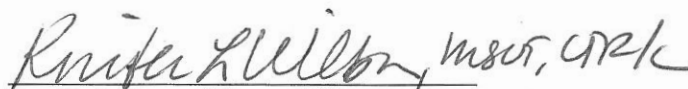


Listening to the client: Experiences of occupational therapy services shared by an
Anishinaabe tribal member

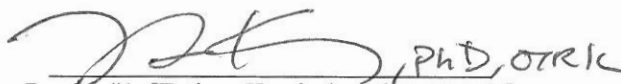
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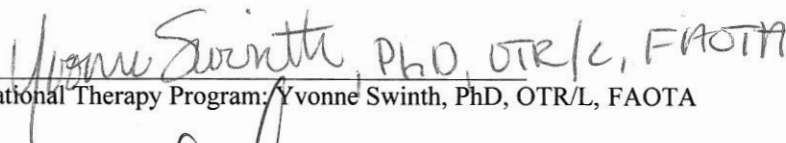
This research, submitted by Lauren Brown MSOTS & Tessa Currie MSOTS, has been approved and accepted
in partial fulfillment of the requirements for the degree of
Master of Science in Occupational Therapy from the University of Puget Sound.



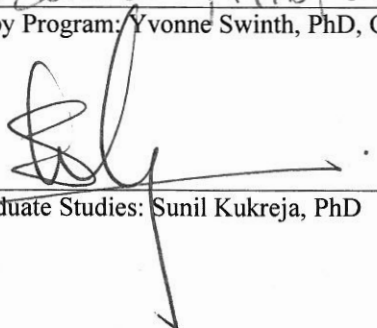
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Abstract

The indigenous American consumer perspective is lacking within occupational therapy research. By better understanding the experiences of individuals who identify as indigenous and who have received occupational therapy, practitioners can work to create a more effective therapeutic relationship, more relevant goals, and more effective treatment. A phenomenological approach to qualitative analysis was used to explore the perspective of one indigenous woman and her experience with occupational therapy. Themes that emerged include: 1) know the individual's background and the tribal and regional history, 2) treat the whole including family and community, and 3) use a functional, practical and individualized approach relevant to the cultural context. This information will help to expand the information available to occupational therapy practitioners regarding culturally competent practice.

Listening to the client: An experience of occupational therapy services shared by an Anishinaabe tribal member

Qualitative methods were used to explore the perspective of one indigenous American woman and her experience with occupational therapy. Throughout the process, the investigators encountered a medley of terms used to describe the same concepts. For the purpose of the current paper, the investigators have carefully decided to use the following terms:

Indigenous: To refer to individuals who identify as American Indian/Alaska Native (AIAN), Indian, and Native American. Preference of terms is specific to the person depending on age, region, past experience, and community history. In choosing indigenous, the current paper seeks to respect the preference of our participant. When referencing specific research, the terminology reflects that of the cited source.

Settler society: To address the colonizing society of North America, which most commonly includes those of a European ancestry. Literature also makes reference to this group as the dominant culture, a term expressly not used as it feeds into an underlying language of dominance and submission. Settler society allows for the greatest detail and transparency of terms.

Health inequity: Refers to the difference in social and environmental factors caused by injustices, resulting in increased rates of disease, poorer outcomes of health statistics, or lesser access to health services. Health inequity differs from health inequality, which refers only to a measure of change in health statistics that may have resulted from uncontrollable factors such as the natural genetic differences between individuals.

The United States is a multicultural mosaic that is increasing in diversity, necessitating a reevaluation of treatment approaches for medical and mental health conditions to insure equality of care. Historically, the U.S. has not treated all ethnicities equitably. It has been recorded that

“populations of color” receive lower quality health care than white people, even when controlling for factors such as insurance status, income, age and severity of conditions (Havens, Yonas, Eng, & Farrar, 2011). Injustices have been served, particularly among the cultural minorities of this country. The indigenous population is one such group that has experienced cultural misunderstanding and under-representation in healthcare (U.S. Commission on Civil Rights, 2004). According to the 2010 census, 28.4% of indigenous persons were living at or below poverty, compared to the national poverty rate of 15.3% (U.S. Department of Commerce, U.S. Census Bureau, 2011). Individuals living in a lower socioeconomic status often experience a compromised quality of life, which can lead to occupational deprivation, a situation where an individual is unable to engage in necessary or meaningful activities due to external restrictions outside of his control (Reitz, 2014). Occupational therapy is a critical intervention that can be used to restore participation in meaningful occupations, but only if therapists fully appreciate the cultural factors that can influence occupation. Thus, it is essential that occupational therapists serving indigenous individuals understand the cultural context that underlies meaningful occupations within their communities.

When the client is from a different cultural background from the therapist's, the practitioner must reach beyond her own lived experience to develop a rapport with the client in a meaningful and therapeutic manner. Being culturally sensitive is one method to improve effectiveness of and satisfaction with health care services. To accomplish this Havens et al. (2011) argue that practitioners must explore avenues of antiracism and cross-cultural education in order to disassemble inequalities between racial, or cultural, groups. Occupational therapy uses a holistic approach that regards each individual as unique. Pachter (1994) wrote that using culturally sensitive approaches aided in developing client-practitioner relationships, more

accurate diagnoses, and improved patient satisfaction. In order to provide effective occupational therapy, practitioners must design interventions that are relevant to the client's everyday needs and priorities. Without a cultural understanding of the client's values and beliefs, therapists may not be able to accurately assess those needs and focus therapy toward meaningful occupation (Chiang & Carlson, 2003).

Healthcare inequities

Healthcare inequity has gained attention in many health-related fields (Braveman & Bass-Haugen, 2009). The Healthy People 2010 report set a goal to eliminate health disparities in the U.S. by 2020 (U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, 2010). Minority populations are often affected by such health care injustices, leading to limited opportunities to contribute to society in a meaningful way (Braveman & Bass-Haugen, 2009).

In recent decades occupational therapy practitioners have become more proactive in addressing multiculturalism within practice (Evans, 1992; Kronenberg, Simó, & Pollard, 2005). Practitioners are beginning to recognize that the quality of health care is of great importance for all populations, as one of the foundations of the field is that practitioners collaborate with individuals of all ages to develop, maintain, or regain participation in daily living (American Occupational Therapy Association, 2010). Similarly, providing interventions that integrate the service recipients' goals, motivations, habits, and values should be paramount in delivering client-centered occupational therapy. A client's ethnicity, socioeconomic class, gender, or political leanings are just some of the aspects that a practitioner could recognize and integrate into the treatment approach to increase the effectiveness and quality of occupational therapy

(Kronenberg et al., 2005). Without consideration for these aspects of culture and a willingness to reflect on one's own biases an inequity of health services can arise (Dillard et al., 1992).

Healthcare disparities have also been linked to socioeconomic status, belonging to a minority race, and location of residence (AOTA, 2010). According to the Office of Minority Health and Health Equality, the AIAN population is considered one of six minority groups in the U.S. (U.S. Department of Health and Human services, Centers for Disease Control and Prevention, 2010). The 2010 census reported that people who identify as AIAN alone or in addition to another race accounted for 1.7% of the U.S. population, approximately 5.2 million people, and this population is increasing at nearly twice the rate of the total U.S. population (U.S. Department of Commerce, United States Census Bureau, 2010).

As the AIAN population grows, currently existing healthcare disparities will likely be exacerbated. Over time, the differences in quality and access to healthcare manifest in observable differences in health statistics. In 2010 the life expectancy of AIAN individuals was recorded to be 2.4 years less than the U.S. population as a whole, though this was considered to be a conservative estimate and is likely even shorter (Barnes, Adams, & Powell-Griner, 2010). The AIAN population experience many health conditions such as diabetes, alcoholism, suicide, and cardiovascular disease at rates much higher than the U.S. population (U.S. Commission on Civil Rights, 2004). AIAN individuals are 2.6 times more likely to receive a diagnosis of diabetes than non-Hispanic whites of a similar age (U.S. Commission on Civil Rights, 2004). Moreover, the AIAN population has the highest rates of type II diabetes in the world and adults are 420 times more likely to die from diabetes than adults in the general public (U.S. Commission on Civil Rights, 2004). Additionally, heart disease is the primary cause of death among AIAN persons and stroke is the fifth leading cause of death. This increase in cardiovascular disease among the

AIAN population is concerning as the U.S. population as a whole has experienced a 50% decrease in heart related diseases (U.S. Commission on Civil Rights, 2004). Risk factors for cardiovascular disease include high blood pressure, cigarette smoking, high cholesterol, obesity, and diabetes (U.S. Department of Health and Human Services, Center of Disease Control and Prevention, 2000). The U.S. Department of Health and Human Services, Center of Disease Control and Prevention (2000) noted that 63.7% of AIAN men and 61.4% of AIAN women reported a presence of one or more of these risk factors. Many AIAN individuals also presented with additional risk factors including unemployment, less education, and those reporting a health status as fair or poor (U.S. Department of Health and Human Services, Center of Disease Control and Prevention, 2000). The compounding factors of diabetes and cardiovascular disease have had a devastating impact on the indigenous population.

The Role of Occupational Therapy

Occupational therapists bring essential knowledge of the conditions and comorbidities that accompany diabetes and cardiovascular disease. For example, Huntley (2014) identified that the role of the occupational therapist was to educate on risk factors and preventative care, conduct assessments of physical and cognitive functions, create a rehabilitation plan, and develop client and caregiver skills to increase independence and participation in meaningful activities.

Occupational therapists conduct evaluations and treatment using the guidance of the Occupational Therapy Practice Framework (OTPF; AOTA, 2014), which outlines client factors, including body functions as they relate to daily life. Body functions relevant to the conditions stated above include musculoskeletal, cardiovascular, respiratory, and endocrine functions (e.g., how blood vessels and the heart affect cardiac functions) (AOTA, 2014). Client factors also

include values, beliefs, spirituality, and the environment of the client (AOTA, 2014). These client factors help structure treatment and enhance participation in valued activities to promote health, wellness, and participation for people with or without disability-related needs (AOTA, 2014). The consequences of poor health reach beyond the physical body functions of a disability and cause a negative impact on the socio-economic development of indigenous communities. Left unaddressed, a continuing cycle appears where lesser quality health services leads to poor health, decreasing the ability for those to contribute to successful community development and thereby widening the socio-economic gap (U.S. Commission on Civil Rights, 2004).

Indigenous Populations

Although the above-mentioned disparities address the indigenous population as a whole, it is important to note that the indigenous population is immensely diverse and that each person holds his own values and beliefs. The current paper seeks to respect such diversity while simultaneously working to understand the threads of commonality that can help promote effective occupational therapy within indigenous populations. Generalizations regarding indigenous communities are made with an understanding that the indigenous population does have a shared history of oppression in the U.S. that contributes in multiple ways to healthcare disparities in this population (Hodge & Limb, 2010). By identifying this shared history, as well as recognizing common cultural values and beliefs, experts in the field have identified overarching themes that shed light on the underlying factors that contribute to the healthcare inequities of AIAN populations (Hodge & Limb, 2010). These themes include concerns such as limited access to health services, limited access to health insurance, insufficient federal funding, disproportionate rates of poverty, and under-representation in health related research (Basset, Tsosie & Nannauck, 2012; Keightly et al., 2011; U.S. Commission on Civil Rights, 2004). These

compounding factors expose the indigenous population to a greater risk for inequitable treatment within the settler society and culture.

An Individualized Approach

Many of the factors such as the lack of government financial support and less access to adequate health services require change on a system level, as these are difficult to influence as an individual practitioner. The factors listed above parallel those present in many minority groups, yet the specific nature of such disparities is unique to the indigenous population due to aspects such as the historical legacy between the U.S. and Native tribes and the resulting structure of U.S. government systems of support such as the Indian Health Services (Goins, Spencer, Goli, & Rogers, 2010; Kirsh, Trentham, & Cole, 2006; U.S. Commission on Civil Rights, 2004).

There are, however, other factors contributing to inequity such as the quality of care indigenous individuals receive, the cultural competence of the healthcare practitioner, and the lifestyle choices of the client; all of which can contribute to a decline in an individual's health and can be addressed on a client level by healthcare professionals (U.S. Commission on Civil Rights, 2004). For example, a qualitative study that sought to understand the perspective of Native American elders on healing post brain injury found that, in their view, therapy needed to include the healing of the spirit and an understanding of traditional methods of healing through an exchange between traditional and Western knowledge (Keightly et al., 2011). Kirsh et al. (2006) used a phenomenological approach with semi-structured interviews to uncover the need for practitioners to recognize the power dynamic between client and practitioner, the provision of a safe treatment environment, and the biases that might lead to inadvertent discrimination. Furthermore, Bassett et al. (2012) and Gone (2009) explained the American Indian healthcare consumers' perspective by highlighting the role that historical trauma plays in the healing

process. Bassett et al. (2012) also found that elders believed that a strong connection to native culture promoted healing, emphasizing the need for practitioners to support clients through cultural awareness and sensitivity.

Rationale

While researchers have made notable progress in identifying and understanding the causes of disparities in healthcare and identifying strategies to ameliorate the problem, the indigenous healthcare consumer perspective is still lacking in the healthcare literature. Most consumer insights have appeared in the fields of psychology and social work and do not address how an occupational therapist can incorporate these recommendations into daily practice with indigenous clients (Bassett et al., 2012; Gone, 2009). Occupational therapy is unique in that professionals aid the client by developing and adapting habits and routines as he navigates activities of daily living following a major event such as a stroke or a diabetes-related amputation as well as more routine surgeries such as hip or knee replacements. Without research, occupational therapists are less able to use evidence-based techniques in serving indigenous populations with treatment equivalent to services received by those of the surrounding settler society.

Researchers from Australia and Canada have published more research than those from the U.S. that addresses occupational therapy service delivery to First Nations people. Australian studies portrayed the perspective of occupational therapists who worked with First Nations clients (Nelson et al., 2011; Stedman & Thomas, 2011). These studies offered some helpful insights but did not incorporate the perspective of First Nations individuals themselves, a significant limitation in studies to date (Nelson et al., 2011; Stedman & Thomas, 2011).

International authors have called for the representation of minority consumer perspectives on services (Kirsh et al., 2006; Nelson et al., 2011; Stedman & Thomas, 2011).

Purpose

Although practitioners in the U.S. can learn from research conducted in fields other than occupational therapy, or in other countries, such research does not supplant the need for research in occupational therapy that is focused directly on the experiences of clients who identify themselves as belonging to indigenous cultures. By better understanding the experiences of indigenous individuals who have received occupational therapy, practitioners can work to create a more effective therapeutic relationship, more relevant goals, and more effective treatment. Therefore, the purpose of this study is to describe the lived experience of indigenous adults who have received occupational therapy services in a rehabilitation setting in the Pacific Northwest.

Method

Research Design and Rigor

Qualitative research seeks to explain the dynamic human experience as it is perceived by the participant within his own environment (Portney & Watkins, 2009). Within qualitative methodology, phenomenology allows for a theoretical framework to emerge in an evolutionary process as the data are collected, coded, and analyzed (Taylor & Francis, 2013). This process has allowed the investigators to organize concepts based upon the themes that emerged from the data rather than on a predetermined framework. As it was the goal of this paper to uncover the rehabilitation experience of indigenous individuals, a phenomenological approach was most appropriate.

Guba's model was used in the data collection, coding, and analysis process in order to enhance the rigor of the study and ensure the trustworthiness of findings (Krefting, 1991).

Guba's concepts of truth-value, applicability, consistency, and neutrality helped guide the investigators in establishing the worth within their findings (Krefting, 1991).

To enhance rigor and credibility of the findings during data collection, the interviewer started with broad questions allowing the participant to share her own experience before moving on to more specific follow-up questions. Throughout the interview process, questions were repeated or rephrased for clarity and truth-value. A variety of types of questions were used including indirect questioning as well as hypothetical situational questions (Krefting, 1991). A second investigator was present during the interview to take field notes that allowed for triangulation of the data. Throughout the data analysis, an audit trail was kept of all data, process notes, and coding materials. Each investigator took time to analyze the interview and field notes before coming together to discuss findings. At the point of consensus among the two investigators and the readers, findings were shared with the participant via telephone through a member checking procedure to ensure trustworthiness of the findings. Where possible, themes and discussion thereof use the participant's own words and phrases in a practice of 'in vivo' coding (Straus & Corbin, 1990).

Participants

To be considered for inclusion, participants must have identified as belonging to the indigenous population, be 18 years of age or older, English speaking, and have received occupational therapy services in the last five years. Also necessary was the participants' willingness to sign a consent form to participate in the current study and be audio recorded during a 60-120 minute interview. Ideally, three to five individuals who met the inclusion criteria would participate in the current study. Participants for the study were recruited using a snowball sampling method. Flyers explaining the current project and contact information for the study

were passed on, via nominating sources such as faculty, students, and community members, to individuals who may fit the inclusion criteria (Appendix A for flyer). This allowed possible participants to contact the investigators only if they were interested in participating, thereby avoiding any possible coercion. Interested participants were given a brief telephone screening to insure eligibility (Appendix B for screening questions). These recruiting methods resulted in one voluntary participant. The resulting paper is an exploration of this individual's experience.

To promote confidentiality, the participant has been given the pseudonym Mamaangigidigwe. She is a 63-year-old female who identifies with the Anishinaabe tribe from Turtle Mountain in North Dakota. Mamaangigidigwe explained that her tribe refers to themselves as Anishinaabe, while the federal government recognizes the tribe under the name Chippewa.

On her paternal side, her grandfather is of French and English descent with the history of French persecution of the Huguenots in the 1500's resulting in immigration to the Americas in the 1600's. Her paternal grandmother is Irish and this history includes persecution and immigration to the Americas. Her father was born in Montana, into the American settler society.

Mamaangigidigwe's mother was born in North Dakota and moved to Portland when she was 18. Her maternal grandmother was labeled as ½ Native under the Dawes Act, probably Mohawk, although not much is known of her history. Her maternal grandfather was Anishinaabe, Cree and French. Mamaangigidigwe's maternal great grandmother was full blood Pembina, an Anishinaabe sub group. Mamaangigidigwe's maternal history follows a group of people who moved freely between the Midwest and Canada, part of both the indigenous and settler/fur trading communities of the region.

Mamaangigidigwe now lives in North Seattle with her husband, as she declined the option to live on the Quileute reservation. Mamaangigidigwe believes that there are now more individuals from Turtle Mountain currently residing in the Pacific Northwest than in North Dakota. Within her Native community, Mamaangigidigwe is seen as a trusted academic with a Master's degree in nursing and anthropology followed by a PhD in womens' studies. Within the settler society, she is seen as a "rabble rouser," one who does not always follow the rules. For herself, she is a radical, but one who appreciates the importance of humor in the little things.

In 2012 she underwent left knee replacement surgery and received occupational and physical therapy during her 3-day hospital stay, one day longer than average due to medical complications. She followed up with outpatient physical therapy after discharge and believes that it would have been helpful to have followed up with an occupational therapy home visit. There was confusion regarding a possible occupational therapy home visit. Mamaangigidigwe feels that she was so distracted by the pain post-surgery that she did not always know what was expected of her for outpatient follow-up. Mamaangigidigwe did continue with outpatient physical therapy but has since been discharged from all rehabilitative services. She never regained full range of her knee and has trouble with flexion past 90 degrees due to her surgeon inserting an oversized artificial meniscus.

Instrument

A semi-structured interview, primarily using broad, open-ended questions, was used to explore the participant's experience of receiving occupational therapy (See Appendix C for guiding questions). More specific follow-up questions were used to gain a more in-depth understanding during the interview process. The interview was audio recorded for transcription by an outside source. One investigator conducted the interview while the other investigator

observed the interview, noting changes in body language, facial expressions, emotional responses, and changes in tone of voice. The interview lasted for 75 minutes. Each investigator kept a field journal to record her own thoughts and behaviors and reflected on how her own perspective influenced data collection and analysis (Krefting, 1991). All sources of information described below were used for triangulation of the data during analysis.

Procedures

Investigators conducted a mock interview using the proposed open-ended questions with a layperson, unfamiliar with the current study. Two additional experienced qualitative researchers observed the mock interview and provided feedback regarding research questions and interview technique. Participant recruitment followed approval by the University of Puget Sound Institutional Review Board. Once the participant was identified, an interview was scheduled and conducted. Upon arrival, the participant was given a \$20 gift card. At that time, a description of the study was given to the participant and a consent form to participate was signed. The interview was conducted in a quiet and private meeting space at the University of Puget Sound, a location selected by the participant.

Data Analysis

Data consisted of an audio recording, a transcript and field notes from the initial interview, as well as all follow-up communications. After spending extensive time reviewing the data, a posteriori coding technique was used. Each investigator analyzed the data independently before consulting as a team. Upon completion of independent coding, investigators met individually with a third party experienced in phenomenology to reflect on findings. Both investigators then compared notes and discussed findings until consensus was reached regarding

common themes that emerged. Member checking was conducted to ensure credibility of the themes.

Results

Preface

“It is politically fraught. And you just have to be really aware of what it is you are trying to say.”

Mamaangigidigwe explained the work of Anderson and Hokowhitu (2007) and the “void” that is present between the structure and beliefs of the settler society and those of indigenous communities. In reflection of their work, she explains:

There is a void of understanding, and there is no possible way that you are actually ever going to understand the other person. And [Anderson and Hokowhitu] say, unfortunately what happens with that void is the people who have the most power, who are the colonizers and the settlers, tend to fill the void with what they think ... the indigenous people are thinking. And which is not at all what the indigenous people are thinking. It is just their lens, their perception of what the indigenous people are thinking.

The current paper seeks to acknowledge this “void” and respect its presence rather than fill it. In this spirit of transparency, the authors wish to share that they are of European-American descent and have grown up within, and continue to live as part of the settler society. Values and beliefs within the settler society are typically rooted in a hierarchical framework, with an emphasis on systems of power and control. The authors have benefited from privileges that members of the settler society have gained at the expense of those who are not, including the indigenous communities who have made great sacrifices and endure lasting historical and psychological trauma as a result of the systematic oppression of the settler society.

While it is only possible for these authors to write from this lens, the current paper seeks to share the findings with an aspiration to build a bridge across the “void” rather than fill it with assumptions.

Themes

“You have to know your anatomy, your physiology, your pathophysiology- you have to know all that. But that is not what you do. What you do is help people.”

During the 75-minute interview, Mamaangigidigwe shared many examples of effective and ineffective exchanges with her healthcare team during her hospital stay, as well as her day-to-day experiences that have shaped her perspective. Researchers identified three themes that best addressed our research question regarding culturally-relevant, individualized occupational therapy intervention; 1) know the client’s background, 2) treat the whole, and 3) maintain function, practicality and individualization throughout the treatment process.

Know Client Background

“My god, it is just not that hard to learn...In the past I would have said, oh you just have to respect people, but I don’t think that is good enough anymore. Especially with the Internet.”

Knowing the background includes knowing the groups of people in the area one serves and the underlying factors that influence an individual’s daily routines.

You’ve got to know the people-you have got to know the history. You have got to just take the time and learn that history of how did this group of people get here?... you have an individual who is in a group and how did that larger group get to be in this place? And what are the effects of the larger group by the surrounding society?

Knowing the background starts with familiarizing one’s self with terminology, such as whether an individual prefers to be identified as “Native American”, “Indian”, “indigenous” or another term. Knowing the history of the culture can help the therapist to understand the context for how they have developed within the greater society, and how one culture influenced another. For the indigenous people, systemic racism has occurred for hundreds of years. There continue to

be lasting repercussions, and it would behoove therapists to consider their own biases paying specific attention to those that may be unconscious.

To familiarize oneself with a culture's background a therapist should seek to understand how their client's perspectives and priorities may be completely different from the therapist, in ways the therapist could not have imagined. Understanding the context of the client within the larger society will aid in informing the treatment approach. For example, Mamaangigidigwe described that indigenous culture views all beings as equals and recognizes the interconnectedness of life. She goes on to say that the hierarchical system that is the foundation of the settler society is reflected in the medical field with the use of a biomedical approach, which is unfathomably different from the indigenous culture.

...basically what we are asking is to get people who are in a hierarchical mode of thinking where their notions are better than or above most of their clients... clearly this is reflected in the Egyptian religions Christianity, Judaism, and Islam... in which there is a hierarchy of the universe set up with God's up here, and women are probably down at the bottom... And it's like as long as you have a vertical structure of value in place, I don't see it happening, to be frank... there is that internalized ideology of what I know is better than what you know. So how do we get rid of that? Boy, that's when it gets real scary. Until we can get rid of hierarchically based religions and monotheism, I don't think it is going to happen. Those are fighting words for most people.

Treat The Whole

...the nurses were all about the pain medication... and the physical therapist was all about what my knee looked like and moving and bending my knee. But the occupational therapist was like, yes, your knee is there, but you are a person, and you have to function.

Mamaangigidigwe eloquently reminded researchers that she was not just a knee replacement, or a study in pain management, but a person with a family, who was living with a condition that affected her participation in daily life. She reflected on advice from a former coworker who said to treat a client as a friend, opposed to a 1-hour therapy commitment, yields

more opportunities to listen to individuals: what they need, how they learn, and involving other important people or practices into therapy. Treating a client as a friend includes being compassionate and sharing human contact. Reflecting on the 3 days she was in the hospital, Mamaangigidigwe states:

The OT person was the only one who touched me. Which was shocking to me. I even formally complained to the nursing department and talked to the head of nursing... But the OT just came right up, and you know, held my arm.

One of the most concrete reflections that Mamaangigidigwe shared was about the importance of including her family in therapy. She explained her experience while she was recovering as being very disorienting due to the pain. She was sent home with a “book size of papers”. She felt that there was a disconnect between the hospital knowing that her family was going to care for her and actually following through with specific hands-on family education throughout the recovery process. In reflection, Mamaangigidigwe advises, “don’t assume [my family] know[s] ...they are only going to do what I ask them to do, whereas if there had been more training for my family, that would have been nice.” Mamaangigidigwe recognized that this may not be true for everyone but feels family is important for herself as well as many of the indigenous people she knows. She shared that her definition of family may be different than many from the settler society; “I still get together with, well I call it my natal family. My natal family includes my brothers and sisters and my mother’s cousin’s granddaughter, and I mean, it is just a whole different definition of family.” Mamaangigidigwe remembers

Learning that not everyone is so involved with extended family...you see yourself as normal until you realize that not everyone else does it this way. I didn’t realize that until I met more and more white people whose families evidently are not part of their lives, because my family is still.

Taking the time to know the person and the support network they rely upon will better aid in comprehensive, client centered care.

Function, Practicality & Individualization

“And [occupational therapy] was so practical. It was like, you know, just wanting to help me be able to live my life. And it was so like me-oriented.”

Listening to what the clients need and actively asking what is most important and how they think they will best meet that goal is integral to the therapeutic process. It is important to collaborate with the individual receiving services and their support network. Through this collaboration the therapist can identify the specific performance skills within the client’s routine that would benefit from skilled intervention and improve the therapeutic experience. After all, individualized treatment plans are best accomplished by including the client in the process. Mamaangigidigwe only received occupational therapy services in the hospital setting, but she agreed that at least one home visit from the occupational therapist could have helped to solve a lot of problems for herself and her family, who were supporting her during the healing process, contributing to the function and practicality of treatment by problem solving and educating the service recipient in their natural setting.

Discussion

Positive Trends in Occupational Therapy

Mamaangigidigwe highlighted many components of the client-therapist relationship that are already ingrained within the application and philosophy of occupational therapy. The field already embraces the client-centered approach and encourages therapists to consider their therapeutic use of self when working with their client (AOTA, 2014). The OTPF provides a framework to allow the client’s culture to be considered and addressed directly. Values and beliefs are addressed under client factors, culture is a direct component of the context and environment, and habits, routines, rituals and roles make up a client’s performance patterns

(AOTA, 2014). Being mindful of one's therapeutic use of self by creating intentional relationships is directly outlined within the OTPF service delivery model. Within this model, therapists are expected to foster a mutual relationship where therapist and client work together. The therapist must purposefully shift the power dynamic, allowing the client more control as they set priorities and goals (AOTA, 2014). Additionally, the occupational therapy code of ethics calls directly on the therapist to ensure she has the self-awareness and cultural competence to approach client-therapist differences (Reitz et al., 2005). These elements help to ensure the practitioner is working with the client within her own context and according to her own priorities. However, there is still a gap between the stated framework and applying these ideals within the therapy setting.

Power and Positionality

So what can one do to address the differences between the settler society and the indigenous people without filling the void? Mamaangigidigwe shared that this may be an impossible endeavor. However, occupational therapists can start by asking the client whom, from their community, they want to include in their treatment program. If therapists initiated services by including family members, caregivers, and other identified individuals, the therapist can begin to disassemble the hierarchical power dynamic by sharing role responsibilities (Kirsh et al., 2006). Healthcare professionals are taught to be the specialists; shared decision making may lead them to feel that their knowledge is being undermined. Yet, it should be remembered that through intentional questioning, information can be shared and a respectful and effective therapeutic relationship can be established. Mamaangigidigwe's suggestions bring to light the importance of considering how the client and their community would like information presented:

written, verbally, how decisions will be made, and by whom, and how many options should be presented.

Furthermore, practitioners can accept that others may be functioning within a framework of values and beliefs that are completely different from their own. Mamaangigidigwe's insights remind us that there is always going to be a void between indigenous philosophies and those of the settler society. The settler society's philosophy is rooted deeply in a long ancestry of civilization built upon a monotheistic religion, ingrained in a hierarchical model of power. For practitioners who identify with the settler society, this is an opportunity to recognize that an indigenous client's perspectives may be rooted in a different system of thought, one that could be completely dissimilar to the hierarchical framework of the settler society. Beginning this dialogue about culture and systems of power should be addressed through multiple avenues such as within the occupational therapy curriculum and through site-specific training for employers. Occupational therapy students and practitioners should approach this subject with the understanding that it is an ongoing process. Students can take the initiative to include concepts of anti-racism and allyship into their daily life and studies. Additionally, therapists can choose to use their continuing education credits to further understand cross-cultural and power dynamics in the rehabilitation setting. Taking time to understand the history of the settler society and its foundation in religious hierarchy, and understanding the history of indigenous communities helps to give context to the void and can encourage self-reflection to discover personal biases or misunderstandings. Without first creating this context, the fundamental differences in thinking and resulting privilege of the settler society remains invisible (Case, 2012).

As Mamaangigidigwe suggests, the Internet is a valuable resource to gather information as long as one uses their professional filter to decipher credible sources. The homepage for the

United States Census Bureau (2015) is one such resource for preliminary facts about the people one might be serving in any given area. Programs such as the Modern Language Association (2015) have websites that offer an interactive map of the United States with the census information of language speakers. This is just one of many websites that works to make census information more accessible. However, it should be recognized that the census does not identify different groups of indigenous people or the many different native languages spoken in the U.S. In order to know the history of the indigenous people who were in the area, one must dig deeper into the shared history of the settler society and understand how the land was taken away and reallocated and the trauma that was caused in that process. This history is best understood when explored from both the settler society and indigenous perspective.

Unconscious Biases and Allyship

Literature supports two concepts that can be of value to the field when addressing cultural competence within occupational therapy. These are the philosophies of anti-racism and allyship. Anti-racism includes the necessary work of reflecting on our own unconscious biases as mentioned above. It also includes concepts such as shared language regarding institutional racism, power, privilege, and priorities, and offers strategies to dismantle systematic oppression (Havens et al., 2011). Allyship is a term that embodies the philosophy that those who are in a position of power and privilege can take informed action to enable the cause of those who do not hold that same power. Informed action is a clear distinction of allyship as it ensures that those who are allies take an active role beyond strict affirmation of minority positions. Although affirmation is important, alone, it can only amount to friendship at best (Brown & Ostrove, 2013).

When talking about the importance of family, Mamaangigidigwe mentioned how she had not considered that other people are not as connected with family, or that they have a different definition for who is included within the definition of “family”. Mamaangigidigwe offers an important lesson with this insight: to acknowledge personal unconscious biases, recognize how one defines their way of life and how one sees the world as “normal”. Members of the settler society are taught through this same reflection that, not only are they normal, but that others who do things differently from them are abnormal, strange and wrong. It is important to work toward uncovering these biases and be open to the ideas others may hold. It is an occupational therapist’s job to help individuals participate fully in their life, which means the therapist must seek to identify what is valuable to the individual and their community, identifying the ‘normal’ of the client, not the therapist.

If the therapist is a member of the settler society, even further work must be done to recognize unconscious biases and to mindfully work to ensure that such biases are not reflected back into the therapy approach. The therapist must therefore commit to an active unlearning of privilege and dominance, lessons one can take from anti-racism literature (Case, 2012). This seems to be what Mamaangigidigwe is also referring to when she mentioned that respect is not enough, one needs to also do the work. Case (2012) also suggests that, as a member of the settler society, by digging deeper into one’s own unconscious biases, one can move beyond feelings of guilt and disappointment into a more productive mindset of action rather than inaction for fear of making further mistakes. If one who is part of the settler society does not allow for mistakes, she will never learn the language of support and allyship (Case, 2012).

In discussion, Mamaangigidigwe shared that when working specifically with indigenous communities it is important to recognize that “consistently any native person has had to

personally involve themselves with being the recipient of racism”. She is not sure of the effects this would have on the dynamic of the healthcare relationship, but believes that systemic racism negatively impacts both the psychology and physiology of a person. Mamaangigidigwe believes that individuals entering the professional field are “going to inherit the ever increasing negative effects of the systemic racism of our contemporary society.” So how does one approach this?

What work can be done?

Literature on allyship reminds one that, by definition, one is a support to a cause but not a member of the specific minority group. As an ally, one can defend a cause, but the individual must be sure that he is following the lead of the minority group by always asking ‘What do *you* want *me* to do? How can I help? As practitioners, the lessons of allyship can be embraced when developing a plan of care and setting goals. The therapist should allow the client to take the lead in explaining her own values and priorities rather than making assumptions (Substance Abuse and Mental Health Service Administration, 2014). The therapist can then use this information to help set meaningful goals with the client.

Although the OTPF does create scaffolding to help ensure therapy is conducted with an awareness of a client’s cultural values, Havens et al., (2011) remind us that cultural competency is not the same as taking an anti-racism stance. They offer that healthcare practitioners need to not only be trained in cultural competency, which focuses on increasing awareness and acceptance of how another may choose to live, but it is imperative that those working in healthcare also receive anti-racism training focused on transparency and accountability for systems of authority, recognizing that modern health care functions within this same system (Havens et al., 2011). Anti-racism training allows practitioners to serve from a position as an ally to the client, a greater step than just understanding, as it involves both components of affirmation

and informed action (Brown & Ostrove, 2013). Taking an anti-racist position or developing one's self as an ally is not necessarily an easy process. Greenberg (2014) suggests that a meaningful first step that anyone can take is to "refus[e] to settle for a society that tolerates racism, poverty, and injustice" (p. 17) and be persistent in one's pursuit of change.

Mamaangigidigwe's clear distinction that "anybody whose skin is not pink...[is] going to be oppressed in this society" is the best place to start when taking an anti-racist stance.

Mamaangigidigwe suggested that an individual begin this process by acknowledging one's self when he or she has a racist thought, and taking the time to reflect on how such a reaction came to be rooted in the unconscious. This process of recognizing what has become natural and therefore invisible can begin early when future practitioners are at the bud of their education. Teaching students to identify when they have a racist reaction and uncovering the invisible allows a person to consider a more neutral thought process.

Application

Individuals belonging to the settler society have conducted the majority of research on this topic. To best accommodate for the undeniable differences in cultural lenses, the research and clinical fields of practice would most benefit from indigenous people pursuing this question of culturally relevant occupational therapy. Further work needs to be done to diversify the field allowing for more occupational therapists from cultures other than the settler society and resulting in more indigenous researchers interviewing indigenous people.

Furthermore, rehabilitative institutions can employ specialists to conduct anti-racism trainings. These formal trainings are an initial step to guide therapists, and the field as a whole, along the process to dismantling racism, and therefore inequalities, within their own mindset and therapeutic interventions. Havens et al. (2011) explain that one component of this training

explicitly addresses the power dynamic that has been upheld by institutional racism, mirroring Mamaangigidigwe's reference to the detrimental effects of the power dynamics, formed by the hierarchical structure within the settler society.

Limitations

This study only includes the perspective of one indigenous woman; therefore, generalizations must be made with caution. It is unknown the reasons that others did not choose to participate, as the authors worked to recruit participants through many different avenues. Mamaangigidigwe did confirm that there is a large amount of distrust within indigenous communities regarding any type of 'research,' particularly research conducted by anyone who is an "other" or an outsider to their community. Therefore, it is important to recognize that key perspectives may be missing from those who chose not to participate. Including the perspective of additional individuals who identify as indigenous would strengthen findings. Future research could continue to seek methods to bridge the cultural gap and improve the efficacy and satisfaction of occupational therapy services.

The authors of this paper have deeply considered whether their own background within the settler society should be considered a limitation to the study. While all agree that more internal research of indigenous people is needed, the authors also support the concepts of productive allyship and feel that there is a place for communication across groups of people in an effort to build strong bridges, expand awareness, and use one's own privilege to challenge and dismantle systems that support racism and inequity (Case, 2012). Therefore, the authors will leave it to the reader to ascertain if this work has benefited or been limited by the specific perspectives of the authors in question.

Conclusion

While this is only the perspective of one indigenous individual, the insights that Mamaangigidigwe offers are invaluable. The themes that arose during the interview include know the individual's background and the tribal and regional history, treat the whole including family and community, and use a functional, practical and individualized approach relevant to the cultural context of the client. The cultural competency of the practitioner can be enhanced by integrating concepts of allyship and anti-racism into occupational therapy practice because ultimately, "it behooves you to be respectful and helpful because it reflects back on you"; everything is connected.

References

- American Occupational Therapy Association. (2014). Occupational therapy practice framework: Domain and processes (3rd ed.). *American Journal of Occupational Therapy, 62*, 625-683.
- American Occupational Therapy Association. (2010). Agency for Healthcare Research and Quality. Retrieved from <http://www.aota.org/-/media/Corporate/Files/Advocacy/Health-Care-Reform/Overview/AOTA%20HCQ%20Strategy%20and%20Plan%20Feedback.pdf>
- Anderson, C., & Hokowhitu, B., (2007). Whiteness: Naivety, void and control. *Junctures, 8*, 39-49.
- Barnes, P. M., Adams, P. F., & Powell-Griner, E. (2010). Health characteristics of the American Indian or Alaska Native adult population: United States, 2004–2008. *National Center for Health Statistics: National Health Statistics Reports 20*, 1-22.
- Bassett, D., Tsosie, U., & Nannauck, S. (2012). “Our culture is medicine”: Perspectives of native healers on post trauma recovery among American Indians and Alaska native patients. *Permanente Journal, 16*, 19-27.
- Braveman, B., & Bass-Haugen, J. D. (2009). Social justice and health disparities: An evolving discourse in occupational therapy research and intervention. *American Journal of Occupational Therapy, 63*, 7-12. doi: 10.5014/ajot.63.1.7
- Brown, K., & Ostrove, J. (2013). What does it mean to be an ally?: The perception of allies from the perspective of people of color. *Journal of Applied Social Psychology, 43*, 2211-2222. doi: 10.1111/jasp.12172
- Case, K. (2012). Discovering the privilege of whiteness: White women’s reflections on anti-racist identity and ally behavior. *Society for the Psychological Study of Social Issues, 68*, 78-96. doi: 10.1111/j.1540-4560.2011.01737.x

- Chiang, M., & Carlson, G. (2003). Occupational therapy in multicultural contexts: Issues and strategies. *British Journal of Occupational Therapy*, *66*, 559-567. doi: 10.1177/030802260306601204
- Dillard, M., Andonian, L., Flores, O., Lai, L., MacRae, A., & Shakir, M. (1992). Culturally competent occupational therapy in a diversely populated mental health setting. *American Journal of Occupational Therapy*, *46*, 721-726. doi:10.5014/ajot.46.8.721
- Evans, J. (1992). What occupational therapists can do to eliminate racial barriers to health care access. *American Journal of Occupational Therapy*, *46*, 679-683. doi:10.5014/ajot.46.8.679
- Greenberg, J. (2014). Beyond allyship: Multiracial work to end racism. *Tikkun Magazine*, *29*, 11-16. doi: 10.1215/08879982-2394389
- Goins, R., Spencer, S., Goli, S., & Rogers, J. (2010). Assistive technology use of older American Indians in a southeastern tribe: The Native elder care study. *Journal of the American Geriatric Society*, *58*, 2185-2190. doi: 10.1111/j.1532-5415.2010.03140.x
- Gone, J. (2009). A community-based treatment for Native American historical trauma: Perspectives for evidence-based practice. *Journal of Consulting and Clinical Psychology*, *77*, 751-762. doi: 10.1037/a0015390
- Havens, B. E., Yonas, M. A., Eng, E., & Farrar, V. D. (2011). Eliminating inequities in health care: Understanding perceptions and participation in an antiracism initiative. *Health Promotion Practice*, *12*, 848-857. doi: 10.1177/1524839910370423
- Hodge, D., & Limb, G. (2010). A Native American perspective on spiritual assessment: The strength and limitations of a complementary set of assessment tools. *Health and Social Work*, *35*, 121-131.

- Huntley, N. (2014). Cardiac and pulmonary diseases. In M. V. Radomski, & C. A. Trombly Latham (Eds.), *Occupational therapy for physical dysfunction* (pp. 1300-1326). Baltimore, MD: Lippincott Williams & Wilkins.
- Keightley, M. L., King, G. E., Jang, S., White, R. J., Colantonio, A., Minore, J. B., & Longboat-White, C. (2011). Brain injury from a First Nation's perspective: Teachings from elders and traditional healers. *Canadian Journal of Occupational Therapy, 78*, 237-245.
doi:10.2182/cjot.2011.78.4.5
- Kirsh, B., Trentham, B., & Cole, S. (2006). Diversity in occupational therapy: Experiences of consumers who identify themselves as minority group members. *Australian Occupational Therapy Journal, 53*, 302-313. doi: 10.1111/j.1440-1630.2006.00576.x
- Krefting, L. (1991). Rigor in qualitative research: The assessment of trustworthiness. *American Journal of Occupational Therapy, 45*, 214-222. doi:10.5014/ajot.45.3.214
- Kronenberg, F., Simó, A. S., & Pollard, N. (2005). *Occupational therapy without borders: Learning from the spirit of survivors*. Edinburgh, UK: Elsevier/Churchill Livingstone.
- Modern Language Association (2015). Language Map with Enrollment Data. Retrieved from <http://arcgis.mla.org/mla/Default.aspx>
- Nelson, A., Gray, M., Jensen, H., Thomas, Y., McIntosh, K., Oke, L., & Paluch, T. (2011). Closing the gap: Supporting occupational therapists to partner effectively with First Australians. *Australian Occupational Therapy Journal, 58*, 17-24. doi: 10.1111/j.1440-1630.2010.00912.x
- Pachter, L. M. (1994). Culture and clinical care: Folk illness beliefs and behaviors and their implications for health care delivery. *JAMA, 271*, 690-694.
doi:10.1001/jama.1994.03510330068036

- Portney, L. G., & Watkins, M. P. (2009). *Foundations of clinical research: Applications to practice* (3rd ed.). Upper Saddle River, NJ: Pearson Education.
- Reitz, S. M. (2014). Health promotion theories. In B. A. B. Schell, G. Gillen, M. E. Scaffa & E. S. Cohn (Eds.), *Willard & Spackman's occupational therapy* (12th ed., pp. 574-587). Baltimore, MD: Lippincott Williams & Wilkins.
- Reitz, S., Arnold, M., Franck, L., Austin, D., Hill, D., McQuade, L., Knox, D., Slater, D., & Commission of Standards and Ethics. (2005). Occupational therapy code of ethics. *American Journal of Occupational Therapy, 59*, 634-642. doi:10.5014/ajot.59.6.634a
- Stedman, A., & Thomas, A. (2011). Reflecting on our effectiveness: Occupational therapy interventions with indigenous clients. *Australian Occupational Therapy Journal, 58*, 43-49.
- Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage. doi: 10.1111/j.1440-1630.2010.00916.x
- Substance Abuse and Mental Health Service Administration. (2014). *Tips for disaster responders: Understanding historical trauma when responding to an event in Indian country*. Retrieved from <http://store.samhsa.gov/product/Understanding-Historical-Trauma-When-Responding-to-an-Event-in-Indian-Country/SMA14-4866>
- Taylor, B., & Francis, K. (2013). *Qualitative research in the health sciences: Methodologies, methods and processes*. New York, NY: Routledge.
- U.S. Census Bureau (2015). *Interactive maps*. <http://www.census.gov/geography/interactive-maps.html>
- U.S. Commission on Civil Rights. (2004). *Broken promises: Evaluating the Native American health care system: September 2004*. Retrieved from <http://www.usccr.gov/pubs/nahealth/nabroken.pdf>

U.S. Department of Commerce, U.S. Census Bureau: 2010 Census Briefs. (2010). *The American Indian and Alaska Native population: 2010: January 2012*. Retrieved from

<http://www.census.gov/prod/cen2010/briefs/c2010br-10.pdf>

U.S. Department of Commerce, U.S. Census Bureau. (2011). *Facts for features: American Native and Alaska Native heritage month: November 2011*. Retrieved from

http://www.census.gov/newsroom/releases/archives/facts_for_features_special_editions/cb11-ff22.html

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention.

(2010). *Healthy People 2010 Final Review: November, 2011*. Retrieved from

http://www.cdc.gov/nchs/healthy_people/hp2010/hp2010_final_review.htm

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention:

Office of Communication. (2000). *Facts about heart disease and stroke among American Indians and Alaska Natives: June 2, 2000*. Retrieved from

<http://www.cdc.gov/media/pressrel/r2k0602.htm>

Appendix A

Join the HealthCare Conversation

Do you identify as American Indian/Alaska Native?

Have you ever had an experience with Occupational Therapy?

If yes, please share your experience with two occupational therapy students who want to bring your ideas into the conversation.

If you want to participate in a 60-120 minute casual interview with students from the University of Puget Sound, please call the number below!

Thank you in advance, your participation is greatly appreciated. We look forward to speaking with you!

CALL 253-879-3514 and say you're calling about participation in this project

Appendix B

“Thank you for your interest in participation! I would like to ask you some brief questions.”

1. What year were you born?
2. Do you identify as American Indian or Alaska Native?
3. When did you receive occupational therapy?
4. Please tell me a little bit about the occupational therapy services you received

Appendix C

Guiding Questions for Semi-Structured Interview

- Please tell me about your experience receiving occupational therapy.
 - Where did you receive OT?
 - What challenges were you facing that required OT services?
 - When did you receive OT? For how long?
 - Were you happy with the services you received?
 - What did the OT help you do?
- What are three or more things you could share about yourself that might help an OT be more helpful when working with you?
- If you were to need OT again, what would you hope would be different about treatment?
- Do you feel that the OT was able to understand what was most important to you during your rehabilitation process?
- There is research that suggests that a “culturally sensitive” approach should be used in working with clients who identify as a different culture from the therapist. What does “culturally sensitive” mean to you?
- Imagine that you have just finished seeing your OT and you are planning to meeting up with your best friend. How would you explain your experience in OT to this friend?

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