

THESIS

USERS' PERSPECTIVES OF CLINICAL UTILITY OF THE DAILY EXPERIENCES OF
PLEASURE, PRODUCTIVITY AND RESTORATION PROFILE
IN A CAREGIVER SUPPORT GROUP

Submitted by

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ABSTRACT

USERS' PERSPECTIVES OF CLINICAL UTILITY OF THE DAILY EXPERIENCES OF PLEASURE, PRODUCTIVITY AND RESTORATION PROFILE IN A CAREGIVER SUPPORT GROUP

Occupationally-focused assessments that consider the client's occupational experience in context are crucial to providing interventions that are meaningful and ecologically valid for our clients. Yet, few assessments go beyond an evaluation of typical occupational performance to recognize the contextual elements that provide depth to an individual's occupational experience. The purpose of this paper is to report on a utility study of one such assessment, The Daily Experiences of Pleasure, Productivity and Restoration Profile (PPR Profile), used by an occupational therapist with a group of spousal caregivers. This pragmatic, single case study design sought to capture caregivers' perceptions of utility in completing the PPR Profile and discussing it with an occupational therapist. Four major themes emerged: *initial perspectives of using the PPR Profile*, *using the PPR Profile was helpful, but difficult*, *using the PPR Profile provided opportunities for change*, and *recommendations for using the PPR Profile*. The results support the use of the PPR Profile to capture and discuss contextual occupational experiences as a client-centered and ecologically valid occupational therapy assessment to guide interventions for caregivers to self-manage their health. Discussion focused on issues that occupational therapists need to consider in using the PPR Profile. While these results are promising in one setting, further research is warranted.

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CHAPTER ONE: LITERATURE REVIEW

With rising health care costs, there is continued need to evaluate assessments, programs, and interventions used in clinical situations to ensure practitioners' efforts are not only beneficial to clients and useful for practitioners, but are also cost effective. Occupational therapists are not exempt from this, and so should continue to research assessments, programs, and interventions used in the field for their clinical utility. This review of academic literature will discuss clinical utility, the Daily Experiences of Pleasure, Productivity and Restoration Profile (Atler, 2013), and caregivers.

Utility

In simple terms, clinical utility is an essential property of assessments, programs, and interventions that is used to determine usefulness in everyday practice. While defined differently in various fields, clinical utility is generally used to indicate whether an assessment, program, or intervention is easy to use, takes a reasonable amount of time to administer, has an acceptable format to both client and practitioner, provides useful information to the client or practitioner, and improves clinical outcomes (First et al., 2004; Law et al., 1990; Smart, 1996; Toomey, Nicholson & Carswell, 1995). An additional feature of utility studies may include cost effectiveness as more health care practitioners are being required to meet quality care standards within their departments (Gruchy & Rogers, 1990; Koska, 1992; Parkinson et al., 2014; Schulz et al., 2014) and to prove the medical necessity of assessments and treatments for reimbursement for services.

An examination of existing occupational therapy literature on utility found that the majority of studies sought to evaluate utility from a therapist's viewpoint. To illustrate this, one

client-centered measure which has been widely studied and extensively used in the practice of occupational therapy is the Canadian Occupational Performance Measure (COPM) (Law et al., 1990), a self-report tool for clients that assesses self-perception of occupational performance. Many utility studies on the COPM focus on aspects of utility from the therapist's viewpoint (Chen, Rodger, & Polatajko, 2002; Toomey et al., 1995; Wressle, Marcusson, & Henriksson, 2002) than on the client's experiences of utility (Jenkinson, Ownsworth, & Shum, 2007; McColl et al., 2000). Of those that examined utility from the client user's point of view, McColl and colleagues (2000) surveyed past consumers of occupational therapy services regarding their satisfaction with the assessment process, while Jenkinson and colleagues (2007) examined the utility of the COPM for pre- and post-intervention assessments. Ultimately, these studies reflect the value inherent in assessing utility of assessments to ensure quality care delivery by the practitioner as well as a satisfactory and beneficial care experience for the client.

While current utility studies on assessments in occupational therapy from the clients' perspectives are limited, there has been a call to involve the client-centered approach sooner in the development process of tools and assessments in order to envision the future consumers of services (Hammel et al., 2008; Hammell, 2007; Law, Baptiste, & Mills, 1995). This client-centered progression mirrors a growing trend in exploring client-centered care in occupational therapy research as a whole. Seeking to understand how care is delivered by a practitioner and perceived by the client gives a more complete view of clinical utility.

The Daily Experiences of Pleasure, Productivity and Restoration Profile

The field of health care is currently experiencing a shift toward greater client-centered care. One way in which health care practitioners can facilitate this is to provide support for people to manage their own health practices through greater awareness of their actions, activities,

and occupations (Barlow et al., 2002; Hildenbrand & Lamb, 2013; Thompson, 2014). The experiences people have as they participate in daily occupations are influenced by their needs, preferences, abilities, and environments (Kielhofner, 2002). Occupational therapists can help to guide people's awareness of their subjective experiences, in part, by helping individuals to gain greater awareness and understanding of the complexity of their daily activities, all the while also supporting their own health (Clark et al., 2012; Clark, Jackson, & Carlson, 2004; Eklund & Erlandsson, 2011; Eklund et al., 2009; Eklund, Leufstadius, & Bejerholm, 2009; Erlandsson, 2012). This heightened awareness of one's occupations and of one's experiences during these occupations is central to finding occupational balance and supporting greater health (Alsaker et al., 2006; Backman, 2005; Bendixen et al., 2006; Primeau, 1996).

Scholarship by Pierce (2003) and Atler (2014) asserts that experience in occupation is a complex construct consisting of at least three simultaneous dimensions: productivity, pleasure, and restoration. Productivity refers to a sense of accomplishment; the term pleasure captures the experience of enjoyment; and restoration seeks to represent the concept of feeling renewed or reenergized (Atler, 2014; Pierce, 2003). Pierce believed that occupations should not simply be categorized according to their relative function or their area of activity performance (e.g. self-care, health management, recreation) because these categories "appear to be simplistic, value laden, decontextualized, and insufficiently descriptive of subjective experience" (Pierce, 2001, p. 252). Instead, she believed that the dimensions of productivity, pleasure, and restoration – concepts rooted in the history of occupational science research (Hammell, 2009; Jonsson, 2008; Jonsson & Persson, 2006; Matuska & Christiansen, 2008; Wilcock, 1993; Wilcock, 2006) – could reflect people's experiences in various combinations in their occupations. The experience of having coffee with a friend could be simultaneously pleasurable and restorative, though the

specific levels of pleasure and restoration experienced could vary at different coffee outings. No two experiences will be captured in the same way.

Atler (2013) designed the Daily Experiences of Pleasure, Productivity, and Restoration Profile (PPR Profile) based on Pierce's work in order to put forth a validated tool that could capture people's daily experiences of occupation and provide a means for people to reflect upon their daily activities to gain knowledge about the complexity of their activities. The tool was designed to be used with a broad range of adults across the ability spectrum as a developing time-use tool. Users are asked to record their activities in the context of their daily life including when, where, and with whom the activity occurred.

During development of the PPR Profile, much attention was given to construction that would support later clinical utility. The PPR Profile was pre-tested with nineteen adults who participated in three rounds of cognitive interviews to gain insight into a user's process of completing the PPR Profile and gather feedback on user perception of instructions; layout and format; rating scale and the constructs of pleasure, productivity, and restoration (Atler, 2013). Information gathered led to revision and simplification of terminology, examples, and instructions to improve client utility. Additionally, it was found that the process of using the PPR Profile did promote client self-reflection and heightened awareness of time use. These initial examinations supported design of the tool. Next, two additional studies were conducted. Pilot testing of the PPR Profile was conducted with forty-seven adult participants in order to gather data regarding the internal reliability of the rating scale used in the PPR Profile as well as to examine the validity of the PPR Profile (Atler, 2013). A second study was conducted with twenty-three adults who had experienced stroke (Atler, 2012). Results from these two studies indicated that, for many, the PPR Profile can support greater thoughtfulness, intention, and

reflection on one's actual activities of daily living, perhaps sponsoring increased awareness of and attention to one's use of time. However, the PPR Profile has not yet been examined in a clinical setting to formally investigate utility using a structured protocol to guide reflection, goal development and health promotion.

Caregivers

Caregivers represent a growing population within the United States, providing an estimated \$450 billion in unpaid care for their loved ones (American Association of Retired Persons (AARP) Advocacy Across the States, 2014; Feinberg, Reinhard, Houser, & Choula, 2011). Though not all caregivers care for elderly adults or the infirm (some caregivers are parents caring for children with special needs, while others are grandparents providing principal care for grandchildren) the focus of this study relates to adults who provide unpaid physical, emotional, and psychological care for another adult who may have one or more conditions or a disability (Hileman, Lackey, & Hassanien, 1992).

A large number of adults requiring care from family members and others are of the elderly population. The Centers for Disease Control and Prevention (CDC) (2013) reported that, by the year 2038, the population of Americans aged 65 years or older will double and will account for roughly 20% of the U.S. population. Many of these older adults will experience injury, disease, and disability and may require caregiving. In fact, the CDC reports that “two out of every three older Americans have multiple chronic conditions, and treatment for this population accounts for 66% of the country's health care budget” (2013, p. ii).

It has been previously established that many families take primary responsibility for providing care to their chronically ill and disabled elderly members (Montgomery, Gonyea, & Hooyman, 1985). Knowing that medical costs for care will continue to grow, those in the health

care industry must realize that many more families will make accommodations to provide care for their aging spouse, parent, family member, or friend themselves. Currently, about 44 million adults provide, on average, 8 hours of care per week for a family member for an average duration of 4.3 years and this number is expected to grow (Reinhard, Given, Petlick & Bemis, 2008). As the number of caregivers expands, groups such as AARP (AARP, 2014) are calling on the United States Government to enact bills that would provide funding to hospitals to educate caregivers and to include them in the medical process of caregiving. More can be done to support caregivers in their ability to care for themselves as well as for their loved ones.

Traditionally, the role of a caregiver is understood to be giving assistance with activities of daily living (ADLs) and instrumental activities of daily living (IADLs). But this description cannot fully capture the daily experiences of caregivers (Reinhard, 2004). As Reinhard and colleagues describe, “assistance with bathing does not capture bathing a person who is resisting a bath. Helping with medications does not adequately capture the hassles of medication administration, especially when the care recipient is receiving multiple medications several times a day, including injections, inhalers, eye drops, and crushed tablets” (2008, p. 2). To highlight the lived experience of caregiving, the AARP shares a typical scenario of a single mom caring for her 83-year-old mother diagnosed with hypertension, Alzheimer’s, and rheumatoid arthritis (Feinberg et al., 2011). The caregiver feels anxious and depressed as all her time is consumed by work, caregiving, and “coordinating multiple health care providers, arranging transportation and home-delivered meals, managing multiple, complex medications and other health-related tasks, [and] handling challenging behavioral issues” (Feinberg et al., 2011, p. 2). Exhausted and overwhelmed, the caregiver is too busy to see a doctor about her bad cough, collapses at work, and is hospitalized for pneumonia (Feinberg et al., 2011).

Though the report above is representative of the experience of many caregivers, it is important to note that a day-to-day experience can vary greatly with some days being easy or enjoyable and other days being overwhelming and unbearable. Each caregiver will experience and cope with these daily tasks of caregiving differently based on a variety of factors including, but not limited to, the diagnosis, age, and functional ability of their loved one (Montgomery, Gonyea, & Hooyman, 1985). Yet, research into the lived experience is limited, particularly from the caregivers' perspective. What stands to be gained from personal, detailed insights into caregivers' unique lived experiences is an understanding of how to better support them as they provide effective and lasting care both for their loved ones and for themselves (Feinberg et al., 2011). Little may be known about individual caregivers' lived experiences, but information presented in the research indicates that caregiver experience is based, in part, on fluctuating levels of health impacts, burden, and gain.

Health impacts. There is a full range of negative, positive, and neutral impacts that caregiving can have on an individual's life, self-image, and health. In fact, caregivers are sometimes viewed by health care providers as 'secondary patients' who are at heightened risk for injury and adverse events due to the potential stressors of caregiving (Reinhard, Given, Petlick, & Bemis, 2008). Reported health risks include physiological, psychological, and behavioral risks, all contributing to a reported higher risk of premature death among caregivers (Reinhard, Given, Petlick & Bemis, 2008). Providing care is often a physical task that takes a toll on one's body function and structure, promoting fatigue or injury. Physiological changes can include lower immune functioning, increased blood pressure, and increased risk of cardiovascular disease due to stress and poor nutrition (Reinhard, Given, Petlick & Bemis, 2008). Stress, social isolation, sleep disturbances caused by anxiety or a loved one's poor sleep habits, and decreased

participation in other life roles can lead to depression and other negative psychological effects (Hasselkus, 2011; Hemmingsson & Jonsson, 2005; Reinhard, Given, Petlick, & Bemis, 2008; Whiteford, 2010). Finally, as in the example given in the AARP report above, caring for a loved one can often cause one to ignore one's own health symptoms, perpetuating increased health risk behaviors and neglect of one's own health. Knowing these health impacts in a general way can give attention to the issue of supporting caregivers in their task; however, hearing individual experiences from the caregivers themselves may put these health risks into greater context and allow health care practitioners to create appropriate and tailored careplans for individual caregivers.

Caregiver burden. In addition to health concerns, another major factor that negatively impacts the life of the caregiver is the sense of burden they feel caring for their loved one. Burden is defined variously, though it essentially incorporates the oppressive or worrisome financial, physical, and emotional impact borne by those who provide care for the chronically ill (Dunkin & Anderson-Hanley, 1998; Hunt, 2003; Montgomery, Gonyea, & Hooyman, 1985). A caregiver who feels a significant sense of burden will likely feel a greater negative impact and react more strongly to hassles (minor events that can cumulatively cause significant impacts on health), strains (tension felt as a result of exertion), and stress (where the perceived sense of stress is the most important factor) (Hunt, 2003).

A clear delineation has been made between experiences of subjective and objective burden. Objective burden is defined as “observable, tangible costs to the caregiver resulting from the... [patient's] illness, e.g., behaviors required by the caregiver or disruptions that the client's behavior [or illness] causes for the caregiver” (Jones, 1996). Sources of objective burden may include the actual physical, emotional, or financial demands of caregiving. Objective burden can

vary based on the age, capabilities, resources, and knowledge of the caregiver, as well as the age and condition of the patient. Not all caregivers feel a sense of burden, and the amount of financial, physical, and emotional demand a caregiver faces is not always linked directly to the sense of burden that is felt by the caregiver (Dunkin & Anderson-Hanley, 1998; Montgomery, Gonyea, & Hooyman, 1985). In other words, subjective burden and objective burden are different concepts and can both be experienced simultaneously and at different levels within the same family (Montgomery, Gonyea, & Hooyman, 1985).

In contrast to objective burden, subjective burden refers to the caregiver's appraisal of their task (Jones, 1996). Often, the perceived or subjective burden seems to be based more on an individual's coping skills and ability to adapt to change rather than on the demands – however great or negative – of their current situation (Hunt, 2003; Montgomery, Gonyea, & Hooyman, 1985). Specifically, “some caregivers appear to adapt to the challenges of caregiving over time even as the patient continues to deteriorate, whereas others report continuing and increasing strain and burden (Dunkin & Anderson-Hanley, 1998, p. S54). Other factors that may impact subjective perception of burden are the caregiver's age, gender, economic stability, ethnicity, support system, and level of education (Dunkin & Anderson-Hanley, 1998; Hunt, 2003; Montgomery, Gonyea, & Hooyman, 1985).

Caregiver gain. Some caregivers report positive overall experiences and benefits that outweigh or counter a sense of burden. Caregiver gain – the positive benefits of providing care for another including, “presence of feelings of satisfaction, personal growth, and the idea that caregiving can provide enhancement and enrichment of the caregiver's life” – can also be experienced (Dunkin & Anderson-Hanley, 1998, p. S54). Other research describes different types of ‘satisfactions of caring’ (Nolan et al., 1996). Noonan and Tennstedt (1997) examined

the connection between meaning and psychological well-being in caregiving by examining 131 caregivers. Results from the study found that the level and type of meaning that caregivers experienced in their role of caregiver was closely related to their experiences of stress and depression, even when demographic and stressor variable had been controlled (Noonan & Tennstedt, 1997). Through personal interviews and questionnaires with 289 caregivers, Cohen, Colantonio, and Vernich (2002) report that 70% of the population they studied felt they were happy about caring or had positive feeling about it. To be specific, caregivers cited companionship and a sense of fulfillment/reward as the top two positive outcomes of caregiving. Cohen et al. also report that caregivers who felt positive outcomes of caregiving were less likely to report experiencing depression, burden, or poor health, noting that the positive experiences may help to buffer the caregiver from the negative experiences a caregiver might have (2002). Other valued experiences reported by caregivers and documented by researchers include enhanced self-esteem; improved spiritual, social, or intellectual condition; a sense of satisfaction and positive returns; the ability to find or make greater meaning out of the experiences of caregiving; and an enhanced or enriched life due to greater life roles (Dunkin & Anderson-Hanley, 1998; Hunt, 2003; Kinney et al., 1995).

Interventions and current research. Though perhaps not an obvious conclusion, consideration of the caregiver and their role in patient care is a crucial aspect to ensuring the health and wellness of any patient (Dunkin & Anderson-Hanley, 1998). Past interventions used with caregivers to increase caregiver gain and decrease caregiver burden focus on supporting the caregiver emotionally and physically. Education on the illness their loved one is experiencing, including learning about symptoms, causes, and the expected course of the illness has been shown to improve patient quality of life as well as improve caregiver sense of self-efficacy and

decrease caregiver perceptions of burden (Dunkin & Anderson-Hanley, 1998; Reinhard, Given, Petlick, & Bemis, 2008; Zientz et al., 2007). Being prepared to respond to and manage specific patient problems is also associated with higher quality of life for both the caregiver and their loved one (Houts et al., 1996). A caregiver's objective sense of burden has also been shown to be lowered or mitigated by increasing support to the caregiver in areas such as transportation, equipment, respite, finances, and legal planning (Dunkin & Anderson-Hanley, 1998; Montgomery, Gonyea, & Hooyman, 1985). Counseling or emotional regulation training to educate and support caregivers in coping skills and stress management can also be beneficial (Reinhard, Given, Petlick, & Bemis, 2008) Participating in support groups has shown modestly positive effects on caregiver depression, but has had little impact on perception of burden (Dunkin & Anderson-Haley, 1998).

Current research with caregivers covers a range of topics, including the medical costs of caregivers (Zhu et al. 2014), documenting caregiver experience (Giesbrecht, 2013), providing education and/or training to caregivers, and understanding caregiver depression (Ornstein et al., 2014; Swartz, Henry, & Hefferen 2014) or quality of life in relation to perceived burden (Butow et al., 2014; Flynn Longmire et al., 2014; Hazzan et al., 2014; Karakis et al., 2014; Razani et al., 2014; Shahi et al., 2014; Stepp et al., 2014; Suri et al., 2014). Missing from this list is research into the experiences of daily activities of caregivers – information that would help health care providers to provide better holistic and tailored care to caregivers.

Because of these statistics and the growing financial strain on our healthcare system, there is a push to provide greater preventative care, especially for our older population. In the 2013 report on The State of Aging and Health in America (CDC), a call to action is issued for health care professionals to develop and consider initiatives that would use data on the unhealthy

daily activities and behaviors of individual older adults to guide their health care interventions. It is suggested that data be examined to evaluate activities that include stress, nutrition, physical activity, and medication use, among others (CDC, 2013). Qualitative research that examines caregivers' experiences in daily activities could provide rich data to guide understanding and intervention planning (Kramer, 1997). Additionally, because caregivers are often hesitant to seek out health care for themselves, research studies that inquire into caregivers' daily activities can provide a more holistic understanding of caregivers' experiences of satisfaction, gain, burden, and stress (Hunt, 2003).

CHAPTER TWO: USERS' PERSPECTIVES OF CLINICAL UTILITY OF
THE DAILY EXPERIENCES OF PLEASURE, PRODUCTIVITY AND RESTORATION
PROFILE IN A CAREGIVER SUPPORT GROUP

Introduction

Client-centered occupational therapy practice aimed at enabling people to manage their own health is growing as today's health care environment changes (Barlow et al., 2002; Hildenbrand & Lamb, 2013; Thompson, 2014). Many people live life habitually, often not paying attention to their daily occupations or the ways in which their occupations directly contribute to their health status (Clark, Jackson, & Carlson, 2004; Spanos, Vartanian, Herman & Polivy, 2014). Defined variously in the literature, 'occupation' here refers to a one-time occurrence shaped by subjective perception and experience; eating lunch with one's co-workers on Monday is a unique occupation that will never be exactly replicated (Pierce, 2003). Our chosen occupations shape one's health in relation to how well one's use of time supports one's values and goals (Yerxa et al., 1990). Increased awareness of one's participation in daily occupations may promote self-identification of occupations that either support or detract from health goals (Eklund & Leufstadius, 2007; Erlandsson et al., 2011; Pierce, 2003).

Understanding and assessing an individual's participation in occupations for the purpose of meaningful intervention planning is complex. A complete understanding of an individual's participation in occupation cannot be captured by an outside observer. The subjective occupational experience of the individual, referred to hereafter as occupational experience, provides a glimpse into the way each individual experiences and perceives meaning in the context of their occupation, including their environment, their abilities, and the skill demands of

their occupation (Hammel et al., 2008; Yerxa et al., 1990). Awareness of one's occupational experiences is often not intuitive; however, occupational therapists can foster awareness of the complexity of daily occupations by encouraging attention to occupational experiences throughout the day (Clark et al., 2012; Clark, Jackson, & Carlson, 2004; Eklund & Erlandsson, 2011; Eklund et al., 2009; Eklund, Leufstadius, & Bejerholm, 2009; Erlandsson, 2012). This awareness of occupational experience is central to finding balance among an array of occupations that support health, yet there are few clinical assessments that seek to record or examine occupational experiences (Erlandsson, Eklund, & Persson, 2011; Jonsson, 2008).

The purpose of this paper is to report on a utility study of one such assessment, The Daily Experiences of Pleasure, Productivity and Restoration Profile (PPR Profile) (Atler, 2013), used by an occupational therapist with a group of adults reported to have challenges in maintaining their health: caregivers. A brief review of caregivers and their health-related risk is presented, followed by a discussion on the need for additional assessments to capture occupational experience and a description of The PPR Profile.

Caregivers

The need for caregivers is likely to rise as the population of older adults with injury, disease, and disability grows (CDC, 2013). While current research may include caregiver perspectives, much of it does so in hopes of better understanding the condition, needs, and experiences of the caregiver's loved one, supporting the traditional understanding of a caregiver as one who gives assistance with others' occupations (Hazzan et al., 2014; Meeker, Waldrop, Schneider, & Case, 2014). Research often neglects to consider a caregiver's occupations outside of providing care for their loved one and therefore does not capture how caregivers often become 'secondary patients' who are themselves at heightened risk for injury, health degradation, and

premature death due to the physiological, psychological, and behavioral stressors of caregiving (Reinhard, 2004; Reinhard, Given, Petlick, & Bemis, 2008). Too often, caregivers provide excellent, round-the-clock care for their loved one and neglect their own health needs (Clyburn, Stones, Hadjistavropoulos, & Tuokko, 2000; National Alliance for Caregiving, 2009). Current assessments for caregivers aim to measure caregivers' health, sense of burden, depression, coping, support, task requirements, and ability to provide care (Family Caregiver Alliance, 2006). Assessments that capture caregivers' daily occupational experiences could support caregivers to better self-manage their health through greater occupational awareness.

Capturing occupational experience

Occupationally-focused assessments that consider the client's occupational experience in context are crucial to providing interventions that are meaningful and ecologically valid for clients of occupational therapy (Coster, 1998). Yet, few assessments go beyond an evaluation of general perceptions of occupational performance to recognize the contextual elements that illuminate the nuances of an individual's real time occupational experience (Coster, 1998). Top-down assessments designed to include the client's voice in the treatment process such as the Canadian Occupational Performance Measure (COPM)(Law et al., 1990) and the Occupational Questionnaire (OQ)(Smith, Kielhofner, & Watts, 1986), are currently used in practice. Through a semi-structured interview, the COPM gathers information about the client's perception of or satisfaction with their performance of occupations in daily living over time. The OQ is a self-report time-use diary in which clients record their typical daytime activities and, for each activity, answer 4 questions regarding the type of activity, the client's satisfaction with their activity performance, the importance of the activity, and the enjoyment level of the activity. What is not captured by the COPM or the OQ are the client's subjective, unique, and

contextually-specific occupational experiences that, over time, give insight into a client's occupational balance and health (Hammel et al., 2008; Pierce, 2003). Assessments are still needed in the field of occupational therapy to provide insight to both clients and occupational therapists into clients' contextually-situated occupational experiences (Coster, 1998; Eklund & Erlandsson, 2011; Erlandsson, 2012; Hammel et al., 2008; Murphy, Lyden, Smith, Dong, & Koliba, 2010; Pierce, 2003).

The PPR Profile

To answer the call for a tool to support client examination of occupational experiences, the PPR Profile (Atler, 2013) was developed to capture users' experiences of pleasure, productivity, and restoration and to promote awareness of occupational experiences. Scholarship by Pierce (2003) that informed the development of the PPR Profile asserts that occupational experience is a complex construct consisting of at least three simultaneous dimensions: productivity, pleasure, and restoration. The term pleasure indicates the experience of enjoyment, productivity refers to experiencing a sense of accomplishment, and restoration represents the concept of feeling renewed or reenergized (Atler, 2014; Pierce, 2003). Each occupational experience, then, is comprised of an "irreplicable blend" of pleasure, productivity, and restoration that can contribute to one's conception of health, balance, and well-being (Pierce, 2003, p. 45).

As a time-use diary intended for use with a broad range of adults across the ability spectrum, the PPR Profile requires users to identify their occupations (including duration, location and context) throughout the day and identify their level of experiences of pleasure, productivity, and restoration for each occupation. Users identify their level of experiences of pleasure, productivity, and restoration using a 7-level Likert item for each dimension (see Table

1). The tool can be completed independently by the user throughout their day, or retrospectively with the assistance of an occupational therapist as a “yesterday interview” in which an occupational therapist prompts the caregiver, through conversation, to recall each of the previous day’s activities and experiences and then record them onto the PPR Profile.

Conscious attention was given to engaging potential users in the development and validation of the PPR Profile (Atler, 2013). Cognitive interviewing during field tests provided input from users that guided refinement of definitions and layout of the tool (Atler, 2013). Qualitative data gathered through interviews following use of the PPR Profile directed further examination of constructs, gave insight into the perceived burden of completing the PPR Profile, and revealed that the process of using the PPR Profile did promote user self-reflection and heightened awareness of time use (Atler, 2013). A study evaluating user-perceived utility showed that the PPR Profile required time and energy to complete, though it also led to increased awareness of occupations, contexts, and experiences and promoted opportunities for reflection (Atler, 2015). To date, no research has been done examining the use of the PPR Profile by an occupational therapist in practice.

Purpose

Therefore, the purpose of this study was to capture users’ perspectives of the PPR Profile by examining its clinical use with an occupational therapist. Continuing to use a client-centered approach to instrument development, (Atler, 2015; Hammell, 2007; Hammel et al., 2008; Law, Baptiste, & Mills, 1995), the specific research question guiding this study was: what are caregivers' perspectives of the utility of completing the PPR Profile and using it with an occupational therapist in a group setting? A qualitative, open-ended query approach was used to

provide narrative, explanatory, and rich data that could contribute to a more comprehensive and nuanced understanding of how the PPR Profile will be used in practice (Sandelowski, 1997).

Methods

Design

A pragmatic qualitative single case study design was employed. Pragmatism focuses on the ‘what’ and ‘how’ in the research question (Creswell, 2003) and applies analytic methods that provide insight to the research question having real-world practice implications (Mackenzie and Knipe, 2006; Savin-Baden & Howell Major, 2013). Qualitative case study methods allow researchers to examine a phenomenon contextually and from multiple sources to uncover and explore a range of perspectives that converge and promote greater understanding of the phenomenon (Baxter & Jack, 2008). A pragmatic qualitative case study design helped uncover user perspectives of utility to inform future clinical use of the PPR Profile.

Researcher’s position

In qualitative research, there is a need for “a critical examination of the ways in which the researcher and the research process shaped the research relationship, data collection and data analysis” (Hammell, 2002, p. 179). An interest in mental health studies, coupled with scholarship in education, composition, rhetoric, and World Literature, fostered my appreciation of narratives that give voice to individuals’ experiences and perceptions. A desire to empower individuals through the healing and identity-forming capabilities of occupation led me to my current position of graduate student in the occupational therapy department at Colorado State University where I am writing a thesis and working as a graduate research assistant with the developer of the PPR Profile. My experiences culminate in a respect for compassionate client-centered care and for the

inclusion of individuals' experiences and perceptions in decision-making in medical, community, and rehabilitative care settings.

Participants

Following ethical approval from the university's institutional review board, researchers visited a local caregiver support group to explain the study and seek participants. Facilitated in part by an occupational therapist (OT), the drop-in, member-driven support group encourages caregivers to bring forth topics of interest spanning a range of informational, emotional, and practical themes. The caregiver support group continued to meet as regularly scheduled throughout the duration of this study. The study was described in full (see Table 2 for overview) and 6 of the 10 regularly-attending group members gave informed consent to participate. Data from 5 participants were included in this report; data from the 6th study participant were excluded from this report as the participant was no longer actively caregiving and therefore had differing experiences with his or her PPR Profile. Those who chose not to participate in the study were either no longer actively caregiving or stated that they did not have the time to participate in the study. Participants were female, ranged in age from 57-82, were caregivers for their spouse, and had been participating in the caregiver support group for at least 1 year. Most of the caregivers lived in the community with their spouse and all participants were actively caregiving for a spouse who had cognitive loss. Some care recipients also had additional physical challenges. Individual contexts varied, such as their spouse's diagnosis, the years each had been a caregiver, and the level of support they received from family and medical staff.

Procedure

See Table 2 for an overview of the study, including a brief description of procedural activities, data collection and data analysis. Prior to the introduction of the study to the

caregivers, the OT associated with the caregiver support group was invited to participate in the research study as a member of the research team. As such, training was provided for the OT to include the purpose, theoretical foundation, format, and use of the PPR Profile, as well as using the PPR Profile to guide goal-setting with caregivers. To reduce potential burden and support participation, caregivers were given the option to complete the PPR Profile for 1-3 days either independently or retrospectively as a “yesterday interview” in which a member of the research team prompted the caregiver, through conversation, to recall each of the previous day’s activities and experiences and then recorded them onto the PPR Profile. Two caregivers chose to complete the PPR Profile independently and 3 chose to complete the PPR Profile as a “yesterday interview.”

After each caregiver completed the PPR Profile for at least one day, caregivers shared their experiences with the OT in a semi-structured one-on-one interview. Many caregivers also engaged in discussion, reflection, and goal-setting related to their PPR Profile with the OT. Because of an established rapport with the caregivers, the OT associated with the caregiver support group was selected to conduct the semi-structured interviews as their existing relationship would potentially promote the caregivers’ comfort and candidness (Krueger & Casey, 2009). Among members of the research team, the OT likely held the least bias toward the value of the PPR Profile, and so would be able to interview caregivers most neutrally. Questions asked by the OT during the interviews sought to promote discussion on the experience of filling out the PPR Profile, likes and dislikes regarding the PPR Profile, and caregivers’ feelings toward their completed PPR Profile. Four of the five interviews concluded with caregivers identifying a goal that would support their health or well-being, such as scheduling a meeting with a resource

person, performing healthier behaviors like meal-planning and exercise, or building alone time into each day.

After all caregivers participated in a one-on-one interview with the OT, the caregivers attended a focus group to share with the researchers their experiences of completing the PPR Profile and discussing it with the OT. Focus groups have a unique ability to help researchers understand participants' point of view and allow researchers to organize discussion with a select group of individuals to gain several perspectives on the same topic, perhaps providing insight into people's shared understandings and individual differences (Gibbs, 1997; Krueger & Casey, 2009). Held immediately following the regularly-scheduled caregiver support group, the focus group lasted ninety minutes and provided an opportunity for caregivers to share their perspectives, likes and dislikes, and recommendations regarding the completion and use of the PPR Profile. Caregiver feedback was sought by two methods: (1) in hand-written responses to a worksheet asking about initial impressions and actual experiences; and (2) in verbalized responses to semi-structured questions (see Table 3). Focus group questions were designed based on a content analysis (Miles et al., 2014) of the one-on-one interviews, a review of literature on utility (Smart, 2006), and focus group best practice (Krueger & Casey, 2009).

Three weeks after the focus group discussion and preliminary analysis, caregivers were invited to attend a member check in order to confirm and/or deepen researchers' existing understandings of the caregivers' perspectives. A member check can function "as a means of verifying the accuracy of a participant's words, but it has also been used as means of equalizing power relationships within the research relationship by enlisting participants as members of the research team" (Koelsch, 2013, p. 171). Held immediately following the regularly-scheduled caregiver support group, the 5 caregivers who attended the member check offered feedback

regarding a list of twenty-six quotations (compiled from the focus group discussion and the one-on-one interviews) that researchers felt were representative of caregivers' perspectives on what it was like to fill out and use the PPR Profile (see Table 3 for examples). Though individual perspectives and related experiences varied among the caregivers present, all caregivers felt that the selected quotations were representative of the group's perspectives as a whole and did not feel as if any of the quotations were misrepresentations. At this time, caregivers were encouraged to share additional experiences and impressions since having completed the PPR Profile, discussing it with the OT, and participating in the focus group discussion. The one-on-one interviews, focus group, and member check discussions were audio recorded and later transcribed verbatim. Research memos were kept independently by both researchers throughout the study.

Data Analysis

A priori codes derived from the focus group questions were used to deductively code the focus group transcription, in keeping with the researchers' use of a pragmatic research paradigm (Gibson & Brown, 2009). For example, answers to the focus group question, 'What were your initial impressions of the study?', such as "I thought it would be a lot of work, but interesting," were coded as 'Initial impressions' (see Table 3). Examination of the relationships within and among a priori codes led to the selection of four main concepts corroborated by both researchers. These four concepts, along with a selection of key statements, were presented to the caregivers at the member check (See Table 3).

Following the member check, all data (transcribed one-on-one interviews, transcribed focus group, written responses, and transcribed member check) were re-examined and discussed by the researchers. During the discussion, the researchers made the decision to not include data

from one participant in the presentation of perspectives of caregiver utility as he/she was not currently providing care for her spouse. Re-examination of the transcribed data resulted in several themes that represented caregiver's perspectives on the utility of the PPR Profile as used with an OT. Next a peer review was conducted with an expert qualitative researcher unfamiliar with the coding process. Following discussion and negotiation of the peer review, themes were merged to combine similar concepts and titles discussed.

Trustworthiness

Triangulation of data to determine codes, triangulation of analysts with both researchers coding data, peer review, and a member check increased the credibility of the research (Savin-Baden & Major, 2013). Additionally, research memos were written at various points throughout the study as a means to increase rigor and support reflection on researcher bias, process, and reactions (Malterud, 2001).

Results

Four major themes related to the caregiver-perceived utility of using the PPR Profile with an OT in a group setting emerged. The first theme, *initial perspectives of using the PPR Profile*, provided insight into the caregivers' perspectives on completing the PPR Profile and discussing it with the OT. The second theme, *using the PPR Profile was helpful, but difficult*, captured the caregivers' perspectives on the benefits and difficulties of completing and discussing the PPR Profile. The third theme, *using the PPR Profile provided opportunities for change*, offered insight into the various perceived effects of using the PPR Profile and the ways in which it led to changes in caregivers' awareness, perception, and action. The last theme, *recommendations for using the PPR Profile*, included recommendations the caregivers made for future use of the PPR Profile. Identifying information of caregivers was deleted from excerpted data to maintain

confidentiality. Some excerpts included from the data have been shortened and/or edited to improve readability and concision.

Initial perspectives of using the PPR Profile

Caregivers' perspectives regarding the PPR Profile included perspectives on the PPR Profile itself, the format of the PPR Profile (independently filling it out on paper versus completing it verbally as a "yesterday interview" with researcher), and the one-on-one interview conducted with the OT.

PPR Profile. Caregivers reported that completing the PPR Profile was "a lot to do" and "time-consuming," and a few perceived it to be "overwhelming," though all caregivers were able to complete at least one day of the PPR Profile. Additional perspectives on the PPR Profile were that it was "easy to understand" and provided helpful directions and examples, though more space could be provided to write additional activities. While some caregivers said the PPR Profile "accurately captured my day," others said that the PPR Profile did not capture the nuances of their day without the one-on-one interview. Also, some caregivers said it was good to be able to take the PPR Profile along with them and complete it throughout their day, others said it was difficult to interrupt their activities to fill it out.

Regarding the rating scale for pleasure, productivity, and restoration, caregivers perceived the rating scale to be necessary, though they reported that the term "pleasure" did not always fit their occupational experiences and was even humorous, at times. Caregivers explained that many of their caregiving experiences were neither pleasurable nor displeasurable – they were simply tasks that had to be completed. One caregiver explained the level of pleasure in the occupational experience of taking care of a loved one, "It's the median line...It's just there and you just have to do it. It just it is what it is" (P5).

Format of the PPR Profile. All caregivers reported preferring the method of delivery of the PPR Profile that they had chosen. For example, one caregiver who completed the PPR Profile independently in the context of the day explained how this method helped him/her to capture all of the day's occupations, "It was a lot of work that I recorded on the PPR Profile, where I would have diminished it in a conversation with a researcher" (P4). Conversely, a caregiver who opted to complete the PPR Profile as a "yesterday interview" with a member of the research team explained that this method was helpful as the researcher "asked the right questions, which was good because you could talk about your answers and make it understandable for the point you wanted to get across. I'd always rather talk to somebody" (P5). A caregiver who initially completed the PPR Profile as a yesterday interview with a researcher and then completed more of the PPR Profile independently in the context of her day saw merits to both formats: "It helps to talk to someone and get their feedback and see where you may be going the wrong way and that helps. But, to sit down and to write down what you're thinking is to me very helpful" (P2).

One-on-one interview with the occupational therapist. Caregivers overwhelmingly reported positive perceptions of the interview with the OT, describing it as a "personal" experience and a necessary compliment to completing the PPR Profile. The caregivers described the OT as a good listener who was affirming, empathetic, encouraging, and saw each caregiver as a unique and valuable individual. Some caregivers reported that their completed PPR Profile gave purpose to the interview and provided an opportunity to share, explain, and reflect on the daily experiences. For some caregivers, the interview helped them to better identify and talk about their daily experiences in a way that the PPR Profile, alone, was not able to do. One caregiver said, "The OT helped me give the answers I was afraid to give and couldn't explain on paper. The OT was able to wade through all the nitty gritty stuff I never share and was trying to

hold on to” (P5). Another shared that the OT “really pulled out some things that I hadn’t put a name on. And it was more helpful than just doing it on my own” (P2).

Using the PPR Profile was helpful, but difficult

Caregivers perceived the process of completing the PPR Profile and discussing it in an interview with the OT as both helpful and potentially difficult. For example, one caregiver responded that what he/she liked about completing the PPR Profile was “thinking about my life as a caregiver.” When the same caregiver answered what he/she did not like about completing the PPR Profile, he/she said, “the same thing” (P2). Perceived benefits of using the PPR Profile will be discussed first, followed by the perceived difficulties.

Using the PPR Profile was helpful. Caregivers used the words “beneficial,” “good,” “helpful,” “interesting,” and “enjoyable” to describe their experiences with the PPR Profile. One caregiver shared, “The PPR Profile was good for me because I could look at it and process what I could do to improve or say hey, I’m doing a pretty good job at some things” (P3). Another caregiver explained, “Completing it helped me think: how do I really feel when I look at my experiences? Seeing on paper where I’m feeling more positive and less positive helps me see there’s a lot more I wish I could be doing” (P4). Another said that looking over her PPR Profile “makes me feel really good because it makes me feel like I’m taking care of myself” (P1).

Caregivers also resoundingly reported that discussing the PPR Profile provided for them a space in which they could be honest about their experiences as a caregiver. One caregiver explained the feelings of “relief” in “knowing that somebody understood” (P2). Another described the use of the PPR Profile as “an opportunity to just empty out and analyze what you were doing” (P3).

Caregivers also shared their belief that the use of the PPR Profile – especially through discussion in an interview with the OT – validated them as an individual. Meeting with the OT made one caregiver feel like “I am a person. I do more than I think I do, but somewhere in my role as a caregiver is me” (P5). Another discussed how talking about their PPR Profile made him/her “feel good about taking time to care of my own health that I felt like I couldn’t do, but that I need to do” (P4). Several caregivers also discussed how good it felt to have attention given to their own individual and non-caregiving-related needs: “I hadn’t done much goal-setting since I became a caregiver for my spouse. I thought goals were supposed to be about my spouse and caregiving. I didn’t think that I was allowed to have a goal, something for myself” (P1).

Using the PPR Profile was difficult. Just as caregivers reported perspectives of benefits to completing the PPR Profile and discussing it with the OT, they also expressed their perspectives on the aspects of the process that were hard for them. In addition to citing difficulties in finding the time to complete the PPR Profile in a typical caregiving day, caregivers also shared their thoughts on the potential psychosocial implications of sharing and reflecting upon their honest occupational experiences. One difficulty occurred in the process of filling out the PPR Profile. When asked what they did not like about completing the PPR Profile, one caregiver replied, “admission” and “having to really face the reality of my situation” (P3). Another explained that, when filling out the PPR Profile, “Sometimes I felt I should cheat because it sounded bad when I rated my levels of experience. I thought, is this really true? I struggled with thinking, what is my life? How do I feel about this? It was difficult” (P2). Upon seeing their ratings of pleasure, productivity, and restoration during their occupations, one caregiver shared, “I felt kind of bad that the things I do with my spouse are not the positive things in my day. The really positive things were the things when my spouse was not there” (P4).

Several caregivers admitted that it was difficult to be confronted with the proof that their days are very busy and that they do not participate in many health-promoting occupations for themselves. One caregiver spoke about feelings that emerged upon reflection of the completed PPR Profile: “90% of my day is for someone else and that’s sort of depressing. It makes you aware that it’s not really what you thought your future was gonna be” (P4). Another explained that, as a caregiver, “You’re doing this and you’re doing that and you can’t do anything for yourself because you have to always be caring and listening for your spouse” (P5).

Caregivers voiced concern over a lack of ability to make changes as a result of greater awareness of their health needs. One caregiver explained, “Seeing my PPR Profile showed me that I need to do more for myself, but it is also frustrating to know that I just don’t have the time” (P5). Another added that they were left with the feeling of “can I really do anything additional that I’m not already doing?” (P3).

Caregivers discussed the vulnerability involved in recording and sharing their occupational experiences with others, citing the potential for misunderstanding: “I might say, ‘please don’t report me to protective services when you hear this!’ I wonder, if I really tell you how I was so frustrated, but I’m still a good caregiver, you might not understand” (P4). Another caregiver talked about the difficulty in opening up to others about their daily experience, explaining, “How do I tell someone the full story when they see me just for one day when my spouse doesn’t want to get dressed or I haven’t yet prepared lunch?” (P5). He/she continued, “You worry all the time that someone is going to say you’re not taking care of your spouse – someone who doesn’t know what it takes to take care of them” (P5). Considering both the perceived benefits and the perceived difficulties of completing the PPR Profile, all caregivers felt

that they benefitted from the experience of using the PPR Profile and agreed that they would recommend it for use with other people.

Using the PPR Profile provided opportunities for change

Caregivers reported a range of individual perspectives and experiences influenced by completing the PPR Profile and discussing it with an OT. During and following this process, most caregivers identified opportunities for change such as experiencing greater awareness, setting goals, or a perceptual change that influenced their occupational choices and experiences. Each of the subthemes are discussed below.

Experiencing greater awareness. All caregivers indicated that completing the PPR Profile and talking about it with the OT increased their awareness about their occupations and associated experiences. Caregivers explained that they were often on autopilot throughout their day, performing their caregiving tasks without much awareness or reflection. Either intentionally or unintentionally, many did not actively consider their daily occupational experiences or their perspectives on their caregiving role. One caregiver offered as explanation, “You can accept something without really accepting it” (P3). Another caregiver shared, “The PPR Profile really made me stop and think about what I was doing or had done and why. Sometimes you’re just going through the day and you aren’t aware of what you’re doing or feeling” (P2). One caregiver explained that the process of completing the PPR Profile and discussing it with the OT directed her thoughtfulness by guiding her reflection on occupational experiences: “I don’t think in those terms. I don’t think about what is affecting me. I know that I am affected and sometimes I feel stressed or feel upset, but what is it that did that? This made it more concrete” (P2).

Other caregivers described how the use of the PPR Profile helped them to understand their perceptions of their occupations: “It made me see how much time I was spending doing

something that I don't consider to be important" (P1). Greater awareness of occupations and experiences also helped some caregivers recognize how their experiences impact their emotions. For example, one caregiver explained: "Some days my morning routine of helping my spouse get ready can be frustrating. Filling out the PPR Profile made me aware of the elements of our routine that make it a good day or not that good" (P4).

Setting goals. While all caregivers reported that use of the PPR Profile increased their thoughtfulness and awareness of their occupations and occupational experiences, many caregivers – though not all – engaged in goal-setting. Those that set goals reported that they perceived this to be a positive opportunity embedded into the use of the PPR Profile. Aspects caregivers perceived as valuable for setting goals were reviewing their completed PPR Profile, recognizing areas for growth independently or through discussion with the OT, and receiving supportive feedback and encouragement from the OT.

Seeing their activities and rated experiences helped many caregivers see how much they already do. For example, one caregiver said, "When you see [your daily occupations] in black and white, sometimes that helps" (P2). Another caregiver added, "When you put down all your activities, it's a lot of stuff. A lot of things that I probably never even thought of before" (P4). In regard to reviewing her occupational experiences, another caregiver said, "Before, I didn't always do things for myself, so it makes me feel really good [to see my daily occupations] now because it makes me feel like I'm taking care of myself" (P1).

Reviewing their PPR Profiles helped several caregivers identify goals. Some caregivers self-selected health-related goals to take better care of themselves, such as wanting to "plan more nutritious meals", to "exercise more", or to "make an appointment to financially plan for the future". For example, one caregiver said he/she had been talking about wanting to go to the gym

more, and talking about the PPR Profile with the OT provided the opportunity to actually make the change: “It was a huge goal and it took me a while to build up to it. You know, I’ve been doing a lot of talking about it, but now I’ll do it” (P4). Another caregiver shared the experience of reviewing her PPR Profile and recognizing opportunities to involve her spouse in more meaningful shared occupations: “I thought, what can I do to involve [my spouse] more? We can’t hold conversations anymore; it’s just two or three word sentences. So, what else could I do to involve the two of us together as a couple?” (P3).

The role of the OT during the discussion of the PPR Profile clearly influenced goal-setting. One way caregivers felt supported in goal-setting was encouragement from the OT. One caregiver shared, “the OT encouraged me to pursue my creative interests, and before I knew it, within two weeks, I was at the fabric store. I hadn’t been there in over a year, but I used to go there all the time” (P1). The caregiver went on to explain that the support from the OT helped him/her to not feel guilty about taking time to participate in occupations for him/herself: “I’m feeling much better. Before, I felt guilty. I thought, ‘I shouldn’t do that, I should be with my spouse’. But if you don’t take care of yourself, you aren’t any good for the person you are taking care of” (P1). Caregivers also reported that they appreciated being able to share their goal-setting. “It was good to tell [the OT] ‘I’m going to look at how I can take the time and just go to invest in myself,’” one caregiver told researchers (P4). He/she continued, “[Being held accountable by the OT] is a good way to stay on top of things. Even if you’re caught and you’re not following through, it’s a reminder to keep going!” (P4).

Changing perceptions. Several participants reported that completing and discussing the PPR Profile not only made them more thoughtful and aware of their activities, experiences, and emotions, but that it helped them to see things differently. Differences were noted in how

caregivers saw their identity and their occupations and routines. For example, after examining her occupational experiences, one caregiver reported, “[I] understand myself better” (P3). The process of completing the PPR Profile and discussing it with the OT helped another caregiver to share the challenges of caregiving and realize that one can seek help while still remaining strong: “I’ve always been the strong person in my family, and I’ve always expected myself to be strong. Meeting with the OT has made me realize yeah you’re strong, but you also need help sometimes” (P5). For another caregiver, seeing her experiences with occupations made him/her more aware led to thinking about her occupations differently. This caregiver intentionally added more positive occupation in each day: “I think needing something positive to happen in every day gives me something to look forward to, and then I am better able to deal with the things that are more frustrating” (P4).

Recommendations

Caregivers’ recommendations regarding the PPR Profile included recommendations for the PPR Profile itself, its use in a one-on-one interview, and its use with other potential clients.

PPR Profile. Caregivers had a range of ideas to improve usability of the PPR Profile. All the caregivers recommended continuing to offer users the flexibility of completing the PPR Profile either independently or as a “yesterday interview” with assistance from someone trained in the administration of the PPR Profile. Some caregivers thought that an addition of multiple choice options for categories of the PPR Profile such as location and context might make it easier to complete. Other caregivers cautioned that making too many parts of the PPR Profile multiple choice would decrease the level of self-reflection the PPR Profile encourages. Others thought that providing more space to write for each occupation would allow for greater explanation of

occupational experiences and perhaps reduce the opportunity for a misunderstanding of caregiver experience by an OT or other health professional looking at the completed PPR Profile.

One-on-one interview with the occupational therapist. All caregivers recommended continuing to pair the completion of the PPR Profile with a follow-up interview with an OT. Caregivers noted that the opportunity to discuss one's occupations and occupational experiences is crucial to providing context to the OT so as to avoid misunderstanding of caregivers' written occupations and occupational experiences. Additionally, caregivers saw immense value in participating in guided reflection during an extended interview with an experienced and/or skilled therapist who is empathetic, listens without judgment, is trustworthy, and sees the caregiver as an individual with their own personality and occupational needs.

Use of the PPR Profile. Caregivers all recommended the future use of the PPR Profile with others, especially with other caregivers. However, caregivers gave differing recommendations on when and how the PPR Profile should be used. They recommended that careful consideration be given to the caregiver's stage in their caregiving process, their readiness for self-reflection and/or change, and the support system available to the caregiver.

Discussion

This study is the first to examine users' perspectives of the PPR Profile in practice and, as such, illustrates important findings for its potential use and further research. The results revealed that using the PPR Profile with caregivers provided benefits and difficulties, increased their awareness, enabled health-related goal-setting, and impacted their perceptions. These findings support the use of the PPR Profile to capture and discuss contextual occupational experiences as one opportunity for caregivers to self-manage their health. Themes from the results will be

discussed prior to presenting the general implications for use of the PPR Profile and discussing limitations to the study and future research.

Regarding the PPR Profile tool itself, caregivers' perspectives were similar to other users' perspectives (Atler, 2015); however, providing options appeared to reduce burden. Caregivers and non-caregivers both felt the PPR Profile was burdensome when considering the time and energy it required, but that it did capture their occupations and occupational experiences in the context of their day (Atler, 2015). The results of this study suggest that providing options for completing of the profile, such as completing it independently or as a "yesterday interview," may provide greater flexibility to caregivers that may reduce the potential burden. Additional recommendations made by the caregivers indicated possibilities for future development, including additional writing space and the potential development of an online or digital version of the tool. Use of a client-centered approach to evaluating the PPR Profile led to important insights about how we can make the assessment tool more practical and acceptable (Smart, 2006), particularly for people who may have greater demands on their time. This study reinforces the importance of engaging users early in the process of developing and evaluating client-centered assessments (Atler, 2013).

The opportunity to pursue meaningful, intentional, and individually tailored goal-setting with the encouragement and guidance of an occupational therapist empowers clients to actively influence their occupational experiences (Doig, Fleming, Cornwell, & Kuipers, 2009; Kielhofner, 2005). The results of this study provide initial insight into how the PPR Profile, used by an occupational therapist, can become an additional tool for use in a community setting to enhance client-centered practice. Caregivers responded positively to the opportunity to discuss their contextual occupational experiences with an occupational therapist, citing the experience as

meaningful. It is helpful to hear feedback from caregivers that the use of the PPR Profile is meaningful and helpful; however, we also understand that occupational therapists should be cautious in considering when it will be best to use the PPR Profile with clients. It will be essential for occupational therapists to critically evaluate when and how to use the PPR Profile to guide goal-setting and services (Coster, 1998).

Literature shows that discussing one's occupational experiences with an occupational therapist can foster awareness, and that such awareness is essential for change (Clark, Jackson, & Carlson, 2004; Erlandsson, 2012). Previous utility research of the PPR Profile (Atler, 2014; Atler, 2015) showed that the tool promoted users' awareness of their occupations and contextually-situated occupational experiences. In this study, we found that using the PPR Profile with caregivers supports similar types of awareness, supporting the clinical use of the PPR Profile. At the same time, echoing findings of the use of the PPR Profile with a sample of community-dwelling adults with stroke (Atler, 2012), using the PPR Profile with a more stressed and/or vulnerable population may add an additional burden or cost. Not only does the PPR Profile take time and energy to complete, but there are additional psychosocial elements to consider. Results of this study suggest that, for the use of the PPR Profile with caregivers, consideration must be given to caregivers' personal strengths and weaknesses, their position in their caregiving process, and the supporting and limiting contexts of their environment (Family Caregiver Alliance, 2006; Reinhard et al., 2008). It is important to realize that increased awareness – as was seen with the use of the PPR Profile – can bring greater emotions that could potentially be positive or negative for the client.

Implications for practice

The occupational therapist's role in the use of the PPR Profile appears to be of prime importance. Consideration should be given to the potential for fit, both between the occupational therapist and the PPR Profile as well as between the occupational therapist and his or her client. Because the assessment captures personal, specific, qualitative information about clients' occupational experiences, the occupational therapist considering the use of the assessment must be prepared and comfortable with gathering and processing this type of data. Additionally, as seen with this study, the level of comfort and rapport the occupational therapist has with his or her clients will influence the quality and therapeutic value of the collected data and the interview session or sessions held with the client.

Occupational therapists should be poised to evaluate potential users of the tool for readiness and be prepared to guide next steps in service provision. As we learned in this study, caregivers all felt that other caregivers would benefit from using the PPR Profile, but differed in their recommendations of when in a caregiver's journey the tool might be most beneficial. Client-centered motivational interviewing (Miller & Rollnick, 2002) or assessments connected with the transtheoretical model of behavior change (DiClemente & Prochaska, 1998) could enable practitioners to understand client health-related readiness to change (Nieuwenhuijsen, Zemper, Miner & Epstein, 2006; Stoffel & Moyers, 2004).

Helping clients to engage in personal reflection, as illustrated with the use of the PPR Profile may lead to greater awareness of the emotions and meanings related to their occupational experiences (Dubouloz et al., 2004, Dubouloz, 2014, Eakman, 2015). Use of empathetic and nonthreatening ways to engage a client's intrinsic motivation for change might also be used in goal-setting (Stoffel & Moyers, 2004). This heightened awareness comes through reevaluation of

personal goals and transformation of meaning that can lead to intentional changes in behavior, as was seen with several caregivers. Supporting this type of awareness, reflection, and conscious change in discussion with an occupational therapist could lead to a client's ability to better self-manage his or her health by intentionally pursuing more positive occupational experiences (Eakman, 2015).

When use of the PPR Profile results in an increased awareness of the incongruencies between a client's beliefs about what life should be like and a personal appraisal of his or her current situation, occupational therapists may help the client to simplify and manage his or her awareness and reactions (Dubouloz, 2004; Dubouloz et al., 2010; Park & Folkman, 1997; Park & Folkman, 2010). Several models have been proposed to guide occupational therapists to enable clients in resolving this discrepancy (Dubouloz et al., 2010; Park & Folkman, 1997; Park & Folkman, 2010). To add to this understanding, caregivers in this study shared a range of perceived difficulties resulting from the completion and discussion of their PPR Profile, yet they repeatedly emphasized the positive role the occupational therapist played for them in the process of the study. This reemphasizes the value of developing a therapeutic relationship with the client, assessing the client for readiness before administering the PPR Profile, and individualizing a plan of care to support the client through his or her reflection, goal-setting, and behavioral changes (Coster, 1998).

Limitations and future research

As the PPR Profile was used with only 6 caregivers in one setting, the results are context-bound and cannot be generalized to a larger population. Specifically, the caregivers were recruited from a community setting caregiver support group that had an occupational therapist as one of the facilitators. Freed from considerations of reimbursement, the occupational therapist

was able to dedicate as much time to one-on-one interviews as caregivers needed. Because of an already established relationship between the caregivers and the OT, perhaps this led to more intimate sharing of experiences. In addition, the caregivers were highly motivated to help researchers understand their experiences of caregiving. This may have influenced their willingness to participate. The presence of the researchers may have influenced their positive reviews of utility; however, as caregivers seemed quite frank and forthcoming in the full range of their perceptions of using the PPR Profile, the researchers believe that there was no bias in this regard.

Further research of the use of the PPR Profile by an occupational therapist is needed. Specifically, further research is needed to understand how the tool can be used in different settings, potentially including outpatient and mental health settings. Further research is also needed using the PPR Profile with a variety of client groups. Additional research could also help to better understand the impact and potential use as a tool to promote changes in health behavior. Understanding occupational therapists' perspectives of utility would also be beneficial.

Conclusion

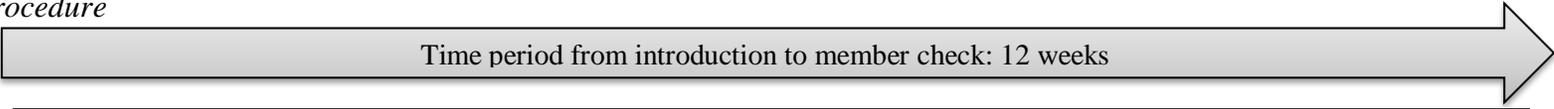
The results of this study support the use of the PPR Profile to capture and discuss contextual occupational experiences as a client-centered and ecologically valid occupational therapy assessment to guide interventions for caregivers to self-manage their health. Findings revealed that using the PPR Profile with caregivers provided benefits and difficulties, increased their awareness, enabled health-related goal-setting, and impacted their perceptions. Discussion focused on issues that occupational therapists need to consider in using the PPR Profile. While these results are promising in one setting, further research is warranted.

Table 1

Scale to identify levels of experience

Pleasure: <i>Experiencing enjoyment</i>	Productivity: <i>Feeling like “I got something done”</i>	Restoration: <i>Experiencing my energy restored</i>
Extreme displeasure	Extremely unproductive	Extremely drained
Moderate displeasure	Moderately unproductive	Moderately drained
A little displeasure	A little unproductive	A little drained
Neither displeasure nor pleasure	Neither unproductive nor productive	Neither drained nor renewed
A little pleasure	A little productive	A little renewed
Moderate pleasure	Moderately productive	Moderately renewed
Extreme pleasure	Extremely productive	Extremely renewed

Table 2
Procedure



	Introduction of study	PPR Profile	One-on-one interview	Focus group	Member check
Details	<ul style="list-style-type: none"> - OT participated in training with researchers -Caregivers learned about the study -Participating caregivers gave informed consent 	<ul style="list-style-type: none"> -Caregivers completed the PPR Profile (independently or as a “yesterday interview”) 	<ul style="list-style-type: none"> -Caregivers engaged in a one-on-one interview with the OT 	<ul style="list-style-type: none"> -Caregivers participated in a focus group discussion with researchers -Caregivers completed worksheets to capture initial impressions and actual experiences of PPR Profile and one-on-one interview 	<ul style="list-style-type: none"> -Caregivers participated in a member check discussion with researchers -Caregivers clarified, confirmed, and added to a compiled selection of significant statements
Data collected	<ul style="list-style-type: none"> -Caregiver demographic information 	<ul style="list-style-type: none"> -Completed PPR Profiles 	<ul style="list-style-type: none"> -Audio recording for verbatim transcription 	<ul style="list-style-type: none"> -Audio recording for verbatim transcription -Completed worksheets 	<ul style="list-style-type: none"> -Audio recording for verbatim transcription

Table 3
Data Analysis

Focus group sample questions	A priori codes and sample data	Main concepts presented at member check	Final themes
What were your initial impressions of the study?	<p><i>Initial impressions</i></p> <ul style="list-style-type: none"> ○ “I thought it would be a lot of work, but interesting” (P4) 	<p><i>What it was like to fill out the PPR Profile and talk about it</i></p> <ul style="list-style-type: none"> ○ “It really made me stop and think about what I was doing or had done” (P2) 	<p><i>Theme 1) Initial perspectives of using the PPR Profile</i></p>
What were your actual experiences of the study?	<p><i>Actual experiences</i></p> <ul style="list-style-type: none"> ○ “It was helpful to talk to someone in person” (P5) ○ “The OT pulled out some things that I hadn’t put a name on. And it was more helpful than just doing it on my own” (P1) 	<ul style="list-style-type: none"> ○ “It was helpful to talk to someone in person” (P5) ○ “It was hard for me to stop and think because sometimes you’re just in the flow of it and you just do whatever it is that needs to be done” (P2) 	<p><i>Theme 2) Using the PPR Profile was helpful, but difficult</i></p>
What were your likes and dislikes regarding the study?	<ul style="list-style-type: none"> ○ “It was hard for me to stop and think because sometimes you’re just in the flow of it and you just do whatever it is that needs to be done” (P2) 	<p><i>Perceptions of the one-on-one interviews</i></p> <ul style="list-style-type: none"> ○ “[The OT] was uplifting...and gave helpful feedback” (P3) 	<p><i>Theme 3) Using the PPR Profile provided opportunities for change</i></p>
What are your recommendations?	<p><i>Likes</i></p> <ul style="list-style-type: none"> ○ “[The OT] was uplifting...and gave helpful feedback” (P3) ○ “I liked doing it; well, I liked talking about it better than filling it out” (P1) <p><i>Dislikes</i></p> <p><i>Recommendations</i></p>	<p><i>The importance of pairing the PPR Profile with the one-on-one interview</i></p> <ul style="list-style-type: none"> ○ “The OT pulled out some things that I hadn’t put a name on. And it was more helpful than just doing it on my own” (P1) ○ “I liked doing it; well, I liked talking about it better than filling it out” (P1) <p><i>Recommendations</i></p>	<p><i>Theme 4) Recommendations</i></p>

CHAPTER THREE: REFLECTION

Before beginning the masters degree program in Occupational Therapy at Colorado State University, I loved World Literature and teaching students to write. I did not imagine, when I changed careers, that I could ever feel so passionate again about what I would *do*. This program has changed me, and the process of designing and carrying out a research study under the tutelage of Dr. Karen Atler has played a large part.

I have learned a lot about myself in this process. I learned that I can easily get lost in the literature of our profession – learning about people’s stories of illness and disability, about assessments meant to gather the just-right information from clients, about interventions and outcomes that can change lives, and about the theory that underlies our fervent beliefs in the power of occupation. I learned that the passionate naiveté I had as a young teacher (and thought I had eradicated from my system) is alive and well in my dreams of working with my future clients and righting all the wrongs in the world. I learned, too, that even though I have natural curiosity, I am not a natural researcher. At times, I felt lost in the vocabulary of ‘qualitative’, ‘inductive,’ ‘pragmatic,’ and ‘iterative processes’ – I am a foreigner who is only beginning to speak the language. My reading, alongside my halting attempts at writing, have shaped me as a qualitative researcher keenly interested in the stories people have to tell about their occupations and experiences. I have learned that I have a place in the realm of occupational science and occupational therapy research.

One of the aspects of my thesis research process that has been most special to me has been working with and learning from Karen. On the day she interviewed me for a graduate research assistantship, I arrived nervous and left inspired. Karen’s passion for helping others

shines through all she does – teaching, gardening, mentoring, and writing. She inspires me with her tireless work ethic, her love of teaching, and her ability to pursue her biggest dreams. My favorite times with her were the ones we spent at her table in her office, discussing theory, offering hypotheses, questioning each other, and making our way together toward meaning. Those were some of the most intellectually stimulating moments of my career and I will cherish them. Hopefully, there will be more to come.

Another incredible gift I have received in the process of my thesis research has been the opportunity to learn from the caregivers who participated in this study. I was honored and humbled by their trust in us and in our ability to expose their honest stories to the occupational therapy community and the research community at large. The caregivers shared their daily difficulties, their heartbreaks, their faith, their love, and their perseverance with us and they have inspired me. I think of them when I am with the man that I love; I think of their words when I meet other caregivers; and I will carry their spirit when I begin practice as an occupational therapist myself.

As I move on to the next chapter in my career, I will carry these experiences with me and call on them to guide me in my future practice and research. I am still not entirely sure where I best fit in the occupational therapy world – acute care? Community? Pediatrics? Research? Teaching? – so I am grateful that we are in a profession that allows for and supports diversity, change, and adaptation. I hope to have a long career in helping others by meeting them where they are right now and helping them get to where they want to be. My experience as a thesis student will guide me well as I continue to cultivate my love of learning and pledge to pursue rigorous inquiry, the highest ethical standards, and a desire to share the healing and balancing powers of occupation.

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