ISPAD-JDRF FELLOWSHIP AWARD 6-MONTH PROGRESS REPORT

Dates: January 1, 2022 – June 30, 2022

Psychometric Testing of the Diabetes Health Management and Distress Scale- Parents of Young Children (DHMDS-PYC)

Primary Investigator: Vanessa Jewell, PhD, OTR/L

Mentor: Beth Pyatak, PhD, OTR/L, CDECS, FAOTA

T1D Diabetes Wellness Lab: Julia Shin, EdD, MS, OTR/L, Sarah Fellman, OTD, OTR/L, & Emily Knezevich, PharmD, CDECS; Noor M.H. Addasi, MD; Amy A. Abbott, PhD, RN, Yongyue Qi, PhD, MS; Marion Russell, OTD, OTR/L; Amy Thompson, MS, OTR/L
This is a 6-month report on the progress from January 1, 2022 through June 30, 2022 from the project titled, *Psychometric Testing of the Diabetes Health Management and Distress Scale-Parents of Young Children (DHMDS-PYC)*.

**Significance**

Type 1 diabetes is one of the most prevalent chronic childhood conditions, threatening the health and wellness of children and families, requiring immediate intervention and ongoing maintenance to prevent serious health complications such as cardiovascular disease, blindness, neuropathies, and stroke (CDC, 2017, 2020). With diabetes ranked as the seventh leading cause of death in adults, it becomes even more critical that children living with diabetes have access to high quality healthcare services and can successfully complete their health management routine due to the chronicity of the disease (CDC, 2017). The impetus of the disease management often falls to parents to prevent or delay long-term health complications. Though it is well-known that as blood glucose management improves, so does quality of life (Arditi, et al., 2019; Shim et al., 2019), psychosocial factors continue to heavily influence the implementation of health management tasks, even more so than diabetes knowledge and education, making diabetes health management even more complex (Gebremedhin et al., 2019; Jewell, Lee, et al., 2021; Noser et al., 2019; Polonsky, et al., 2005). The disease is omnipresent, and caregivers must be vigilant in completing and/or facilitating their child’s diabetes management routine. However, this vigilance may lead to severe emotional stress for the parents, especially after a young child’s diagnosis (Jewell et al., 2020; Noser et al., 2019). The importance of parental psychosocial well-being, coping and adaptation skills, and competence and confidence with diabetes health management tasks is critical to lower the risks of diabetes distress for both parents and children and improve long-term health outcomes for the children living with type 1 diabetes (Helgeson et al., 2012; Jewell, Lee, et al., 2021; Jewell, Wozniak et al., 2021).

The aim of this project is to complete the initial psychometric testing of a novel occupational therapy diabetes-specific assessment, which will in turn provide key information that can further prepare occupational therapy practitioners to develop and implement novel occupational therapy interventions aimed to improve child health outcomes, health management, and family quality of life. This assessment is titled the *Diabetes Health Management and Distress Scale-Parents of Young Children* and is being developed as part of a currently funded study titled the *Impact of COVID-19 on Family Quality of Life and Healthcare Access for Families with a Child with Diabetes* (American Occupational Therapy Foundation Grant #AOTFIRG21Russell). However, the grant only covers the development of the assessment. Therefore, it is imperative that psychometric testing is completed to ensure the validity and reliability of the assessment.

**Innovation and Benefits**

Raising a child with a chronic condition impacts life participation for the whole family unit, especially regarding a caregiver’s use of time, health, and activity choices (Fingerhut, 2013). Current standards of care for T1D have expanded beyond the daily monitoring of glucose levels, and these developments include: receipt of culturally relevant and sensitive healthcare plan, dietician consultations, physical activity recommendations, school and childcare considerations, psychosocial screening and care, screening of co-morbidities, management of cardiovascular health, and healthy lifestyle behavior training (ADA, 2021). *The proposed study*
is innovative as it is the first known study to test a newly developed assessment that is aligned with both the ADA’s 2021 Standards of Care for Adolescents and Youth along with the Occupational Therapy Practice Framework (American Occupational Therapy Association, 2020). The new assessment measures parent-specific diabetes distress and ability to complete health management routines for/with their young child with T1D. Further, the proposed study is innovative as the this is the only assessment that measures parental diabetes distress of young children (current assessments measure diabetes distress for parents of adolescents, young adults, and adults) and furthermore it is the only occupational therapy specific assessment for parents of children diagnosed with diabetes (Jewell et al., 2021).

It is imperative that healthcare professionals have an increased understanding of how the parents’ diabetes distress and health management routines for their young child with T1D (such as accessing endocrinology services and managing medications and health insurance).

The findings from this study are critical so novel occupational therapy interventions may be developed and evaluated to support the physical and psychosocial well-being of families with children with T1D. Occupational therapy practitioners can address the management of chronic health conditions, such as T1D, while providing supports to the family/caregiver to improve diabetes health management through examination of a family’s roles, routines, and habits (Cahill et al., 2016; Pyatak et al., 2011; Pyatak, et al., 2018). However, accurate evaluation of the effectiveness of novel interventions is imperative to advance the provision of diabetes care. Therefore, the development and testing of this novel occupational therapy diabetes assessment is critical to the advancement of healthcare practices and improved child health outcomes (e.g., blood glucose control, diabetes self-management, cardiovascular disease, neuropathies).

**Approach**

**Aims:** The overarching aim of this study is to establish the initial psychometric properties of the *Diabetes Health Management and Distress Scale- Parents of Young Children*. Aim 1: establish content validity and preferred response format. Aim 2: establish ecological validity; Aim 3: determine internal consistency and construct validity. Aim 4: establish the cut-off scores for each subdomain.

<table>
<thead>
<tr>
<th>Phase I</th>
<th>Phase II</th>
<th>Phase III</th>
<th>Phase IV</th>
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<tbody>
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<td>Establish the content validity and preferred response format</td>
<td>Establish the ecological validity</td>
<td>Determine the internal consistency and construct validity</td>
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<td><strong>Design</strong></td>
<td>Nonexperimental methodological study</td>
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<td><strong>Sample</strong></td>
<td>Stakeholders N=10 a. Parents of young children with T1D (ages 0-12) b. Healthcare providers/diabetes</td>
<td>Occupational therapy practitioners, diabetes educators, and researchers (n=6) from the</td>
<td>Prospective sample 2021; caregivers (n=200; Creighton Type 1 Diabetes</td>
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<td>Procedures</td>
<td>Content validity and response format: Two focus groups (one for parents and one for healthcare providers), administered via virtual platform (i.e., Zoom) to gather feedback related to the assessment. Focus groups will be recorded and transcribed verbatim.</td>
<td>Ecological validity: Healthcare providers will rate the degree to which the DHMDS-PYC reflects health management tasks in their natural (i.e., home/community) environment and provide verbal feedback to the research team.</td>
<td>After recruitment of parents of young children with type 1 diabetes occurs, the participants will complete the DHMDS-PYC along with the Zarit Caregiver Burden Scale.</td>
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| Analysis | Content validity: Through descriptive content analysis, researchers will code all focus group transcriptions. Findings will be integrated into the assessment. 
Response format: Descriptive (ranges, frequencies). | Descriptive (ranges, frequencies) | Internal consistency- Cronbach’s alpha 
Construct validity (specifically convergent validity)- | Cut-off values determined from convergent validity testing with the parent-specific diabetes distress domain and the Zarit Caregiver Burden Scale |
| **Benchmarks for Success** | 1) Development of the focus group questionnaire 
2) Focus group findings/themes | 1) Development of the ecological validity questionnaire 
2) Quantitative and qualitative findings | 1) Successful recruitment of 200 participants 
2) Results report | 1) Successful recruitment of 200 participants for the normative sample 
2) Results report |
Alignment for Future Research

Establishing psychometric properties for an occupational therapy-diabetes specific assessment will allow for the evaluation of novel occupational therapy interventions that are client-centered, occupation-based, theory-driven, and manualized. This topic directly aligns with current NIH funding. Not only will the proposed project continue to build our interdisciplinary research team, but it allows for mentorship and building of Dr. Jewell, an early-stage investigator. The proposed project includes key personnel from occupational therapy, medicine, nursing, pharmacy, biostatistics, and community stakeholders. However, the larger diabetes research team has collaborated with/continues to collaborate with the following disciplines: occupational therapy, nursing, pharmacy, medicine/endocrinology, cyber systems, community stakeholders (clinicians, patients, caregivers, advocacy organizations, senators), undergraduate assistants from a variety of programs, business, and statistics, and healthcare professional students. This project will allow for continued growth and development of our interdisciplinary team and build rural community relationships, a traditionally underserved population in research.

Overview of Timeline and Progress to Date

Light blue = original proposed timeline

X = completed task

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<thead>
<tr>
<th>YEAR 1</th>
<th>Task</th>
<th>Month</th>
<th>Q1</th>
<th>Q2</th>
<th>Q3</th>
<th>Q4</th>
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<tr>
<td></td>
<td></td>
<td>Prior to Grant Start Date</td>
<td>January-March 2022</td>
<td>April-June 2022</td>
<td>July-Sept 2022</td>
<td>Oct-Dec 2023</td>
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<tr>
<td></td>
<td>Comprehensive literature review</td>
<td>x</td>
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<tr>
<td></td>
<td>Identify research assistant/s</td>
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<td></td>
<td>IRB Approval</td>
<td>x</td>
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<td></td>
<td>Establish group process and decision-making model</td>
<td>x</td>
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<td></td>
<td>Complete research capacity building training with research assistant/s and</td>
<td>x</td>
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stakeholders; including diabetes-related training and assessment development

| Stakeholder input regarding questionnaire development and any necessary survey modifications; piloting of surveys | x |
| Recruitment for Phases I-IV | Done for Aims 1-3 |
| Implement Phase I-III | x |
| Analyze findings surveys and focus groups | Done for Aims 1-3 |
| Dissemination of findings | Partially met |

**Current Progress**

The T1D Wellness and Research Lab meet weekly to discuss the progress from the prior week, update goals and objectives, and plan the activities to complete for the upcoming week. The PI (Jewell) continues to meet regularly with both her mentor (Pyatak) and the research team.

**Comprehensive Literature Review**

The PI completed a comprehensive literature review prior to the study initiation to serve as a foundation for the study and future dissemination efforts.

**Identify Research Assistants**

We emailed doctoral level occupational therapy students from the Phoenix campus at Creighton University to share information about the project and request applications for a research assistant position. The PI (Jewell) and a co-investigator (Shin) completed interviews and selected two graduate-level research assistants with experience working with diverse clients and family and human development. The research assistants completed necessary paperwork and started with the team on January 14, 2022.

**Institutional Review Board Approval/s**

The PI completed all necessary paperwork and documentation to receive Institutional Review Board approval from Creighton University. As the PI is transitioning to another institution on July 1, 2022, she will complete and submit a second IRB package at that time.

**Establish Group Process and Decision-Making Model**

The research team discussed various models for group decision-making. The team decided on decision by consensus as the primary model. This model required open communication, so all members are able to feel that they have an equal chance to contribute. Consensus allows for a clear solution that most team members agree with and those that oppose
the decision would get a fair chance to influence the decision. Should disagreement arise and consensus could not be reached, or if there were budgetary concerns, then decision by formal authority, or the PI, would make the final decision after listening to all team members.

**Research Capacity Building**

After a strengths-based approach to determine roles and needs for the team members to successfully complete the project deliverables, the team members engaged in research capacity building. The PI had previously built an online self-paced course that focuses on diabetes management and research training. All team members completed required trainings (such as CITI/IRB/research ethics) and needed trainings to fulfill their roles (such as Lifestyle Redesign training, leading focus groups). The PI and co-I traveled to the University of Southern California, the host institution, for a week to get 1:1 mentoring and training in Lifestyle Redesign, diabetes management, research capacity, and assessment development.

**Focus Group/Interview Questionnaire Development**

Through an iterative process, the research team and stakeholders developed a focus group questionnaire to facilitate the pilot testing of the novel occupational therapy diabetes assessment. The final questionnaire included questions related to the assessment’s response format, content validity, and ecological validity. The questionnaire included 11 questions, with probing questions as needed.

**T1D Assessment Piloting**

The novel assessment was based on the American Diabetes Standards of Care for Youth along with the Occupational Therapy Process Framework – 4th edition. Utilizing a nonexperimental, methodological design, two phases of assessment development and testing were completed. Stakeholders (n=27) provided feedback on the content validity, ecological validity, and response format through a focus group, individual interview, or written comments. All interviews were transcribed verbatim and coded with the written comments. Researchers integrated feedback into the assessment through an iterative process. Assessment revisions improved the overall format and validity. Overall, stakeholders reported good content validity, preferred response format, and ecological validity for the *Diabetes Health Management and Distress Scale- Parents of Young Children*.

**Next Steps**

We are in the process of recruiting for Aims 3 and 4. To date, 204 caregivers have completed the online version of the *Diabetes Health Management and Distress Scale- Parents of Young Children*. The statistician will complete analyses for internal consistency and construct validity to finalize Aim 3. Next, we will recruit a prospective normative sample of caregivers of young children to determine cut-off values determined from convergent validity testing with the parent-specific diabetes distress domain and the Zarit Caregiver Burden Scale. Accurate evaluation of the effectiveness of novel interventions is imperative to advance the provision of diabetes care. Therefore, the testing of this novel occupational therapy diabetes assessment is critical to the advancement of healthcare practices and improved child health outcomes.
References


