should consider the importance of a client's psychological resources with respect to employment.

2.2 INTRODUCTION

Employment plays a key role in providing individuals with economic security, social participation, and access to health insurance and healthcare. Employment also contributes to personal identity and promotes physical and psychosocial health. However, not everyone can access the benefits of employment. For example, adults with physical disabilities experience higher rates of unemployment and underemployment than the general population. According to

American Community Survey estimates for 2013, nearly 10 million people ages 18 to 64 reported an ambulatory disability and of these, only 24% were employed (Erickson, Lee, & von Schrader, 2015). This is in stark contrast to the 75% employment rate reported by people without a disability for that same year. Specific employment rates reported in the literature for adults with physical disabilities such as multiple sclerosis (MS), muscular dystrophy (MD), post-polio syndrome (PPS), and spinal cord injury (SCI) vary widely depending on the definition of employment used and the time at which employment is measured following onset of disease or injury. For example, unemployment rates ranging from 24% to 80% have been cited in the literature on employment and work loss for people with MS (Johnson, Bamer, & Fraser, 2013; Julian, Vella, Vollmer, Hadjimichael, & Mohr, 2008). Similarly, reported unemployment rates following SCI range from 26% to 78% (Lidal, Huynh, & Biering-Sørensen, 2007).

Several individual and societal level factors believed to be associated with employment status for adults with physical disabilities have been examined in previous studies. Sociodemographic factors that frequently have been associated with unemployment for this population include older age (Hirsh, Molton, Johnson, Bombardier, & Jensen, 2009; Krause, Kern, Horntrich, & Ziemssen, 2013), female gender (Minis et al., 2010; Sweetland, Howse, & Playford, 2012), nonwhite race (Krause, Saunders, & Staten, 2010), and disability cash assistance (Chiu, Chan, Bishop, Da Silva Cardoso, & O'Neill, 2013; Ottomanelli, Sippel, Goetz, & Ciper, 2011), whereas higher levels of education pre- and post-injury/disease (Krause & Reed, 2009; Sweetland, Howse, & Playford) has been associated with employment. In addition, the presence of specific symptoms such as pain (Shahrbanian, Auais, Duquette, Anderson, & Mayo, 2013), fatigue (Johnson, Yorkston, Klasner, Kuehn, Johnson, & Amtmann, 2004), depression (Burns, Boyd, Hill, Hough, & Elliott, 2010; Honarmand, Akbar, Kou, & Feinstein,

2011), anxiety (Tan-Kristanto & Kiropoulos, 2015), perceived cognitive dysfunction (Krause, Kern, Horntrich, & Ziemssen, 2013), and physical impairment (Moore, Harding, Clarkson, Pickersgill, Wardle, & Robertson, 2013) also have been found to be associated with unemployment. Whether someone is employed or not also has been related to social and environmental factors such as perceived discrimination or support by employers and the local community (Neath, Roessler, McMahon, and Rumrill, 2007; Nevala, Pehkonen, Koskela, Ruusuvoori, & Anttila, 2015).

Beyond these sociodemographic and disease factors, there has been a recent interest in the relationship between psychological assets and employment outcomes for people with physical disabilities. Unlike many sociodemographic and disease factors, psychological assets are potentially modifiable. Psychological assets such as self-reliance (Burns, Boyd, Hill, Hough, & Elliott, 2010), degree of motivation (Ottomanelli & Lind, 2009), and internal locus of control (Krause & Broderick, 2006) have been positively correlated with employment for this population. The research on psychological assets and employment is limited, however, and more evidence is needed to confirm and extend these findings.

Using data from a longitudinal survey project exploring factors associated with participation for individuals aging with MS, MD, PPS, and SCI living in the United States, the purpose of the present study is to determine the relative importance of resilience and self-efficacy in explaining employment status when other sociodemographic and disease variables are also examined. In this analysis, we seek to answer the following research questions:

1. What are the sociodemographic and disease characteristics of adults with physical disabilities?

2. What are the unique effects of resilience and self-efficacy on employment status for adults with physical disabilities after controlling for covariates?

Because a well accepted theory of psychological assets and employment has not yet been formulated, we used the constructs of resilience and self-efficacy as a conceptual guide for this study. Based on the extant literature supporting these two factors as psychological assets, we hypothesized that individuals who are employed would report higher levels of resilience and self-efficacy than those who are not employed. This study is an initial step in identifying individuals who may benefit from interventions to strengthen their psychological assets with regard to employment.

2.3 BACKGROUND

2.3.1 *Resilience and Self-efficacy*

The construct of resilience has been defined and operationalized in a variety of ways by researchers. In the early waves of research in this area, resilience was considered a biological characteristic or personality trait (e.g., hardiness or invulnerability to adversity) that some individuals have and others lack (Werner & Smith, 1982). In studies where resilience has been conceptualized as a steady state quality, the construct has been operationalized as an outcome. Much of the research using an outcome-based approach involves, “the study of responses to acutely adverse but time-limited stressors” (Mancini and Bonanno, 2010 in Kolar, 2011, p. 424). The authors of the Connor-Davidson Resilience Scale (CD-RISC), for example, have conceptualized resilience as a personality trait that reflects an individual’s ability to effectively cope with stress (Connor & Davidson, 2003). The CD-RISC measures resilience on five factors interpreted by the authors to mean personal competence, high standards, and tenacity (factor 1), trust in one’s instincts, tolerance of negative affect, and strengthening effects of stress (factor 2),

positive acceptance of change and secure relationships (factor 3), control (factor 4), and spiritual influences (factor 5). Although the CD-RISC is the best-known instrument for assessing resilience, some have claimed that the instrument was developed without a clear explication of the theoretical framework (Windle, Bennett, & Noyes, 2011). Moreover, the psychometric quality of the instrument has been the subject of recent investigations (Arias González, Crespo Sierra, Arias Martínez, Martínez-Molina, & Ponce, 2015).

Increasingly, researchers have treated resilience as a dynamic process of adaptation that involves the interaction between a host of risk and protective factors across individual, social, and societal levels (Kolar, 2011; Luthar, Cicchetti, & Becker, 2000). Protective factors have been defined by resilience researchers as both internal assets of the individual (e.g., high self-esteem) and external strengths in a system (e.g., health insurance) that are thought to moderate the impact of adversity on adaptation. Conversely, risk factors have been defined as measurable characteristics of individuals (e.g., low self-esteem) and their environments (e.g., lack of jobs) thought to predict negative outcomes (Kolar, 2011; Wright, Masten, & Narayan, 2013). Implicit in the conception of resilience as a dynamic process is the understanding that an individual may be resilient at certain times and not at others depending on the relative strength of protective factors compared to risk factors at the given moment (Wright, Masten, & Narayan, 2013). Few instruments have been developed where resilience has been operationalized as a dynamic process. For example, the Youth Resiliency: Assessing Developmental Strengths survey (Donnon, Hammond, & Charles, 2003) and the California Healthy Kids Survey (Sun & Stewart, 2007) were designed to examine resilience in school-age youth and include items on both individual-level factors and other systems of influence such as school and the wider community. However, these instruments scored poorly in an assessment of their psychometric

properties by Windle and colleagues (2011) who also commented that the scales were not designed to look at change within individuals over time. There are no published instruments for adult populations that take a process-based approach to measuring resilience.

Arguably, the definition and operationalization of self-efficacy has been subject to less debate in the scholarly literature. The concept of self-efficacy first emerged from social learning theory and has been defined as the degree of confidence in an individual's ability to perform behaviors related to a specific condition (Bandura, 1977). Important to the concept of self-efficacy is that perceived versus actual ability is a stronger predictor of one's achievement of a desired outcome. As the study of self-efficacy evolved, this construct, like resilience, was re-conceptualized as a dynamic interplay between personal, behavioral, and environmental influences (Bandura, 1986). Self-efficacy has been operationalized in most instruments as an individual-level protective factor that enhances adaptation. In the literature, self-efficacy and resilience are frequently examined together. For example, in a meta-analysis of demographic and psychological variables related to resilience in nonclinical populations (Lee et al., 2013), of all the protective factors examined in this study self-efficacy was found to have the strongest relationship with resilience. This particular finding is not surprising given the authors purposefully selected for inclusion only those studies that measured resilience using the CD-RISC and the Resilience Scale for Adults (Friborg, Hjemdal, Rosenvinge, & Martinussen, 2003), and self-efficacy is thought to be closely related to the concept of personal competence that makes up one of the subscales of the CD-RISC (Rees, Breen, Cusack, & Hegney, 2015). A more recent review of resilience and physical illness (Stewart & Yen, 2011) found a significant relationship between self-efficacy and resilience across disease categories. However, in only two

of the reviewed studies was resilience measured directly; in the others, factors thought to be indicators of resilience such as psychological and physical well-being were measured.

2.3.2 *Psychological Assets and Rehabilitation*

Guccione (2014) noted that a client's resilience and self-efficacy are rarely evaluated in the context of the rehabilitation setting. Psychological assets have been understudied in people with chronic conditions and traumatic injuries despite evidence to support strong relationships between resilience and self-efficacy and improved psychosocial and physical functioning (White, Driver, & Warren, 2008). Research on psychological assets and the rehabilitation of people with physical disabilities has been conducted largely using an outcome-based approach to identify characteristics associated with people who maintain functionality in the face of adversity. For example, Silverman and colleagues (2015) found that resilience is associated with improved functional outcomes such as depressive symptoms, social participation, and physical functioning in individuals aging with physical disabilities. In a study on psychological factors and adjustment outcomes in those newly diagnosed with MS (Tan-Kristanto & Kiropoulos, 2015), the authors reported that lower levels of personal competence (measured on the CD-RISC subscale) significantly predicted both depressive and anxiety symptoms. Psychological resources also have been examined in individuals with SCI (Peter, Müller, Cieza, & Geyh, 2011), and the authors found evidence for the relationship of self-efficacy with better mental health outcomes and higher subjective well-being. While strengthening psychological resources to support successful adjustment to disability is an aim of rehabilitation programs, Peter and colleagues identified few intervention studies of acceptable quality for enhancing these resources.

Beyond improving their psychosocial and physical functioning post onset of disease or injury, many individuals with physical disabilities have the goal of maintaining or regaining employment. As discussed previously, there is a paucity of studies on psychological assets and employment outcomes for people with physical disabilities. For example, in a review of 118 peer-reviewed studies on the variables and strategies related to the successful employment of people with disabilities (Saunders, Leahy, McGlynn, & Estrada-Hernández, 2006) there were no studies on resilience or self-efficacy. Interest in the relationship between psychological assets and employment status in people with disabilities is recent, and further research on possible areas of intervention that might keep individuals with physical disabilities employed longer is clearly needed.

2.4 METHODS

2.4.1 *Participants and Procedure*

The present study draws from extant data collected as part of the Rehabilitation Research and Training Center (RRTC) on Healthy Aging and Physical Disability. Eligible individuals were 18 years of age or older, were able to read and understand English, and self-reported a physician's diagnosis of MS, MD, PPS, or SCI. Project year five data, the most current dataset at the time of this study, was analyzed. Between October 2014 to May 2015, individuals with MS, MD, PPS, and SCI were recruited through invitation letters sent to disability-specific research registries (e.g., the University of Washington Participant Pool and the University of Rochester MD Registry), invitation letters to former research participants at the University of Washington, and web and print advertisements. Individuals who were eligible and interested in participating were either mailed a self-report paper questionnaire or directed to an online version of the questionnaire. Questionnaires were sent to 1,949 individuals, of which 1,582 were completed

and returned to the researchers. Nine questionnaires were determined to be invalid, because three individuals incorrectly reported a diagnosis of MS and six individuals returned questionnaires after the dataset had been finalized ($N = 1,573$). Consistent with previous studies on employment in people with physical disabilities (Botticello, Chen, & Tulsy, 2012; Chiu, Chan, Bishop, Da Silva Cardoso, & O'Neill, 2013), individuals who were older than the retirement age of 65 years were excluded from the analysis ($n = 654$). Therefore, complete data from $N = 919$ individuals were used for analyses.

2.4.2 *Statement of Ethics*

The Institutional Review Board at the University of Washington reviewed and approved procedures for the primary study. Accordingly, all applicable institutional and governmental regulations concerning ethical use of human subjects were followed during the course of this research. Participants were given a \$25 honorarium upon study completion.

2.4.3 *Measures*

Survey data was collected on sociodemographic and disease characteristics. Variables included in this analysis are chronological age, gender, marital status, race, education level, disability benefits, and employment status. Participants also completed a battery of self-report measures. The following measurement instruments were selected for inclusion in this analysis: the CD-RISC-10; the UW-CORR Self-Efficacy Scale for Disability Management (UW-SES); the Patient-Reported Outcomes Measurement Information System (PROMIS®, www.nihpromis.org) for pain interference, fatigue, depression, anxiety, sleep disturbance, and physical function; and the Quality of Life in Neurological Disorders (Neuro-QoL) for cognitive function. Each measurement system is briefly described

2.4.3.1 Resilience.

Resilience was measured using the short-form (10-item) version of the CD-RISC-10 (Campbell-Sills & Stein, 2007; Connor & Davidson, 2003). This questionnaire assesses the extent to which the respondent is able to adapt and deal with change and stress on a 5-point scale ranging from “Not true at all” (0) to “True nearly all the time” (4). Summary scores range from 0 to 40 points, and higher scores indicate more of the concept being measured. The CD-RISC-10 demonstrates adequate reliability and validity in a variety of samples including individuals with physical disabilities (Kilic, Dorstyn, & Guiver, 2013) and older adults (Jeste et al., 2013).

2.4.3.2 Self-efficacy.

Self-efficacy was measured using the short form (6-item) version of the UW-SES (Amtmann, Bamer, Cook, Askew, Noonan, & Brockway, 2012). This questionnaire assesses the extent to which a respondent is confident in managing challenges related to physical disability on a 5-point scale ranging from “Not at all” (1) to “Completely” (5). The final score is represented by a *t*-score, a norm-referenced standardized score, with a mean of 50 and a standard deviation (SD) of 10. There is evidence of the validity and reliability of the UW-SES in older adults with physical disability (Amtmann, Bamer, Yorkston, & Smith, 2014).

2.4.3.3 Pain interference.

Pain interference was measured using the PROMIS Pain Interference Short Form 4a (Amtmann et al., 2010; Revicki et al., 2009), which assesses pain impact in key areas of functioning, including daily and social activities. Pain interference is measured on a 5-point scale ranging from “Not at all” (1) to “Very much” (5). All the PROMIS instruments selected for this study use a 7-day recall period. The final score for all PROMIS measures is represented

by the *t*-score, a norm-referenced standardized score with a mean of 50 and a SD of 10. There is evidence of the validity and reliability of the PROMIS pain interference item bank in individuals with MS (Askew, Kim, Chung, Cook, Johnson, & Amtmann, 2013).

2.4.3.4 Fatigue.

Fatigue was evaluated by questions from the PROMIS Fatigue Short Form 4a (Amtmann, Cook, Bamer, Roddey, Kim, & Kraft, 2011). Respondents are asked to rate their experience of fatigue and the impact of fatigue on physical, mental and social activities. Fatigue is measured on a 5-point scale ranging from “Not at all” (1) to “Very much” (5). There is evidence of the validity and reliability of the PROMIS fatigue short form in individuals with MS (Bamer, Cook, Roddey, & Amtmann, 2009; Cook, Bamer, Roddey, Kraft, Kim, & Amtmann, 2012).

2.4.3.5 Depression.

Depression was measured using the PROMIS Emotional Distress Depression Short Form 4a (Pilkonis, Choi, Reise, Stover, Riley, & Cella, 2011), which assesses negative mood and negative views of self. Depression is measured on a 5-point scale ranging from “Never” (1) to “Always” (5). There is evidence of the validity and reliability of the PROMIS depression item bank in individuals with MS (Amtmann et al., 2014).

2.4.3.6 Anxiety.

Anxiety was measured using the PROMIS Emotional Distress Anxiety Short Form 4a (Pilkonis, Choi, Reise, Stover, Riley, & Cella, 2011), which assesses fear, anxious misery, hyperarousal, and somatic symptoms related to arousal. Anxiety is measured on a 5-point scale ranging from “Never” (1) to “Always” (5).

2.4.3.7 Sleep disturbance.

Sleep disturbance was measured using the PROMIS Sleep Disturbance Short Form 4a (Buysse et al., 2010; Yu et al., 2012), which assesses both sleep quality and sleep intensity. Sleep quality, for example, is measured on a reverse-coded 5-point scale ranging from “Very poor” (5) to “Very good” (1). There is evidence of the validity and reliability of the PROMIS sleep disturbance short form in individuals with MS and SCI (Fogelberg, Vitiello, Hoffman, Bamer, & Amtmann, 2015).

2.4.3.8 Physical function.

Physical function was measured using the PROMIS Short Form version 1.0 Physical Function Samples with Mobility Aid Users 11a (Rose et al., 2008). Physical function is a measure of self-reported capability of one’s upper and lower extremities and of activities of daily living. Physical function is measured on a 5-point scale ranging from “Without any difficulty” (5) to “Unable to do” (1). There is evidence of the validity and reliability of the PROMIS physical function item bank in individuals with spinal disorders (Hung et al., 2014) and individuals with MS (Cook, Dudgeon, Roddey, Johnson, Bamer, & Amtmann, 2009).

2.4.3.9 Cognitive function.

Cognitive function was assessed using the Neuro-QoL Measures Version 1.0 Applied Cognition-Executive Function and Applied Cognition-General Scales (Gershon et al., 2012). The Neuro-QoL measurement system includes health-related quality of life self-report assessment tools that span physical, social, emotional and cognitive functioning for individuals with neurological disorders. Some items in the cognitive function sub-domains use “In the past 7 days” as context while others use the lead-in phrase “How much difficulty do you currently

have.” The final score is represented by the *t*-score, a norm-referenced standardized score with a mean of 50 and a SD of 10. There is evidence of the validity and reliability of the Neuro-QoL short forms in individuals with MS (Miller et al., 2015).

2.5 DATA ANALYSIS PLAN

Analyses were carried out using the Statistical Package for the Social Sciences (SPSS) Statistics® version 23.0. First, data were screened for violation of statistical assumptions. Second, data were analyzed using multiple logistic regression with sequential predictor entry. Sequential predictor entry specifically allows for testing incremental improvement in model fit as predictors are added to the model. For ease of interpretation gender (1 = male, 0 = female), marital status (1 = married/cohabitating, 0 = not married/cohabitating), race (1 = White, 0 = not White), education level (1 = college, 0 = no college), and disability benefits (1 = yes, 0 = no) were dummy coded; and age and resilience were standardized. Chronological age, gender, marital status, race, education level, and disability benefits were entered in Block 1; pain interference, fatigue, depression, anxiety, sleep disturbance, physical function, and cognitive function in Block 2; and resilience and self-efficacy in Block 3 with employment status (1 = employed; 0 = not employed) as the outcome.

2.6 RESULTS

2.6.1 *Univariate Analysis*

The sociodemographic and disease characteristics for the entire sample and stratified by employment status are summarized in Table 2.1. The average age of participants was about 54 years ($SD = 9.06$). Almost two thirds of participants (63%) were women. Approximately 64% were married or living with a partner. For statistical purposes racial categories were collapsed

into White (86%) and not White (14%). In terms of education level, 78% reported attending college. Most participants (60%) were receiving some type of disability cash assistance.

Finally, about 33% of participants indicated that they were employed full or part time, while 67% reported they were not employed at the time of the survey.

Table 2.1.

Sociodemographic and Disease Characteristics by Employment Status

Measure	Total	Employed	Not Employed
Sample Size	919	301	618
Gender ^a			
Male	343 (37)	109 (36)	234 (38)
Female	575 (63)	192 (64)	383 (62)
Marital status ^a			
Married/Cohabiting	584 (64)	212 (70)	372 (60)
Not married/Cohabiting	334 (36)	89 (30)	245 (40)
Race ^a			
White	787 (86)	271 (90)	516 (84)
Not White	130 (14)	29 (10)	101 (16)
Education level			
College	715 (78)	267 (89)	448 (72)
No college	204 (22)	34 (11)	170 (28)
Disability benefits ^a			
Yes	562 (61)	63 (21)	499 (81)
No	353 (39)	238 (79)	115 (19)
Age	53.52±9.06	50.65±9.88	54.93±8.29
Pain	56.22±10.03	52.79±9.08	57.89±10.05
Fatigue	55.70±10.78	53.37±10.13	56.83±10.92
Depression	52.61±9.05	50.47±8.35	53.65±9.20
Anxiety	51.57±9.46	50.69±8.78	52.00±9.75
Sleep	52.10±8.47	50.54±7.81	52.86±8.68
Physical function	37.03±11.10	41.72±11.45	34.77±10.20
Cognition	48.70±9.50	51.34±8.75	47.41±9.59
Resilience	-0.06±1.02	0.17±0.90	-0.17±1.06
Self-efficacy	47.81±9.72	50.24±9.21	46.62±9.75

Note. Values are $M \pm SD$ or as n (%).

^aNumbers may not add to total due to missing data.

Point-biserial correlations and Pearson chi-square values among all variables were calculated (see Appendix D for the correlation matrix). Preliminary analyses showed no

violations to the absence of multicollinearity and singularity ($r \geq 0.90$; Tabachnick & Fidell, 2000). Additionally, none of the variables had a variance inflation factor (VIF) value above 10. Independence was assumed for this sample. Therefore, the assumptions for logistic regression were found tenable. Of the demographic variables, only gender was not significantly correlated with employment status. There was a very weak association between marital status and race with the outcome, $\chi^2(1) = 8.98, p < 0.01$ and $\chi^2(1) = 7.45, p < 0.01$, *Cramer's Vs* = 0.01. There was a weak association between education and employment, $\chi^2(1) = 30.81, p < 0.001$, *Cramer's V* = 0.18 and a moderate association between age and employment, $r_{pb} = 0.22, p < 0.001$. The association between disability benefits and employment was very strong, $\chi^2(1) = 310.35, p < 0.001$, *Cramer's V* = 0.58, which could mean that the variables are measuring the same concept (Tabachnick & Fidell, 2000).

The associations between all the disease characteristics and the outcome were statistically significant. There was an inverse relationship between pain and employment, $r_{pb} = -0.24, p < 0.001$, and a positive relationship between physical function and employment, $r_{pb} = 0.29, p < 0.001$, both of moderate strength. There were weak relationships between fatigue, depression, sleep, cognition and employment, $r_{pb} = -0.15, p < 0.001$; $r_{pb} = -0.17, p < 0.001$; $r_{pb} = -0.13, p < 0.001$; and $r_{pb} = 0.19, p < 0.001$ respectively. The association between anxiety and employment was very weak, $r_{pb} = -0.07, p < 0.05$.

Finally, the associations between the psychological factors resilience and self-efficacy with employment were also statistically significant yet weak, $r_{pb} = 0.16, p < 0.001$ and $r_{pb} = 0.18, p < 0.001$.

2.6.2 *Multivariate Analysis*

A multiple logistic regression with sequential predictor entry was used to predict

employment status using $N = 884$ individuals with physical disabilities. Thirty-five individuals were excluded from the logistic regression analysis due to missing data. As shown in Table 2.2, chronological age, gender, marital status, race, education level, and disability benefits were entered in Block 1 and were found to have a significantly better model fit than the null model with no predictors, $\chi^2 = 364.73$, $p < 0.001$, Nagelkerke Pseudo- $R^2 = 0.47$ (correct classification hit rate of 81%, which was better than the null model's hit rate of 67%). Block 2 which included pain interference, fatigue, depression, anxiety, sleep disturbance, physical function, and cognitive function improved model fit to the data, χ^2 change = 381.07, $p < 0.001$, Nagelkerke Pseudo- $R^2 = 0.49$ (correct classification hit rate increased to 82%).

Finally, Block 3, which included resilience and self-efficacy, improved model fit to the data, χ^2 change = 385.14, $p < 0.001$, Nagelkerke Pseudo- $R^2 = 0.49$, and sensitivity and specificity were 74% and 87% (correct classification hit rate increased slightly to 83%).

Table 2.2

Model Fit Results for Employment Status

	χ^2 change		χ^2 total		Pseudo R^2	HR
Block 1	--		364.73	***	0.47	0.81
Block 2	16.34	*	381.07	***	0.49	0.82
Block 3	4.07		385.14	***	0.49	0.83

Note. $N = 884$. Block 1 chi-square change test $df = 6$; Block 2 $df = 13$; Block 3 $df = 15$.

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

The coefficients from a logistic regression model are in log-odd units. Log odds are not a natural metric; therefore, they are not directly interpreted. For ease of interpretation, log odds were converted to predicted probabilities. Results from the final model with all predictors indicated that chronological age was uniquely predictive of employment after controlling for disease characteristics, $b = -0.44$, ($SE = 0.10$), $Wald(1) = 21.12$, $p < 0.001$ (Table 2.3).

Individuals who were at least one SD above average on age had an 18% predicted probability of

being employed, and those who were at least one *SD* below average on age had a 34% predicted probability of being employed. Marital status also was uniquely predictive of employment, $b = -0.47$, ($SE = 0.22$), $Wald(1) = 4.63$, $p < 0.05$. Individuals who were married had an 18% predicted probability of employment. Education was uniquely predictive of employment, $b = 0.84$, ($SE = 0.25$), $Wald(1) = 11.00$, $p < 0.01$. Individuals who had attended college had a 44% predicted probability of employment. Disability benefits was uniquely predictive of employment, $b = -2.70$, ($SE = 0.22$), $Wald(1) = 156.13$, $p < 0.001$. Individuals who received disability benefits had a 2% predicted probability of being employed. Of the disease variables, only anxiety was uniquely predictive of employment, $b = 0.03$, ($SE = 0.02$), $Wald(1) = 4.23$, $p < 0.05$). Individuals who were at least one *SD* above the mean on anxiety had a 26% predicted probability of being employed, and those who were at least one *SD* below the mean on anxiety had a 25% predicted probability of being employed. Finally, although self-efficacy was not significant ($b = -0.02$, ($SE = 0.02$), $Wald(1) = 1.33$, $p > 0.05$), resilience was uniquely predictive of employment status, $b = 0.29$, ($SE = 0.14$), $Wald(1) = 4.05$, $p < 0.05$. Therefore, individuals who were at least one *SD* above the mean on resilience had a 31% predicted probability of being employed, and those who were one *SD* below the mean on resilience had a 20% predicted probability of being employed.

Table 2.3

Log-Odds for the Associations between Predictor Variables and Employment Status

	Block 1		Block 2		Block 3	
	<i>b</i>	<i>e^b</i>	<i>b</i>	<i>e^b</i>	<i>b</i>	<i>e^b</i>
<i>Coefficients</i>						
Intercept	-0.19	0.83	-1.91	0.15	-1.08	0.34
Gender	0.32	1.37	0.33	1.39	0.32	1.37
Marital status	-0.40	0.67	-0.47 *	0.63	-0.47 *	0.63
Race	0.34	1.41	0.29	1.34	0.26	1.29
Education level	0.96 ***	2.60	0.89 ***	2.40	0.84 **	2.31
Disability benefits	-2.93 ***	0.05	-2.69 ***	0.07	-2.70 ***	0.07
Age	-0.45 ***	0.64	-0.41 ***	0.66	-0.44 ***	0.65
Pain			-0.01	0.99	-0.01	0.99
Fatigue			-0.00	1.00	-0.00	1.00
Depression			-0.02	0.98	-0.01	0.99
Anxiety			0.03	1.03	0.03 *	1.03
Sleep			0.00	1.00	0.00	1.00
Physical function			0.02	1.02	0.02	1.02
Cognition			0.03	1.03	0.02	1.02
Resilience					0.29 *	1.33
Self-efficacy					-0.02	0.98

Note. $N = 884$. Employment dummy coded with 1 = employed, 0 = not employed; Gender dummy coded with 1 = male, 0 = female; Marital status dummy coded with 1 = married/cohabitating, 0 = not married/cohabitating; Race dummy coded with 1 = White, 0 = not White; Education level 1 = college, 0 = no college; Disability benefits dummy coded with 1 = yes, 0 = no.

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

2.7 DISCUSSION

The purpose of the study was to examine whether resilience and self-efficacy are significant predictors of employment in adults with physical disabilities after controlling for the effect of sociodemographic and disease covariates. Overall, the study yielded several significant findings. We found that resilience but not self-efficacy was uniquely predictive of employment status. This finding, in part, supports our hypothesis that individuals higher on resilience are more likely to be employed. Education also was uniquely predictive of employment in this

study. Not surprising, individuals with higher levels of education were more likely to be employed, which has been a consistent finding in both MS and SCI populations (Krause & Reed, 2009; Ottomanelli & Lind, 2009; Sweetland, Howse, & Playford). Other sociodemographic factors that were uniquely predictive of employment in this study were age and marital status. The finding that higher age, considered a risk factor, is associated with unemployment is consistent with previous studies in this population. In addition, although we found that those who were married or cohabitating were less likely to be employed, findings from previous studies have been mixed (Botticello, Chen, & Tulskey, 2012; Saunders, Leahy, McGlynn, & Estrada-Hernández, 2006). Finally, although receiving disability benefits was uniquely predictive of employment status this factor might be tautological with employment in that people with disabilities become eligible for Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) primarily through unemployment or low income.

The finding that resilience was a significant predictor of employment status after controlling for sociodemographic and disease factors implies that the internal and external resources of resilience should be considered in rehabilitation research and practice. As discussed previously, research on the relationship between resilience and functional and employment outcomes for people with physical disabilities could be enhanced by a clearer and more differentiated conceptualization and operationalization of the construct. Windle and colleagues (2011) observed that most resilience measures were not developed with an explicated model of psychological resilience. This precludes the development of a theory of resilience and employment for people with physical disabilities as well as interventions to improve the psychological resilience of individuals with disabilities who are in various stages of preparing for, obtaining, or maintaining employment.

Further, contrary to the findings of previous studies (Burns, Boyd, Hill, Hough, & Elliott, 2010; Roessler & Rumrill, 1994) we found that self-efficacy was not a significant predictor of employment status after controlling for the effects of covariates. Although the shared variance between self-efficacy and the outcome was low, $r_{pb} = 0.18, p < 0.001$, there was considerable overlap between self-efficacy and resilience, depression, anxiety, and fatigue ($r = 0.69, p < 0.001$; $r = -0.57, p < 0.001$; $r = -0.48, p < 0.001$; $r = -0.46, p < 0.001$ respectively). Therefore, self-efficacy might not have contributed anything unique to employment status after accounting for the other predictors. In future studies, researchers might consider examining the association between resilience and self-efficacy and employment status in separate models.

Findings from this study should be interpreted with caution due to a number of important limitations. First, we excluded from this analysis individuals who were older than the retirement age of 65 years ($n = 654$) and of this group, 63 individuals were employed. While we are interested in examining the relationship between psychological assets and employment status in this group, we could not account for those who were over the retirement age and not working in the current logistic regression model. Also, this was a convenience sample and might not represent the entire population of people with physical disabilities. Specifically, women, non-Hispanic Whites, and individuals with post-secondary education were overrepresented in this sample. Additionally, this study was cross sectional and, as such, precludes inferences about the causal and directional relationships among variables. In a related matter, given the debate in the scholarly literature on the definition and operationalization of resilience a single-point measurement of this factor may not be representative of the patterns of the disease-related resilience process for the study participants.

2.8 CONCLUSION

We found in this study preliminary evidence to suggest that rehabilitation professionals should consider the importance of a client's psychological resources with respect to employment. To our knowledge, this is the only published study examining the association of resilience and employment status in individuals with physical disabilities. The findings from this study and previous research (Lee et al., 2013) suggest that rehabilitation researchers and providers should also be cognizant of the protective and risk factors associated with psychological assets and employment for this population. While sociodemographic factors generally are not amenable by intervention from rehabilitation professionals, a knowledge of these factors in conjunction with psychometrically sound measures of psychological assets might be used to identify individuals whose beliefs and behaviors may limit the extent to which they prepare for, obtain, or maintain employment.

Chapter 3. DURABLE MEDICAL EQUIPMENT REUSE AND RECYCLING: UNCOVERING HIDDEN OPPORTUNITIES FOR REDUCING MEDICAL WASTE

3.1 ABSTRACT

We conducted a basic interpretive qualitative study in the UW Medicine regional healthcare system for the purpose of investigating hospital practices for the management of unwanted durable medical equipment (DME) and understanding how healthcare providers conceive of their role in preventing DME waste. Study informants were targeted at the patient and healthcare systems levels. Analysis of data revealed that some UW Medicine hospitals were implementing sustainability practices to reduce DME waste generated by the healthcare facilities. This included a DME reuse program at one hospital for uninsured and low-income patients. However, we also found that healthcare providers were not educating patients on ways to sustainably manage their unwanted DME. This finding might point to a disconnect between practices to prevent DME waste and clinical decision making for patient care and merits additional investigation.

3.2 INTRODUCTION

The healthcare industry has a large and costly impact on the environment. The production and disposal of healthcare waste result in green house gas emissions and pollution, which are thought to have a substantial impact on the environment and public health (Thakur & Ramesh, 2015). Disposing of an estimated 4 billion pounds of waste into commercial incinerators and landfills annually, the U.S. healthcare industry is the second largest contributor

to landfills after the food industry (Diconsiglio, 2008). Both landfilling and incinerating waste have environmental and social costs. The decomposition of landfill waste is one of the largest sources of methane emissions resulting directly from human activity (Powell, Townsend, & Zimmerman, 2016). Medical waste incineration can also emit significant quantities of toxic pollutants into the atmosphere (National Research Council, 2000; Windfeld & Brooks, 2015). Given the increasing salience of environmental issues to public health, many healthcare facilities across the United States are attempting to reduce their environmental impact by minimizing the amount and toxicity of their waste.

Although many sectors in the healthcare industry produce medical waste, most of the research on medical waste management has been focused on hospitals. The hospital operating room, one of the largest users of medical supplies and thereby producers of healthcare waste (Kagoma, Stall, Rubinstein, & Naudie, 2012), has been the target of most healthcare greening practices. Specifically, studies have been conducted to investigate the safety of reprocessed single use medical devices (Conrardy, Hillanbrand, Myers, & Nussbaum, 2010; Hailey, Jacobs, Ries, & Polisena, 2008) and cost savings from the reprocessing of commonly used devices (Jacobs, Polisena, Hailey, & Lafferty, 2008; Kwakye, Brat, & Makary, 2011). While more healthcare facilities are implementing single use medical device reprocessing programs, the opportunity for diverting from landfill other types of procured goods, most notably DME, has received little attention.

DME is defined as a reusable item that exists primarily to provide a therapeutic benefit for individuals diagnosed with a medical condition or illness (Centers for Medicare and Medicaid [CMS], 2015). There is a wide spectrum of non-complex and complex rehabilitation technology (CRT) that falls under the CMS definition of DME including walkers, power

wheelchairs, shower benches, and hospital beds. Older adults with chronic health conditions or short-term disabilities are the primary users of DME in the United States (Centers for Disease Control and Prevention, 2015; Pressler & Ferraro, 2010). While most individuals use DME at home to support daily activities, hospitals also furnish DME during inpatient stays. Given a steady increase in the prevalence of chronic health conditions associated with an aging population, there is both an unmet need and growing demand for DME. While meeting this need is a pressing issue in healthcare, we must also consider the practical impacts of a surplus of used DME that will eventually be disposed of as landfill waste.

3.3 RESEARCH PROBLEM

The three most likely pathways for DME that is no longer needed include disposal by hospitals as medical waste, disposal by DME users as home medical waste, or diversion from these waste streams through reuse and recycling. Currently, there are no published studies on the management of DME waste or the potential impact of DME waste on the environment. Using an exploratory qualitative approach, we investigated practices for DME reuse and recycling in the UW Medicine regional healthcare system as a first step in understanding how hospitals manage DME waste and how healthcare providers conceive of their role in preventing DME waste. Our starting point for this inquiry was not at the point where unwanted DME becomes part of the waste stream. Instead, we began further upstream with healthcare providers and DME prescription and provision. To explicate this issue the following research questions were addressed:

1. What are the clinical practices and healthcare processes for prescribing and providing DME to hospital patients including those to prevent DME waste?
2. How do hospitals manage DME that is no longer needed?

3. What are the policy and procedural barriers as well as the benefits and unintended consequences for a hospital-based DME reuse program?

In this study, we describe the process for patients to acquire both new and used DME and environmental sustainability practices for reducing DME waste generated by hospitals. We also identify the potential barriers and facilitators to a hospital-based DME reuse program and discuss the professional and organizational behaviors to support DME reuse and recycling initiatives. Findings from this study might be of interest to hospital administrators, hospital sustainability and environmental health committees, and healthcare providers to inform solutions for reducing the amount of non-recoverable waste from DME that goes into the landfill.

3.4 INFORMING LITERATURE AND FRAMING IDEAS

Although U.S. hospitals implement a spectrum of sustainable practices to support the environment and human health (see Practice Greenhealth, 2015), the locus of this study is practices for medical waste management. The waste management hierarchy (U.S. Environmental Protection Agency [EPA], 1989) is a useful framework to consider the environmental effects of medical waste in general and of DME in particular as well as to guide the analysis and interpretation of our data. The EPA has proposed a four-tiered waste management hierarchy to guide waste-management decision making with the goal of reducing the amount of disposable waste that goes into the landfill. We have modified the EPA's model by uncoupling the concepts of source reduction and reuse to distinguish these practices for waste reduction in healthcare (Figure 3.1).

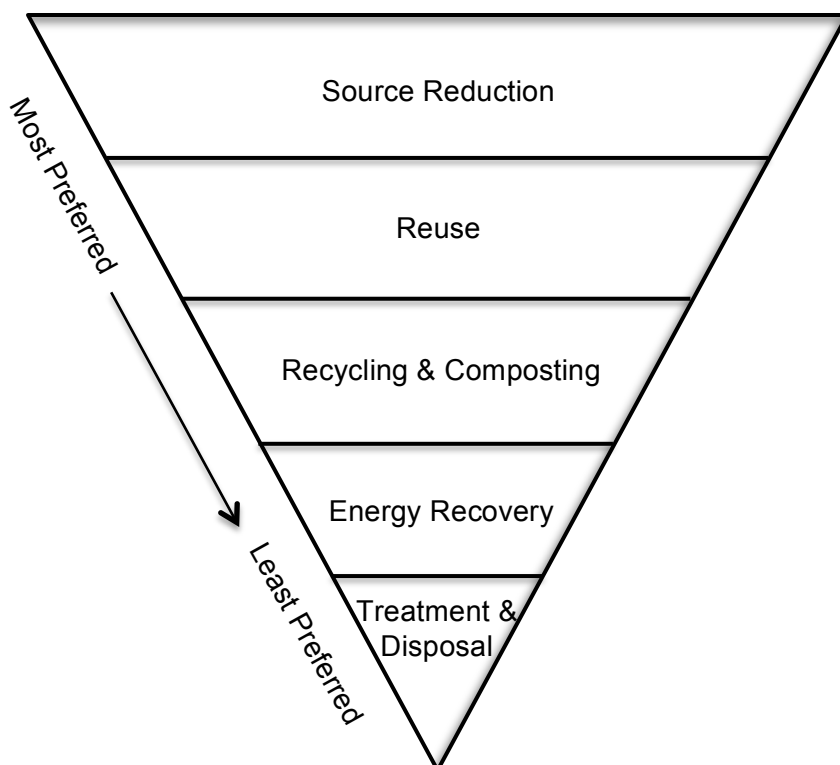


Figure 3.1. As illustrated in the figure, practices for waste management are prioritized from most to least preferred. Adapted from Sustainable Materials Management: Non-Hazardous Materials and Waste Management Hierarchy, in *EPA*, n.d., Retrieved March 16, 2016, from <https://www.epa.gov/smm/sustainable-materials-management-non-hazardous-materials-and-waste-management-hierarchy>.

We discuss the practices for waste reduction that are relevant to our study targeting research on environmental sustainability in healthcare (often referred to as *green* healthcare) and the reuse of assistive technology (AT; an umbrella term which includes any item, piece of equipment, or product system that enhances an individual's independence in activities of daily living).

3.4.1 *Source Reduction*

Source reduction implies reducing the amount or toxicity of waste at its original source (EPA, 1998; O'Leary & Walsh, 1995). There are several classifications of healthcare waste including municipal solid waste (e.g., paper and packaging), non-infectious medical waste (e.g., IV bags and tubing), regulated medical waste (e.g., blood products and infectious sharps), and

hazardous waste (e.g., pharmaceuticals and mercury containing devices; “*Reducing regulated,*” n.d.) as well as government laws and standards of practice for the management of these waste streams. Researchers have found that many U.S. healthcare facilities dispose of 70-85% of overall waste as regulated medical waste (RMW; Kaplan, Sadler, Little, Franz, & Orris, 2012; Shaner & McRae, 1996) even though most items used for patient care pose no risk of contamination. In fact, most of the waste produced by healthcare facilities is municipal solid waste consisting of mostly paper/cardboard and plastic (Kaplan, Sadler, Little, Franz, & Orris, 2012; McGain & Naylor, 2014), suggesting a high potential for recovery and recycling.

Most of the research on healthcare waste has been focused on strategies for reducing RMW and municipal solid waste including waste segregation (Laustsen, 2007). In a hospital waste management program, appropriately segregating waste is often a first step in source reduction. Waste segregation involves clearly identifying the various types of waste then following proper procedure for handling each type separately. It has been observed in many hospitals that these waste streams are often mixed together as they are generated, collected, transported and finally disposed (CGH Environmental Strategies, 1999). RMW requires special treatment and costs hospitals more money to dispose of than municipal solid waste (Kaplan, Sadler, Little, Franz, & Orris, 2012; Shaner & McRae, 1996) providing hospitals with a financial incentive to reduce their RMW. Waste segregation, therefore, has been recommended as an effective and practical way of reducing the volume of RMW generated by hospitals (Kwakye, Brat, & Makary, 2011; Melamed, 2003).

Waste segregation, however, is considered low-hanging fruit in terms of sustainable healthcare. Environmentally preferable purchasing (EPP) is another strategy for source reduction and in recent years, there has been a move by hospitals to address waste issues in the

purchasing department (Conrardy, 2010). EPP involves identifying products or services that, “have a lesser or reduced effect on human health and the environment when compared with competing products or services that serve the same purpose” (Executive Order 13693, 2015). Life cycle assessment (LCA) is a way to take into account the costs and the environmental and human health impacts associated with the production, use, and disposal of a product (Ison & Miller, 2000). LCA has been applied to some extent in the healthcare sector to improve decision making for the purchase of medical devices. For example, in an LCA case study of seven medical devices, Unger and Landis (2016) determined that reprocessing offers economic, global warming, and human health benefits over the same devices as disposables. There are very few published LCAs of DME. Cooper et al. (1996) compared the fatigue life of depot and rehabilitation manual wheelchairs. However, the LCA methods used in this study were incomplete: The researchers examined the life-cycle costs but not the potential environmental or human health impacts of these types of wheelchairs. There are no legal obligations requiring manufacturers of medical equipment to assess and provide the environmental and human health impacts of their products (McGain, Story, Kayak, Kashima, & McAlister, 2012). Therefore, while many hospitals are incorporating EPP and LCA into their acquisition process, the environmental and health data on DME is limited.

3.4.2 *Reuse*

McGain, Story, Kayak, Kashima, and McAlister (2012) have categorized medical devices into three groups by their usage: single use disposable (SUD), reusable, and reprocessed. Reusable devices can be disinfected or sterilized within the healthcare facility, whereas reprocessed devices must be cleaned, sterilized, recalibrated, or remanufactured before reuse and generally by a third party. While nearly 24% of all U.S. hospitals are reprocessing SUDs to save

money and reduce medical waste (U.S. Food and Drug Administration, 2014), more evidence is needed to establish the environmental sustainability of reprocessing SUDs versus purchasing new devices. However, there is evidence to suggest that reprocessing SUDs is less expensive and can decrease the amount of hospital waste that goes into the landfill (Kwakye, Pronovost, & Makary, 2010).

The reuse of AT predates the reprocessing of SUDs. AT reuse was borne of a need for overcoming the financial barriers to obtaining equipment by the uninsured and underinsured (Kniskern, Phillips, & Patterson, 2008) not as a solution for reducing the unwanted equipment that enters the waste stream. Typically, there are multiple sources of payment for any single item of AT including Medicare, Medicaid, and private insurance. Most health plans cover AT, which means lack of insurance is not the primary reason many people are unable to access the adaptive equipment they need. For example, a study by Cohen and Perling (2015) found that 86% of the customers who approached an AT reuse program for a mobility device had insurance with a DME benefit but were unsure how to access this benefit. Community-based AT reuse programs have offered an affordable alternative to costly equipment for seniors and people with disabilities. Presumably, the practice of AT reuse has environmental as well as social and economic benefits. Yet, we only have descriptive information on AT reuse program operations (Burke, 1997; The National Assistive Technology Technical Assistance Partnership, 2011; Walker, Walker, & Bean-Kampwerth, 2012) and the economic benefits of AT reuse programs (Li Pi Shan, Chrusch, Linassi, Sankaran, & Munchinsky, 2012). There is no empirical evidence on the environmental impact of AT reuse programs.

3.4.3 *Recycling*

The first priority, to reduce the amount of hospital waste, is in general acceptance; however, the remaining waste needs to be taken care of as efficiently as possible. Recycling is defined as, “the series of activities by which materials that are no longer useful are collected, sorted, processed, and converted into raw materials and used in the production of new products” (EPA, 1998). Materials commonly recycled by healthcare facilities include cardboard, batteries, aluminum cans, fluorescent lamps, and computer and electronic waste (Practice Greenhealth, 2015). Recycling is typically the least expensive waste stream for hospitals to manage. Studies have been conducted on the recycling potential of medical plastic wastes (Lee, Ellenbecker, & Moure-Eraso, 2002) and the environmental benefit and cost savings of single-stream recycling (Riedel, 2011). Because reuse and recycling are often used interchangeably by AT reuse organizations and in the literature, it is difficult to isolate data on the outcomes and benefits (environmental or otherwise) of AT recycling.

3.5 METHODS

This study on the hospital-based practices for managing unwanted DME was designed as a basic interpretive qualitative study (Merriam, 2009). A descriptive approach was well-suited for our purpose of exploring a phenomenon that is scarcely documented in the scholarly literature. Because the central concern of interpretative research is to construct a holistic understanding of the research context (Patton, 2002), we used a range of interconnected methods of data collection, which included interviews, a focus group, and document review.

3.5.1 *Setting and Participants*

The setting for this study was the UW Medicine regional healthcare system, which includes UW Medical Center (UWMC), Harborview Medical Center (HMC), Northwest Hospital and Medical Center (Northwest), Valley Medical Center (Valley) as well as other affiliated healthcare facilities in Seattle, Washington. UWMC and HMC have demonstrated a commitment to environmental sustainability that spans several decades. UWMC and HMC consistently have received the Top 25 Environmental Excellence Award, Practice Greenhealth's highest honor for hospitals, and recognized in the top 50 greenest hospitals in America by Becker's Hospital Review. Therefore, UW Medicine seemed an optimal setting for collecting information on hospital environmental sustainability practices.

Most research on hospital sustainability has not included participation by clinicians (McGain and Naylor, 2014). In this study, clinical therapists and physicians in the rehabilitation and acute care units were purposefully selected as informants due to their expertise in prescribing and providing DME. Other informants who, because of their positions at UW Medicine, could provide a deeper insight into the payer process for DME included clinical services managers and social workers. For descriptions of hospital process and procedure related to DME, we solicited the participation of experts in compliance, infection control, clinical engineering, and equipment surplus. In total, 11 interviews were conducted with informants who make decisions about DME at the patient-level and the systems-level.

Themes that emerged from the analysis of interview data were further refined in a focus group of seven participants. For the focus group, we purposefully selected individuals with knowledge of and experience with the reuse and recycling of DME in multiple contexts

including representatives of local DME and AT reuse organizations and DME suppliers. We also included experts in environmental sustainability practices at the University of Washington.

3.5.2 *Data Collection*

The study design incorporates a complementary mix of data collection methods to facilitate a deeper understanding of the same phenomenon (Denzin, 1978). First, semi-structured interviews were conducted with informants over a four-month period in 2015. Interviews lasted 60 to 90 minutes each. The original protocol was piloted to assess the clarity and order of the questions with a therapist who has played an extensive role in the prescription and provision of DME to patients in a clinical setting. The final protocol contained several specific questions that were asked of everyone (e.g., “Describe your role at the University with DME”) and open-ended questions that were followed up by probes (e.g., “How do patients get DME for use at home or in the community? Take me step-by-step through this process”). Because qualitative research is often an emergent process (Glaser & Strauss, 1967) the protocol evolved as new information was collected, and questions were tailored to different informants. Interviews were audiotaped and later transcribed verbatim.

The focus group was conducted on-site at the University of Washington and followed the completion of the key informant interviews. Focus groups are advantageous when the interaction among participants can serve to produce more information (Creswell, 2007). The focus group protocol followed a semi-structured format and examined in further detail the processes and policies for DME reuse and recycling within UW Medicine and at community organizations with DME reuse programs. The focus group was useful for exploring big picture questions (e.g., “How could the current systems for DME reuse and recycling be improved?” and “What are the opportunities for collaboration between UW Medicine and community reuse and

recycling programs?”). One member of the research team facilitated the discussion, and a second research team member collected field notes of behavior that would not be apparent in an audio recording. The focus group discussion was captured in realtime by a CART provider, and an uncorrected transcript was provided to the research team for analysis.

We also collected organizational documents from study informants targeting laws, rules, regulations, and guidelines on DME. We compared the messages in the organizational documents with the study informants’ descriptions of their clinical practices to understand how these healthcare policies are interpreted (Murphy & Dingwall, 2003). These organizational documents also provided supplementary research data on the potential policy and procedural barriers and facilitators to a hospital-based DME reuse program.

3.5.3 *Ethical Considerations*

In most cases quality improvement activities do not require Institutional Review Board (IRB) approval for these activities to be conducted with participant consent. However, an application was submitted to the University of Washington IRB prior to the start of the original study. Although the study was determined to be non-human subjects research, informed consent was obtained from the study participants for both the interviews and the focus group.

3.5.4 *Data Analysis*

We applied conventional qualitative content analysis (Hsieh & Shannon, 2005) to the interview and focus group data and followed the procedure for inductive category formation described by Mayring (2001). The process began with a line-by-line open coding of the data. Initial codes were derived from the research questions for the original study. The principal investigator and co-investigator independently reviewed a subset of the transcripts, and results

were compared for inter-coder agreement. Operational definitions were assigned to each code (Miles and Huberman, 1994), and codes were subsequently classified into categories. An example of the organization of data for the category of processes for DME prescription and provision is provided in Table 1.

Table 3.1

Organization of Data for the Category of Processes for DME Prescription and Provision

<u>Category</u>	<u>Code</u>	<u>Description</u>	<u>Quotation</u>
Processes for DME prescription and provision	Assess patient for DME	Determine whether and what type of DME is medically necessary	“I’m diagnosing this client for MS, ALS, whatever the neurological disease may be. They need a mobility solution, and we step in along with the therapist at the evaluation.”

Once a provisional coding scheme was developed, the investigators commenced an iterative process of coding, checking in, modifying the coding scheme, and final coding of the interview and focus group data. The analysis of the data was validated by the research study advisory committee, which was comprised of experts in DME prescription and provision, payer policy for Medicare and Medicaid, and AT reuse.

3.6 FINDINGS

The purpose of this study was to investigate DME reuse and recycling within the UW Medicine health care system. We focused our inquiry on the clinical practices and healthcare processes for both the prescription and provision of DME and the reuse and recycling of unwanted DME. The analysis of the interview and focus group transcripts resulted in 19

categories, which have been organized under seven themes that communicate our interpretation of the main points of the study (Sandelowski & Leeman, 2012).

3.6.1 *Obtaining DME is a Complex Process for Patients and Providers*

Informants at UWMC and HMC were asked to detail the process to obtain DME for patients discharging from the hospital. Based on their accounts, a recommendation for DME is based on medical necessity, which is determined by the clinical therapists during a patient assessment. For patients who require complex equipment such as a custom power wheelchair, an assistive technology professional (ATP) also takes part in the initial assessment of the patient. The ATP in consult with the patient and therapist will select the appropriate equipment and assist in writing the medical justification for the equipment order. The payer, typically the patient's health insurance provider, is contacted before writing an equipment order to determine whether the recommended equipment is covered. Then, the patient's physician writes a prescription for the equipment and signs off on the order. Finally, the therapist and other hospital staff work with patients and their family members to ensure the equipment is obtained prior to the patient's discharge from the hospital.

This process can vary in a number of ways depending on the DME payer, the type of equipment (i.e., non-complex or complex rehabilitation technology), and the DME vendor. The role a healthcare provider plays in the process can also vary (or roles can overlap) according to the healthcare facility. For example, UWMC has an equipment specialist for the acute care and inpatient rehabilitation units, a non-clinical staff whose role is to streamline the DME process. This person serves as the interface between the payer and the hospital and patient. Conversely, at HMC the therapist or the care coordinator might be working with the DME vendor and the insurance provider to obtain the necessary equipment for a patient.

Informants also were asked to describe what they perceived as the patient's role in this process. In response, one informant described the patient's role as "speak[ing] clearly about what his or her needs are." A physiatrist discussed the importance of patient input on the selection of DME. He explained that patients often perceive a device like a power wheelchair as an expression of their identity; therefore, providers must take into account a patient's preference for a particular piece of equipment. Others discussed the patient's role in the insurance submission and appeals process. While some informants had expectations that patients take an active role in the process for obtaining equipment, we observed that patients were out-numbered by providers, which raises some concerns about the patient's voice in this process.

3.6.2 *A Patient's Options for DME Vary by Coverage and Cost*

At the crux of this process is funding. Coverage for a patient's DME is dependent on the source of health insurance (e.g., a private plan or government plan) and the type of health insurance plan (e.g., PPO or HMO). Once a patient's coverage for DME has been verified, someone involved in the patient's care – the equipment specialist, the care coordinator, the DME vendor, or the patient's therapist – discusses the costs and options with the patient. According to the study informants, health insurance providers frequently deny coverage of DME as a matter of course. Patients then submit to an appeals process that might still result in a denial. For instance, certain categories of DME, such as bathroom equipment, are regularly denied.

From the perspective of informants, patients who are uninsured or underinsured face significant challenges in obtaining DME. Patients of HMC and UWMC typically are not discharged without essential equipment, which means these patients might remain in the hospital longer than necessary. Informants stated that it is in the best financial interest of the hospitals to find solutions for reducing these patients' lengths of stay and contain hospital costs. Some

patients are referred to the medical social workers, who can purchase DME in situations where lack of equipment is holding up discharge. In the case of HMC, Washington State's largest safety net hospital, much of their patient population qualifies for charity care. Washington State's law on charity care requires all hospitals to cover medically necessary hospital services for patients with incomes less than or equal to 100% of the Federal Poverty Level. According to study informants, the equipment for many patients is covered under this policy.

Not all patients will meet the eligibility criteria for charity care, however, and many might still need assistance in covering the out-of-pocket costs for equipment. Informants were asked what, if any, information on purchasing affordable DME, new or used, was provided to patients. Some of the acute care and inpatient rehabilitation units maintain equipment resource lists that include suppliers of both new and used equipment. Informants involved in patient care said they provide their patients with this information either verbally or in writing and, in singular instances, locate the equipment themselves. Others said referring patients to alternate sources of DME is the role of the equipment specialist, the care coordinators, or the nurse care managers. We infer from the data that the reuse and recycling of used DME is not a consideration in the process for patients to obtain DME, which is not to say that the reuse of DME is not related, albeit peripherally, to how some patients acquire equipment.

3.6.3 *Prescribing Patients DME Often Precludes Thinking on Reuse and Recycling*

Up until this point, we have described processes for DME reuse that are directly related to patient care with the understanding that once equipment is discharged with a patient it might eventually end up in the landfill as home medical waste. Eventually some patients will replace or dispose of their used equipment. We asked the informants to describe what, if any, information they provide patients about managing DME they might no longer need. Informants

stated that they did not instruct patients on how to sustainably dispose of their equipment. A therapist explained her reasoning in this way:

I would have to say that's an area that I don't talk about very often. It's because the whole idea is I want them to have it for whatever reason I want them to have it. I'm thinking about the here and now....I do get people on occasion that will ask me, what do I do with it? I always encourage them to find a senior center or a church they can donate it to, but it's not something in my spiel that I customarily tell people.

For this therapist, her immediate concern seemed to be securing equipment for patients before they left the hospital. Other informants questioned whether discussing DME disposal, especially at point of discharge, might send a mixed message to patients about the importance of the prescribed device to their health. A psychiatrist said that he would be more inclined to discuss the disposal of DME with patients who have temporary conditions and could turnover an assistive mobility device in a matter of months than with patients who have chronic health conditions and life-long needs for their devices.

Similarly, informants made the point that not all DME is appropriate for reuse. CRT like power wheelchairs is typically patient specific and, if reused, could pose health and safety risks to other patients where as a pair of crutches in good condition could be reused safely. While it should be acknowledged that not all DME is appropriate for reuse, recycling the core components of some DME might still be a viable option. Regardless, there was not a systematic approach by these hospitals to educate the healthcare providers or the patients on options for reusing and recycling unwanted equipment.

3.6.4 *Hospitals Implement Sustainability Practices to Reduce DME Waste*

All hospitals own DME such as beds, mobility equipment, and bathroom equipment that is used by patients during stays and must be maintained and eventually disposed of by hospitals. While there are no reuse or recycling directives related to the process for patients to obtain or

dispose of DME at HMC and UWMC, there are formal and informal policies in place for the reuse and recycling of hospital-owned DME. The concept of DME triage emerged from this study. In DME triage, the condition of used equipment is evaluated and the priority for either reuse or recycling is determined.

Informants at UWMC and HMC were asked about the triage process for hospital beds and wheelchairs. Beds are costly for hospitals to replace and according to informants, a bed will continue to be maintained providing it does not compromise the health or safety of patients and staff. Trained technicians in the clinical engineering departments at UWMC and HMC are responsible for repairing all beds in these hospitals. According to one technician at HMC, when a hospital bed is truly at the end of its lifecycle, it is stripped of major hardware (some of which is reused) and the plastic and metal components become part of the hospital's recycling stream.

Additional options for the reuse of hospital DME were identified by some informants as sending equipment to the UW Surplus Store and donating equipment to charitable organizations with medical missions. An informant at the Surplus Store was asked to describe the core work of the organization and, more specifically, their process for managing used equipment. According to one of the store manager's, they operate from a philosophy of environmental sustainability. Consequently, the aim of the program is to divert University waste from the landfill, first, by selling what can be reused or repurposed and, second, by recycling what remains. The informant confirmed that they have stocked used DME such as manual wheelchairs, crutches, bathroom equipment, and hospital beds, but she said that this equipment has made up a very small portion of their overall inventory.

Although the Surplus Store seems like a viable local solution for managing some of the hospitals' unwanted DME, a few informants said it is unlikely that much of the hospitals' used

DME is routed there. From their perspectives, there is no utility in surplus hospital beds and wheelchairs when hospital patients use this equipment until the end of its intended lifecycle. The technician from clinical engineering even questioned the ethics of reselling some of the hospital's used DME:

If a bed is surplus because we got a bunch of new ones, and we just have extras, fine. That makes perfect sense. If it's surplus because it's one we cannot fix or we have put an unbelievable amount of time into, the idea of reselling it to somebody else to use as a bed sounds like unethical behavior.

Similarly, an infection control specialist said he would be, "floored if anything that's used for patient care, specifically beds and wheelchairs, would ever be surplus for sale to the public."

The manager for the Surplus Store, however, did not seem to share their concerns regarding the potential hazards of used DME and said the Surplus Store complies with regulations on laboratory equipment decontamination that would also apply to hospital DME.

Consistent with the principle of DME triage, a few informants said that an option sometimes considered for used hospital DME is donating it to charitable organizations that serve low resource countries. One of the retail and service suppliers of mobility equipment to UW Medicine has implemented a system for reusing and recycling their wheelchairs that includes triage of equipment outside the United States. They routinely donate reusable wheelchairs to organizations that run used medical equipment centers such as Bridge Disability Ministries (Bridge), a Seattle-based organization, and Wheelchairs for the World, an international organization serving South America. A physiatrist, familiar with these types of charitable organizations, shared his opinion of sending secondhand equipment from a resource-rich country to a low resource country:

Sometimes you see these sorts of programs where they're recycling things to low resource settings, which is debatable, I guess. Why should someone who's poor get

recycled equipment instead of new equipment?...I think the idea is good. You're trying to benefit people, but are you doing that for your [emphasis in original] family?

We expect, however, that almost none of UWMC's or HMC's used beds or wheelchairs are routed to organizations like Wheelchairs for the World for the same reasons their used DME typically does not end up at the Surplus Store.

3.6.5 *Provider Values are Oriented Toward a Concern for the Environment*

While saving money seems to be a strong incentive for UWMC and HMC to engage in environmentally sustainable healthcare practices, informants also expressed a sense of professional and/or personal obligation toward waste reduction. When asked about his company's motivation to reuse and recycle wheelchairs, a mobility device vendor responded,

Can you just imagine if all this stuff just ended up in a landfill? There's wiring in there. There's batteries. I mean, all that stuff would just be horrific environmentally. It'd be horrible. It's not a super egregious activity to participate in, so it's just the right thing to do.

This sentiment that reusing and recycling used DME was the, "right thing to do" resonated with many in this study. A director of campus-wide sustainability initiatives described it as, "our individual and collective responsibility to use things for the duration of the lifespan for which they were built." In keeping with the principles of EPP, informants from the focus group framed the discussion in terms of product stewardship and implicated not only the user and the health system but also the manufacturers of DME. These informants' expressed professional and/or personal values of environmental sustainability, which seem to be in support of initiatives by UWMC and HMC to reduce the impact of DME waste on the environment.

3.6.6 *A Hospital-Based DME Reuse Program Develops in Response to Local Needs*

In the course of our investigation, we discovered a hospital-based DME reuse program in the UW Medicine healthcare system. Since December 2014, the acute care unit at Valley has partnered with Bridge to provide uninsured and low-income patients with the necessary equipment to discharge safely from the hospital. The partnership between Valley and Bridge began, according to a study informant involved in the start-up effort, through a serendipitous encounter:

How we got started was we had a staff engagement survey, and one of the big issues with our inpatient [acute care] team was these crazy, immediate ASAP discharges. Nobody has any equipment. There's no money. There's no family to help them get to the next place. We're giving away our brand new equipment, so we don't have it the next day for our inpatients for training and trials. Bridge Ministries actually called me because we have a very large children's therapy program – outpatient center down the hill. They [Bridge] have a lot of pediatric equipment, so that's how they contacted me. I said, well, what do you think about the adult piece, because the staff are really frustrated.

The rationale for the program was having (used) DME on hand would expedite the discharge process, reduce a patient's length of stay and, thereby, save the hospital money. She stated that the acute care staff also thought there was potential for the program to address post-discharge concerns like patient readmission. Patients who have the necessary DME are typically at a reduced risk for falls and secondary infections. From these therapists' perspectives, issuing used instead of new equipment was a tenable solution because the equipment in question was non-complex equipment (e.g., front-wheeled walkers and tub transfer benches). Valley's DME reuse program is a means-tested benefit congruent with Washington State's charity care policy; therefore, only patients with incomes at or below 100% of the Federal Poverty Level are eligible.

Although the staff of Valley's acute care unit coalesced around the idea of housing a DME reuse program, other departments internal to Valley and in UW Medicine had to be brought on board to develop a practicable reuse policy. Early phases of development involved

deciding logistics including personnel, facilities, and inventory. They also had to categorically address concerns like patient safety, hospital liability, and general liability for Bridge. This was accomplished through a patient consent and release form for used equipment. The policy was reviewed and signed off on by Valley's Chief Operating Officer, the hospital's attorney, and UW Medicine Compliance. Although the program is small in scale, the acute care staff anticipates savings in direct costs to the hospital. The DME reuse partnership between Valley and Bridge sheds new light on the feasibility of a hospital-based DME reuse program at HMC or UWMC.

3.7 DISCUSSION

In this study, we investigated practices for DME reuse and recycling in the UW Medicine regional healthcare system as a first step in understanding how hospitals manage DME waste and how healthcare providers conceive of their role in preventing DME waste. We found that some of the UW Medicine hospitals have included processes for reducing DME waste in their plans for environmentally sustainable healthcare. These processes include repairing equipment until product end-of-life, donating viable used equipment, salvaging parts from expired equipment, and recycling core materials from equipment that has no reuse potential. While there may be opportunities to enhance these processes, non-traditional medical-community partnerships in DME reuse such as the partnership between Valley and Bridge warrant more research. We also found that although healthcare providers expressed professional and/or personal values of environmental sustainability and supported further DME reuse and recycling initiatives at UW Medicine, they were not educating patients on ways to sustainably obtain or dispose of equipment. This finding might point to a disconnect between practices to prevent DME waste and clinical decision making for patient care and merits additional investigation. Both

non-traditional medical-community partnerships in DME reuse and recycling and the education of healthcare providers in environmentally sustainable healthcare are discussed in more detail as meaningful and potentially high impact hospital-based interventions.

3.7.1 *Medical-Community Partnerships in DME Reuse and Recycling*

Prior to initiating this study, we knew of only two hospital-based DME reuse programs: the trauma program at University of California Davis Medical Center (UCDMC) and the Medical Equipment Recycling Program at the University of Pittsburgh Medical Center. No data on program outcomes have been reported (see Wright, 2012 for a description of the UCDMC pilot program); therefore, there is still little information on hospital-based DME reuse programs. The Pass It On Center (www.passitoncenter.org), a national collaborative for the reutilization and coordination of AT, has issued quality indicators for AT reuse programs. These indicators could be instructive for hospitals interested in developing a new reuse program or in evaluating an existing program.

Some of the main concerns from the perspectives of healthcare providers and administrators for implementing a hospital-based DME reuse program that emerged from our study include patient health and safety, employee safety, hospital liability, and general liability for the community-based reuse organization. Some study informants also discussed characteristics of the organization that could either promote or hinder new sustainability initiatives such as organizational structure, resources, culture, and change. For instance, we found that UW Medicine is not an umbrella organization. Informants described the structure as loosely coupled, meaning UWMC, HMC, Valley, and Northwest operate, to some extent, as autonomous entities. We understand from informants that hospital policies and procedures generally are not the same for these entities. The implication is that a one-size-fits-all program

on DME reuse and recycling is unlikely to work in all circumstances. Therefore, initiatives for DME reuse and recycling may need to vary by hospital, unit, or patient population given differences in organizational characteristics.

Informants in this study also identified potential regulatory barriers and facilitators at the state and federal levels to a hospital-based DME reuse program. In Washington State, the Health Data and Charity Care policy (1998) has facilitated access to DME for low-income patients. A potential policy barrier at the federal level is the Anti-Kickback Statute (2010). This statute prohibits the exchange of anything of value that could influence a federal beneficiary's (i.e., Medicare or Medicaid patient's) choice of business. Receiving free equipment through a reuse program might be construed as patient inducement under this statute. The Charitable and Other Innocuous Programs provision of the Affordable Care Act (2010), however, has created new anti-inducement exemptions that might favor a program of this nature. Given the array of laws and regulations that govern healthcare, an in-depth policy analysis might be warranted as part of a comprehensive feasibility study for implementing a hospital-based DME reuse program.

In addition to the obvious benefit of reducing the amount of unwanted materials that go into the landfill, the potential benefits of a hospital-based reuse program that were identified in this study primarily include those that might save the hospital money. Informants also named possible benefits to patients that include lowering out-of-pocket costs, expediency, and equity. These benefits have been addressed in the literature on AT reuse programs. Additionally, a hospital-based DME reuse program might benefit community-based DME reuse organizations. Informants questioned whether the moral, economic, and legal burdens of DME reuse and recycling have been shifted from patients, healthcare facilities, and the medical device industry to the community-based reuse DME organizations. Perhaps more hospital-based DME reuse

programs would balance the scales as concerns the responsibility and accountability for DME waste.

3.7.2 *Educating Providers in Environmentally Sustainable Healthcare*

Healthcare providers have an opportunity to manage the environmental impact of their practices (McVeigh, 1993). Given the point of origin for most DME is healthcare facilities, it follows that the management of DME waste should include healthcare providers. According to our findings, healthcare providers might benefit from education and training in three core areas: 1) the impact of healthcare delivery on the environment, 2) organizational processes for reducing hospital waste including DME reuse and recycling, and 3) community-based DME reuse organizations and the processes for patients to obtain and dispose of used equipment. The education of healthcare providers in these core areas could lead to professional behaviors of DME reuse and recycling with the goal of preventing unwanted DME from entering the hospital waste stream. Since healthcare providers frequently are the primary source of information for patients about assistive devices (Ehrlich, Carlson, & Bailey, 2003), healthcare providers could also play a role in educating patients on how to sustainably manage DME to prevent unwanted equipment from entering the home medical waste stream.

We found that in the routine delivery of care, a healthcare provider's clinical decision making was not driven by knowledge of the impact of healthcare delivery on the environment or existing processes for reducing hospital waste including DME reuse and recycling. Findings from previous studies on environmentally sustainable healthcare indicate that employees may not know which medical items are reusable or recyclable or may not be aware of institutional policies and practices for reuse and recycling (Dunphy, 2013; Rambur, Vallett, Cohen et al., 2010; Topf, 2005; Tudor et al., 2008). In a study on single-stream recycling (Riedel, 2011),

healthcare employees benefitted from explicit education about what items should be recycled to reduce the hospital's RMW. In contrast to a previous finding that greening processes need to occur in gradual increments (Laustsen, 2007), Conrardy and colleagues (2010) observed that healthcare providers in a hospital operating room were quick to accept green practices. Nonetheless, knowledge of sustainability may not translate to routine behaviors if the organizational culture lacks a sense of collective responsibility or community (Dunphy, 2014). Changes in practice instead require healthcare organizations to develop a culture of interprofessional responsibility for issues such as sustainability (Naylor & Appleby, 2013). Given these considerations, hospital collaboration with existing community-based DME reuse organizations appears to be an important first step in assuring sustainable use of DME.

Furthermore, while individual healthcare providers may value sustainability, evidence suggests that employees may not transfer personal behaviors of reuse and recycling to the workplace. These values instead are diffused due to the assumption that individual behavior will not make a difference (Topf, 2005; Tudor et al., 2008). Rambur and colleagues (2010) found that implementation of institutional processes that allow employees to engage in behavior that aligns with their personal values helped to support ethical behavior in the workplace. Similarly, Dunphy (2014) concluded that economic rationalism and other situational constraints in the workplace contributed to disconnect between personal and professional behaviors related to sustainability. Therefore, the explicit education and training of healthcare providers in environmentally sustainable healthcare practices may help to align their personal and professional values.

3.8 LIMITATIONS AND FUTURE DIRECTIONS

This was an exploratory study using qualitative methods conducted as a first step in developing local solutions for reducing the amount of non-recoverable waste from DME that goes into the landfill. These findings based on the experiences of some healthcare providers may inform thinking for other academic medical centers that are considering hospital-based initiatives for sustainable DME waste management; however, readers must consider their local conditions when interpreting these results. For this study we purposefully sampled healthcare providers in rehabilitation and acute care in-patient hospital units; however, patients' needs for DME span the healthcare continuum. Investigations of this phenomenon with healthcare providers in primary care or palliative care, for example, may reveal different processes for managing unwanted DME and conceptualizations of healthcare provider roles in preventing DME waste.

Although we found relevant research findings in the literatures on practices for waste reduction in healthcare and AT reuse, more data on the phenomenon of DME waste must be generated to substantiate it as an environmental issue that requires a response by the healthcare sector. Specifically, LCAs on the environmental impact of DME are needed. Also, while there is a small research base on the management of home medical waste (see Ikeda, 2014; Subratty & Nathire, 2005), there are no published studies on how users of DME dispose of equipment that is no longer needed. Qualitative methods are well suited for describing the processes to acquire and dispose of equipment from the perspective of DME users, and an inductive approach may reveal opportunities for reducing domestic medical waste. In a related fashion, it is important to include the DME user perspective in decisions regarding the integration of hospital waste management policy into patient care. Dunphy (2014) reported that clients' environmental values may influence the degree to which client-centered practice and practices for environmental

sustainability are compatible. Therefore, it is essential that future research on this topic include DME users to ensure that we do not pursue the improvement of DME waste management at the expense of patient care.

Chapter 4. THE EXPERIENCE OF HOMECARE PROVIDERS AND BENEFICIARIES WITH ENHANCED TRAINING REQUIREMENTS IN WASHINGTON STATE

4.1 ABSTRACT

The objective of this study was to understand the experiences of consumers and homecare aides with Washington State Initiative 1163, a measure that requires homecare aide certification of long-term care workers. This study was conducted as a first step in developing strategies to evaluate consumers' satisfaction with their care. We applied conventional qualitative content analysis to semi-structured interviews with 17 consumers and 10 homecare aides. Common research themes that were identified include customized care, consumer-directed care and shared decision-making, satisfaction with services, quality of instruction, and relevance of the training to homecare work. The findings of this study are consistent with the literature indicating the relationship between the consumer and the homecare aide is an important component of the delivery and receipt of homecare services. Similarly, we found that consumers and aides were in favor of an approach to training that would preserve consumers' roles in directing elements of their homecare.

4.2 INTRODUCTION

In 2011 Washington State voters passed Initiative 1163 (I-1163), a measure that requires homecare aide (HCA) certification of long-term care workers providing personal care assistance for seniors and people with disabilities. The term "long-term care worker" refers only to individuals who are providing personal care assistance in residential settings and consumers' homes and does not include persons employed in nursing homes, hospitals, hospice agencies, or

adult day care or day health care centers (House Office of Program Research, 2011). The term “consumer” refers to the users of personal care assistance. Under this mandate individuals must complete 75 hours of training using a curriculum approved by the Washington Department of Social and Health Services (DSHS), pass a certification exam and skills test administered by the Washington Department of Health, and undergo state and federal background checks (Skillman & Basye, 2011). The intent of the initiative is to ensure that long-term care workers are qualified and competent to provide services to State consumers of the Medicaid Home- and Community-Based Services (HCBS) waiver program. Prior to 2011, long-term care workers in Washington had fewer training requirements. The State provided workers with 22 hours of basic training and 10 hours of continuing education per year through contracts with Area Agencies on Aging. The new process for training, certification, and background checks of long-term care workers was set in place on January 7, 2012. As of December 2013, approximately 5,000 HCAs have been certified through this process (Washington State Auditor’s Office, 2014).

Initiative 1163 was sponsored by the Service Employees International Union (SEIU) Healthcare 775 Northwest. SEIU is the largest health care union in the U.S and since the passing of I-1163 in Washington State, is also the largest homecare worker training provider nationally. The SEIU Healthcare NW Training Partnership (Training Partnership), the non-profit school created by the Union, collaborates with the State and other entities in delivering the HCA training and certification program. Proponents of I-1163 claim the new legislation will result in safer care for seniors and people with disabilities and a more stable and professional long-term care workforce. It has been suggested that increased training of long-term care staff coupled with more on-site monitoring of facility-based workers might contribute to the prevention of the abuse and neglect of consumers (Lewin Group, 2006). Additionally, inadequate training of

long-term care workers has been identified as a predictor of job dissatisfaction in a variety of long-term care settings and of job turnover and lack of intent to stay on the job (Sengupta, Ejaz, & Harrison-Kojetin, 2012). Scala, Hendrickson, and Regan (2008) have recommended combining employer-based or state-sponsored training with career ladders, opportunities for advancement, and wage increases to improve employee satisfaction and reduce turnover.

4.3 RESEARCH PROBLEM

The Training Partnership contracted with the University of Washington on the first phase of a potential multiphase study to develop a battery of self-report instruments for evaluating consumers' satisfaction with their care and for assessing health-related quality of life outcomes presumed to improve with quality caregiving. A parallel instrument for HCAs would be developed to assess their perceptions of the homecare needs of the consumers they serve as well as of their needs for additional training. The intent is to repeatedly administer these instruments to track consumer and HCA outcomes over time. The current phase of this study uses exploratory research to identify domains relevant to the new HCA training and certification program from the perceptions of some consumers and HCAs. As illustrated by the research questions that guide this inquiry, our aim is to understand the process for giving and receiving home-based care and the experiences of consumers and HCAs with Washington State's upgraded training and certification requirements:

1. How do consumers and HCAs describe the delivery and receipt of homecare services?
2. To what degree do HCAs attribute their knowledge of and skills for providing homecare services to the state-mandated training?

3. From the perceptions of consumers and HCAs, what impact, if any, does the state-mandated training have on consumer homecare services?

This study is a response to the call by Kaye and Harrington (2015) for more information on the outcomes of state mandated long-term care worker training. Most of the research on long-term care workers has been focused on issues of workforce development and retention including determinants of employee turnover. There is a much smaller research base on long-term care worker training and credentialing programs. For example, previous studies have been conducted on the impact of training on homecare workers' job satisfaction (Coogle, Parham, Jablonski, & Rachel, 2007; Lopez, White, & Carder, 2014; Nishita, Hayashida, & Kim, 2014), attitudes of certified nursing assistants and home health aides toward training (Sengupta, Ejaz, & Harris-Kojetin, 2012; Sengupta, Harris-Kojetin, & Ejaz, 2010), and consumer and homecare worker knowledge of health and wellness issues (Schopp et al., 2007). Few education interventions including pre-employment and in-service training programs that have been designed to improve the quality of homecare services have been evaluated empirically (see Luz & Hanson, 2015). In this article, we describe some of the issues of the Washington State HCA training and certification program that were salient to the consumers and HCAs in our study.

4.4 INFORMING LITERATURE AND FRAMING IDEAS

There are currently no national workforce standards for HCAs, and training programs and certification processes for direct care workers vary from state-to-state (Kelly, Morgan, & Jason, 2013). With the implementation of I-1163, Washington is the first state to mandate that all long-term care workers providing personal assistance, whether employed by an agency or directly by a consumer, complete a standardized training curriculum and skills test to be certified as an HCA. Issues of long-term care worker training are not unique to Washington; however, we

provide an overview of the Washington Medicaid HCBS waiver program, the long-term care workforce in the State, and Washington's HCA training and certification program for the purpose of contextualizing our study.

4.4.1 *Washington's Medicaid Homecare Program*

Shifting long-term care from nursing facilities and other institutional settings to less expensive home- and community-based settings continues to be a major thrust of Medicaid cost-containment efforts. For the last 20 years, Washington State has been experimenting with new approaches to ensure that the use of less expensive home- and community-based care translates into budget savings and control over long-term care spending. According to 2011 estimates, the average cost for home- and community-based care for an individual in Washington is \$1,870 per month, whereas the average cost for nursing home care is \$4,250 per month. Washington serves 2.3 times more individuals per dollar in home- and community-based settings as compared to nursing homes. Since 1996, increased utilization of home- and community-based alternatives has resulted in an estimated \$3.34 billion dollars in savings to the State (Banijamali, Hagopian, & Jacoby, 2012). The most utilized Medicaid HCBS waiver programs by aging adults and people with disabilities in Washington State are Community Options Program Entry Services (COPES) and Medicaid Personal Care (MPC). Washington DSHS administers these programs and depending on individuals' incomes, will pay for all or a portion of the waiver supports and services.

4.4.2 *Washington's Homecare Workforce*

Under the Medicaid HCBS waiver program, individuals have the option of self-directing their care. This means that individuals receiving services can choose their

homecare provider rather than having the state assign one (Home and Community Services, 2012). HCAs generally fall into two categories: an individual provider (IP) and an agency provider (AP). An IP might be a relative or a household member, although the parent of a consumer who is a minor or the consumer's spouse might not be a paid IP under most programs. With an IP, consumers act as the employer in choosing, hiring, and supervising their providers. In Washington, DSHS administers the background check and pays for a provider's training. Alternatively, consumers might choose to receive care from an AP, an employee of a licensed homecare agency.

Washington's homecare workforce is comprised of nearly 42,300 workers (Palazzo, Skillman, Basye, & Morrison, 2013). A recent survey of a sample of HCAs in Washington State conducted by SEIU 775 found that 80% are women, almost 70% are White, 58% are age 50 years and older, 66% work part time, 18% have a college degree, and 8% lack a high school diploma (Center for Health Workforce Studies, 2011). Most are IPs and work in consumers' homes; however, APs might work in consumers' homes, adult family homes, or boarding homes. These findings are similar to homecare worker demographics reported in a national survey of home health workers (Stone, Sutton, Bryant, Adams, & Squillace, 2013). It was reported in a separate study that at least one in five HCAs in Washington is a recent immigrant (Banijamali, Hagopian, & Jacoby, 2012) suggesting that homecare is an entry-level job for some people arriving to the United States (Institute for the Future of Aging Services, 2007).

4.4.3 *Washington's HCA Training and Certification Program*

The model for the Washington HCA training and certification program is a two-hour orientation, a three-hour safety lesson, and a 70-hour basic curriculum. The 70-hour basic curriculum includes 16 modules on a range of topics such as the homecare team, managing the

homecare environment, and infection control as well as population-specific modules on dementia, mental health, and physical and developmental disabilities. The premise of this model is that individuals are trained globally in a core curriculum to create a foundation of skills that can be used in a wide variety of care settings. The competencies for the Washington HCA training and certification program are similar to those identified in the Personal Care Services training program designed by the Paraprofessional Healthcare Institute (2009) and the Personal and homecare Aide Training (PHCAST) Program, a three-year demonstration grant program established by the Patient Protection and Affordable Care Act (ACA; U.S. Department of Health and Human Services, *n.d.*). Under the Washington State program, Certified HCAs also have an annual continuing education requirement of 12 hours. Instruction in the basic curriculum is delivered primarily in the classroom, where as the continuing education classes are taught both in the classroom and online. The Training Partnership continues to experiment with modalities of instruction and will offer a blended learning program for the 70-hour basic curriculum where the delivery of content and instruction is both online and in a classroom.

4.5 METHODS

We conducted a basic qualitative study (Merriam, 2009) with the purpose of gaining an initial understanding of some consumers' and HCAs' experiences with the Washington State HCA training and certification program. Qualitative research methods are often employed as first steps in developing self-report instruments on health-related quality of life outcomes (see Amtmann, Cook, Johnson, & Cella, 2011). The central task of qualitative research, to explicate the ways people come to understand their situations (Miles & Huberman, 1994, p. 7), fit with our purpose of capturing information that was most important to consumers' and HCAs' in their own words.

4.5.1 *Participants and Setting*

The sample for this study was primarily derived from a database maintained by the Training Partnership. The Training Partnership recruited both HCAs and consumers who met the following sample selection criteria: at least 18 years of age, proficient in spoken English, reside in the Seattle-metro area, and available for a one-hour interview with a study investigator. Additionally, only HCAs that completed the certification program and provided in-home services for at least one year were eligible. Consumers must have received in-home services for at least two weeks by an HCA certified by Washington State. This minimum requirement was established to ensure that consumers had sufficient exposure to homecare services to describe their experiences.

Contact information for individuals who met the sample selection criteria was forwarded to the researchers by the Training Partnership. Because consumer recruitment goals were not initially met, additional recruitment efforts were conducted by the researchers. A notice was sent to subscribers of the Northwest Regional Spinal Cord Injury listserv, an Internet mailing list on the topic of spinal cord injury maintained by the University of Washington. Several participants were enrolled in the study through this venue and through snowball sampling, where subjects were recruited by referral. HCA interviews were conducted in community settings such as libraries, where as consumer interviews were conducted in their homes or by phone as an accommodation. Participation in this study was completely voluntary, and eligible participants received a \$25 gift card as compensation.

4.5.2 *Ethical Considerations*

In most cases quality improvement activities do not require Institutional Review Board approval. However, informed consent was obtained from the study participants. Every effort

was taken to protect the participants' rights and welfare, including their confidential information. To protect confidentiality of the study participants, consumers and HCAs were assigned a number (e.g., C01) in place of their names. These numbers accompany quoted material. Additionally names, when used by study participants, were replaced with pseudonyms to further anonymise the research data. Participants were advised through the consent process of any limits on the investigators' ability to ensure that their information would remain confidential. Participants were also informed that they were free to withdraw from the study at any time. This information was clearly stated in both consumer and HCA consent forms.

4.5.3 *Data Collection*

We conducted participant interviews over a six-month period from October 2014 to March 2015. Two interview protocols with different lines of questioning for consumers and HCAs were used. These protocols were based on topics of interest for the Training Partnership and on the expert opinion of the researchers. The interviews followed a semi-structured schedule that included open-ended questions on the types of services provided (e.g., "Please tell me about a typical homecare aide encounter."), consumer satisfaction with services (e.g., "What services have you been most satisfied with?"), preparedness for the job (e.g., "What kinds of caring activities do you feel trained and qualified to provide?"), and needs, if any, for additional training (e.g., "For what kinds of caring activities do you feel you need more training?"). The researchers encouraged participants to elaborate freely on each topic and asked for additional description or definition when information shared was vague and/or unclear to the investigators. All interviews were audiotaped and later transcribed.

4.5.4 *Data Analysis*

Conventional qualitative content analysis (Hsieh & Shannon, 2005) was used to analyze the interview data, which is an approach commonly used for generating domains measured through self-report instruments. We also followed the procedure for inductive category formation described by Mayring (2001). Data were analyzed independently and separately by the two researchers who conducted the consumer and HCA interviews. First, each transcript was read several times to grasp the essence of the entire interview. Coding of the data proceeded with a line-by-line analysis of the responses to the interview questions. Open-coded data were organized into categories. Once a provisional category system was developed, the researchers commenced an iterative process of coding, checking in, modifying the coding scheme, and final coding of the interview data. At the end of this cycle, the two researchers made conclusions that were validated by the other members of the research team.

4.6 FINDINGS

Participant demographics were collected at the end of each interview for the purpose of describing our sample group. Twenty-seven participants (17 consumers and 10 HCAs) were interviewed. The average age of HCAs was 45 years (with a range of 26 to 64 years). All but one HCA had completed 12th grade, three of the HCAs had advanced degrees. In this sample, IPs and APs were represented equally. Most of the HCAs did not have a second job. The average age of consumers was about 53 years (with a range of 31 to 71 years). Most of the study participants, both consumers and HCAs, were women.

Our findings are organized under two themes: components of person-centered delivery of care and assessment of the HCA training. Although none of the study participants used the term “person-centered care (PCC),” what they described as consumers’ needs for individualized

services, social and emotional support, and their personal agency in making decisions about their care are considered attributes of the PCC concept (Morgan & Yoder, 2012). Additionally, we were not tasked with a formative evaluation of the new HCA training; however, several of the categories when taken together provide a snapshot of how participants experienced the training and their perspectives on how best to modify or revise the training. These categories are presented below with some typical quotes from the interviews to illustrate the nature of each category.

4.6.1 *Components of Person-Centered Delivery of Care*

4.6.1.1 Customized care.

An array of services was necessary for consumers to remain comfortably in their homes as opposed to nursing homes or other institutional care settings. Participants described homecare services that generally fell under the categories of instrumental activities of daily living (IADLs) and activities of daily living (ADLs). HCAs were typically assisting consumers with IADLs such as meal preparation and clean up, shopping, community mobility, health management, and financial management and with ADLs such as bath and personal hygiene, dressing, functional mobility, bowel and bladder management, feeding, and toilet hygiene. HCAs also assisted consumers in activities related to obtaining sleep and rest. The services described by consumers and HCAs are typical of those referred to as HCBS as opposed to home health services such as intermittent skilled nursing care, physical therapy, and occupational therapy that would be covered under Medicare.

Although all the consumers in this study required some level of these homecare services for their basic survival and well-being, the service needs for each consumer were highly individualized. For example, among consumers with spinal cord injury (SCI), there was

significant variability in self-reported functional impairment. C12 described how the classification of his SCI did not necessarily convey his abilities.

I'm a quadriplegic, technically a quadriplegic. C4 [cervical vertebra four] complete is my neurological diagnosis but functionally, I'm kind of a weak C5 [cervical vertebra five].... So, I'm capable of quite a bit more than your average person would think, but I'm definitely not able to be fully independent.

This consumer could perform many of his ADLs independently like brush his teeth, shave his face, and feed himself. With adaptive technology, he could also drive a car. However, there were limits to what he could do independently without fatiguing. He expressed his choices in terms of energy utilization, "Some people just don't want to spend the energy on something they can't do. Like, I can put a shirt on now, which is necessary for me to do myself and presents energy costs associated with it." Putting on a shirt, despite the impact on his energy reserves, was important for his sense of personal agency, where as activities that he considered less important to his independence, such as laundry, were delegated to his HCA. According to these consumers, characteristics of the home environment such as living alone or with others and preferences for order and cleanliness also determined the type and frequency of homecare services.

Consumers and HCAs detailed needs for social and emotional support that were not detailed in the typical plan of care for ADLs and IADLs. HCAs frequently identified listening and empathizing as ways in which they provided social and emotional support. HCA07 said it was important for aides to be patient listeners and receptive to clients' stories:

The older age group, they often want to tell stories, or communicate about their family, or tell you about things they've done in their life—as long as you give some indication that you're open to wanting to hear about those things.

Sometimes, the provision of social and emotional support was linked to a consumer's disability.

Some consumers reported that their disability had a significant impact on their ability to engage

in leisure and social activities. For those with no family or friends, their HCAs were their only connections to a world outside their homes. HCA04 described a unique way she provided social support:

She haven't left the house in 10 years. Her only world is the aide that come in, her friend, and the TV. I take pictures and I come in there, and I show her all the pictures of what's happening in the world.

This notion of providing social and emotional support as a component of homecare service was not limited to relationships between agency providers and consumers. Even aides who were providing care for a relative discussed how important it was to simply be there so that the consumer was not alone. From the perspectives of consumers and HCAs, providing social and emotional support was an instrumental component of personal care for consumers' health and well-being.

4.6.1.2 Consumer-directed care and shared decision-making.

The majority of consumers identified the need and desire to manage some aspects of their services as a key issue in the delivery and receipt of home-based care. Consumers often framed this issue in terms of communicating their needs and expectations to their aides. Generally, communication with the HCA was about the specific tasks that needed to be completed, how the tasks should be done, and upcoming scheduling issues that might affect future appointments.

At the start of the HCA's shift, consumers wanted to outline the tasks that needed to be accomplished during that time. Most consumers felt that their role was to delegate tasks; however, they encouraged input from the HCA on how and when to do these tasks. There were many systems used by the consumers to communicate their needs. These systems were most often a verbal conversation at the beginning of the HCA's shift. Some consumers, especially

those who had experienced conflict with their aides about incomplete tasks, had developed written tools to more clearly communicate their expectations. C07 developed a system that included a laminated checklist of routine tasks. During each shift he asked HCAs to cross off tasks as they completed them. He described the reason this checklist was created:

It was hard because that was my first provider, so I didn't really have the skills yet to be like, oh, this is what I need to have done. That was the initial one where my friends were like, we're going to make this easy for this person. We're just going to write the tasks out, and then it's on laminate. You just cross it out with a dry erase marker when it's done. Then you can be like, yeah, you did one thing.

Consumers also described communicating with HCAs regarding how and when to complete household tasks such as laundry or cleaning. Sometimes, consumers preferred tasks to be completed in a particular order and other times, consumers wanted aides to complete tasks using a particular method. Some consumers appreciated when the HCA asked the consumer how they preferred routine tasks to be accomplished. As C05 explained, asking how tasks should be completed not only made the visit go more smoothly but it also saved the consumer additional effort:

She had a certain way she did it, but she asked me before she did it and I really thought, wow. That impressed me that she asked me if there is a particular way you want your [bed] cover sheet on. I said, yes, this way, and she did it the way my sister did it. She told me how she did it, and we laughed about that, but I really appreciated that she thought of that because otherwise I would have gone in and changed the sheet.

Consumers saw communication as crucial in clarifying both HCA roles and their expectations for services.

4.6.1.3 Satisfaction with services and the caring relationship.

Consumers appreciated when HCAs were confident in performing tasks but also conscientious about consumers' comfort. For critical tasks, such as showering, wound care, and anti-embolism stocking application, consumers felt that HCAs were well prepared for the job.

C05, who received assistance with showering, discussed her aide's performance of this task, "When it came time to help me clean up or take my shower she didn't blink an eye. It didn't bother her at all. It didn't faze her...knowing what to do, just maturity. It showed. It counts." Many consumers echoed this sentiment in regards to ADLs such as personal hygiene.

Although consumers wanted to maintain control over many aspects of service delivery, having HCAs that understood what needed to be done and were willing to complete the tasks with minimal direction was important to consumers. Frustration occurred when consumers needed to constantly remind their HCAs how to accomplish a daily task. Although consumers expected to provide HCAs with some on-the-job training, they wanted their aides to remember the specifics of how to accomplish tasks after a routine had been established.

Many of the consumers and HCAs viewed their relationships as an important element of the caregiving experience. Although the proper performance and completion of services were important to consumers, good rapport was considered an essential component to the consumer-HCA relationship. If the consumer and aide did not get along, the consumer often perceived the overall quality of services as deficient. These conflicts were most prevalent with new HCAs and often worked themselves out overtime. For example, C08 was training a new aide and described the process for establishing a working relationship:

I think it's very important that both of you realize that you need to learn about each other and that you don't just come in and do for the other person. It's really a relationship and if it doesn't become a meaningful relationship, it won't work. There will always be things that you need to learn about them and they need to learn about you and if you continually get frustrated, it's not going to work very well. Like right now, [my aide] is getting to know me and I'm getting to know her. There's tension, but it's lessening.

Getting along with an HCA was certainly desirable, and personalities made a substantial difference in the longevity of the relationship.

HCAs described a spectrum of attitudes toward the consumer-HCA relationship and

toward caregiving; however, most considered the compatibility between them and the consumer as important to the effectiveness of the caregiving relationship as their knowledge of proper procedure or their application of skill. For HCAs who were assisting a non-relative, many expressed the need to regard the consumer as a family member in order for them to continue in a line of work that they often described as emotionally and physically demanding. Even with family members, the consumer-HCA dynamic was complex. For example, HCA03 discussed how the relationship with his partner changed when she acquired a disability.

[We] had our entire life ahead of us, and then she has this accident. We had to drastically think differently about what to do, and it's basically problem solving the entire time. I never thought trying to help someone with their physical disabilities and things would be—it's difficult. When I see other people talk about it, especially in my training classes, I can empathize very much because we went through a whole lot more than I think any of my friends will probably ever [experience] until 70 or something like that.

As a result he took on the role of the caregiver and attended to his partner's needs for health management, community mobility, and meal preparation as well as emotional and social well-being. Whether a non-relative or family, the HCAs in this study had varying conceptions of their role as the caregiver, which was often complicated by the personal nature of homecare work.

4.6.2 *Assessment of the Washington State HCA Training*

4.6.2.1 Quality of instruction.

HCAs in this study favorably regarded the quality of instruction they received in the certification training. HCAs stated that instructors used a variety of teaching strategies to appeal to a range of learning styles, such as audio, visual, and kinesthetic. HCAs unanimously agreed that they retained the most information from the hands-on activities and demonstrations. In response to the question, "What part of the training did you enjoy the most?" HCA10

responded with the following:

Certainly the hands on, and most of it was....We would go over a lesson out of the book, then it was demonstrated, and we had an opportunity to interact and to participate and learn how to do it correctly. That was very important to me.

The training required active participation by the HCAs, which was described as both a practical strategy for teaching transfer techniques and range of motion exercises, for example, and for keeping students engaged.

Most HCAs were confident in their instructors' knowledge. Instructors who had first-hand experience with providing homecare services, generally, had credibility with the HCAs. HCA08, an IP, was impressed that almost all of her instructors had field experience and seemed to relate most to the instructors that had cared for a family member:

The ones with family members, how they made it work for them and how the book [training manual] says this and this but at our house because she has this or she has that, we have to do this. Which—it's nice to see. There is a little leeway in this. You have to get used to whoever and adapt it.

On the other hand, some HCAs stated that instructors should stick to the curriculum and not filter it through their personal experience. HCA03 distinguished between the approach of "young" instructors and "older" instructors to teaching the curriculum:

Even though the training program is supposed to be a solid curriculum and standardized, it was not in the way that other instructors taught it. An example would be small differences in whether or not instructors would be using the Prometric curriculum for skills testing as opposed to, say, out of a textbook or maybe their own version of it from their own personal experiences, right? But I like a lot of the young instructors. The older instructors, I think, were the ones that they had their own spin on how things should be even though it may not have been actually in the curriculum.

Ultimately, HCA03 and others were concerned that they would not pass the certification exam if they did not learn the curriculum as it was laid out in the training manual. HCA08 was worried that she would not pass the exam because her, "brain was kind of getting a little confused" between instructors' personal experiences and the competencies that they would be tested on.

Because the consequence of failing the exam was losing their jobs, this high-stakes testing was a source of anxiety for all the HCAs.

4.6.2.2 Relevance of training to homecare work.

Almost all HCAs in this study said that the training was related to their work, though they regarded the training content as “commonsense knowledge” or rudimentary. Many of the HCAs in this study had been providing homecare services to family members or friends for several years and said they were well-versed on several of the training topics such as housekeeping, bathing, and meal preparation. A few HCAs with college degrees (a nurse who had been trained outside of the U.S., an IT specialist, and a former higher education administrator) said the HCA training did not provide them with any additional skills for the job. Although the training might not have introduced many of these HCAs to new concepts or techniques in homecare service delivery, several said that there was value in simply knowing they had been providing care appropriately. Prior years providing homecare services as well as previous work experience and education might have been factors in how HCAs in this study perceived the utility of the training.

Among HCAs there was a commonly held belief that the roles and work environments of the IPs and APs differed, and their perceptions of the utility of the training were organized around this belief. Most IPs said the curriculum was geared toward providers working in institutionalized care, such as a skilled nursing facility or group home, and not toward providers assisting friends or family members in their homes. Family members who were employed as HCAs said they were reluctant to participate in the State’s mandated training. HCA03 said he was highly unlikely to implement all of the precautions he was taught in the infection control module with his partner in their home. Similarly, HCA08, who was primary provider for her

brother, commented that the difference between her home and a skilled nursing facility was that she was not required to keep a sterile environment. Thus, the general sentiment among IPs was that a mandated training made sense for individuals who were working in institutionalized care or who were pursuing a career in homecare services but was not necessary for individuals who were providing services to a family member or friend.

HCAAs were asked what training topics were most useful to them. A majority of HCAAs responded that the classes on boundary setting, self-care, and effective communication had the most practical value. These topics were inter-related for many HCAAs. The lesson on provider self-care resonated with HCA05:

Stress management, that's a subject that some people don't ever think about or talk about. We just go, go, go. Now, they've [the training instructors] asked those questions. What do you do to relieve stress? There was that day where everyone had to go around and say, I do this. I listen to music, I exercise, I play with my dog. Whatever it is. The focus on how to relieve stress is present...I'm sure there's a lot of burnout, but at least it's talked about. It's not ignored.

These topics have salience given some HCAAs' concerns about the overlap of their professional arena and consumers' private arena.

4.6.2.3 Perceived impact of training on quality of care.

Although we hoped to obtain more information on consumers' perceptions of the impact of the training itself on the quality of their homecare, results were ambivalent. Almost all the consumers in this study were aware that their HCAAs were required to complete a training and certification program; however, many were uncertain what topics were covered or what skills were taught. There were some consumers in this study, individuals who had been managing their homecare services for many years, that were critical of Washington State's approach to training HCAAs. From their perspectives, a one-size-fits-all approach to HCA training did not

adequately address their individual homecare needs and was not inclusive of the on-the-job training that most consumers were providing to their aides. Many of these consumers, like C12, described how they were active agents in their care:

I have no concerns about whether or not that person had any medical background. I was mostly concerned about whether they were teachable, whether they were a decent person to be around, those kinds of things. Because at least for me, I'm not detached from my own care. I'm not along for the ride, not paying attention. It's up to you to do your job. I participate in that, obviously, and a lot of it comes down to decisions that only I can make that they're [HCAs] not going to make for me.

These particular consumers were opposed to what they viewed as a presumption of the training program, namely that consumers were not experts in their own care.

4.6.2.4 Logistical demands.

Although the Training Partnership has made several improvements to the training and certification program since early 2012, consumers and HCAs have continued to express some dissatisfaction with the process for training and certification. Prior to the mandated training, consumers said that hiring an HCA was much easier. Many consumers who primarily employed IPs experienced the most issues in getting a new provider ready to work. For example, during this study one consumer lost his provider and was distressed not only by the disruption in the continuity of his care but also by what he characterized as a burdensome process for hiring a new HCA. He was without services and relying on his roommate to assist with his basic needs until a new provider could be hired and trained. His story was not uncommon as other consumers shared similar hardships in employing HCAs in a timely manner.

The new system for training also was perceived as burdensome by many of the HCAs in this study. Classes were primarily offered during the regular workweek, and the HCAs for whom homecare was not their primary job had to take time off of work to attend training.

Several of these HCAs also had to arrange for an alternate provider while they were in class.

HCA03 described the burden of the training on him and his partner:

Oh, I was worried. I was worried because of the job. I was worried that I wouldn't be able to finish it. I was worried it was going to take up way too much of my time, and it did take up a lot of my time. Sometimes I would take two classes in one day, and that's all day. On one of my days off I would need to help Mia [the consumer], so we really had to rearrange our schedule.

Many HCAs said they had to travel throughout the Seattle-metro area to complete all the courses in the allotted time. Costs associated with the HCA training and certification, such as for travel and administrative fees, were reported as hurdles by several HCAs and consumers.

4.7 DISCUSSION

The perceived quality of human interaction was an important component of the delivery and receipt of homecare services. An inevitable by product of homecare services was a certain degree of intimacy that was valued by both consumers and HCAs. For consumers, perceptions of compatibility often translated into opinions of the overall quality of their homecare services, and a good consumer-HCA relationship was thought to have a significant impact on their health and well-being. For HCAs, providing homecare was more than just completing a task, and both their job satisfaction and intent to stay on the job were frequently tied to how they perceived the relationship with their consumers. Several HCAs even said they would not work for someone with whom they did not have a personal connection. Moreover, most HCAs felt the nature of homecare work was such that there was no clear distinction between their occupational activities and the personal interactions with the consumers they served. Although HCAs aspired to provide services with compassion while maintaining professionalism, striking this balance was a challenge for many in this study. In fact, navigating this relationship was difficult for most HCAs regardless of whether the consumer was a family member or non-relative.

A distinction must be made between the social and emotional supports that many HCAs provided to consumers as a natural outgrowth of the caregiving relationship that we describe in this study and companionship services as they are defined in the U.S. Department of Labor's Homecare Final Rule (Final Rule) on the Application of the Fair Labor Standards Act (FLSA) to Domestic Service (2015). Under the Final Rule, companionship services that are still exempt from FLSA are fellowship and protection. Fellowship is defined as "engaging the person [consumer] in social, physical, and mental activities" and protection as "being present with the person in his or her home, or to accompany the person when outside of the home, to monitor the person's safety and well-being" (29 CFR § 552.6). The provision of fellowship is not a reimbursable service under Medicaid. Prior to the Final Rule, in some states Medicaid would reimburse for the provision of protection but only for individuals with mental disabilities (Seavey & Marquand, 2011). The HCAs in our study were primarily engaged in providing care; thus, social and emotional support of the consumers they served was connected to their performance of ADL and IADL services.

We also found that consumers in this study put a high premium on directing their homecare services. This included all aspects of employment from recruiting to training their aides. Themes emerged from the interviews that were related to the perceived value of a standardized, competency-based HCA training program compared to a customized, consumer-provided training. In a consumer-provided training, consumers or their family members are the primary drivers in the training of their HCAs. Many consumers in this study did not have a clear picture of how the State-mandated training benefited them and felt the on-the-job training they provided to their HCAs was a better fit for their individual needs. Likewise, many HCAs said the State's training curriculum presented aging, disability and homecare services in broad

strokes, where as the consumer-provided training was tailored to meet each consumer's specific needs. These HCAs said they were unlikely to implement anything from the State's training that conflicted with what consumers desired for their in-home care. Notably, consumers and HCAs were not opposed to training per se and were in favor of an approach that would preserve consumers' roles in directing elements of their homecare in the current context of competency-based standards and formal training for long-term care workers.

The training and certification of HCAs, particularly new workers, is gaining prominence because state and federal policy makers are funding more Medicaid HCBS waiver programs in response to legal mandates and consumers' preferences for service delivery. Specifically, the ACA includes a number of provisions, such as the Personal and Homecare Aide State Training (PHCAST) Program, to support the expansion and development of more training for direct care workers (Stone & Bryant, 2012). This tension between competency-based standards and formal training for long-term care workers and customized, consumer-provided training has yet to be addressed in the literature. In our study, none of the HCAs reported receiving any instruction on how to incorporate the consumer-provided training they received on hire into the State's training and certification program. In future research on long-term care worker training, it might be useful to include a focus on the construct of a hybrid training model, one that combines a competency-based curriculum and consumers' expertise in their own care.

Finally, considering the lack of national standards for training and certification of long-term care workers and absence of an adequate research base on state mandated long-term care worker training, it might be valuable to learn more about other issues related to the implementation of the Washington State training program. First, it might be useful to clarify the perceived differences in service roles for IPs and APs as they relate to the training curriculum.

Participants, mostly IPs, in this study had been providing homecare to a family member or friend for several years, yet their prior expertise was not acknowledged in the State's training program. Second, perspectives on the efficiency of the training and certification process deserve additional investigation. Findings from this study and the Washington State Auditor's Office indicate that the upgrades to Washington State's training and certification requirements had the unintended consequence of making it more difficult to hire an HCA especially for consumers using IPs. HCAs were faced with their own challenges like trying to manage the training schedule while working another job.

4.8 LIMITATIONS AND FUTURE DIRECTIONS

This was an exploratory study using qualitative methods, and the findings based on the experiences of consumers and HCAs might be useful for informing additional research on Washington State's training initiative. The researchers acknowledge that these findings might not be generalizable. We used samples of convenience. Some of the consumers and all of the HCAs were recruited from lists provided by the Training Partnership. Some consumers were recruited through the Northwest Regional Spinal Cord Injury listserv and might have more expertise in advocating for services and directing their care likely resulting in experiences, expectations, or perspectives on this issue that are different from other recipients of home- and community-based care.

We conclude by acknowledging that evaluating the outcomes of the HCA training will be complex. This study was conducted as the first step in developing strategies to evaluate consumers' satisfaction with their care and for assessing health-related quality of life outcomes presumed to improve with quality caregiving. Qualitative methods were used to elicit the insider perspectives of both consumers and HCAs. These themes and others that emerged from the

qualitative inquiry could be incorporated into the next steps of research. One outcome that might be of value to the Training Partnership would be to develop a battery of questionnaires for the purpose of evaluating the impact of the HCA training statewide and longitudinally. The development of a measurement tool would involve several steps including but not limited to the following: 1) formulation of an expert panel to identify and prioritize survey domains and develop definitions, 2) validation of expert panel results with consumers and HCAs, 3) survey item development including a review of any existing instruments and outcomes from qualitative pilot studies on this topic, and 4) focus groups and cognitive interviews with a broader pool of consumers and HCAs leading to field testing of the measurement tool.

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APPENDIX A

Memorandum on Employment for People with Physical Disabilities

To: Washington State Division of Vocational Rehabilitation (DVR)

From: Anne Ordway, Analyst, University of Washington

Date: July 1, 2016

Subject: **Invest in research on psychological assets to improve employment outcomes for people with severe and chronic disabilities**

Unemployment and underemployment rates for adults with physical disabilities are estimated to be disproportionately high in comparison to both the general population and other groups of people with disabilities. A range of sociodemographic and disease factors have been cited as the primary reasons for unemployment in this population, including older age, less education, pain, fatigue, and depression. However, it is likely that whether someone is employed is also associated with psychosocial factors.

In a recent preliminary study on resilience, self-efficacy, and employment status in individuals with multiple sclerosis, post-polio syndrome, spinal cord injury, and muscular dystrophy it was found that individuals who reported higher levels of resilience were more likely to be employed. Psychological assets are potentially amendable to intervention; however, more research is needed before deploying interventions targeting individual resilience.

Psychological assets are not often explored in the context of rehabilitation. As the largest organization providing employment services and supports to people with disabilities in Washington State, Washington DVR must consider the critical important of furthering this research. The Rehabilitation Research and Training Center (RRTC) on Healthy Aging and

Physical Disability at the University of Washington has been exploring factors associated with participation for individuals aging with physical disabilities. I suggest these two institutions leverage their resources to continue to identify client characteristics associated with successful employment as well as effective interventions for improving the employment outcomes for people with disabilities.

APPENDIX B

Memorandum on Durable Medical Equipment

To: The Honorable Patricia Murray

From: Anne Ordway, Analyst, University of Washington

Date: July 1, 2016

Subject: **Promote healthy aging of older adults by improving access to durable medical equipment**

Introduction

As more Americans choose to age in place there has been an increased need for older adults to purchase durable medical equipment (DME). Older adults with chronic conditions or short-term disabilities are the primary users of DME. Although only an estimated 2% of older adults lack health insurance (Smith & Medalia, 2014), millions more are underinsured, making it very difficult or impossible for them to obtain needed DME to improve and maintain their health and independence. DME reuse, the process of reclaiming and redistributing previously owned equipment, has precedence as a feasible solution for increasing the availability of equipment and containing out-of-pocket costs for those in need.

Older Adults Rely on DME for their Health and Well-Being

The Centers for Medicare and Medicaid Services define DME as any reusable item that exists primarily to provide a medical function and encompasses a wide range of items including wheelchairs, scooters, walkers, hospital beds, shower chairs and commodes. Older adults with chronic medical conditions or injuries may require DME for the performance of daily activities such as working, getting around their homes, and participating in social activities. In 2012,

nearly 8 million Medicare fee-for-services beneficiaries age 65 and older purchased DME (Centers for Disease Control and Prevention, 2015). Older adults who cannot access durable medical equipment are at greater risk of institutionalization, social isolation, and secondary conditions related to injury.

Lack of Access Doesn't Mean Lack of Insurance

Typically, there are multiple sources of payment for any single item of DME including Medicare, Medicaid, and private insurance. Most health plans cover DME, which means lack of insurance is not the primary reason many people are unable to access the adaptive equipment they need. The unfortunate reality is that those who have health insurance with a DME benefit have less coverage than ever before. Recent changes in the Medicare program have made access to DME more challenging for beneficiaries. The Affordable Care Act has expanded coverage, but implementation and adherence has been inconsistent across states. As a result, many older adults are forced to pay out-of-pocket for their DME. According to 2009 estimates, total out-of-pocket spending on DME was nearly \$19 billion (U.S. Census Bureau, 2012).

DME Reuse is a Common Sense Solution

DME reuse programs are a common sense solution to improving access to DME for those who are uninsured, underinsured, or have insufficient funds to meet out-of-pocket costs. DME reuse is the business of reclaiming, refurbishing, and redistributing previously owned medical equipment. DME that is in good condition is matched to the specific needs of the beneficiary. Most DME has a lifespan that goes well beyond the period it is typically used by an individual. Thousands of devices with the potential to provide benefit to other individuals in need are disposed of each year or sit unused in basements or garages across the country. DME reuse programs facilitate the connection of an available resource to a population that needs it.

Action Means a Nationwide Expansion of Hospital-based DME Reuse Programs

Currently, the nation's DME reuse programs primarily accept donations of used equipment in their local communities. Unfortunately, DME reuse programs are few and far between, and many older adults do not have access to them. In the wake of health care reform, the time is right to increase the scope of DME reuse throughout the country. There are models for medical-community partnerships in DME reuse including ones at academic medical centers in Washington, California, and Pennsylvania that provide an affordable alternative to costly equipment for seniors and people with disabilities. These programs should be systematically investigated at the national level and the feasibility for expansion of DME reuse programs should be explored. As a ranking member on the Senate HELP Committee, your support on this issue could mean not only substantial cost savings to our health care system but also increased access to needed equipment for the healthy aging of older Americans.

APPENDIX C

Memorandum on the Homecare Workforce

To: Washington State Department of Social and Health Services (DSHS)

From: Anne Ordway, Analyst, University of Washington

Date: July 1, 2016

Subject: **Guarantee stable work hours for homecare workers in Washington**

Introduction

Washington State is facing a shortage of homecare workers. Homecare services are essential to the health and well-being of many of Washington's older adults and people with disabilities. Inadequate staffing of homecare workers contributes to decreased quality of care for aging adults and people with disabilities and to increased costs for both public and private long-term care employers (Institute for the Future of Aging Services, 2007). Guaranteeing stable work hours is a tenable solution to the issues of recruiting and retaining homecare workers.

Demand for Homecare Workers is Outpacing Supply

The number of individuals in Washington age 65 and older is expected to increase from 25,000 people per year to more than 40,000 people per year (Banijamali, Hagopian, & Jacoby, 2012). By 2030, individuals age 65 and older will represent one-fifth of the State's population. Additionally, chronic disease rates are increasing. Approximately 56,000 individuals in Washington reported impairments that impact their ability to live independently (Erickson, Lee, & von Schrader, 2014). Although the demand for skilled homecare workers in Washington is high, the supply of workers is low. Washington's homecare workforce is comprised of approximately 42,300 workers (Palazzo, Skillman, Basye, & Morrison, 2013). Washington is

expected to need nearly 35,000 more homecare workers to meet demand by 2030 (Banijamali, Hagopian, & Jacoby, 2012).

Vacancies and Turnover have become a Serious Problem

Data for Washington suggest that about half of all homecare workers leave their jobs every year (Banijamali, Hagopian, & Jacoby, 2012). High rates of HCA turnover have negative effects on the State and clients. The cost for the employer of replacing a worker is high and for clients, HCA turnover adversely affects continuity of care. Responses from a 2011 survey of former homecare workers in Washington indicated that the main reasons workers left the direct care profession were pursuit of better employment opportunities, including a job with better hours, wages, and benefits. Most HCAs in Washington work part time and are employed in temporary, per-diem jobs. This temporary and as-needed status of homecare workers correlates to low wages and low income rates as well as inadequate health benefits. Insufficient and unstable work hours drive many homecare workers to seek more reliable employment.

Additional Training Requirements may not Result in more Homecare Workers

Initiative 1163 has made it essential to upgrade tens of thousands of homecare workers. The required training is expected to create pathways to other healthcare careers that could make the occupation more attractive to potential candidates and those already in the field. Critics of I-1163 argue that the initiative is a misplaced investment in training and education. A recent audit revealed that after a \$40 million investment, only 5,000 HCAs have completed the training and are certified (Washington State Auditor's Office, 2014). Also, the failure of workers to complete training and certification has resulted in a higher turnover rate than before the initiative was in place.

A Guaranteed Hours Program is Good for the Client, Homecare Worker, and State

Ensuring an adequate supply of homecare workers in Washington requires approaches to attract new workers to the field and to prevent current workers from leaving the long-term care workforce. A guaranteed hours program could be an effective strategy to ensure stable hours and income for homecare workers while also improving their consistency and quality of care. One example of a guaranteed hours program is blending regular hours with replacement hours worked and on-call hours not actually worked. This solution is not only endorsed by current and former homecare workers in Washington but is also supported by a reasonable evidence base including programs piloted in various states (Paraprofessional Healthcare Institute, 2007). Ensuring full-time work at the current hourly wage not only provides a stable schedule for homecare workers but also moves these workers out of poverty. In addition, guaranteed full-time hours help meet the needs of long-term care clients while improving the quality of care they receive.

APPENDIX D

Point-Biserial Correlations and Pearson Chi-Square Values for all Variables

Measure	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.	13.	14.	15.	16.
<i>Outcomes</i>																
1. Employment status	--															
<i>Block 1 Predictors</i>																
2. Gender	0.25	--														
3. Marital status	8.99 **	6.84 **	--													
4. Race	7.45 **	0.72	14.00 ***	--												
5. Education level	30.81 ***	11.63 **	5.95 *	2.60	--											
6. Disability benefits	310.35 ***	9.61 **	61.63 ***	13.38 ***	21.42 ***	--										
7. Age	0.22 ***	-0.05	0.12 ***	0.04	-0.02	0.13 ***	--									
<i>Block 2 Predictors</i>																
8. Pain	-0.24 ***	-0.01	-0.05	-0.11 **	-0.05	0.30 ***	0.13 ***	--								
9. Fatigue	-0.15 ***	-0.18 ***	0.00	-0.02	0.01	0.15 ***	0.06	0.52 ***	--							
10. Depression	-0.17 ***	-0.04	-0.16 ***	-0.02	-0.04	0.22 ***	-0.02	0.40 ***	0.48 ***	--						
11. Anxiety	-0.07 *	-0.10 **	-0.11 **	-0.03	0.02	0.11 **	-0.02	0.37 ***	0.46 ***	0.74 ***	--					
12. Sleep	-0.13 ***	-0.09 **	-0.09 **	-0.07 *	-0.04	0.16 ***	0.01	0.42 ***	0.47 ***	0.36 ***	0.34 ***	--				
13. Physical function	0.29 ***	-0.24 ***	0.23 ***	0.09 **	0.14 ***	-0.41 ***	-0.07 *	-0.29 ***	-0.07 *	-0.24 ***	-0.12 ***	-0.14 ***	--			
14. Cognition	0.19 ***	0.16 ***	0.25 ***	0.03	0.06	-0.18 ***	-0.10 **	-0.33 ***	-0.52 ***	-0.43 ***	-0.46 ***	-0.30 ***	0.03	--		
<i>Block 3 Predictors</i>																
15. Resilience	0.16 ***	0.05	0.09 **	0.02	0.11 **	-0.15 ***	0.05	-0.25 ***	-0.37 ***	-0.25 ***	-0.51 ***	-0.29 ***	0.15 ***	0.47 ***	--	
16. Self-efficacy	0.18 ***	0.01	0.10 **	-0.00	0.07 *	-0.20 ***	-0.06	-0.39 ***	-0.46 ***	-0.57 ***	-0.48 ***	-0.33 ***	0.30 ***	0.45 ***	0.69 ***	--

Note. $N = 919$. Employment dummy coded with 1 = employed, 0 = not employed; Gender dummy coded with 1 = male; 0 = female; Marital status dummy coded with 1 = married/cohabitating, 0 = not married/cohabitating; Race dummy coded with 1 = White; 0 = not White; Education level 1 = college; 0 = no college; Disability benefits dummy coded with 1 = yes; 0 = no.

* $p < .05$, ** $p < .01$, *** $p < .001$.

VITA

Anne Ordway earned a doctoral degree in rehabilitation science from the University of Washington in 2016. Anne examines disability across the lifespan. Her research interests include development of the long-term care workforce, access to healthcare services and supports for people with disabilities, and retirement and labor market exit of individuals aging with a disability. Anne has taught courses on systems and organizational change and disability studies and has extensive experience in providing training and technical assistance to the state departments of vocational rehabilitation. She is joining the Health and Aging Policy Fellows Program from Fall 2016 to 2017 through a National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) funded postdoctoral fellowship in rehabilitation policy research at the University of Washington. She hopes to gain hands-on experience at the federal level in social and health policy development and implementation as it relates to individuals aging into and with disability. Anne also holds a master's degree in rehabilitation counseling from San Diego State University and a bachelor's degree in English from John Carroll University.