

APPLYING THE OCCUPATIONAL SCIENCE FRAMEWORK WITH A
LATINO CAREGIVER FOCUS GROUP TO DEVELOP A NEEDS ASSESSMENT

A thesis submitted to the faculty at Stanbridge University in partial fulfillment of the
requirements for the degree of Master of Science in Occupational Therapy.

by

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Certification of Approval

I certify that I have read Applying the Occupational Science Framework with a Latino Caregiver Focus Group to Develop a Needs Assessment by Chi-Him Chan, Marin Guerrero, Jessica Kussman, and Jamie Tran and in my opinion, this work meets the criteria for approving a thesis submitted in partial fulfillment of the requirements for the degree of Master of Science in Occupational Therapy at Stanbridge University.



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Dedication

This thesis is dedicated to our translator along with the participants of the focus group, who donated their time to further the research endeavors of the occupational therapy field and its impact on Latino and Hispanic caregivers.

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These authors would like to acknowledge the hard work, dedication, and unyielding support from our thesis advisor Denise Miller, MBA, OT/L. Her guidance has been crucial to understanding the needs of this population and the importance of occupational therapists in addressing the growing needs of caregivers and their concerns.

Abstract

By the year 2035, the number of citizens aged 65 years and older are projected to surpass the number of citizens under the age of 65 in the United States. This trend presents a crisis as this aging population will require more caregiving resources. For the Latino community, the role of caregiving often falls on family members to fulfill. This thesis aimed to identify the needs of the Latino caregiving community and utilizes the Occupational Science Framework to explore how elements of the socio-cultural, symbolic evaluative, and transcendental subsystems affect their caregiving experience and how occupational therapists can better address their needs. Researchers administered a questionnaire to a group of five Latino caregivers seeking information regarding their experience assisting their care recipients with self-care activities of daily living (ADLs), instrumental ADLs (IADLs), and the impact of caregiving on their lives. The researchers also conducted post-questionnaire focus groups with the participants to elicit feedback about their experience completing the questionnaire. Results indicated that all of the participants were immediate family members of the care recipient and identified as Catholic. While participants reported that they received sufficient education on providing care, the answers they provided about their experience in assisting with IADLs and the personal impact they experienced from caregiving highlighted the occupational imbalance they experience. These results indicate a need for occupational therapists to provide resources and education tailored to the caregivers themselves in conjunction to the interventions provided to the ones they care for.

Applying the Occupational Science Framework with a Latino Caregiver Focus Group to
Develop a Needs Assessment

According to a projection by the U.S. Census Bureau (2008), the population of older adults (aged 65 or older) will surpass the population of young persons (aged under 18) by the year 2035. The rapidly increasing ratio of older adults demands more caregivers to attend to their needs, and the decreasing ratio of young persons will result in less supply of caregiving resources. Caregiving tasks can include assisting with activities of daily living (ADLs; e.g., bathing and dressing), instrumental ADLs (e.g., money management, scheduling, transportation), medical care, and emotional support. The role of caregiver often requires specific skills, time commitment, and stress management. Feinberg and Levine (2015) identified a need to use caregiver assessments to help address the complex role of caregivers as they often play an important role in the health of the older adults. Latino/Hispanic older adults, when compared to non-Latino/Hispanic Whites, have a stronger preference to receive care from a family member as opposed to a paid outsider (Min & Barrio, 2009). It has also been found that Latino/Hispanic caregivers have worse health outcomes (Adams, Aranda, Kemp, & Takagi, 2002). Latinos/Hispanics may often experience the healthcare system differently due to their cultural values and barriers to access (Chapman et al., 2018; Min & Barrio, 2009; Ransford, Carrillo, and Rivera, 2010).

Occupational therapists (OTs) . who are “skilled in evaluating all aspects of the domain, their interrelationships, and the client within his or her contexts environments” (American Occupational Therapy Association [AOTA], 2014, p. S4), can integrate the unique cultural factors of the Latino/Hispanic caregivers to provide them with more

complete caregiver assessments. Our research conducted a focus group with Latino/Hispanic caregivers in order to analyze and understand their responses to questions based on an occupational science-based framework. The questionnaire was based on the results of a systematic review of relevant literature and the application of the occupational science framework, which provided relevant support to this population based on distinct and critical cultural needs. Outcomes and responses of the focus group were used to identify future recommendations for a needs assessment.

Literature Review

Utilizing the occupational therapy curricular threads at Stanbridge University and the AOTA research agenda as guidance, researchers analyzed literature in all areas of research regarding Latino/Hispanic caregivers. Overall, general findings in the research literature remained constant. The literature analysis supported the major research goals of the Occupational Therapy Research Agenda, particularly the goal to “increase the relevance, acceptability, and usefulness of evidence-based scientific findings in improving occupational therapy (rehabilitation)” (AOTA & American Occupational Therapy Foundation [AOTF], 2011, p. S6). The literature analysis revealed that a) the Latino/Hispanic population is underserved within the healthcare community, b) there is a need for interventions geared towards this particular population and the need will only continue to grow as the Latino/Hispanic representation grows, and c) current questionnaires and assessments available did not encompass the occupational science framework that will be incorporated in this occupation-based focus group. Finally, through literature analysis, researchers found that there is a lack of evidence in occupational therapy practice regarding the population of Latino/Hispanic caregivers.

The most current research was provided by the fields of gerontology, social work, and nursing. The researchers anticipate that their hypotheses will increase occupational therapy's research capacity. The researchers anticipate that their hypothesis, with the foundation of the occupational science framework, will uncover meaningful and critical information regarding this population and their important occupation of caregiving.

The comprehensive findings of research have been separated into 3 categories: research that supports the problem statement, the needs assessment, and lastly, the methodology.

Problem Statement

The lack of literature in understanding the Latino/Hispanic caregiver experience has created a gap in research, which researchers are anticipating will be filled by the occupational science framework (Carrion & Nedjat-Haiem, 2013). There is currently a lack of information on what needs are pertinent to this population and how occupational therapists can address these needs. Findings on the Latino/Hispanic population and cultural attitudes towards caregiving proved to be a prevalent topic in understanding the ethnography of this population. Latino/Hispanic individuals tend to be more hesitant to seek out professional help (Carrion & Nedjat-Haiem, 2013; Mendez-Luck & Anthony, 2015) as they often look at caregiving as an obligation, duty, and commitment to their loved ones (Mendez-Luck & Anthony, 2015). End-of-life topics tend to be a difficult and taboo subject to discuss (Carrion & Nedjat-Haiem, 2013), and religion plays a large role in the way the Latino/Hispanic culture views caregiving (Mendez-Luck & Anthony, 2015).

Though most current research is supported in other fields outside of occupational therapy, there were various issues found that correlate with the domains outlined by the Occupational Therapy Practice Framework. These include issues related to understanding and approaching caregiver stress and burden (Mendez-Luck & Anthony, 2015), issues on caregiver-related education, and the needs among caregivers in performing ADLs for their loved ones (Mahoney, Coon, & Lozano, 2016). Lastly, understanding that there is a caregiver burden among this population was important in constructing the problem statement. The literature analysis reinforced the need to address this population. It was found that Latinos/Hispanics have one of the worst outcomes for healthcare and have a high morbidity rate (Ortega, Rodriguez, & Vargas Bustamante, 2015). Though they have one of the worst outcomes for physical health, they are providing a greater amount of caregiving for their loved ones (Ortega et al., 2015) because of their self-sacrificing principles (Mendez-Luck & Anthony, 2015).

Needs Assessment

The next findings among research support a needs assessment. Current research provides information on relevant reference models. These reference models were used to gain a greater understanding of what caregiver related needs can be addressed from an occupational therapy framework. The researchers analyzed several examples of other needs assessments so critical categories for the caregiving population could be better understood (Merritt, 2011).

Through literature analysis a more thorough understanding of a questionnaire versus a needs assessment was discovered. Many questionnaires were found such as an assessment provided by occupational therapist Brenda K. Merritt (2011) called the AMPS

or the Assessment of Motor and Process Skills. These questionnaires were used to gain a greater understanding of distinct and relevant areas regarding the needs of the caregiver (Ferrario, Zotti, Ippoliti, & Zotti, 2002). However, no questionnaire found during literature analysis answered critical questions of who will be providing assistance and how can occupational therapists support these individuals?

Researchers found that by developing a needs assessment, the outcome will provide relevant support to this population based on distinct cultural needs (Merritt, 2011). Lastly, important provisions were found that future occupational therapy practitioners could advocate for their patients and their caregivers. Because some of the greatest challenges for Latino/Hispanic caregivers are focused on understanding government programs and accessing information, researchers plan on taking provisions of the CARE Act, also known as Caregiver Advise, Record, Enable Act and using these to support the needs assessment and occupation based categories (Caceres & Perez, 2018).

Methodology

The literature analysis supported the methodology. Studies were found that support successful ways to collect participants for the Latino/Hispanic culture. Typically, success in recruiting participants was based on cultural qualities (Herrera, Lee, Palos, & Torres-Vigil, 2008). For example, researchers collecting data on this population in San Diego posted flyers in nearby catholic churches and local senior centers (Herrera et al., 2008). These are important phenomenological considerations to make in order to ensure cultural understanding and respect towards this population while conducting research. Valuable insight was gained in regards to cultural barriers such as language, gender, and generational roles among families (Herrera et al., 2008).

Improved caregiver burden and distress was found to be one of the strengths of current literature (Magaña, Ramírez García, Hernández, & Cortez, 2007). However, a common limitation was that convenience samples were small, and few studies were generalizable to either a variety of individuals or more than one gender.

Current literature also provided researchers with useful support in ensuring that the needs assessment is reliable and valid. Researchers anticipate that the structure and frame of the needs assessment will be distinguishable from other healthcare professions such as social work or nursing (Stewart et al., 2005). Ultimately, important information was gathered in order to provide a foundation. The needs assessment will provide even further research on how occupational therapy can support the needs of Latino/Hispanic caregivers using the occupational science framework.

Statement of Purpose

The purpose of this research was to conduct a focus group to gather information to be used in a needs assessment of individuals that identify as Latino/Hispanic and who are providing care for someone over the age of 65. This research addresses the gap in services provided to the Latino/Hispanic caregivers by conducting focus groups with Latino/Hispanic caregivers using a questionnaire to learn about the needs of Latino/Hispanic caregivers through their responses to the questionnaire. The questionnaire is created from a literature review on the needs of caregivers and the values of the Latino/Hispanic population and supported by the occupational science framework. Analysis on caregivers' responses to the questionnaire leads to better understanding on concerns most relevant to Latino/Hispanic caregivers. This information can help healthcare providers in serving the Latino/Hispanic caregivers by addressing their

culturally relevant needs. Current research suggests that there is a lack of evidence regarding the population of Latino/Hispanic caregivers, creating a gap in research.

Furthermore, this creates a disparity in access to healthcare and resources.

Latinos/Hispanics are a significant population to address via research because they have one of the worst outcomes for healthcare even though they are providing a greater amount of caregiving for their loved ones when compared to other cultural groups (Ortega et al., 2015). Additionally, those age 85 years and older are the fastest growing group in the United States. The number of Hispanic elders is currently 5.6% but will increase to 16.4% over the next 50 years (Bennett & Flaherty-Robb, 2003). When addressing the population of 85 years and older, there may be even greater language and cultural barriers than those age 65-84. By 2030, one in five Americans will be 65 or older; this population will exceed the number of children less than 18 years of age for the first time in U.S. history. This population is also becoming more diverse, with the Latino/Hispanic population in particular (65 years and older) expected to quadruple during the same period. This age cohort has the highest need for long-term services; consequently, the number of formal and informal caregivers has grown in response to serve the needs of this rapidly growing group of older adults. At 21% of the estimated 40 million caregivers in the U.S., non-white Hispanic caregivers have the highest reported prevalence of caregiving among any other race or ethnic group. Members of the Latino/Hispanic population, in a large part due to their cultural values, place family as a central part of their lives. They have a significantly higher preference to receive and provide informal care for their loved ones over receiving care from professional caregivers. A study by Min and Barrio (2009) found that 73.3% of Latinos/Hispanics

prefer receiving care from family members compared to 32.6% of non-Latino/Hispanic Whites. Within this culture caregiving is viewed as a duty and often ties into the cultural values of *familismo*, which refers to the importance of strong family loyalty, closeness, and contributing to the wellbeing of the family (Min & Barrio, 2009). However, the role and occupation of caregiver requires additional effort, skills, and resources from the caregiver, which often results in increased caregiver stress and burden. For instance, a report from AARP found that, on average, Latino/Hispanic caregivers spend 44% of their income on their care recipient whereas Caucasian caregivers spend only 14% (Rainville, Skufca, & Mehegan, 2016). Latino/Hispanic caregivers are also more likely to have significant depressive symptoms (89%) than Caucasian caregivers (66%) (Adams et al., 2002). While current research surrounding this topic is supported in other fields outside of occupational therapy, there are several related issues that have not been specifically addressed by other medical professionals that correlate with the domains outlined by the Occupational Therapy Practice Framework (AOTA, 2014). This include issues related to understanding and approaching caregiver stress and burden, caregiver-related education, and caregivers needs when performing activities of daily living for their loved ones. Our research also contributes to the goals in AOTA & AOTF's research agenda by identifying the impact of the cultural values of Latino/Hispanic caregivers on activity engagement through a community-based participatory research project. It applies the themes from the Stanbridge University MSOT curriculum about diversity in order to address Latino/Hispanic values and provide an occupation-based focus. We think this information will be used to help build rapport with the Latino/ Hispanic community, to understand their cultural needs from their perspective and how we can better address these

individuals, meet their needs, and also provide insight for future training curriculums with medical professionals. Our research analysis of the responses by the Latino/Hispanic caregiver focus group is going to result in recommendations for a needs assessment with this population. This needs assessment, based on the occupational science framework, will benefit the healthcare profession in understanding the needs of the Latino/Hispanic caregiver and how to best serve them.

Theoretical Framework

The framework chosen for this thesis topic is occupational science. Occupational science most closely aligns with the goal of this thesis topic, which is to understand the phenomena experienced by Latino/Hispanic caregivers. One of the first principles of occupational science is to not only note that humans are occupational beings but also to explain the necessity to study in depth what makes humans occupational beings.

According to this frame of reference, it is essential to look at a person's life experiences to gain a better sense of the multitude of complex factors that influence how a person participates in their daily occupations. For this thesis, Latino/Hispanic caregivers join in the occupation of taking care of their loved ones, in all of its complexities. According to occupational science, "we define occupation, simply, as chunks of culturally and personally meaningful activity in which humans engage "(Clark et al., 1991, p. 301).

Every day, Latino/Hispanic caregivers must make decisions about what they will and will not do to provide care for their loved ones, and several factors can influence these decisions according to occupational science (Clark et al., 1991).

Occupational science is comprised of six subsystems that influence the decision of each person to participate in daily occupations. The physical subsystem involves the

physical system of the human body, and how it allows individuals to engage in their occupations (Clark et al., 1991). The biological subsystem involves the biological drive humans have to be competent, and the combination of sensory systems and their impact on behaviors (Clark et al., 1991). The information processing subsystem addresses executive functioning components and their effects on the engagement of occupations (Clark et al., 1991).

The most meaningful of the six subsystems that are of greatest significance to this thesis topic is the socio-cultural subsystem. This subsystem aims to understand the person's perceptions of cultural and social expectations which could influence occupational behavior (Clark et al., 1991). Occupational science expresses the importance of how knowledge in the area of the interrelationships between social and cultural expectations and occupational behavior of individuals are carried out within social contexts (Clark et al., 1991). The Latino/Hispanic population has its own sets of expectations that must be considered to fully understand behaviors of Latino/Hispanic caregivers.

The symbolic-evaluative subsystem incorporates the person's perception of the value of an occupation (Clark et al., 1991). For the Latino/Hispanic population, caregiving is considered a duty or called *marianismo* that should be completed by primarily female family members, which would make caregiving a more valuable occupation for this population (Mendez-Luck & Anthony, 2015).

Lastly, the transcendental subsystem of occupational science focuses on the meaning the person ascribes to their previous life history and the motivation that helps them achieve their occupations (Clark et al., 1991). Included in this subsystem is the

sense of life satisfaction, purpose, and quality of life which is seen as a result of engagement in personalized occupations (Clark et al., 1991). This subsystem identifies similar questions that this research aims to answer, such as how Latino/Hispanic caregivers are motivated based on their own experiences, and how does engagement in caregiving affect the caregiver's sense of life satisfaction, purpose, and quality of life.

To outline the model's characteristics, it is assumed that occupation must be studied both in the immediate environment and the person's life experiences, and that although behavior can be observed, occupation is not fully understood without considering how it is significant to the individual (Clark et al., 1991).

Specifically, for our methodology, occupational science is naturally interdisciplinary, since it incorporates subsystems from disciplines other than occupational therapy, such as biology, psychology, and anthropology (Clark et al., 1991). This frame of reference will allow for the future development and analysis of a needs assessment that can be used with interdisciplinary teams. It also enables occupational therapist to gather data on the balance of work, rest, and leisure for Latino/Hispanic caregivers, but also how they develop the intelligence of how to perform their caregiving duties (Clark et al., 1991). Occupational science encourages methodologies that allow detailed description and analysis for not only occupational performance, but also the phenomenological experience of the person engaging in the occupation (Clark et al., 1991). The needs assessment that will be developed based on this frame of reference aims to accomplish this task: to gather data on detailed descriptions of functions Latino/Hispanic caregivers provide, and to document their experience as a caregiver within the Latino/Hispanic culture.

Methodology

This research is a Level VI qualitative design (Winona State University, 2018). Researchers conducted a focus group with Latino/Hispanic caregivers to gather information about their experiences as a caregiver. The focus group will consist of two parts: in the first part, participants will complete a questionnaire; in the second part, researchers will conduct a focus group with the participants to gather feedback about the content of the questionnaire to make recommendations for future iterations of the questionnaire. In order to be included in this research, participants must be 18 years old or older, identify as Latino/Hispanic, speak English and/or Spanish, and care for someone 65 years or older. In order to recruit participants, researchers developed a flyer that includes the purpose of this research, participant inclusion criteria, where the focus group will be conducted, and the researchers' contact information. The flyer was posted in areas in Southern California with a high density of Latino/Hispanic residents, such as near Catholic churches, senior centers, and in areas surrounding public transportation stops. The flyer has also been distributed through social media (i.e., Facebook) and emailed to several Latino/Hispanic caregiver support groups. If needed, more participants may be recruited through snowball sampling. Sample size for each focus group will be 2 - 3 participants. The focus group will be conducted at Stanbridge University.

Before receiving the questionnaire and beginning the first part of the focus group, participants will receive instructions from the researchers regarding the process and an informed consent form that they must read and sign in order to participate. Participants will be reminded that their responses are anonymous, will be kept confidential, and that they can skip any questions or withdraw from participating at any time. Once participants

have completed the consent forms, researchers will then administer the questionnaire (consisting of approximately 30 questions) to participants. The questionnaire will be paper-based and written in English or Spanish; participants will have the option to answer the questionnaire in their language of choice. The questions will be a mixture of qualitative and quantitative questions that will ascertain information about different aspects of a Latino/Hispanic caregiver's life; these aspects include, but are not limited to, activities of daily living that they assist their care recipient with, their daily levels of stress, the coping mechanisms that they use to deal with stress, and the influence of spirituality on their daily lives. Questions are simply written to be easily understood and to lower the risk of being misinterpreted. Questions also address each subsystem of the Occupational Science framework; however, a majority of the questions will address the sociocultural subsystem, the symbolic evaluative subsystem, and the transcendental subsystem in order to gather information about the culture-specific needs of the targeted population. Along with being tied into the framework, the questions are also supported by recurring themes from the systematic literature review conducted by the researchers. For the Spanish version of the questionnaire, questions will be written to be translated as closely as possible from English to Spanish. If participants' primary language is Spanish, their responses will be interpreted by a neutral third party who is bilingual in both English and Spanish. The answers will be coded in both qualitative and quantitative.

Following completion of the questionnaire, researchers will conduct a (verbal) question-and-answer focus group with participants to gather qualitative information about the participants' experience while completing the questionnaire. Possible focus group questions will include "In this group of questions, order the questions in order of best to

worst in terms of how each one addressed your experience as a caregiver” and “Were there any questions that were not on the questionnaire that you think should have been asked in order to address your experience as a caregiver?” Following completion of the focus group, researchers will then analyze the responses from the participants to determine which questions prove important to this population and which questions should be eliminated from further iterations of the questionnaire. Researchers may also consider feedback regarding the wording of questions.

There are several advantages to utilizing a questionnaire and focus group format to gather data for this research. Questionnaires are quick and relatively easy to administer, and as they are paper-based, participants will not need to have access to a computer or the Internet and there is no chance of their responses being traced through IP addresses. Also, as none of our group members are fluent in Spanish, having the questionnaire written in Spanish and the participants filling them out themselves removes the need of having a translator/interpreter present during administration of the questionnaire. The advantage of utilizing a focus group format is that researchers will gain immediate feedback on the questionnaire that they can utilize to inform future iterations of the questionnaire (i.e., which questions to remove, recommended revisions of the questions themselves, etc.).

After all of the data has been collected, researchers will utilize the Dedoose software to code the responses from the questionnaire into themes. The themes will be based on the occupational science framework; parent threads will include subjects such as physical systems of the human body and how it allows individuals to engage in their occupations, the biological drive individuals have to be competent, information

processing and its effects on the engagement in occupations, individual's perceptions of cultural and social expectations that could influence occupational behavior, the individual's perception of the value of an occupation, and the motivation that helps the individual achieve their occupations.

Possible Limitations

There are several possible limitations with this research. Due to the small sample sizes of the focus groups and the specificity of the target population (Latino/Hispanic caregivers over the age of 18), the generalizability of the results to other populations of caregivers will be low. Also, there is the possibility of self-report bias by having the participants fill out the questionnaires themselves. Finally, as this is a questionnaire that has been developed by the researchers and has not been tested and re-tested through other research groups before this administration, the reliability and validity of the questionnaire has not yet been established.

Ethical and Legal Considerations

Since this thesis requires participation from members of a specific population, informed consent must be obtained in order to ensure ethical behavior. Informed consent is a moral requirement for research involving subjects to ensure that voluntary and informed participation is acquired (Helgesson & Eriksson, 2011). Informed consent should be part of the inclusion process when selecting participants for the research topic (Helgesson & Eriksson, 2011).

In order to maintain professional ethics, the participants of the research will sign a consent form acknowledging that they have read and understood what will be expected of them during this research process. Participants will also have the ability to have in-person

discussions about the consent form before signing (Hammer, 2017). The consent form will identify the target population, which for this thesis project is the caregivers of Latino/Hispanic patients age 65 and older (Hammer, 2017). Participants will be informed that they will not receive compensation for their participation in this thesis, but that they do have the option to drop out of the research process at any time for any reason (Hammer, 2017). Participants may be given the option of choosing to skip questions they may receive on their survey (Hammer, 2017).

Other considerations that must be noted are that since this is an at risk population, there may be fear of legal actions based on nationality. Participants may be hesitant to participate in this research, whether they are in the country legally or not, due to fear of deportation of themselves or family members (Lahman, Mendoza, Rodriguez, & Schwartz, 2011). Another consideration is that some questions that may be asked on our survey may make the participants feel vulnerable, and thus cause them discomfort when completing the survey (Lahman et al., 2011). In order to protect participants, their identity will remain anonymous when possible, or pseudonyms will be used to protect the identity of the subjects (Lahman et al., 2011).

Lastly, it is important to note that while protecting the participants of the research, scientific integrity must also be maintained. In order to do so, survey questions will be appropriate for the audience based on literature reviews of the target population (Hammer, 2017). Survey questions will also be tested to ensure their reliability and validity (Hammer, 2017). In addition, bias will be minimized wherever possible, whether it is researcher bias or participant bias (Hammer, 2017).

Discussion

Researchers distributed the questionnaire at the personal address of the participants. The participants filled out the questionnaire at their dining room tables with the researcher and the third-party translator present in order to answer any questions the participant's may have had. After receiving the completed questionnaire, researchers then analyzed the participants' responses, and found common themes evident throughout the results. Among the 5 participants, 2 were male and 3 were female. Coding in the software, Dedoose, helped the researchers to analyze the current data and find the critical themes shared between participants that will reflect how occupational therapy can be utilized among this population.

We first coded the data by creating descriptors for all participants. The primary descriptors were based on "Personal Demographic Information" from the questionnaire itself. This included: age, gender, level of education, and marital status. We also added two additional descriptors; the first being "language," based on which language the participant answered the questionnaire: either English or Spanish, and the second being "participant number" which the researchers randomly assigned a numeric code to identify the subject. In regard to age, we created descriptor fields that grouped specific ages together: Ages 25 and under, 26-50, 51-75, or 76 and over. 3 of 5 participants were aged 26-50, 1 participant was aged 25 and under, and the last participant was aged 51-75. Marital status varied, and did not appear to influence caregiving. 3 participants are currently married, 1 participant is single, and 1 is separated. Level of education also varied among participants, as 2 participants have obtained an associate's degree, 1

participant has obtained a bachelor's degree, and 2 participants have obtained some level of high school education.

Results

After creating codes and descriptors for each participant, we then analyzed the data based on the open-ended answers provided in the questionnaires. We entered all descriptive data that the participants provided us in to the Dedoose software. We first separated the data by the categories on the questionnaire: activities of daily living, instrumental activities of daily living, personal impact on caregiving, and post-questionnaire feedback. After separating these categories, we then had the chance to analyze and code common themes among each participant.

We found 9 common themes and sub-themes that reveal trends and patterns among the participants. The first theme is "care provided" with sub-themes being "ADL's, emotional support, and IADL's." We found that among the care provided, ADL's are typically limited to dressing and self-care, emotional support is important for the participants to provide their care recipient through "keeping them company," and all subjects were providing IADL support in the form of transportation, grocery shopping, laundry, or meal preparation.

The next theme is "caregiving resources" with sub-themes being "family members," "healthcare professionals," and "other caregivers." We found that there is a trend among participants to use their family members for respite care and as a caregiving resource. If they have any questions in regards to healthcare, they consult with either their care recipient's physician or staff members at a healthcare clinic. The participants' whose care recipient required durable medical equipment felt as if they were adequately trained,

however they received their training from a physician, and the durable medical equipment required is rarely used.

“Diagnosis” of the care recipient received is the third theme. Both care recipients of the participants were diagnosed with a heart related condition requiring a pacemaker, along with a number of comorbidities. While this is coincidental, as there were only 2 care recipients among 5 subjects, it was important to note as a theme.

“Impact and barriers” is the fourth theme with sub-themes being “adequate training”, “financial barriers”, “language barriers”, and “personal impact of caregiving”.

This theme and its sub-themes are some of the most important for our research.

Participants reported that they felt confident and adequately trained in how to use and operate equipment and distribute medications. They also felt that they do not need to be trained in caregiving, as if a question were to arise, they would consult the care recipients’ physician. However, participants also revealed that a barrier to Latino and Hispanics receiving training in caregiving is a lack of knowledge in regards to who can qualify for healthcare and what services they can receive. Financial barriers were also expressed, as lack of insurance was the primary concern. One participant stated “Sadly [we] think [insurance] is only for U.S. citizens and are not able to get medical help.”

Language did not appear to be a concern among the participants, however, the Spanish speaking participants acknowledged that they had a bilingual family member with them there to translate. Lastly, though no participant felt that caring for a family member was a burden, they did express that caregiving does impact their ability to take care of their own personal needs and they foresee caregiving being more difficult in the future due to their own health, children, or work responsibilities.

The next two themes, “religion” and “relationship to the patient” reveal the importance of familial duties for Latino and Hispanic individuals. All participants practice the Catholic faith and are related to the care recipient by either being their daughter, or a maternal grandchild.

During the post-questionnaire, participants were asked to circle the “most relevant questions,” which is our next theme. We found a trend in participants circling the following questions; 2: How did you become the caregiver for the care recipient?, 22: how do you cope with stress?, 14: Do you have time to take care of your own personal needs? (i.e., cooking, cleaning, picking up your children from school), and 23: Do you foresee any difficulties in the future that might affect your ability to provide care? If so, what difficulties? (i.e., getting older, medical complications, work, children). Researchers determined that there was a pattern among these questions if 2 or more participants circled the question.

Our eighth theme is “motivation” and determining why the participant decided to care for their care recipient. We found that all participants reported that they cared for their care recipient because they are a family member and because it makes them feel good.

Lastly, we found a trend in “time spent providing care.” All participants are providing some type of care for their care recipient every day ranging from 1-5 hours per day to over 20 hours per day.

While there are currently a large number of common themes evident in our research, it will be necessary for the questionnaire to be retested in order to further

consolidate the most important themes and allow for our data to be generalizable to a larger population.

Application to Occupational Therapy

Based on the responses received from the focus group, the use of the Occupational Science Framework enhances the researchers' goal of understanding the phenomenological experience of Latino caregivers. The current data suggests that the participants practice the Catholic faith, and this is an important factor to consider, their role of caregiving is not entirely influenced by religious beliefs. The responses of the focus group correlate with current literature that concludes that among the Latino/Hispanic population, caregiving is a familial duty. The current data also revealed, as hypothesized, that caregivers may not be addressing their own needs since they spend large amounts of time caring for their relatives. The majority of the patients' instrumental activities of daily living such as driving, shopping, and meal prep were max caregiver assistance. Although the amount of time and assistance the caregivers provided their relatives in completing their IADLs leaves the caregivers less time to engage in activities they enjoy, most stated that it was not a burden to provide care. These cultural and social circumstances experienced by the participants are aligned with the socio-cultural subsystem of the Occupational Science framework. Occupational therapists seek to use a more holistic, culturally competent approach when working with clients and their caregivers, and these cultural influences suggested by the participants are vital for practicing clinicians to be aware of since it influences the caregivers' occupational performance in their duties while providing care.

Some of the participants of the focus group attributed great value in their role of being a caregiver to their loved ones, which can be correlated with the symbolic-evaluative subsystem of Occupational Science. Although previous research has identified that caring for family members is typically the role of female family members, having a male caregiver complete the questionnaire offers additional insight into a possible paradigm shift towards male members of a Latino family providing care. Knowing the value placed on the role of caregiving by the caregivers themselves is essential for practicing therapists to recognize so that they can better understand the caregiver's motivation while performing their role.

Lastly, the transcendental subsystem seeks to understand a person's motivation for engaging in an occupation, and how that engagement affects their overall life satisfaction and sense of purpose. Based on the responses from the focus group, providing care for their loved ones has impacted their ability to engage in meaningful occupations themselves, whether it was due to financial burden, emotional burden, or less time available. However, any necessary changes will be made among the participants, as it is the familial duty to care for the elderly. As a profession, occupational therapy seeks to use a client's motivation to form meaningful interventions, which is why the transcendental subsystem is so paramount for understanding Latino caregivers' needs and for providing client-centered care for these caregivers. While an occupational therapist can educate the caregivers on how to achieve occupational balance, the therapist must keep in mind that providing care is an occupation for these participants due to their cultural mindset, call to duty, and familial ties.

Limitations

The small sample size of 5 participants limits the generalizability of the results to other populations of Latino and Hispanic caregivers, as predicted. Particularly due to participants being of the same family and answering questions based on the same care recipient. 3 subjects answered the questionnaire based on 1 care recipient; the additional 2 subjects answered the questionnaire based on another care recipient. This was due to difficulty in recruiting participants, as our flyers and advertisements were provided in English and not responded to from the general Latino/Hispanic population, which is an additional limitation. Researchers looked within their own circle of family members and acquaintances to recruit participants, which may have also impacted the participants' self-reporting. During distribution of the questionnaire, one Spanish-speaking participant requested that our third-party translator write down the answers for them. Due to our translator being a third-party translator, this created difficulty in ensuring complete accuracy during this unpredictable request. Also, self-report bias was found as there were inconsistencies in the level of care that the participant is reporting versus the number of hours that the participant is actually providing care. Finally, as this is a questionnaire that has been developed by the researchers and edited based on the original outcomes of the themes coded, re-testing has not yet occurred, therefore the reliability and validity of the questionnaire has not yet been established. Though we found common themes that reflect a correlation between the participants interviewed for our study and the current literature available, there still needs to be more research done among this population to determine how occupational therapy can provide unique, but necessary support to these individuals.

Conclusion

Although providing care for the rapidly growing senior population is quickly becoming a national crisis, the current reimbursement model does not adequately support caregiving and caregiver needs. An estimated \$470 billion of unpaid care was provided by family members in 2013 (Carrion & Nedjat-Haiem, 2013). Despite the vital role of informal caregivers, there is a gap in current research about the experience and needs of Latino/Hispanic caregivers, causing this population to be underserved by health professionals. This may be due in part to the fact that this population is hesitant to seek out help or that they encounter obstacles (i.e., language barriers, financial barriers, etc.) when doing so. They may also feel as if it is their culturally bound duty to shoulder the burden of care for their loved ones, which play a significant role in why they engage in the caregiving role.

To truly understand how occupational therapists can contribute to the research of the Latino caregiver, we must first determine which categories of need are the most critical for this population. This was achieved by categorizing caregiver needs into distinct and relevant occupational domains. A needs assessment, formulated by the results of this focus group, will help delineate the specific needs of this population and provide a guide for future interventions and treatment plans. Once data is collected on the needs of the Latino/Hispanic caregiving community, it will allow occupational therapy to justify its role in aiding this population. Occupational therapy can address issues related to caregiver stress and burden, client education, and the performance of ADLs while these clients provide care for their loved ones. The field's holistic approach can incorporate the culture specific-needs into client-centered interventions in ways that other

disciplines may not be able to. We believe that at the conclusion of this research, we will be able to contribute valuable information about the needs of Latino/Hispanic caregivers and how occupational therapists can contribute to the whole person integration of humans as occupational beings within their cultural context.

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Appendix A

Original Date:	October 10, 2018
Dates Revised:	

CAREGIVER QUESTIONNAIRE

All questions and identifying information contained in this questionnaire is strictly confidential.

PERSONAL DEMOGRAPHIC INFORMATION	
DOB: <input type="checkbox"/> M <input type="checkbox"/> F	ZIP CODE:
Marital status: <input type="checkbox"/> Single <input type="checkbox"/> Partnered <input type="checkbox"/> Married <input type="checkbox"/> Separated <input type="checkbox"/> Divorced <input type="checkbox"/> Widowed	
Highest Level of Education: <ul style="list-style-type: none"> <input type="checkbox"/> No schooling completed <input type="checkbox"/> Less than high school <input type="checkbox"/> Some high school, no diploma <input type="checkbox"/> High School Graduate/GED <input type="checkbox"/> Some college credit, no degree <input type="checkbox"/> Trade/technical/vocational training <input type="checkbox"/> Associate degree <input type="checkbox"/> Bachelor’s degree <input type="checkbox"/> Master’s degree <input type="checkbox"/> Professional degree <input type="checkbox"/> Doctorate degree 	
Religion:	

CAREGIVER RECIPIENT INFORMATION

YOU AND YOUR CARE RECIPIENT	
1. Does your care recipient have a specific diagnosis or medical condition?	

<p>2. How did you become the caregiver for the care recipient?</p>	
<p>3. What is the relationship between you and your care recipient?</p>	
<p>4. Approximately how many hours per day and days per week do you provide care to this individual?</p>	<p> <input type="checkbox"/> 1-2 days per week <input type="checkbox"/> 1-5 hours per day <input type="checkbox"/> 15-20 hours per day <input type="checkbox"/> 3-4 days per week <input type="checkbox"/> 6-10 hours per day <input type="checkbox"/> 20 or more hours per day <input type="checkbox"/> 5-7 days per week <input type="checkbox"/> 11-15 hours per day </p>

ACTIVITIES OF DAILY LIVING	
<p>5. How often do you help this individual with bathing or showering?</p>	
<p>6. How often do you help this individual with toileting or toilet hygiene?</p>	
<p>7. How often do you help this individual with getting dressed?</p>	
<p>8. How often do you help this individual with mealtimes?</p> <p>Please describe how you help this individual.</p>	

<p>(i.e., preparing their meals, providing them with utensils, eating)</p>	
<p>INSTRUMENTAL ACTIVITIES OF DAILY LIVING</p>	
<p>9. Do you help this individual with their household responsibilities?</p>	<p><input type="checkbox"/> Yes <input type="checkbox"/> No</p>
<p>10. If you answered "yes" to the previous question, which responsibilities do you help them with (i.e., household chores, financial planning, maintaining the home) and how often?</p>	
<p>11. Does your care recipient drive?</p>	<p><input type="checkbox"/> Yes <input type="checkbox"/> No</p>
<p>12. If you answered "no" to the previous question, do you assist your care recipient with transportation (i.e., to run errands, to doctor's appointments)? And how often?</p>	

<p>13. Does anyone else help you with your caregiving duties? If so, who helps you?</p>	
<p>14. Do you have time to take care of your own personal needs? (i.e., cooking, cleaning, picking up your children from school)</p>	
<p>15. When you have a question about caregiving, who do you consult?</p>	
<p>16. What religion do you associate with? Do you believe your spirituality/religion influences your caregiving?</p>	
<p>17. How do you think your religious beliefs influence your caregiving? (i.e., it makes you feel good, you will be rewarded, it is a burden you must carry)</p>	
<p>18. Does the individual you care for require any durable medical equipment such as a wheelchair, walker,</p>	

<p>shower bench, or any other equipment not otherwise listed?</p>	
<p>19. Do you feel as though you have received proper training from a medical professional on how to use the equipment needed for your care recipient? From whom did you receive this training?</p>	
<p>20. What other activities, besides caregiving, are important to you?</p>	
<p>21. Do you feel as though your caregiving role leaves you with less time to engage in activities that you enjoy?</p>	
<p>22. How do you cope with stress?</p>	
<p>23. Do you foresee any difficulties in the future that might affect your ability to provide care? If so, what difficulties? (i.e., getting</p>	

<p>older, medical complications, work, children)</p>	
<p>24. Do you feel that medical professionals understand your culture? Why or why not?</p>	
<p>25. Has language ever presented difficulties for you in accessing health care that you or your care recipient need?</p> <p>If so, how? (i.e., medical terminology was used, language barrier, someone else was translating for you)</p>	
<p>POST-QUESTIONNAIRE</p>	
<p>26. Were there any questions that you felt uncomfortable answering? If so, please state which questions.</p>	
<p>27. Which questions do you feel are the most important? Please circle the top 5.</p>	
<p>28. What do you feel is the primary barrier that you have encountered as a</p>	

Latino/Hispanic individual in accessing health care? (i.e., language, help, access to facilities, insurance)	
29. Is there anything that was not addressed/asked that you believe should have been included?	

Appendix B

STANBRIDGE UNIVERSITY RESEARCH CONSENT FORM

Description: You are invited to participate in a research study on your experiences as an individual who identifies as Latino/Hispanic and who is providing care, either as professional or familial caregiver, for patients over the age of 65. You will be asked to participate in a small focus group with other participants, where you will be answering a questionnaire of no longer than 30 questions pertaining to your role as a caregiver. This focus group will not be videotaped, and questionnaires will remain anonymous throughout the duration of this research study.

Intent: The purpose of this study is to conduct a focus group of individuals that identify as Latino/Hispanic and are caring for someone over the age of 65. Through this focus group, we will identify culture-specific needs of this population.

Your Time Involvement: Your participation will take approximately one hour to complete.

Risks and Benefits: While there may not be any direct benefits for you, potential benefits of participating in this study will be a greater knowledge for medical personnel on the experience of Latino/Hispanic caregivers. This will provide greater insight into the issues that Latino/Hispanic caregivers face. There are no known risks associated with participation in this study. As always, there may be a chance of identification when participating in the questionnaire, but all questionnaires will remain anonymous to decrease this risk.

Payment: There will be no payment for participation in this study.

Participant Rights: If you have read and signed this form you are consenting to participate in this study. Participation in this study is voluntary and you have the right to withdraw at any point without penalty. Your alternative is to not participate in this study. You have the right to refuse to answer specific questions. Your identity will not be disclosed at any time. The results of this study may be disseminated at professional meetings, shared with other medical professionals, or published in scientific journals. By signing this consent form, you are agreeing to allow your responses to be used in any of the mentioned public forums.

Contact Information: If you have any questions about this research you may contact the Faculty Advisor: Denise Miller
Email: millerd1717@gmail.com

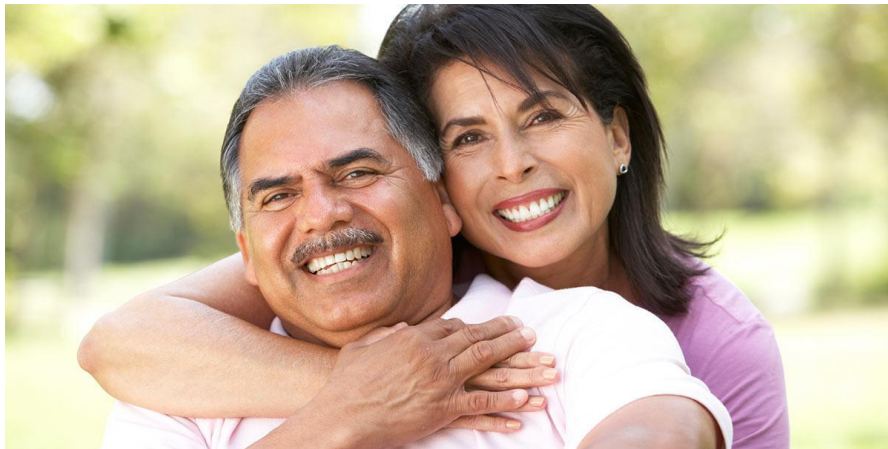
Independent Contact: If you are in some way dissatisfied with this research and how it is conducted, you may contact the Stanbridge University Vice President of Instruction.

Please keep a copy of this signed and dated consent form for yourself.

Signature _____ Date _____

Appendix C

**ARE YOU LATINO/HISPANIC?
DO YOU CARE FOR SOMEONE
OVER THE AGE OF 65?**



Stanbridge University
2041 Business Center
Drive
Irvine, CA 92612

For more information,
please contact us at:
(657) 325 – 0809

or email us
latinocaregiversOT@gmail.com

**Then you are invited to
participate in a focus group to
understand the experience of
Latino caregivers**

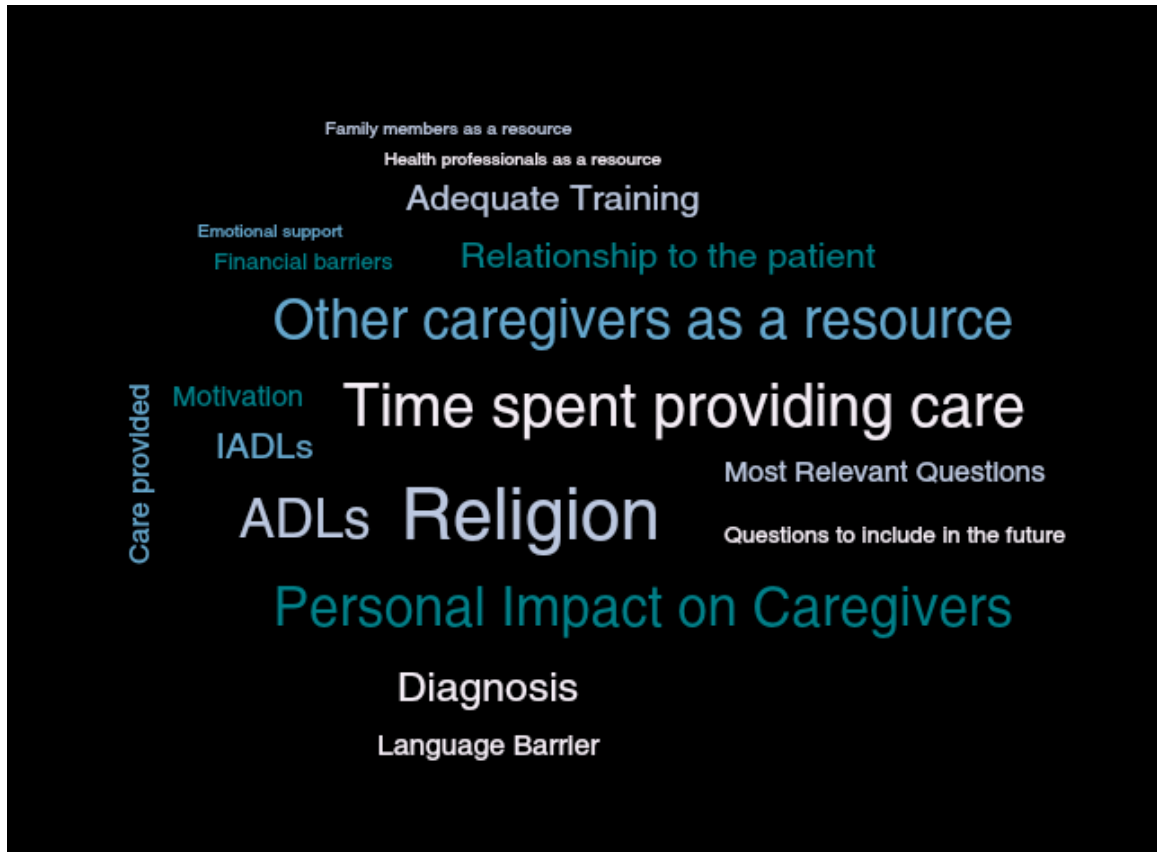
This focus group will consist of a questionnaire of approximately 30 questions, asking what type of care you provide, your relation to the care recipient, and other questions that could help medical professionals learn the specific needs of the Latino/Hispanic community.

The focus group will be conducted at Stanbridge University (2041 Business Center Drive, Irvine CA 92612) as part of a thesis research project for occupational therapy

students.

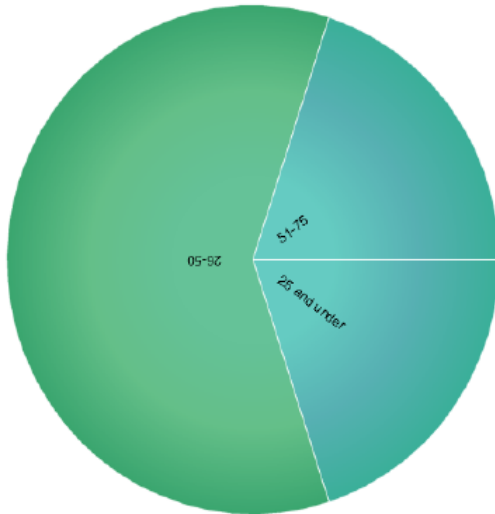
You must be over 18 years of age and live in Southern California to participate. English proficiency preferred, but not required.

Appendix D
Most Common Themes Code Cloud

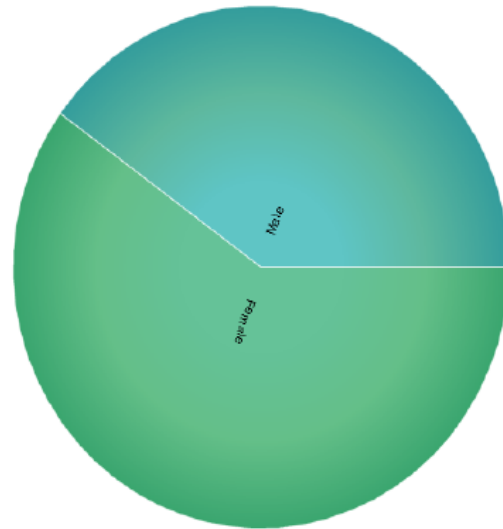


Appendix E

Set: Default, Field: Age



Set: Default, Field: Gender



Set: Default, Field: Level of Education

