DISSERTATION

UNDERSTANDING THE EXPERIENCE OF TYPE 2 DIABETES USING MULTIPLE METHODS AND PERSPECTIVES

Submitted by

Tara C. Klinedinst

Department of Occupational Therapy

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Doctoral Committee:

Advisor: Matt Malcolm

Gene Gloeckner
Karen Atler
Tracy Nelson
Chrissy Chard

ABSTRACT

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Objective: The purpose of this dissertation was to use multiple research methods to gain understanding of the experience of type 2 diabetes. I used quantitative and qualitative methodologies from the perspectives of both safety-net primary care clinic patients and health care providers (HCPs).

Introduction: Type 2 diabetes mellitus (T2DM) is a serious and chronic metabolic disorder in which the pancreas is unable to properly break down glucose in the cell, leaving excess glucose in the bloodstream. Managing T2DM by controlling blood glucose is extremely important for prevention of life-threatening complications (e.g., blindness and limb amputation) (World Health Organization, 2016). Though some people are able to make the necessary changes to control the disease and ward off complications, many are not. In fact, estimates show that one third of people with T2DM are not able to perform the required activities for long-term control of blood glucose (DiMatteo, 2004b). The reality is that long-term lifestyle changes are very difficult, and dependent on many factors within the person, the environmental context, and the activity (Thompson, 2014). Without proper coaching and support to consistently perform diabetes self-management (DSM) behaviors, many more of the nation's 23.1 million people with T2DM will die from complications or develop disabling conditions (Centers for Disease Control and Prevention, 2017), which are responsible for impeding independence in important activities of

daily living. Increased understanding of the complex factors at play within the person, the environment, and the activity is needed to facilitate sustained engagement in healthy behaviors.

For individuals with T2DM, DSM is a fundamental aspect of diabetes care. DSM is the most widely accepted and efficacious method of promoting healthy lifestyle change for people with T2DM (American Diabetes Association, 2018). DSM is often based upon the AADE7 Self-Care Behaviors™, a product of the American Association of Diabetes Educators (AADE) Outcomes Project (Peeples, Tomky, Mulcahy, Peyrot, & Siminerio, 2007). The AADE Outcomes Project was a multi-year study focused on transforming DSME into an evidence-based practice. The AADE7™ behaviors were identified through a review of existing literature, mapping of core areas, and expert consensus (Peeples et al., 2007). The AADE7™ are healthy eating, being active, monitoring, taking medications, problem solving, healthy coping, and reducing risks. However, knowledge of self-care behaviors alone is not sufficient to facilitate long-term behavior change; researchers and practitioners must also understand the underlying factors that support or hinder these behaviors as experienced by the individuals with T2DM (Nagelkerk, Reick, & Meengs, 2006).

Findings from several qualitative studies exploring barriers to DSM have indicated that numerous difficulties exist around taking medication, healthy eating and physical activity. Common barriers include associated cost of medications and healthy diet (Booth, Lowis, Dean, Hunter, & McKinley, 2013; Nagelkerk et al., 2006), negative views of diet (Booth et al., 2013; Thompson, 2014), physical and environmental barriers to exercise (Booth et al., 2013; Youngson, Cole, Wilby, & Cox, 2015), healthy eating in social situations (Ahlin & Billhult, 2012; Booth et al., 2013; Minet, Lønvig, Henriksen, & Wagner, 2011; Thompson, 2014; Youngson et al., 2015), knowledge deficits about DSM and community resources (Ahlin &

Billhult, 2012; Booth et al., 2013; Nagelkerk et al., 2006), helplessness and frustration at lack of glycemic control despite best efforts (Booth et al., 2013; Nagelkerk et al., 2006), unstable DSM routines (Beverly et al., 2012; Minet et al., 2011; Thompson, 2014; Youngson et al., 2015), and lack of willpower to exercise and follow a diet plan (Beverly et al., 2012; Booth et al., 2013; Youngson et al., 2015). Barriers to DSM are complicated, and much like the underlying self-care behaviors, are influenced by aspects of the person, and the physical and social environment. Knowing what *behaviors* are important to DSM and knowing what *barriers* exist to DSM is vital, but this knowledge is not enough to fully understand how these behaviors are motivated, patterned, and performed within social and physical environments (Taylor, 2017).

Understanding more about the intricate nature of these occupations, or the goal-directed activities of daily life, could provide new insights into facilitating behavior change. Despite the large amount of research dedicated to T2DM treatment and intervention, practitioners are still faced with the challenge of how to facilitate long-term engagement in these complex DSM behaviors (Coster & Norman, 2009; Fritz, 2015). The nature of DSM is multi-faceted and ever-changing; context, occupation and person are joined in interactions that are an innate and necessary part of life (Fritz, 2015). In order to help facilitate DSM behaviors, practitioners need to understand the individual occupations of DSM as interconnected and in the context of the surrounding environment. This notion of creating a holistic understanding of DSM has shaped the development of the three studies of this dissertation. These studies are aimed at further understanding, then advancing the knowledge of the experience of T2DM by using multiple methods and perspectives.

Method: This dissertation is comprised of three studies. The first study was a quantitative examination of the relationships between demographic and health variables (DHV) and

performance of instrumental activities of daily living (IADL). IADL are complex daily activities (e.g., medication management and meal preparation) that support life in the home and community (American Occupational Therapy Association, 2014). We used multiple regression to determine which DHV significantly predicted IADL performance in three categories: domestic, outdoor, and leisure/work. The second study is a qualitative exploration of the varied and complicated occupations of DSM using the Model of Human Occupation (MOHO). In this study, we held focus groups of individuals with T2DM, and asked questions to deepen understanding of habits/routines of DSM, the impact of social/physical environment on DSM, and what services/supports participants would find helpful. We analyzed this data using the components of MOHO (volition, habituation, performance capacity and the environment) to conceptualize and organize the information. The third study, also qualitative, examined the perspectives of health care providers. We asked these participants about their insights from working with individuals with T2DM, and what they services/supports they recommend to bolster patient's ability to engage in DSM.

Results: In study 1, we found that present-moment depression, history of depression/anxiety, number of medications, and healthcare utilization significantly predicted different categories of IADL performance. The most powerful predictor was present-moment depression, which was associated with decreased IADL performance across all categories. This finding underscores the importance of mental health screening in primary care to prevent or delay IADL impairment. In study 2, themes related to DSM were identified using MOHO as a conceptual model. This analysis demonstrated how the occupation of DSM was influenced by the components of MOHO: social and physical contexts; values, beliefs and motivations; habits, routines, and roles; and ability and experience. In study 3, HCPs identified three themes related to working with individuals with T2DM in a safety-net primary care clinic. First, HCPs described their perceptions of patient experiences with DSM. Second, the HCPs described barriers and strategies they have encountered when working with individuals with T2DM toward better health. Third, HCPs described services and supports they believed would be beneficial to those who are trying to better manage T2DM.

Conclusion: Type 2 diabetes is a complex disease to manage, especially when individuals experience limited health resources. There are common threads that runs throughout the three studies: the negative impact of depression on IADL and DSM and the existence of multiple obstacles to meeting self-care demands (e.g., poor self-care routines, unsupportive social environments, and limited resources). These factors are not directly attributed to T2DM, but cause additional stress and contribute to the chaotic life circumstances discussed in these studies. These non-diabetes-related stressors impact an individual's ability to engage in DSM. To address these chaotic life problems, we need to engage individuals in non-traditional ways (i.e., in the home/community, including family and social networks in education) to provide more comprehensive care. Future research will work to further understand and reduce non-diabetes-related stressors to free up mental, emotional, and physical energy for DSM.

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DEDICATION

This dissertation is dedicated to Charlie, the love of my life and the little girl who makes this all worthwhile.

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CHAPTER ONE: DEMOGRAPHIC AND HEALTH VARIABLES PREDICT IADL PERFORMANCE IN ADULTS WITH TYPE 2 DIABETES

Type 2 diabetes (T2DM) is a chronic metabolic disorder associated with costly and disabling complications when not well controlled (Centers for Disease Control and Prevention, 2017). Individuals with T2DM are at increased risk for developing impairments in instrumental activities of daily living (IADL) compared to peers without T2DM (Chiu, Mau, Tasi, Hsieh, & Liu, 2004; E. Wong et al., 2013). IADL are activities that support life in the home and community (e.g., medication management, physical activity); performing these activities often requires more complex mental and physical processes than basic activities of daily living (i.e., bathing, eating) (American Occupational Therapy Association, 2014). Diabetes self-management (DSM) relies on the capacity to perform IADL. For example, individuals with T2DM manage their disease through everyday IADL such as meal preparation and physical activity (American Diabetes Association, 2018). Diminished ability to perform IADL may also lead to poor quality of life (QOL), low self-efficacy (Spillman, 2004), high healthcare utilization (HCU) (Malcolm et al., 2018; Spillman, 2004), increased need for personal assistance (Gill & Kurland, 2003), and disabling complications like blindness and amputation (American Diabetes Association, 2018).

In general, individuals with T2DM have difficulty with IADL performance (Kalyani, Saudek, Brancati, & Selvin, 2010). Researchers have studied relationships between demographic and health variables (DHV) and IADL performance in older adults, and to a lesser extent for adults with T2DM. In previous research of older adults, advanced age (Chiu et al., 2004; Connolly, Garvey, & McKee, 2017; Millan-Calenti et al., 2010), female gender (Lázaro, Rubio, Sánchez, & García, 2007; Millan-Calenti et al., 2010), minority status (Andresen & Brownson, 2000), above normal body mass index (BMI) (Larrieu et al., 2004; Woo, Leung, & Kwok, 2007), higher numbers of medications (Connolly et al., 2017; Rozzini, Frisoni, Bianchetti, Zanetti, & Trabucchi, 1993), severity of comorbidities (Daniele, Bruin, Oliveira, & Pompeu, 2013) and recent fall (Chase, Mann, Wasek, & Arbesman, 2012) were associated with IADL impairments and limitations, as well as functional disability (a construct which is often partly measured by IADL (see E. Wong et al. (2013). In older adults with T2DM, limitations in IADL were linked to uncontrolled blood glucose (Bossoni et al., 2008), increased emergency department use (Malcolm et al., 2018), increased hospitalizations (Malcolm et al., 2018; Shinkai et al., 2003), and depression/anxiety (Lenze et al., 2001).

Though there is an abundance of research in this area, we still do not have a comprehensive understanding of how these key variables interact and influence performance of important complex daily activities for individuals with T2DM. There are several reasons for this lack of understanding. First, making direct comparisons between studies is difficult due to heterogeneity of populations and differences in measurement of IADL. Second, relationships between many of these DHV and IADL performance have not yet been examined in adults with T2DM, a population with distinct health and disability characteristics (Wray, Ofstedal, Langa, & Blaum, 2005). To our knowledge, this study is the first to examine these important demographic and health variables in combination and for adults with T2DM. Third, to our knowledge, there are no studies that examine the relationships between DHV and specific categories of IADL performance. Previous research linking DHV to IADL performance have used single-question indicators (i.e., ‘do you have trouble with preparing meals’, ‘doing housework’, etc.) (Kalyani et al., 2010; E. Wong et al., 2013), or whether or not someone has difficulty in any one IADL (Connolly et al., 2017). The underlying skills and abilities required to perform IADL differ greatly between tasks. For example, meal preparation requires the individual to plan, prepare, and serve a meal, whereas grocery shopping entails a similar level of planning, but also requires the individual to navigate the community and transport items (American Occupational Therapy Association, 2014). The Frenchay Activities Index (FAI: Holbrook & Skillbeck, 1983), the dependent variable in this study, consists of three subscales that differentiate between types of IADL. Holbrook and Skillbeck's (1983) exploratory factor analysis contributed to the categorization of these activities into three subscales: domestic, leisure/work, and outdoor. The results of this study will help us better understand why individuals with T2DM experience decreased levels of IADL performance.

Based on previous research, we anticipated lower levels of IADL performance for those who are older (Connolly et al., 2017), of minority status (Andresen & Brownson, 2000); who have higher BMI (Larrieu et al., 2004), higher numbers of daily medications (Connolly et al., 2017), poorly controlled T2DM (Bossoni et al., 2008), higher numbers of comorbidities (Daniele et al., 2013), depression and/or anxiety (Lenze et al., 2001), a recent fall (Chase et al., 2012), and higher healthcare utilization (HCU) (Malcolm et al., 2018). We anticipated the only difference between the subscales will be gender-based: men typically perform work/leisure IADL more frequently than women, and women more frequently perform domestic (Holbrook & Skillbeck, 1983; Lázaro et al., 2007; Millan-Calenti et al., 2010) and outdoor activities (Holbrook & Skillbeck, 1983). Healthcare professionals who work with individuals with T2DM need objective data on IADL performance and the impact of DHV on performance. The goal of our research was to discover which DHV predict frequency of overall, domestic, leisure/work, and outdoor IADL (Figure 1.1).

Methods

Participants

Participants were 93 adults with T2DM from a safety-net primary care clinic providing health services to an underserved population with limited resources (i.e. education, insurance, economic stability). We recruited participants using referral from primary care providers and with flyers. We included adults with previous diagnosis of T2DM, age ≥ 18 years, patient status at the primary care clinic, and ability to read at a 6th grade level or higher. We excluded adults who could not understand written or verbal instructions for questionnaires. All participants provided written informed consent. The institutional review boards for Colorado State University and the primary care clinic approved the research study.

Procedure

We conducted a cross-sectional study. Participants completed self-report questionnaires containing demographic, health, and HCU data (referred to as DHV).We obtained hemoglobin A1C (A1C) and number of medications through the participant electronic medical record (EMR). Participants also completed several paper-and-pencil questionnaires, including the Frenchay Activities Index (FAI) and Hospital Anxiety and Depression scale (HADS) (see Appendix pages 111-117 for questionnaires). Participants completed assessments in a private room at the primary care clinic with a research assistant present. The assessment process took around one hour and participants received a $25 stipend to offset time and transportation expenses.

Measures

The dependent variable in this study was the Frenchay Activities Index (FAI), a questionnaire used to assess instrumental activities of daily living (IADL; see Appendix p. 111) (Holbrook & Skillbeck, 1983). The FAI assesses frequency of 15 general activities in three domains of IADL: domestic (e.g. housework, meal preparation), outdoor (e.g. gardening, walking outside) and leisure/work (e.g. pursuing hobbies and gainful work). The FAI is a 15-question, self-report measure that uses a scale of 0-3 points to assess how often a person performs each type of activity (e.g., 0 = never, 1 = 1-2 times in 3 months, 2 = 3-12 times in 3 months, 3 = at least weekly). The FAI demonstrates good construct validity, particularly in middle-aged and older adults, and test-retest reliability ($r = 0.96$) (Turnbull et al., 2000). Most recently, the FAI has been shown to have good internal consistency reliability ($\alpha = .76$) in adults with T2DM (Atler et al., 2018).

The predictor variables (DHV) were age, gender, minority status, body mass index (BMI), A1C, number of medications, number of common comorbidities of T2DM, HCU, present-moment depression and anxiety (measured by the Hospital Anxiety and Depression Scale), history of depression/anxiety, and recent fall (yes/no). Body mass index, or BMI, is a screening tool used to identify those who may be overweight or obese, and is measured using a simple formula: weight/height^2. A BMI of <18.5 is considered underweight, < 25 is considered normal, < 30 is considered overweight, and 30+ is considered obese (Centers for Disease Control and Prevention, 2015). A1C is a commonly used measure of stable blood glucose control; < 7% is considered “good control” for people with T2DM (American Diabetes Association, 2018). We collected data about common comorbidities of T2DM: kidney, periodontal, and eye disease; neuropathy; heart disease/stroke; frequent infections; and depression/anxiety (Leslie, Lansang, Coppack, & Kennedy, 2013). We collected three measures of HCU: number of physician visits, emergency department (ED) visits, and nights in the hospital over the last 6 months.

The Hospital Anxiety and Depression Scale (HADS) assessed present levels of depression and anxiety in study participants. The HADS identifies present-moment depression and anxiety (termed “caseness”) in patients in non-psychiatric hospital clinics (Zigmond & Snaith, 1983). The assessment consists of 14 questions, 7 each to address depression and anxiety. The HADS has been validated extensively in general medical and primary care populations and demonstrates strong evidence for concurrent validity (r = .60 - .80) with established measures of depression and anxiety (Bjelland, Dahl, Haug, & Neckelmann, 2002). The measure also displays moderate to strong internal consistency (HADS-A α = .83 and HADS-D α = .82) and excellent case-finding ability (sensitivity and specificity = 70 – 90%) (Bjelland et al., 2002).

Statistical Analyses

We conducted all statistical analyses using Statistical Package for the Social Sciences 24 (SPSS, Inc., Chicago, IL, USA). We conducted descriptive analyses of the demographic and health variables (DHV), as well as the subscale and total scores of the FAI to describe the basic features of the study sample and measures used (Table 1.1). To address the research question, we conducted two primary data analyses: means comparisons and stepwise multiple linear regressions. We used the three FAI subscales (i.e., domestic, outdoor, and leisure/work) and the total score as the dependent variable for all subsequent analyses.

We conducted means comparisons to determine if IADL performance differed in each of the DHV (i.e., all but number of comorbidities and physician’s visits) (see Table 1.2). All dependent variables were continuous; therefore, we conducted independent samples t-tests or Mann-Whitney *U* (when the assumptions of normality, homogeneity of variance, and equal sample size were violated) (Field, 2013). We used Shapiro-Wilk values greater than α = .05 to confirm normality. We used Levene’s test values greater than α = .05 to confirm homogeneity of variance. We used a ratio of largest group to smallest group of less than 1.5:1 to confirm equality of sample sizes (Field, 2013). We calculated effect size for each means comparison (Cohen’s *d* for t-test and *r* for Mann-Whitney *U*). We considered the following conventions for effect size: Cohen's *d* (.2 = small, .5 = medium, .8 = large); *r* (.1 = small, .3 = medium, .5 = large) (Field, 2013). We adjusted the alpha level of significance to $\alpha = .0125$ based on a Bonferroni correction (.05/4) to adjust for multiple comparisons (Field, 2013).

For the two remaining DHV (number of comorbidities and number of physician visits in the previous six months), there were no accepted standards for dividing participants into groups. Therefore, we conducted correlations between DHV and the dependent variables. Due to the non-normal distribution of both variables, we selected Spearman's rank order correlations.

To identify which DHV predicted the overall and subscale values of IADL performance, we conducted four separate stepwise multiple linear regressions with each FAI subscale and total FAI scores as dependent variables and the DHV as predictor variables (Tabachnick & Fidell, 2007). We included all variables in the original model and used manual backward elimination to further refine the model. We eliminated the variable with the highest *p*-value and refitted the model until all predictor variables had individual *p*-values < .05 (Field, 2013). Stepwise multiple regression is appropriate for exploratory model building, and backward elimination is preferred over forward selection for minimizing suppressor effects (Field, 2013). In other words, backward elimination considers the effects of all variables together instead of one at a time (as with forward selection).

Missing data. Only 79 of our 93 study participants had recorded values for A1C. A previously published study using the same data set found those who had a recent A1C value in the medical record spent significantly less in nights in the hospital than those who did not have a recent A1C on file, indicating those without a current A1C may not be participating in routine diabetes appointments (Malcolm et al., 2018). Based upon this knowledge, the missing data are not random. Therefore, we conducted all regression analyses that included A1C with only complete cases (n = 79) (Tabachnick & Fidell, 2007). For BMI, one participant answered “don’t know” for weight and height. For recent falls, one participant answered “don’t remember.” We also omitted these cases for regression analyses.

Results

We collected cross-sectional survey and EMR data from 93 participants with T2DM (48 women, 45 men; average age 58.6 ± 11.4 years; 68% white, non-Hispanic, 32% Hispanic/Latina/o, and 69% with an annual income < $20,000). Demographic data according to the variables studied here are displayed in Table 1.1.

Means comparisons

We conducted means comparisons to determine if differences existed between grouped variables for each subscale and total score on the FAI. Detailed results are displayed in Table 1.2. We found that younger adults had significantly lower performance for the FAI leisure/work and outdoor scales compared to the older group. We also found that individuals with a BMI < 25 (indicating normal or underweight) performed overall IADL less frequently than individuals with a BMI ≥ 25 (indicating overweight or obese). Individuals with a history of depression/anxiety scored significantly lower on the leisure/work and outdoor subscales and total scale than those without. Individuals with present-moment depression displayed significantly lower IADL performance on every subscale and the total score. Individuals with present-moment anxiety scored significantly lower on the domestic and leisure/work subscales and the total scale. Individuals who had recently fallen had lower performance of domestic and total IADL. Those who had recently visited the ED had lower performance of outdoor IADL, and those who spent at least one overnight in the hospital had a lower score on domestic, outdoor, and total IADL scales. We found no differences between groups for gender, minority status, A1C, or number of medications. Additionally, there were significant correlations between number of comorbidities and all scales of the FAI; also for number of physician's visits and all scales of the FAI except domestic.

Multiple Regressions

We conducted stepwise multiple regressions with backward elimination to determine which DHV were useful for building a predictive model of IADL performance. We constructed a separate regression model for each of the subscales and the total score of the FAI.

First, we conducted an analysis that predicted performance on domestic IADL. A test of the full model was significant, indicating that, as a whole, the predictors accounted for a significant portion of the variance in domestic IADL performance ($F_{(14, 61)} = 4.87$, $p < .001$). The adjusted R^2 value was .42 indicating that the model explained 42% of the variance in domestic IADL. With all variables included, only the depression score on the HADS ($B = -.40$, $p = .001$) and number of physician visits in previous 6 months ($B = -.24$, $p < .01$) were significant. However, after paring down the model to only significant predictors, depression score on the HADS ($B = -.23$, $p = .01$), number of medications ($B = -.22$, $p = .001$), and total nights in the hospital in previous 6 months ($B = -.01$, $p < .001$) significantly predicted domestic IADL performance ($F_{(3, 88)} = 15.66$, $p < .001$). These regression findings indicated that a 1-point increase in HADS depression score is associated with a .23-point decrease in domestic IADL performance, when all other predictors were held constant. Similarly, each 1-medication increase was associated with a .22-point decrease in domestic IADL performance, and a 1-night increase in hospital overnights was associated with a .01 unit decrease in domestic IADL performance.

Together, the predictors accounted for 33% of the variance in domestic IADL performance (adjusted $R^2 = .33$).

The second analysis used the same DHV to predict performance on IADL related to leisure and work. A test of the full model was significant, indicating that, as a whole, the predictors accounted for a significant portion of the variance in IADL performance ($F(13, 62) = 2.11$, $p = .026$. The adjusted R^2 value was .16, indicating that the model explained 16% of the variance in IADL relating to leisure and work activities. With all variables included, there were no individually significant predictors. However, after paring down the model to only significant predictors, history of depression/anxiety ($B = -1.52$, $p = .027$) and depression score on the HADS ($B = -.27$, $p = .007$), were found to significantly predict IADL performance related to leisure and work activities ($F_{(2, 90)} = 10.95$, $p < .001$). These regression findings indicated that, when all other predictors were held constant, history of depression or anxiety was associated with a 1.52-point decrease in leisure/work IADL performance. Similarly, each 1-point increase in HADS depression score was associated with a .27-point decrease in leisure/work IADL performance. Together, the predictors accounted for 18% of the variance in leisure/work IADL performance (adjusted $R^2 = .18$).

The third analysis used the same DHV to predict performance on outdoor IADL. A test of the full model was significant, indicating that, as a whole, the predictors accounted for a significant portion of the variance in outdoor IADL performance ($F_{(14, 61)} = 2.73$, $p = .003$). The adjusted R^2 value was .24 indicating that the model explained 24% of the variance in outdoor IADL. With all variables included, only the depression score on the HADS ($B = -.34$, $p = .017$) was significant. However, after paring down the model to only significant predictors, depression score on the HADS ($B = -.34$, $p < .001$) and number of physician visits in previous 6 months ($B =$

-.20, $p = .004$) significantly predicted outdoor IADL performance ($F_{(2, 90)} = 14.67$, $p < .001$). These regression findings indicated that a 1-point increase in HADS depression score was associated with a .34-point decrease in outdoor IADL performance, when all other predictors were held constant. Similarly, each 1-visit increase was associated with a .20-point decrease in outdoor IADL performance. Together, the predictors accounted for 23% of the variance in outdoor IADL performance (adjusted $R^2 = .23$).

Lastly, we examined the effect of the DHV on overall IADL performance. A test of the full model was significant, indicating that, as a whole, the predictors accounted for a significant portion of the variance in IADL performance ($F_{(14, 61)} = 4.22$, $p < .001$). The adjusted R^2 value was .38, indicating that 38% of the variance in overall IADL was explained by the model. With all variables included, only the depression score on the HADS ($B = -.90$, $p = .003$) was significant. However, after paring down the model to only significant predictors, depression score on the HADS ($B = -.83$, $p < .001$), number of medications ($B = -.51$, $p < .001$), and total nights in the hospital in previous 6 months ($B = -.16$, $p = .002$), significantly predicted overall IADL performance ($F(3, 88) = 17.88$, $p < .001$). These regression findings indicated that a 1-point increase in HADS depression score was associated with a .83-point decrease in overall IADL performance, when all other predictors were constant. Similarly, each 1-medication increase was associated with a .51-point decrease in overall IADL performance, and a 1-night increase in hospital overnights was associated with a .16 unit decrease in overall IADL performance. Together, the predictors accounted for 36% of the variance in overall IADL performance (adjusted $R^2 = .36$).

Discussion

IADL are complex activities of daily living that are integral to managing T2DM; adults with T2DM, in general, experience difficulty performing these activities well (Kalyani et al., 2010). Our study identified DHV that may contribute to decreased performance of IADL by investigating the relationships among these DHV and IADL in a population of adults with T2DM. The majority of studies that examined IADL performance conceptualized it as uni-dimensional concept (Connolly et al., 2017; Kalyani et al., 2010; E. Wong et al., 2013).In the present study, the FAI is used to examine overall IADL performance as well as performance on subscales based on different categories of activities. This provided a more in-depth and comprehensive picture of the problem than simply investigating overall IADL performance.

The average leisure/work subscale score was the lowest of the three, a full 4 points lower than the domestic subscale (mean = 7.3 vs. 11.3, respectively). This is likely due to the social/demographic makeup of this group of individuals. Nearly 15% of the United States population receives public assistance because of a disability that prevents them from working (Altman & Lewin, 2000); because our data is from a safety-net clinic, the likelihood of individuals with disabilities accessing this clinic is substantially higher. Further, 69% of the individuals in this study earn < $20,000 per year, indicating a high level of unemployment/underemployment and/or reliance on public assistance.

Present-moment depression, as measured by the HADS, was the most powerful predictor of IADL performance among the DHV we studied, with significant relationships to the overall scale, as well as the leisure/work and outdoor subscales. These data suggest that presence of depression may have more of an effect on an individual’s ability to perform IADL outside the home than within the home. Present-moment anxiety was not a significant predictor for any regression analyses, but history of depression/anxiety was significantly associated with decreased performance of leisure/work IADL. These findings support previous research, which indicated a murky relationship between anxiety and IADL performance: in late life, anxiety may be a risk factor for functional disability, though not necessarily independent of depression (Lenze et al., 2001). History of depression has been repeatedly linked to indicators of functional status (e.g., physical activity and IADL performance) in the general population of older adults (Rozzini et al., 1993) and in middle adults with T2DM (Daniele et al., 2013). In this population, depression significantly predicted poor functional status outcomes.

Taken together, our results indicated that both depression and anxiety were related to decreased levels of IADL performance for adults with T2DM. The IADL of leisure/work was the most affected by both present-moment depression and history of depression/anxiety. This finding is supported by the fact that 35% of individuals who qualify for Social Security Disability Insurance in the United States do so on the basis of mental health conditions (Social Security Administration, 2013). The current findings also indicate that present-moment depression may be a better indicator of IADL performance deficits than history of depression. This indicates an imperative need for regular mental health screenings for individuals with T2DM. Depression has a serious impact on cognitive, social and physical functioning, however, it continues to be under-recognized in primary care settings (Barnacle, Strand, Werremeyer, Maack, & Pertry, 2016). Moreover, development of strategies to improve IADL performance for those with depression and anxiety may promote health and well-being for adults with T2DM (Mohanty, Gangil, & Kumar, 2012).

Number of medications also emerged as an important predictor for overall and domestic IADL performance, where an increase in daily medication use was related to a decrease in IADL performance. Interestingly, this relationship did not hold for leisure/work or outdoor IADL. Multiple medications is a simple measure for multimorbidity (Tinetti, Inouye, Gill, & Doucette, 1995), and multimorbidity is associated with poorer functional status (Peron, Gray, & Hanlon, 2011). Therefore, there may have been a floor effect for leisure/work and outdoor IADL for individuals who consume many medications daily. Rozzini and colleagues (1993) found that older adults who were dependent in IADL took significantly more medications than those who were independent in IADL. Similarly, Connolly and colleagues (2017) found that taking 5 or more medications regularly (i.e. polypharmacy) was significantly associated with IADL disability. Polypharmacy is a common and preventable problem for older adults. Adverse drug reactions, increased drug cost, and decreased quality of life are among the associated problems of inappropriate and over-prescription of medications (Rambhade, Chakarborty, Shrivastava, Patil, & Rambhade, 2012). Given that increased medication use is a modifiable risk factor, improved monitoring of daily medications by primary care physicians could prevent further functional decline from adverse effects (Peron et al., 2011).

Number of hospital overnights significantly but modestly predicted IADL performance for the domestic subscale and overall score, where increased hospital overnights was related to decreased frequency of performance. HCU has recently become a variable of interest for health services planning and development (Steinwachs & Hughes, 2008). Understanding more costly forms is especially important. Our study supports previous findings that suggest relationships between hospital overnights and decreased IADL performance (Malcolm et al., 2018) and IADL disability (Shinkai et al., 2003).

There are two potential explanations for this relationship. First, hospitalization can be an indicator of serious health problems, which likely impacts an individual’s ability to perform

IADL. For example, among individuals who are hospitalized for hip fracture, a large proportion do not return to pre-fracture levels of IADL performance (Magaziner, Simonsick, Kashner, Hebel, & Kenzora, 1990). A second potential explanation is the rapid onset of functional decline and lasting IADL impairment associated with hospital stays. Functional decline can begin within 48 hours of admission to hospital (Hirsch, Sommers, Olsen, Mullen, & Winograd, 1990), indicating that even short hospital stays can be debilitating. Additionally, Sager and colleagues (1996) suggest that IADL limitations acquired in-hospital persist for at least three months for 40% of hospitalized older adults. Given the variables studied and cross-sectional nature of this research, we cannot definitively state which scenario is responsible for the IADL limitations seen here.

Number of physician's visits were inversely associated with outdoor IADL, indicating that those who use the physician's office more are engaging less in activities related to community and outside mobility. Millan-Calenti and colleagues (2010) found a similar relationship between functional dependence and increased visits to the physician's office. In the Millan-Calenti study and others (Black & Rush, 2002; Markides et al., 1996), functional dependence was also related to highly prevalent illnesses, like heart failure, stroke, and cancer, potentially explaining the relationship between IADL impairment and visits to the physician. Notably, in our study, this relationship was only true for outdoor IADL. We propose that individuals experiencing chronic illness my impose self-limitations in activities that may be viewed as difficult and unnecessary (e.g., walking outside and gardening) (Mackichan, Adamson, & Gooberman-Hill, 2013).

In contrast to previous research and our hypothesized results, age did not significantly predict IADL performance in the present study. The relationship between age and IADL performance has been the most researched of the DHV mentioned here. In populations of older adults, advanced age was found to be the most strongly associated risk factor for IADL impairment (Connolly et al., 2017; Millan-Calenti et al., 2010; Stuck et al., 1999) as well as a significant predictor of IADL disability (Chiu et al., 2004). A potential explanation for our non-significant finding is that the present sample was not restricted to only older adults (i.e., our sample age range = 34-84 years). Previous research has also not specifically studied safety-net care users, who tend to be younger than non-safety-net users. These safety-net care users may also have higher rates of chronic disease and polypharmacy, which have been associated with IADL impairment (Nguyen, Makam, & Halm, 2016). A second potential explanation for this non-significant effect of age is that younger and middle-aged adults (aged 34-64 years) are experiencing more disability than previous generations. An investigative study of United States disability trends identified a rising trend of reported disability among younger Americans, especially those aged 30-49 years (Lakdawalla, Bhattacharya, & Goldman, 2004). This occurs even as reported disability rates slow for the elderly, supporting the possibility that younger-aged adults in the present sample experience similar rates of disability as the older adults.

A1C, gender, minority status, BMI, recent fall, and number of comorbidities were not predictive of any IADL subscale or total scores. These findings were surprising as well, given previous findings regarding the relationship between these variables and IADL performance. Previous research found glycemic control, as measured by A1C, to be related to IADL disability (Bossoni et al., 2008). Specifically, the highest incidence of IADL disability was found in a group of older adults with poorly controlled blood glucose as compared to those who have good control. Though hyperglycemia, *per se*, is unlikely the cause of limitations in IADL, the increased likelihood of disabling complications, (i.e., stroke and lower limb amputation) that occur with elevated blood glucose (American Diabetes Association, 2018), or the reality that someone who is not participating in DSM may have other, seemingly more pressing concerns (i.e., long work hours or caregiving responsibilities) (Fritz, 2014) may explain this relationship. However, our research showed no relationship between glycemic control and IADL performance. This is likely related to the way we collected A1C. We were not able to collect A1C at the time of assessment, we used the most recent laboratory results in the EMR. Therefore, the A1C we used in our analysis may not have reflected participants' current glycemic control.

Gender is a less-studied, but well-supported indicator of IADL performance. Two studies have shown that IADL performance in the elderly follows traditional lines for gender-based occupations; for example, men tended to be more independent in money, medication, and transportation management, whereas women were more independent in laundry, housekeeping, and cooking occupations (Lázaro et al., 2007; Millan-Calenti et al., 2010). The present research did not support these patterns. We found no significant predictive effect for gender on any subscale. In the present study, we did not collect information regarding whether our participants were in stable partnerships. This may have shed light on why we did not see an effect for gender. If many participants were not partnered, they may perform all necessary IADL (not only traditionally gender-consistent activities). Another potential explanation is the relatively young age of the participant sample (range = 34-84 years). The previous research demonstrated a gender-based occupational divide for elderly adults (Lázaro et al., 2007; Millan-Calenti et al., 2010). Given that more than half of our sample are middle-and younger-aged adults (n = 64), these findings may mimic larger trends of convergence in men's and women's roles in the family and workplace (Risman, 2009).

Minority status did not significantly predict any category of IADL performance in the present sample. Data from the National Health Interview Survey indicated that adults of minority status experienced the greatest difficulties in IADL performance (Jones & Sinclair, 2008). Given these findings, the author anticipated that IADL performance may be lower for participants of minority status in the present study. Interestingly, these two variables were not related in this sample. The overall levels of IADL performance in this sample were lower than established norms (Turnbull et al., 2000); therefore, the possibility exists that IADL performance is consistently low across this group, regardless of racial and ethnic status.

BMI did not significantly predict any IADL performance category in this study. Larrieu and colleagues (2004) found higher BMI to be associated with IADL disability in elderly women. Woo and colleagues (2007) found that older adults who are obese or morbidly obese were impaired in significantly more IADL than those in normal or underweight categories. Elevated BMI may be a sign of poor adherence to self-care behaviors, like healthy meal preparation and physical activity, in individuals with T2DM (American Diabetes Association, 2018); therefore, we anticipated that individuals with high BMI and T2DM may be at increased risk for limitations in IADL performance over normal weight peers. However, more recent multivariate research supports our findings. Connolly and colleagues (2017) demonstrated an association between BMI and basic activities of daily living (e.g., eating, bathing, dressing), but no relationship for BMI and IADL performance. Additionally, in the present sample, there were very few individuals (n = 10) with BMI indicating normal or underweight; therefore, the statistical power to detect an effect for BMI may have been reduced.

We also did not find that recent falls were significantly associated with IADL performance. Based on research by Chase and colleagues (2012), who found that after an injurious fall many older adults report self-imposed activity restriction, including limitations in IADL performance, we anticipated that recent fall would predict frequency of IADL performance. Although nearly 40% of the participants in the present study had a recent fall (n = 36), just over 50% of those who fell experienced an injury (n = 20). Grouping these two participant clusters together potentially limited our ability to detect a relationship. Future research could examine the relationship between injurious fall and IADL performance to determine if the previously observed effect for older adults holds true for this sample of adults with T2DM.

We also found that comorbid conditions did not predict IADL performance for any regression model. This is similar to Rozzini and colleagues' (1993) findings; this study found that number of comorbid conditions was not significantly associated with IADL performance in elderly individuals. The null findings in both our study and Rozzini and colleagues' study may be due to the nature of the comorbidity variable used in the present study. Simply reporting the number of comorbidities may not have fully accounted for the influence of a co-occurring disease on IADL performance. For example, we would not expect to see the same magnitude of deficits from gum disease as from peripheral neuropathy. In previous research, comorbidity severity has been linked to limitations in physical activity in middle-aged adults with T2DM (Daniele et al., 2013). Perhaps a better measure to explore the relationship between comorbidities and IADL performance is the Cumulative Illness Rating Scale, which measures the number *and* severity of comorbidities (Linn, Linn, & Gurel, 1968).

Regarding clinical meaningfulness of the regression findings, some findings were more powerful than others. For example, when examining the final model for overall IADL performance, present-moment depression, number of medications, and number of hospital overnights were all found to be statistically significant. However, when examining the clinical meaningfulness of the results, all are not equal. To begin, with each 1-unit increase in present-moment depression score, the model showed a nearly 1-point decrease in overall IADL performance. Using the FAI scale as an example, each 1 point increase in present-moment depression could translate to a decrease in IADL performance from preparing a meal 1-3 times per month to never preparing a meal. Additionally, each 1-medication increase was related to a half-point decrease in IADL performance; accordingly, each 2-medication increase translated to a full 1-point decrease in IADL performance. Given that the average number of medications taken by participants in this study is 8.6 (range = 0 – 30), this finding is not only statistically significant, but clinically meaningful as well.

Conversely, the finding related to the relationship between number of hospital overnights and overall IADL performance was less straightforward. For each 1-night increase in hospital overnights, there was a .16-point decrease in overall IADL performance. Therefore, in this model, 6 additional nights in the hospital would translate to a 1-unit decrease in IADL performance. This finding, though statistically significant, is difficult to interpret for clinical significance.

Limitations

We report several limitations that should be considered when interpreting these findings. First, we were only able to collect A1C for 79 participants, resulting in potential overfitting of the regression models. According to conservative estimates, one should have at a minimum 5 participants per variable (Green, 1991). In this study, we had nearly six participants per variable in the full model; therefore, this research met the minimum threshold despite missing A1C values for roughly 15% of our sample. Another issue with A1C was time of collection. A1C was not obtained at the time of the survey data. We used the most recent laboratory results in the EMR, which could mean the A1C on record was not indicative of the person's glycemic control at the time of survey data collection. To ensure researchers are getting the most accurate and up-to-date reading, an A1C point-of-care instrument should be used at the time of data collection. Another limitation may exist related to the use of the FAI to assess IADL performance. The FAI asks *how often* one performs certain activities, not if a person *can* perform the activity. There is the possibility that participants have not performed certain activities due to inability or simply preference. Related to the preference of certain activities, the FAI asks about activities that are generally regarded as necessary (e.g., meal preparation, medication management) as well as activities that may be regarded as hobbies (e.g., gardening, reading books). The necessary activities are given the same weight as hobbies with no way to account for preference. The Lawton IADL Scale (Lawton & Brody, 1969), another widely used assessment of IADL performance, assesses *ability* to complete various common IADL using a scale of 0-1, where 0 indicates one cannot perform the activity. Given this dichotomous scale, some researchers argue the Lawton IADL Scale is not sensitive to small, incremental changes in function (Graf, 2008). An additional benefit of the FAI lies in the subscales, which allow us to examine the differences between types of IADL (e.g., domestic, leisure/work), which provides a more in-depth understanding of the phenomenon of IADL performance. Future researchers should develop an assessment of IADL that accounts for the *ability* to complete certain IADL and asks more generally about preferential activities (i.e., are you able to participate in chosen hobbies? vs. are you able to garden?) using an incremental scale (e.g., 0= cannot perform, 1= can perform with help, 2= can perform independently). However, this problem could also be solved by using the information from the Lawton IADL Scale and the FAI in conjunction to examine IADL from different angles.

Conclusion

As expected, we found that depression, anxiety, taking five or more medications, and increased HCU predicted decreased performance of IADL for adults with T2DM. Perhaps the most impactful findings from this study are the associations among modifiable risk factors and IADL limitations: present-moment depression and number of medications were both associated with decreased IADL. Actively monitoring and addressing mental health concerns and polypharmacy are important first steps to prevent or delay the onset of IADL disability and to enable individuals to safely and independently care for themselves at home and in the community. We recommend the use of present-moment depression over history of depression to detect potential IADL impairment. This finding underscores the importance of regular screening for depression in primary care. Overall, this research provides an initial understanding of the multi-faceted and dynamic factors associated with IADL performance for adults with T2DM, and supports previous commentary for a comprehensive, collaborative approach to treating patients with T2DM.

Figures and Tables

Table 1.1 *Demographic, health variables and IADL performance characteristics of study participants*

	Range	Mean (SD)
Age in years (n = 93)	34 − 84	58.6 (11.4)
BMI (n = 92)	17.4 – 55.5	32.6 (8.2)
A1C (n = 79)	4.5 – 15.5	7.2 (1.8)
Number of medications (n = 93)	0 – 30	8.6 (5)
Number of comorbid conditions (n = 93)	0 − 7	2.4 (1.5)
# physician visits- previous 6 months (n = 93)	0 − 20	5.5 (4.3)
# emergency room visits- previous 6 months (n = 93)	0 − 15	1.4 (2.6)
# hospital overnights- previous 6 months (n = 93)	0 − 90	3.5 (13.4)
FAI total score, out of 45 (n = 93)	9 − 45	28 (8.1)
FAI Domestic subscale score, out of 15 (n = 93)	3 − 15	11.3 (3.5)
FAI Leisure/work subscale score, out of 15 (n = 93)	3 − 15	7.3 (3.2)
FAI Outdoor subscale score, out of 15 (n = 93)	3 − 15	9.3 (3.1)
	Frequency (percent)	
Gender, woman (n = 93)	48 (51.6)	
Minority status (n = 93)	30 (32.2)	
Recent fall (n = 92)	36 (38.7)	
History of depression/anxiety (n = 93)	48 (51.6)	
Caseness level of depression (HADS) (n = 93)	23 (24.7)	
Caseness level of anxiety (HADS) (n = 93)	35 (37.6)	

BMI = body mass index, FAI = Frenchay Activities Index, HADS = Hospital Anxiety and Depression Scale

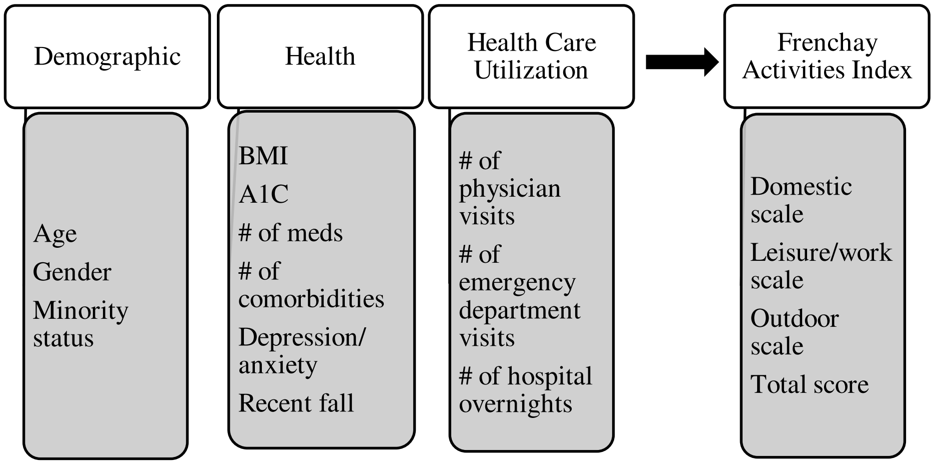

Figure 1.1. The predictor and dependent variables used in this study.

Table 1.2 *Results of means comparisons across all subscales and overall FAI*

	FAI-D		FAI-W		FAI-O		FAI-Total	
Variable	Mean (sd)	Effect size[b]	Mean (sd)	Effect size	Mean (sd)	Effect size	Mean (sd)	Effect size
Age < 65 years	11.23 (3.51)	-.04	6.88* (3.22)	-.22[b]	8.86* (3.10)	-.22[b]	26.97 (8.44)	.39[a]
Age 65 + years	11.48 (3.61)		8.21 (3.20)		10.28 (3.00)		29.97 (7.05)	
Gender, female	11.96 (3.02)	-.18	7.29 (2.99)	0[a]	9.44 (3.09)	.09[a]	28.69 (7.73)	.20[a]
Gender, male	10.62 (3.77)		7.29 (3.55)		9.16 (3.18)		27.07 (8.51)	
Minority status, yes	11.11 (3.19)	-.11	6.69 (3.08)	.31[a]	8.69 (3.35)	-.34[a]	26.49 (8.15)	.31[a]
Minority status, no	11.53 (3.70)		7.68 (3.35)		9.75 (2.90)		28.96 (7.96)	
Body mass index, < 25	9.60 (4.62)	-.12	6.20 (2.25)	-.10[b]	9.49 (3.10)	-.20[b]	23.30* (5.76)	-.22[b]
Body mass index, 25+	11.57 (3.33)		7.43 (3.36)		7.5 (2.87)		28.49 (8.251)	
A1C, < 7.0	11.22 (3.67)	-.07	7.53 (3.43)	.07[a]	9.64 (3.12)	.06[a]	28.40 (8.45)	.02[a]
A1C, 7.0 +	11.85 (3.06)		7.29 (3.01)		9.44 (3.21)		28.59 (7.67)	
Number of medications, < 5	12.24 (2.08)	-.06	7.47 (3.41)	.05[b]	10.65 (2.26)	-.20[b]	30.35 (6.20)	-.13[b]
Number of medications, 5+	11.11 (3.75)		7.25 (3.24)		9.00 (3.22)		27.49 (8.39)	
History of depression/anxiety	10.83 (3.56)	-.18	6.17** (3.02)	-.76[a]	8.71* (2.64)	-.20[b]	25.71** (7.27)	.58[a]
No history of depression/anxiety	11.82 (3.45)		8.49 (3.09)		9.93 (3.48)		30.24 (8.39)	
Caseness level of depression (HADS)[1]	9.83* (3.53)	-.25	5.43** (2.66)	-.34[b]	7.91* (2.60)	-.26[b]	23.17** (7.06)	-.35[b]
Below caseness level of depression (HADS)[1]	11.80 (3.41)		7.90 (3.21)		9.76 (3.16)		29.46 (7.87)	
Caseness level of anxiety (HADS)[1]	10.49* (3.53)	-.22	6.11** (3.09)	-.30[b]	8.69 (2.96)	-.17[b]	25.29* (7.69)	-.26[b]
Below caseness level of anxiety (HADS)[1]	11.81 (3.46)		8.00 (3.17)		9.67 (3.18)		29.48 (8.01)	
Recent fall, yes	10.44* (3.47)	-.23	6.89 (2.92)	-.13[b]	8.61 (3.04)	-.18[b]	25.94* (7.73)	-.21[b]
Recent fall, no	11.84 (3.50)		7.61 (3.45)		9.70 (3.13)		29.14 (8.25)	
0 visits to the ED- previous 6 months	11.71 (3.152)	-.10	7.90 (3.53)	-.18[b]	10.06* (2.93)	-.24[b]	29.67 (7.67)	-.19[b]

1 + visits to the ED- previous 6 months	10.80 (3.93)		6.51 (2.71)		8.34 (3.13)		25.66 (8.82)	
0 hospital overnights- previous 6 months	11.87* (3.05)	-.21	7.72 (3.27)	-.20[b]	9.87** (2.82)	-.28[b]	29.46** (7.30)	-.27[b]
1+ hospital overnights- previous 6 months	9.80 (4.30)		6.12 (2.95)		7.76 (3.43)		23.68 (8.85)	

[a] t-values from independent samples t-tests, Cohen's d for effect size.

[b] when the assumption for equal variances was not met, the Mann-Whitney U test (U) was used, *r* for effect size.

Significance at α < .05* (uncorrected), significance α < .0125** (corrected)

Table 1.3 *Results of Multiple Linear Regression Model for FAI Domestic Score (FAI-D)*

					95 % CI for B			
Model	Significant Predictors	B	*SE* B	*β*	Lower	Upper	Model *F*	Adjusted R^2
FAI-D (Full Model)							*F* (14,61) = 4.87***	.42
	Constant	19.72	3.28		13.17	26.27		
	Age	-.07	.03	-.23	-.14	-.00		
	Gender	.70	.65	.10	-.60	2.00		
	Minority status	-1.0	.69	-.14	-2.38	.39		
	BMI	-.08	.05	-.19	-.17	.02		
	A1C	.32	.21	.16	-.10	.75		
	Number of medications	-.13	.08	-.21	-.29	.02		
	Number of comorbidities	.12	.31	.05	-.50	.73		
	History of depression/anxiety	.28	1.04	.04	-1.79	2.35		
	Depression score on HADS	-.40***	.12	-.41	-.63	-.17		
	Anxiety score on HADS	.15	.12	.17	-.09	.39		
	Recent fall	-.99	.76	-.14	-2.50	.52		
	Number of physician visits in previous 6 months	-.24*	.10	-.29	-.44	-.04		
	Number of ED visits in previous 6 months	-.02	.13	-.02	-.28	.24		
	Number of hospital overnights in previous 6 months	-.05	.04	-.16	-.12	.02		
FAI-D (Final Model)							*F* (3,88) = 15.66***	.33
	Constant	14.93	.68		13.58	16.29		
	Depression score on HADS	-.23*	.09	-.24	-.41	-.06		
	Number of medications	-.22***	.06	-.32	-.34	-.10		
	Total nights in the hospital in previous 6 months	-.01***	.02	-.37	-.14	-.05		

**p* < .05, ***p* < .01, ****p* < .001;
B = unstandardized regression coefficient; *SE B* = standard error of the unstandardized regression coefficient; *β* = standardized regression coefficient.
BMI = body mass index, HADS = Hospital Anxiety and Depression Scale, ED = emergency department

Table 1.4 *Results of Multiple Linear Regression Model for FAI Leisure/work Score (FAI-W)*

Model	Significant Predictors	B	*SE* B	*β*	95 % CI for B Lower	Upper	Model *F*	Adjusted R^2
FAI-W (Full Model)							*F* (13,62) = 2.11*	.16
	Constant	11.729	3.82		4.09	19.37		
	Age	-.02	.04	-.07	-.10	.06		
	Gender	-.22	.76	-.03	-1.74	1.30		
	Minority status	-.77	.80	-.11	-2.38	.84		
	BMI	.01	.05	.03	-.10	.12		
	A1C	.05	.24	.03	-.42	.52		
	Number of medications	-.14	.09	-.23	-.31	.03		
	Number of comorbidities	.14	.70	.02	-1.18	1.48		
	History of depression/anxiety	-1.97	1.06	-.30	-4.09	.16		
	Depression score on HADS	-.20	.13	-.22	-.47	.06		
	Anxiety score on HADS	-.05	.14	-.06	-.32	.22		
	Recent fall	.79	.88	.12	-.10	2.55		
	Number of physician visits in previous 6 months	-.03	.12	-.04	-.26	.20		
	Number of ED visits in previous 6 months	.04	.15	.03	-.27	.34		
	Number of hospital overnights in previous 6 months	-.02	.04	-.05	-.10	.06		
FAI-W (Final Model)							*F* (2,90) = 10.95***	.18
	Constant	9.56	.59		8.39	10.73		
	History of depression/anxiety	-1.52*	.68	-.24	-2.87	-.18		
	Depression score on HADS	-.27**	.10	-.29	-.46	-.07		

**p* < .05, ***p* < .01, ****p* < .001;
B = unstandardized regression coefficient; *SE B* = standard error of the unstandardized regression coefficient; *β* = standardized regression coefficient.
BMI = body mass index, HADS = Hospital Anxiety and Depression Scale, ED = emergency department

Table 1.5 *Results of Multiple Linear Regression Model for FAI Outdoor Score (FAI-O)*

					95 % CI for B			
Model	Significant Predictors	B	*SE* B	*β*	Lower	Upper	Model *F*	Adjusted R^2
FAI-O (Full Model)							*F* (14,61) = 2.73**	.24
	Constant	12.06	3.474		5.12	19.01		
	Age	-.01	.04	-.04	-.08	.06		
	Gender	.14	.69	.02	-1.25	1.52		
	Minority status	-1.13	.73	-.18	-2.60	.34		
	BMI	.02	.05	.05	-.08	.12		
	A1C	.18	.23	.10	-.27	.63		
	Number of medications	-.07	.08	-.12	-.24	.09		
	Number of comorbidities	-.19	.33	-.08	-.84	.47		
	History of depression/anxiety	-.23	1.10	-.04	-2.43	1.97		
	Depression score on HADS	-.30*	.12	-.34	-.54	-.06		
	Anxiety score on HADS	.08	.13	.10	-.17	.33		
	Recent fall	-.36	.80	-.06	-1.96	1.25		
	Number of physician visits in previous 6 months	-.20	.11	-.26	-.41	.01		
	Number of ED visits in previous 6 months	.00	.14	.00	-.28	.28		
	Number of hospital overnights in previous 6 months	-.01	.04	-.04	-.09	.06		
FAI-O (Final Model)							*F* (2,90) = 14.67***	.23
	Constant	12.25	.61		11.03	13.47		
	Depression score on HADS	-.34***	.08	-.37	-.50	-.17		
	Number of physician visits in previous 6 months	-.20**	.07	-.28	-.33	-.07		

**p* < .05, ***p* < .01, ****p* < .001;
B = unstandardized regression coefficient; *SE B* = standard error of the unstandardized regression coefficient; *β* = standardized regression coefficient.
BMI = body mass index, HADS = Hospital Anxiety and Depression Scale, ED = emergency department

Table 1.6 *Results of Multiple Linear Regression Model for FAI Total Score (FAI-Total)*

					95 % CI for B			
Model	Significant Predictors	B	*SE* B	β	Lower	Upper	Model *F*	Adjusted R^2
FAI-Total (Full Model)							*F* (14,61) = 4.22***	.38
	Constant	43.53	8.24		27.05	60.00		
	Age	-.10	.09	-.14	-.27	.07		
	Gender	.59	1.64	.04	-2.69	3.87		
	Minority status	-2.95	1.74	-.18	-6.43	.52		
	BMI	-.06	.12	-.06	-.30	.19		
	A1C	.62	.53	.13	-.44	1.69		
	Number of medications	-.32	.20	-.21	-.72	.07		
	Number of comorbidities	-.37	.78	-.06	-1.92	1.19		
	History of depression/anxiety	-1.44	2.61	-.09	-6.65	3.78		
	Depression score on HADS	-.90**	.30	-.39	-1.48	-.32		
	Anxiety score on HADS	.16	.30	.08	-.43	.76		
	Recent fall	-.52	1.90	-.03	-4.32	3.28		
	Number of physician visits in previous 6 months	-.46	.25	-.23	-.97	.04		
	Number of visits to the ED in previous 6 months	.01	.33	.00	-.65	.67		
	Number of hospital overnights in previous 6 months	-.07	.09	-.10	-.25	.10		
FAI-Total (Final Model)							*F* (3,88) = 17.88***	.36
	Constant	37.66	1.57		34.55	40.77		
	Depression score on HADS	-.83***	.20	-.36	-1.24	-.43		
	Number of medications	-.51***	.14	-.32	-.79	-.24		
	Total nights in the hospital in previous 6 months	-.16**	.05	-.27	-.26	-.06		

*p < .05, **p < .01, ***p < .001;
B = unstandardized regression coefficient; *SE B* = standard error of the unstandardized regression coefficient; β = standardized regression coefficient.
BMI = body mass index, HADS = Hospital Anxiety and Depression Scale, ED = emergency department

CHAPTER TWO: UNDERSTANDING THE EXPERIENCE OF LIVING WITH TYPE 2 DIABETES INFORMED BY THE MODEL OF HUMAN OCCUPATION

An estimated 30.3 million Americans have diabetes, a disease marked by inability to properly use glucose (Centers for Disease Control and Prevention, 2017). Uncontrolled levels of glucose in the blood (measured by HbA1C) in type 2 diabetes mellitus (T2DM) are responsible for many health complications, including peripheral neuropathy, visual impairments, cardiovascular disease, and kidney damage (American Diabetes Association, 2017). To meet target HbA1C values, individuals with T2DM must engage in consistent and lifelong diabetes self-management (DSM) (American Diabetes Association, 2015). DSM comprises the day-to-day self-care actions that individuals with diabetes must do in order to manage their condition. These self-care behaviors include healthy eating, being active, monitoring health condition, taking medications, problem solving, healthy coping, and reducing health risks (Peeples et al., 2007). DSM requires individuals to weigh options and make multiple decisions daily, and to make changes to potentially long-held habits and routines (Fritz, 2014; Powers et al., 2017). These lifestyle changes are universally regarded as challenging; individuals need not only foundational knowledge of DSM, but also physical and cognitive abilities to carry out the recommendations (Ahlin & Billhult, 2012; Booth et al., 2013; Nagelkerk et al., 2006). Consequently, a large proportion of individuals with T2DM experience self-management deficits, disease progression, and socioemotional impacts (e.g., reduced QOL, community engagement, etc.). Approximately 33% of people with T2DM have not been able to consistently perform the required tasks of DSM (DiMatteo, 2004b). In other words, 15 million people with diabetes in the United States are not controlling their blood glucose well (Centers for Disease

Control and Prevention, 2017). Current medical approaches to assist individuals with DSM are well-rooted in scientific evidence, but may not go far enough to personalize treatment (Thompson, 2014).

Recently, occupational therapists have contributed to the conversation about the importance of individuals' life context, habits, and roles in the management of T2DM (Fritz, 2014; Pyatak, 2011; Thompson, 2014; Youngson et al., 2015). Many researchers have examined the complexity of T2DM, and demonstrated that success with DSM is dependent on multiple factors. Many of these factors are outside of personal control. For example, physical and social environments may impact available physical activities, especially during winter months (Thompson, 2014). Needs of family and friends may supersede self-care (Fritz, 2014). Secondary complications of T2DM (e.g., peripheral neuropathy) may interfere with the process of checking blood glucose (Pyatak, 2011). Other researchers have determined a relationship between habits and routines and DSM. Recently, Youngson (2019) found that participants were able to override the habit of stress-eating by sticking to meal routines. According to occupational therapists' research, new routines must be established, and roles (i.e. student, mother) must be reconfigured following an initial diagnosis in order to accommodate DSM-related activities (Fritz, 2014). These examples illustrate the multi-faceted nature of DSM, and the positive influence of established habits and routines. Given the complexity of managing T2DM and the large proportion of individuals who do not consistently manage their condition, a deeper understanding of complex interactions between the person and environment, and the subsequent impact on the activities of DSM is essential. In this study, we explore and conceptualize DSM as an occupation using the Model of Human Occupation (MOHO).

Application of the Model of Human Occupation to DSM

The Model of Human Occupation (MOHO; see Figure 2.1) is a conceptual practice model that explains how occupation, or the goal-directed action of daily life, is “motivated, patterned, and performed” (Kielhofner, 2002, p. 13). MOHO provides a conceptual framework for understanding the complex interactions of day-to-day management of diabetes through exploration of the interwoven aspects of the person and the environment. Kielhofner (2002) conceptualized the person as comprised of volition, habituation, and performance capacities. *Volition*, or universal need to act, encompasses the values, interests, and feeling of self-efficacy that a person attaches to an occupation. *Habituation*, consisting of a person’s habits and roles, are the recurring patterns of occupational performance that guide our daily behavior. *Performance capacities* are the underlying mental and physical abilities that enable participation in occupation (Kielhofner, 2002). Together, these three elements interact with the social and physical environments to produce occupational performance (in this case, performance of DSM behaviors) (Kielhofner, 2002). MOHO is also concerned with the construction of occupational identity and competence, termed *occupational adaptation*. Occupational adaptation occurs when an individual engages in an activity in a given context over time, and is realized through change and development. Most people will experience problems in their lives that require re-examining and re-building of occupational competence and identity (Kielhofner, 2002). Individuals with T2DM may experience setbacks resulting from secondary complications or progressive worsening of the disease over time, necessitating a re-evaluation of DSM behaviors. Application of MOHO to the occupation of DSM is a practical and useful way to study the synergistic relationships among the components of MOHO (Youngson, 2019), as well as the ways individuals with chronic health conditions adapt to diagnosis and management of chronic illness (Taylor et al., 2003).

As a practice model, MOHO is designed to facilitate identification of intervention goals and strategies for occupational therapy (Taylor, 2017). Based on MOHO concepts, participants in a mental health practice identified volition gained through performance of valued occupations as the beginning of the recovery process (Ásmundsdóttir, 2009). Another study, using the MOHO framework with a 16-year-old male with type 1 diabetes, found through evaluation that each subsystem of the person (i.e., volition, habituation, and performance capacity) was dysfunctional. Using this information, the client's therapist bolstered not only the skills and routines for diabetes care, but also his self-confidence by facilitating experiences of success (Curtin, 1991). A previous study by Youngson (2019) applied the theoretical perspective of MOHO to the occupation of DSM; however, the focus of that study was to establish a role for occupational therapy in DSM through the exploration of occupational "forms": testing blood sugar, appointments, diet, exercise, information and education, managing other illnesses, and medication. Through the application of MOHO to the occupation of DSM, Youngson (2019) established the complexity of DSM and the utility of MOHO for conceptualizing T2DM management. We hope to build on the previous findings and provide a more in-depth examination of the interactions between the components of MOHO, as well as examine the concept of occupational adaptation and T2DM. The application of MOHO to the occupation of DSM is the primary aim of this study; therefore, this research is guided by the following question: What is the experience of diabetes self-management through the lens of key components from the Model of Human Occupation?

Methods

Research Design

We have performed secondary analysis of a previous study aimed at gathering information about the experience of managing T2DM and intervention needs at a local primary care clinic. To answer this research question, we engaged in a qualitative description (QD) approach. QD is especially relevant for nursing and health sciences research (Sandelowski, 2000, 2010; Sullivan-Bolyai, Bova, & Harper, 2005) because the approach uses low-inference interpretation and presents results using uncomplicated language. This facilitates translation of information directly into existing health care systems (Sullivan-Bolyai et al., 2005). QD is commonly carried out using the following methods, which are discussed in depth in later sections:

1) **Sampling:** Maximum variation
2) **Data Collection:** QD uses minimally to moderately structured interviews with open-ended questions combined with other pertinent materials, such as health records and field notes (Sandelowski, 2000; Sullivan-Bolyai et al., 2005).
3) **Data Analysis:** Data analysis in the QD approach uses the 6 strategies for thematic analysis (TA) outlined by Braun, Clark, and Terry (Braun, Clarke, & Terry, 2014). TA is common across many different qualitative approaches.
    a. Familiarize yourself with the data
    b. Generate initial codes
    c. Search for themes
    d. Review potential themes
    e. Define and name themes

f. Produce the report

Participants

For the original qualitative study, we recruited a subgroup of participants engaged in a larger cross-sectional study of community-dwelling adults with T2DM who attended a safety-net primary care clinic (Malcolm et al., 2018). The clinic primarily serves underserved populations with few health resources and a higher population of minority patients than other clinics in the area. For the larger study, we included adults who had a diagnoses of T2DM, were 18+ years old, spoke English, and could read at a 6th grade level or higher. For this study, we contacted participants who previously indicated willingness to take part in a focus group. We selected participants using a purposeful sampling technique called maximum variation sampling (Sandelowski, 2000). Maximum variation sampling allowed us to obtain a variety of perspectives and instances by including a broad range of participants who provided rich data (Sullivan-Bolyai et al., 2005). We attempted to include participants with varying degrees of glycemic control, work status, gender, race/ethnicity, and age.

Procedure

We conducted three focus groups at the safety-net primary care clinic. Authors KA, LS, and TK conducted all focus groups during the Spring of 2017. Focus groups lasted approximately one hour and fifteen minutes, and were scheduled during various times and days to encourage diversity of participants. The research team (KA, LS, and TK) developed a semi-structured interview guide to ensure key questions were covered during the focus group interviews. The experienced investigator (KA) and two doctoral students (TK and LS) each served as primary moderator during one focus group. After orientation to the study and consent form review, we provided participants with a list of key questions where they could record initial thoughts. Immediately after focus groups sessions, the research team engaged in debriefing by discussing and recording first impression summaries (Merriam & Tisdell, 2015). Initial thought records and first impression summaries were kept and analyzed as *field notes*.

Consistent with best practice, the interview guide began with general, easy-to-answer questions, progressed to more specific and thought-provoking questions, and ended with a final summary question (Krueger & Casey, 2009). Consistent with the QD approach, the interview guide (Table 2.1) was flexible and included probes to encourage deeper engagement if needed (Merriam & Tisdell, 2015). The guide also used the expert knowledge of the researchers to target areas that have not been previously explored and are amenable to intervention (Sullivan-Bolyai et al., 2005).

Data analysis

We recorded all focus groups and used a paid transcription service for verbatim transcripts. Authors LS and TK analyzed transcripts and field notes (hereafter referred to as *documents*) using thematic analysis, and sorted into codes and themes using NVIVO qualitative analysis software (QSR International, Melbourne, Australia). We initially used an inductive approach, identifying codes and themes based on the content of the data with minimal interpretation. However, we used components of MOHO (Figure 2.1) as sensitizing concepts for the data analysis. Sensitizing concepts are constructs that provide a starting point for data organization and analysis. They are basic and flexible to allow for refinement as the analysis unfolds; they “suggest a direction along which to look” (Blumer, 1954, p. 91). Below are the specific steps we took during data analysis, according to the 6 strategies for thematic analysis as outlined by Braun and colleagues (2014).

1) *Familiarize yourself with the data*. Authors LS and TK read each document and considered them as a whole to gain a preliminary sense of the data. The analysis team engaged in open coding, a process which began with reading the documents and making comments about relevant bits of data in the margins, then began to build consensus around emerging topics (Merriam & Tisdell, 2015).
2) *Generate initial codes*. Next, LS and TK began systematic data analysis. They read through the documents and assigned codes to chunks of data that were relevant to the research question; then developed initial codes to describe the contents of the data, while staying close to the content and participant meaning. LS and TK met weekly during this process to discuss emerging codes. They aimed for enough codes to capture the diversity of the content, but also checked that codes each appeared across multiple data excerpts (Braun et al., 2014).
3) *Search for themes*. At this point in the analysis, they shifted from identifying codes to shaping codes into themes. They analyzed the data in two ways: first, with an inductive process that resulted in initial themes; and second, using the components of MOHO as pre-existing themes. Both of groups of initial themes were the product of an iterative process of analysis and discussion that took place between LS and TK (Merriam & Tisdell, 2015). We created a table to display each theme alongside the relevant data extracts.
4) *Review potential themes.* Next, LS and TK engaged in a quality check consisting of two stages: first, they checked the themes against the collated data; and second, they checked the themes against the entire data set. They re-read each of the documents to determine if themes adequately portray the data set (Braun et al., 2014). During this

phase, they reshaped, added, and discarded themes (Merriam & Tisdell, 2015). These changes were incorporated into the thematic table. At this point, TK met with experienced analyst KA to present the current themes and discussed fit of themes with data. They chose to rework the analysis based on the language of MOHO, being careful to highlight interactions between the components.

5) *Define and name themes.* During this phase, TK named and defined the themes concisely and specifically using the language of MOHO so that each was summed up in a few short sentences (Merriam & Tisdell, 2015). After completing this, she compared themes again to the collated data and the entire data set, confirming congruence between the data and themes as well as among the themes. This process ensured that each theme had a clear focus, scope, and purpose and contributed useful insight to the overall research question (Braun et al., 2014).
6) *Produce the report.* In this phase, TK selected representative excerpts and analyzed, then related them back to research questions and background literature. The final product of this research is a dissertation chapter for submission to an academic journal.

Study trustworthiness

We chose three main strategies to ensure rigor of the study: triangulation, peer review, and reflexivity (Merriam & Tisdell, 2015). First, we used multiple sources of data to triangulate the interview findings: participant's written initial thought records and researchers' first impression summaries. These field notes supplemented the transcribed interviews and provided information about the context and general atmosphere of the focus groups (Merriam & Tisdell, 2015). Second, the research team included an experienced qualitative researcher (KA), who served as peer reviewer, and helped TK shape well-defined themes. A novice qualitative researcher (LS) helped analyze data and build consensus around themes. Lastly, TK engaged in the practice of reflexivity prior to beginning data analysis by critically examining and recording assumptions, experiences, and values related to the experience of managing T2DM.

Results

A total of 10 individuals with T2DM participated in the focus group discussions. Table 2.2 contains demographic characteristics of participants. All names have been changed to pseudonyms. The average age of participants in our study was 58.1 years (range 50 – 78 years old) and 50% were female. Six participants (60%) demonstrated good control of T2DM as measured by an A1C < 7.0%, however, 3 participants (40%) of the sample had A1C ≥ 7.0%, indicating poor control (mean = 6.6, range 5.6 – 8.5) (American Diabetes Association, 2018).

Application of MOHO to the Occupation of T2DM Management

Habituation. *Habituation* in MOHO is the readiness for established patterns of behavior, which are guided by our internalized roles and habits and fitted to the features of the surrounding environment (Kielhofner, 2002). *Internalized roles* are the integration of an internally or externally defined status and the related attitudes and actions; whereas *habits* are the consistent ways we perform in a given environment, and *routines* provide structure and predictability to life (Kielhofner, 2002).

Internalized roles. Participants reflected the influence of internalized roles in their discussion of DSM in two ways: (1) the identification of the self-manager role; and (2) the influence of other roles (i.e. caregiver) on the ability of a person to manage T2DM. Two participants adopted a self-manager role marked by active participation in self-care and long-term control. Brett organized a T2DM information and support group, and Milton advocated for a ketogenic (high-fat, low-carbohydrate) diet. Milton shared:

> [Diabetes] has been in my family for a long time so I set out on a quest ever since I got it to research, study. I've just been devouring books and spending a lot of time listening to different doctors and naturopaths… I love it and I've learned so much… I've had some really good success with controlling blood sugars and it's been pretty exciting. (Milton)

Other participants expressed conflict between their familial roles and the imperative to manage their own T2DM. Two women discussed balancing the needs of family members with their own health requirements. Rose described cooking separate meals for her family and herself, "Well, I have to…My grandson, he is a picky eater, so I cook what he likes. And then I'll cook for… my husband, too, he likes a lot of tortillas and a lot of breads." Jamie lamented the difficulty of caring for her father who has hypoglycemia and dementia:

> Now my father is hypoglycemic… when he feels really dizzy he wants a Pepsi immediately, because that'll help bring it back up. So I'm trying to deal with him and deal with me, and he has dementia and Alzheimer's on top of that, so a lot of times he'll hide my information. (Jamie)

One participant described alignment between his roles and self-care needs. Jacob took pride in his role as the family cook, which supported his personal values of eating healthfully and providing for his wife. Jacob remarked:

> I do my own cooking. I cook seven days a week. My wife loves it because I've got food on the table when she gets home at dinnertime. If you cook your own food, you can't hurt yourself. Processed food has too much sugar, too much fat, too much salt. If you cook

> your own food, you can’t put enough salt, enough sugar, enough fat in it because it will taste awful to you. (Jacob)

Habits and routines. Several participants discussed the importance of establishing and maintaining healthy habits and routines to physical and mental health. Brett stated, “I record every meal, everything. I put down both the carbohydrates and the calories and I look at them at the end of the day and I tally them up and I see what my total is.” For Patty, motivation for counting carbs came from positive feelings associated with caring for herself:

> I’ve had different times in my life where I’ve been more active, done it on a consistent basis, felt better… When I was counting carbs and keeping them within my range and writing it down… I felt better just because I was doing something good for myself. (Patty)

For other participants, fear of worsening health and complications of T2DM helped them return focus to their health. Bill explained the circumstances that led him to re-engage with DSM:

> Then the [feeling of being] bulletproof came back again and then I was out doing construction work…and I got a blister on the bottom of my foot and that didn’t come out so good. I lost my left foot to about the middle of my calf. And then everything hit me again and I’ve been controlling my blood sugars really good, keeping really active. (Bill)

Many participants believed engaging in the routines of DSM was necessary, but the rigidity was “frustrating.” Rose sighed, “just having to check my blood sugar every morning… to determine how much insulin I need to take. I just do it, I complain. I say again I have to do this?” Engaging in and integrating these necessary behaviors of DSM into daily life required development of healthy habits and routines.

Maintenance of these habits involved planning ahead and problem solving when disruptions in daily life occurred. Belinda recounted how she maintained healthy eating habits, "[good T2DM management involves] knowing what you can and cannot eat… And setting up your refrigerator and your cupboard so that's what you have and not the other stuff." However, sometimes participants were not able to plan ahead, and this resulted in diet choices that do no align with ideal DSM practices. Jeff reported, "the schedule at my job is my biggest problem. I forgot my lunch yesterday and that was a problem because I had to make do and what I made do with wasn't as good as I should have." These quotes also illustrate the interdependency of habits and the environment. In the first example, Belinda set up the environment to provide a stable arena for healthy eating, and in the second example, Jeff's dietary decision was driven by the inflexibility of his work schedule.

Performance capacity. *Performance capacity* in MOHO is the ability to perform desired occupations provided by *objective* (physical and mental) factors and *subjective experience*. Physical capacity includes affordances and limitations based on the structure and function of the body, whereas mental capacity depends on abilities related to psychological function (Kielhofner, 2002). Subjective experience also influences performance, and provides a "view from the inside" (Taylor, 2017, p. 77) of the activity and person (Kielhofner, 2002).

Objective physical and mental. In the present study, participants experienced limitations in ability to perform DSM due to a variety of factors, both physical and psychological. Arthritis and obesity prevented traditional forms of exercise for Gina, "I learned what was making my blood sugar go so crazy and it was… non-exercise, because I had many medical problems that keep you very immobile." Secondary complications of T2DM also caused disability and activity limitations. Bill spoke of his difficulty being active after having his foot amputated due to a nonhealing wound. Patty, who struggled with depression, found that even getting out of bed felt insurmountable some days. Patty recounted, “I have difficulty with depression… When I’m in the bed, you know, literally pulling the covers over my head, it’s very difficult to think what good can I do for myself today?” Jamie enjoyed exercise, but found her physical condition limiting, “I can’t do a lot of lifting, I can’t do a lot of throwing and stuff, because I’ve got bad legs, bad hips, my back…. I love using ropes [for exercise], but I can’t, [be]cause I know what it does to me.” As Jamie and Patty illustrated, experiencing physical and emotional barriers to exercise created a tension between volition, or the innate need to act (Kielhofner, 2002), and performance capacity. Some participants valued exercise, but needed “different ways [to] do things to be able to motivate ourselves (Jamie)” because of physical limitations. Another previously active participant was trying to adjust to a new life with physical disability. Bill found that “just trying to keep busy is difficult… I was very active and doing a lot... I was a machinist most of my life… I was on my feet eighteen hours a day and now I’m trying to get disability.”

Subjective experience. The subjective experience of managing T2DM varied. Some participants revealed frustration with not being able to eat what they wanted and discouragement when attempts to control T2DM were not rewarded with improved health. Jamie lamented, “sometimes we get so discouraged being diabetic… ‘man I just want to taste that, man that looks so good’, I’ll take one bite, and eat the whole plate.” When Patty endured a setback with her health, she experienced an “underlying resentment and fear”. She explains, “it’s not there all the time, it’s not like I constantly think about it, but… when [the doctor] said I think it’s best if you go back on the Metformin, I was disappointed.” For Milton, however, being diagnosed with T2DM was an empowering experience. With time, he figured out how to manage his diet for optimal health. Milton exclaimed, “I think it’s fantastic! Because once you find the keys that you're looking for, it's really pretty cool. I've gone back fifteen years in age as far as the body aching, the daily headaches, the lethargy."

Volition. In MOHO, *volition* is the innate need to act. This need to act is influenced by constraints and affordances imposed by the body and environment, one's perceived ability to act effectively (*personal causation*), *values, and interests* (Kielhofner, 2002). According to MOHO, personal causation, values, and interests are woven together and reflected in the way we feel about our world.

Values. Participant's values drove the motivation to care for themselves and their health. Jeff stated, "I think because of my past experiences… because of my makeup, because of where I came from, I was able to accept the fact that I was diabetic and okay, now let's do something about it." Jamie, who had a large, supportive family, stressed the importance of being around for them, "I'm not going to go through the same steps my mother did. My mother was 62 when she passed away. I just had my first great grandbaby, I want to see him graduate." Differences in personal convictions among participants influenced their engagement with DSM. For example, Bill recalled the way his approach to managing his health has changed over the years, "I used to… just eat everything just like I drank everything, but I'm learning control and exercise in my life helps me live life again because my bulletproof days are over." Jacob, on the other hand, does not closely monitor his T2DM, but instead holds a value system of "everything in moderation":

> Life is too short to watch my diet and everything else. I don't do exercise. I've hated exercise all my life… I'll walk and stuff but all these medications that we have now… you can live a good life. I'm not willing to give up anything. (Jacob)

Personal causation. Self-control and willpower, or the ability to exercise control over one's actions (Kielhofner, 2002), were key to success with DSM for some participants. Belinda shared, "The idea is self-control… Which is so important with diabetics…If you have a lot of self-control, you're a better person." This quote not only illustrates the perceived importance of self-control, but also the perception that lack of self-control was a moral problem. Personal causation, though crucial for DSM, was difficult to maintain; sometimes the draw of food cravings or skipping exercise won out. Rose explained:

> And like [everybody else] I really crave that sugar… One of my doctors told me… even better than your diet is exercise. And I did do well but then that kind of faded. You know, I could do it for short periods of time, but then after a while you're bored with it or I'm tired of doing it. (Rose)

This sentiment was echoed repeatedly by participants, but no one articulated it more perfectly than Patty, "When I have something that's really sweet, I usually feel kind of sick. So I will do it anyway [be]cause I want it… it's like 'to hell with it, I'm going to do it anyway'".

Environment. The environment component of MOHO includes the impact of physical and social contexts on what occupations people choose and how they engage in these chosen occupations (Kielhofner, 2002). Participants in this study shared experiences regarding the ways the social and physical environments shaped management of T2DM.

Social Environment. Participants identified ways in which family support helped or hindered maintenance of a healthy lifestyle. Multiple participants indicated that family members who do not have T2DM could not understand the necessary dietary restrictions. Belinda stated, "Family does not understand if they don't have it… And that's so hard when you go for a family meal… 'Here. Have this piece of pie.'" Contrarily, other participants emphasized the positive impact of family members who keep them on track with diet and activity. Rose recounted, "for the most part, they know that I cannot have a lot of the foods that they can eat, so they kind of watch over me, too. They remind me, are you sure you can eat that?" Another participant with adult children emphasized her children's role in helping her maintain physical activity: "I have three kids that keep me accountable to what I do… They keep me active and they call me each day to make sure" (Jamie). In these cases, family members were aware of recommended diet and physical activity, in contrast to the family members in the first examples who were unaware of or not receptive to the needs of study participants.

Physical and social environments were particularly enmeshed with volition for this group. Temptations in the environment created an inner tension between "wants" and "shoulds". One participant noted that temptations exist everywhere, "Just going out anywhere [is hard] because… there's candy everywhere you look…. But if it's not [a busy day], you've got to sit at home and look at all them commercials" (Bill). For those who worked, the break room was a major source of inner tension resulting in a test of personal causation. Gina said, "I'll go in there [and there is] soda, there's pastries [and candy]... I'm real good if I don't take that first one. If I take one, it's all over. Then I'm sneaking them, grabbing them. It doesn't matter. My rule is I don't take that first one."

At work, some study participants used the power of personal causation to avoid tempting items; however, with social and familial opportunities, some reported "it's just easier to stay away" (Gina). Jamie recounted her difficulty navigating a "different way of eating" during family visits to Mexico, "I can't go to Mexico because my in-laws would have to feed me… I tried to explain to them, 'I'll take this, a little bit of it.' 'Why? You don't like my cooking?' They get insulted. So there's a lot of pressure on you when you try to eat correct."

Those who chose to attend social events despite the temptations expressed frustration and a sense of injustice about their condition. Patty stated:

> I guess I have some envy for people who are not in the predicament where they have to think about [what they eat]… [At church reception functions] the tables are groaning under the weight of everything that's there… and there's little skinny people or very fit people that just have everything on their plate… I'm going, 'why wasn't I born with a metabolism of a bird?' (Patty)

Physical environment. Compared to their social environments, participants rarely mentioned their physical environments. One participant described the lack of a neighborhood senior center as a hindrance to exercise:

> I wish there was a senior center near where I live… there is nothing close. I am not going to a gym; I've never felt comfortable there. There's a [large fitness center] right there, but… I get in there and I'm uncomfortable around all these people, I'm very self-conscious about my size." (Patty)

This quote illustrates the dual impact of an unsupportive physical environment and the subjective experience of judgement on personal causation for exercise. In this case, the discomfort of attending a traditional gym overpowered the individual's sense of volition.

Occupational Adaptation and T2DM

According to MOHO, *occupational adaptation* is a cumulative process over the life course, and describes the extent to which humans are able to respond to challenges to achieve well-being (Kielhofner, 2002). *Occupational identity*, or sense of self, and *occupational competence*, a sustained pattern of participation, both undergird a person's ability to adapt to a healthy life after a new diagnosis. In previous research, participants were successful in managing

T2DM when they had a sense of ownership over their condition: when the diagnosis was accepted and healthy habits integrated into the whole life experience (Handley, Pullon, & Gifford, 2010; Youngson et al., 2015). A person's ability to achieve occupational adaptation is influenced by many personal and environmental factors. In the present study, there were examples of occupational adaptation that represented different, but equally successful DSM practices. Each individual's practices are impacted by disease severity, personal values and motivation, and the surrounding context. One on end of the continuum was Brett, who steadfastly recorded each meal that he ate to maintain tight control over his blood glucose. On the other end was Jacob, who took his medications and believed in moderation, but did not monitor his condition. Adaptation is an ongoing process that continues throughout the lifespan; therefore, it would be inaccurate to say that either participant 'arrived' at occupational adaptation. However, these two participants constructed occupational identities that reflected personal values and high level of occupational competence through sustained patterns of engagement with DSM. Through the consistent performance of DSM using methods that fit their value structures, these participants experience well-being related to management of T2DM. These two patterns of engagement represent the most consistent performance of the group. The rest of the participants fell somewhere in the middle, exhibiting patterns characterized by constant adjustment of habits and roles, waxing and waning volition, negotiation with the social environment, and changing mental and physical health characteristics. Their approaches to DSM are quite varied: there is no one way to adapt to a diagnosis of T2DM.

Discussion

The primary aim of this study was to use the lens of MOHO to understand the experience of DSM. Overall, MOHO provided a useful conceptual framework for this research. By using

MOHO to conceptualize the occupation of DSM, we constructed a comprehensive understanding of the experience of individuals with T2DM based on individual components as well as the interactions among them.

Habituation, or the pattern of daily occupation, is another central concept in MOHO. Habituation is guided by our habits and roles and fitted to the characteristics of our environments (Taylor, 2017). These recurring patterns provide stability, allowing familiar routines to unfold. Occupational therapy researchers have theorized about the power of habits for occupations of health promotion and disease prevention (Fritz & Cutchin, 2016). One study of low-income women with T2DM stressed the importance of reconfiguring routines to support the addition of new DSM-related activities (Fritz, 2014). Thompson (2014) and Pyatak (2011) have similarly emphasized the need for development and integration of DSM behaviors into habits and routines of everyday life. Recently, Pyatak and colleagues (2018) demonstrated the power of health-promoting habits and routines by using a structured occupational therapy intervention to improve blood glucose control and quality of life in young adults with type 1 diabetes. They delivered the intervention in participants' homes and focused heavily on adoption and integration of DSM behaviors. The benefits of established habits and routines were also apparent in the present research. Patty, for example, described feeling better when she was active on a consistent basis. Brett experienced success with DSM by recording every meal he ate in order to check his performance at the end of the day. For Rose, the rigidity of DSM routines was "frustrating", but she continued to engage in the routines despite this. The necessity of problem solving and planning ahead is often mentioned in the literature (Fritz, 2014; Peeples et al., 2007), and was echoed by our participants. Stocking cabinets with healthy food and making sure to bring lunches and testing supplies were strategies that bolstered healthy habits and routines.

Performance capacity, or physical and cognitive status and corresponding subjective experience, is the ability to engage in desired occupations (Taylor, 2017). A primary focus of this research area in occupational therapy has been to address the sensory and motor deficits that come with secondary complications of T2DM (Pyatak, 2011). The occupations of DSM require coordination of mental and physical processes to achieve. For example, managing medication is often a multipart process which begins with checking blood glucose through finger prick and selecting and taking the proper dosage of medication. Individuals with T2DM have identified difficulties not only remembering to bring supplies and medications with them (Nagelkerk et al., 2006), but also with fine motor control to open bottles and draw up insulin due to peripheral neuropathy (Futeran, 2001) and limited joint mobility (Somai & Vogelgesang, 2011). In the present study, participants identified difficulty engaging in physical activity as a major challenge. Participants wanted support to adapt exercise to accommodate limited mobility and joint pain, as well as strategies to overcome the debilitating effects of depression. The subjective experience of T2DM spanned a range of responses: some used words like “discouraged”, “resentment”, and “fear”, while another felt “fantastic” after learning to manage the disease. According to Kielhofner (2002), subjective experience helps shape occupational performance, a perspective reinforced in this research: those who identified a positive subjective experience surrounding DSM tended to be more consistent with patterns of health behavior.

Along with capacity for performance, some measure of volition is essential to effectively carry out self-management recommendations (Gomersall, Madill, & Summers, 2011). In fact, lack of willpower is one of the most common patient-reported obstacles to DSM (Beverly et al., 2012; Booth et al., 2013; Youngson et al., 2015). Many individuals with T2DM, like Patty in this study, have attempted to make lifestyle changes with unsatisfactory results (Beverly et al., 2012;

Booth et al., 2013; Whittemore, Chase, Mandle, & Roy, 2002). This is partly due to an inability to consistently carry out self-management recommendations. Having willpower for the short term is not enough; willpower must be maintained across the lifespan. Many participants in this study remarked on the difficulty of maintaining willpower; as Jamie stated, "[managing T2DM] takes a lot of willpower, and sometimes we don't have it". In previous research, participants discussed the feeling that they could "never do enough" (Beverly et al., 2012, p. 1184) to manage T2DM because of the progressive course of the disease. This notion left participants feeling that engaging in the constant struggle with food and exercise was pointless. Another explanation for the perceived difficulty maintaining willpower could be the complex nature of the disease. The participants in our study often knew what choices they wanted to make, but a number of environmental and personal factors impeded best judgement. However, volition is not static. When it diminished, some participants in the present study turned to family for motivation; Milton explained, "I can do this for my health to be here for my grandkids to know".

Previous qualitative research examining DSM demonstrated that self-management activities are complex, dynamic and inseparable from the social and physical environment (Fritz, 2014; Gomersall et al., 2011; Minet et al., 2011; Nagelkerk et al., 2006; Youngson et al., 2015). In the present study, the physical environment was rarely mentioned, likely because participants were not directly asked about the influence of the physical environment on DSM. However, one participant felt the impact of not having a senior center nearby for physical activity. Participants in past studies have commented on the difficulty of finding somewhere to inject insulin in public places (Youngson, 2019), or finding ways to exercise in the winter months (Thompson, 2014).

In accordance with previous research exploring the effect of social and family functions on maintaining DSM recommendations for diet (Thompson, 2014), choosing the correct foods was easy enough when individuals could plan ahead and cook at home. However, family functions and social activities tended to revolve around food, much of which was not in accordance with a healthy diabetic diet. Participants' comments reflect a distinct difference in the level of support from families who were aware of and receptive to DSM needs and those who "do not understand". This finding underscores the importance of involving the family in DSM education, a position advocated by the American Diabetes Association (Powers et al., 2017). These examples illustrate the impact of social and environmental factors on occupational performance, but equally important are the personal factors that motivate and provide structure and function for DSM.

Interactions between MOHO components

The findings presented here offer several snapshots of daily life with T2DM. These comments and stories reveal the rich interplay between volition, habituation, performance capacity, and the environment and how these interactions impact what DSM choices the participants ultimately made (Kielhofner, 2002). The daily management of T2DM reflects the convergence of MOHO components, out of which emerges thoughts, feelings, and actions. Below, we illustrated the interactions of MOHO components and integrated them with existing research.

- **Social environment and values:** For Jamie and Rose, the value of family support helped them stay on track with diet and physical activity. Participants are inseparable from their environments, and family dynamics have a major influence over a person's behavior. Family support can promote adherence to DSM by buffering stress, reducing depression, and providing motivation (Miller & DiMatteo, 2013).

- **Social and physical environment and personal causation:** For many participants, temptations in the environment created inner tension between what they *should* do and what they *want* to do, thereby testing willpower. Participants who lacked the causation to make the “right” choice avoided certain activities. Tests of volition in social and physical environments are a nearly universal obstacle to DSM. Past participants have described scenarios similar to the tension discussed here, and identified strategies of planning ahead or eating beforehand to mitigate activity avoidance (Hall, Joseph, & Schwartz-Barcott, 2003).
- **Physical environment, subjective experience, and personal causation:** Patty experienced diminished personal causation for physical activity resulting from the dual impact of an unsupportive physical environment (lack of senior center) and negative subjective experience surrounding the gym. In other research, individuals often reported being overwhelmed by perceived barriers to physical activity (Booth et al., 2013), but the therapeutic mental and physical benefits of physical activity are well-established (Rebar et al., 2015). Having the social support of an exercise partner alongside an individualized physical activity plan may reduce fears and increase exercise participation (Rasinaho, Hirvensalo, Leinonen, Lintunen, & Rantanen, 2007).
- **Internalized roles and values:** Internalized roles reflected personal values for several participants in the study. Cooking for family members supported values of healthy eating and caring for family, but caregiving for family members also strained DSM. The relationship between internalized roles and values has been explored previously for individuals with T2DM, where family life has been prioritized over self-management (Youngson, 2019). In previous research, reconfiguring routines to accommodate both

family roles and T2DM self-care behaviors produced stability and predictability, which supported consistent engagement in DSM (Fritz, 2014).

- **Habits, routines, volition, and subjective experience:** Subjective experience motivated habits and routines for many study participants. For one participant, the positive experience of caring for herself upheld DSM routines. For another, fear of worsening health catalyzed re-engagement in DSM. The supportive nature of habits and routines for DSM is well-established (Booth et al., 2013; Fritz, 2014; Youngson, 2019), but the volition for continuing to engage in routines is less so. Both autonomous (e.g., positive subjective feelings) and controlled motivation (e.g., fear of health complications) have been shown to support adherence behaviors, but autonomous motivation ultimately promoted long-term maintenance (Shigaki et al., 2010).
- **Habits and environment:** Our participants described the interdependency of habits and environment by reflecting on the establishment of environments that supported healthy behaviors and the impact of social and physical environments on healthy choices. Previous research showed that frequent performance of activity in a consistent environment caused actions to be driven by features of the environment rather than by personal intentions (Lally & Gardner, 2013). Individuals with T2DM may benefit from configuring their environments to support stable routines despite waxing and waning volition and personal causation.
- **Values, personal causation, and objective performance capacity:** In this study, our participants indicated physical (e.g., arthritis, obesity) and emotional (e.g., depression, fear of judgement) barriers to engagement in physical activity. Physical and emotional barriers to exercise make engaging in activity more difficult, thus challenging the

individual's causation and values. Individuals with T2DM have previously identified the impact of co-morbidities and lack of energy on ability to complete DSM behaviors (Booth et al., 2013; Wilkinson, Whitehead, & Ritchie, 2014). This underscores the need for individualized, adaptive physical activity for individuals with T2DM and comorbid conditions.

The summary of findings illustrates the inter-relatedness of the components of MOHO and the dynamic nature of the occupation of DSM. The actions that emerged from these conditions were ever-changing, and subject to influences near and far. The present findings, bolstered by previous research, underscore the need for a complement to the biomedical approach to address DSM; an approach that is comprehensive, addressing interactions among the person, environment, and occupation of self-management. Occupational therapists are well-poised to provide these essential services given our expertise in habits and routines and our holistic approach to intervention (Pyatak, 2011).

Limitations

Several limitations should be considered when interpreting these findings. There are two factors which may have affected the saturation, and thus, transferability of the results. First, the limitations related to the sample. Not only was the sample size limited to 10 participants spread over three one-hour focus groups, the majority of the participants were white (n = 8). If time allowed, the researcher would have collected more data and included more ethnically and racially diverse participants to reach a point where new data became redundant. Second, this is secondary data analysis of a needs assessment for identification of barriers and facilitators to DSM. Therefore, we did not have the conceptual model of MOHO in mind during study design and data collection. Establishing MOHO as the guiding model *a priori* may have provided more targeted questions, but also may have restricted the variety of responses we received. Despite these limitations, this research provides important insight into the complexity and multi-dimensionality of the occupation of DSM, and points to MOHO as a useful model for exploring this subject. Further research would determine the feasibility and clinical utility of implementing the MOHO model for DSM in occupational therapy practice.

Conclusion

Using MOHO to examine the experience of DSM shows how the person with T2DM is intertwined with the social and physical contexts; values, beliefs, and motivations; habits, routines, and roles; and ability and experience. This research highlighted the complexity of DSM through the individual components of MOHO, as well as the inter-relatedness of these components. The use of MOHO to understand the experience of DSM shows the potential for occupational therapy intervention to complement treatment of T2DM, which currently relies largely on a medical model. Attention to each component of MOHO, as well as the interactions between the components, provides valuable information for practitioners to assess and intervene with individuals with T2DM.

Figures and Tables

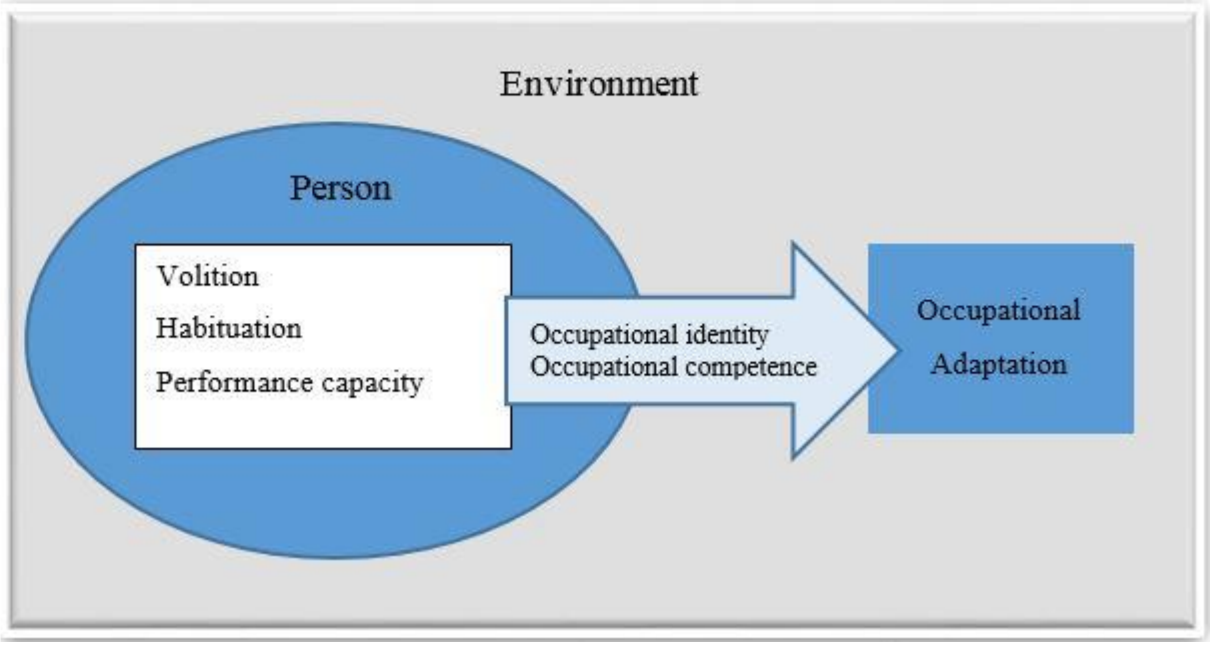

Figure 2.1. The Model of Human Occupation adapted from Taylor (2017, p. 119).

Table 2.1 *List of questions and probes for focus group interviews*

Opening Question (10 min)
Let’s just go around the circle for our first question. Tell us who you are, how long have you been diagnosed with T2DM, and the first thing you ever learned about diabetes.
Transition Question (10 min)
What is it like to live with diabetes? o What things are difficult? What is easier to control? o What challenges, if any, prevent you from addressing your health needs? o Often challenges in our lives bring opportunity for growth and new perspectives –have you or someone else you know experienced new perspectives/attitudes? o Can you describe a time when you experienced conflicting desires… what you know is the “right” thing to do but you want to just “be normal” or do what you want to do? o What kind of unanticipated events have come up for you…..or temptations?
Key Questions (20 min)
Think about your day yesterday. How well did you manage your diabetes? Can you highlight anything that you consistently do to manage your diabetes? o What do you do (to take care of your diabetes)? o How have your routines (or habits) changed? o What role does your family play in your diabetes management? o Can you speak to how the environment helps/hinders your diabetes management? o How do the resources you have available impact your diabetes management? o What other resources do you think would help you or others with diabetes? What is your personal theory of good diabetes management? What does it look like? o What are your beliefs about how to best manage your diabetes and enjoy your everyday life? o Where do you think this belief comes from? What influences these beliefs?
Exit Question (10 min)
Can you think of anything else that is important for us to know when working with people to manage their diabetes?

Table 2.2 *Demographic and health characteristics of study participants*

Name	Age	Gender	A1C (%)	Work Status	Race/ethnicity
Jamie	59	F	6.2	Part-time	Hispanic/Latina
Patty	59	F	5.8	Part-time	White
Rose	71	F	8.5	Retired	Hispanic/Latina
Jeff	62	M	6.1	Full-time	White
Brett	71	M	6.5	Retired	White
Milton	50	M	5.7	Full-time	White
Jacob	69	M	7.1	Retired	White
Belinda	78	F	7.3	Full-time	White
Gina	67	F	7.0	Part-time	White
Bill	53	M	5.6	Unemployed	White

CHAPTER THREE: HEALTH CARE PROFESSIONAL PERSPECTIVES ON TYPE 2 DIABETES MANAGEMENT IN SAFETY-NET PRIMARY CARE

For people with type 2 diabetes (T2DM), the complex and multi-faceted daily diabetes self-management (DSM) routine can be difficult to undertake (Marvicsin & Freeland, 2017). For people with limited health resources, important self-care activities such as healthy eating, regular exercise, managing medications, checking blood glucose, and managing stress, can be even more difficult due to low socioeconomic status (SES), minority status, or low health literacy. In socially disadvantaged populations, T2DM is more prevalent and more difficult to manage (Glazier, Bajcar, Kennie, & Willson, 2006). Relative to groups with more health resources, these groups experience multiple health inequalities including worse health outcomes and decreased ability to adhere to DSM recommendations (Centers for Disease Control and Prevention, 2017). Health inequalities, or socioeconomic differences in health status, may result in premature loss of life and increased disease burden (Braveman, Kumanyika, et al., 2011). Many patients with low SES use safety-net primary care clinics, which treat patients regardless of insurance status or ability to pay for services (Nguyen et al., 2016). Patients at safety-net clinics generally have higher rates of chronic disease, disability, and polypharmacy than non-safety-net users (Nguyen et al., 2016). Correspondingly, this group of individuals requires more complex care than non-safety-net users.

Past research demonstrated agreement between patient and health care provider (HCP) accounts of barriers and supports to DSM, establishing that HCP reliably understand the difficulties faced by those in their care (Booth et al., 2013; Carbone, Rosal, Torres, Goins, & Bermudez, 2007; Längst et al., 2015). Research also suggested that HCPs were aware of the impact of health literacy on retention and integration of new health information (Booth et al., 2013; Längst et al., 2015), as well as compounding effects of social factors, like poverty and food insecurity on DSM (Pilkington et al., 2011); these factors may have eluded patients. Most DSM research focuses on patients' perspectives rather than clinicians' (Nam, Chesla, Stotts, Kroon, & Janson, 2011); however, health care providers (HCP) can offer an important complement to the patient perspective. Understanding the perspectives of HCP may shed light on why safety-net clinic users experience difficulty with DSM and poor health outcomes.

Though the day-to-day activities of DSM are shouldered by patients, health care professionals (HCPs) are responsible for facilitating self-management and providing education and support (Thomas, Moring, Harvey, Hobbs, & Lindt, 2016). In traditional medical models in the United States, this care is delivered primarily by a physician. However, the 'stand-alone' physician model has failed to produce meaningful and lasting change in lifestyle behaviors for individuals with chronic conditions (Milani & Lavie, 2015; Rao et al., 2011). Recently, there have been calls to replace the 'stand-alone' physician model with coordinated, team-based care models (Coleman, Austin, Brach, & Wagner, 2009; Jackson et al., 2013; Milani & Lavie, 2015). These models emphasize patient-centered, evidence-based care provided by team members with diverse perspectives and roles (e.g., physicians, nurses, dietitians, pharmacists, social workers), each with valuable experience and input.

Against the backdrop of health inequalities experienced by socially disadvantaged populations, understanding the experience and recommendations of multidisciplinary safety-net HCPs related to the management of T2DM is vital to improving the quality of diabetes care. HCPs' perspectives may inform quality improvement efforts by highlighting recommendations for services and supports to enhance treatment. HCPs are well-positioned to offer insight into providing care in safety-net primary care clinics given their practice experience and knowledge of clinic and policy-level factors (Pilkington et al., 2011). In this study, we attempt to elucidate HCPs' perspectives through the following research questions:

1) What is the patient experience of managing T2DM from the perspective of health care providers?
2) What are the challenges of providing care to patients with T2DM in a safety-net primary care clinic?
3) What services/resources do safety-net health care providers recommend for patients with T2DM?

Method

Research Design

We used qualitative description (QD) to design this study. QD is recommended when the goal of research is a straight-forward presentation of information in easily understood language for direct application into practice (Sandelowski, 2000, 2010; Sullivan-Bolyai et al., 2005). QD is especially useful for clinical practice because it uses low-inference interpretation and can be translated directly into health care situations. QD is commonly carried out using the following methods, which are discussed in depth in following sections:

1) Sampling: Purposeful or maximum variation sampling
2) Data Collection: QD consists of minimally to moderately structured interviews with open-ended questions used in conjunction with other documents and field notes (Sandelowski, 2000; Sullivan-Bolyai et al., 2005).
3) Data Analysis: Data analysis in the QD approach uses the 6 strategies of thematic analysis (TA) outlined by Braun, Clark, and Terry (Braun et al., 2014).
    g. Familiarize yourself with the data

h. Generate initial codes
i. Search for themes
j. Review potential themes
k. Define and name themes
l. Produce the report

Participants

We recruited six health care professionals (HCPs) who worked directly with patients who have T2DM at a single safety-net primary care clinic. The clinic primarily serves individuals with few health resources and includes a higher population of minority patients than other area clinics. We began selecting HCPs using referral from the clinic medical director, however, as the study progressed, and we learned about different roles within the clinic, we used a maximum variation approach to obtain a variety of perspectives (i.e., differing roles, levels of experience and relationships to patients) (Sullivan-Bolyai et al., 2005). We offered HCPs a $10 gift card in exchange for participation.

The safety-net primary care clinic where we conducted our research employs HCPs that may not be typical of standard primary care in the United States. For example, this particular clinic employs social workers, pharmacists, lifestyle medicine educators, and case managers in addition to physicians and nurses. Additionally, not all patients at this clinic see every provider; their services are available by request or referral from a physician. Next, we briefly present the major roles of these less-typical HCPs, as described by the participants in the interviews. The social worker identified connecting individuals with community resources, like prescription medication discount programs and ancillary medical appointments, as her primary responsibility. The clinical pharmacist shared that her role is to review new medications with patients, often immediately following a new diagnosis. The role of the lifestyle medicine educator is to work with individual patients to create plans to improve their health. Lastly, the case manager identified care coordination for medically complex patients as his major work task. For example, when a patient transitions home from an acute hospital visit, he ensures they have appropriate follow up with the primary care clinic and any concerns are addressed.

Procedure

We conducted six interviews, which took place in the primary care clinic. All interviews were conducted by two researchers (LS + TK) during the Summer of 2018. Interviews lasted approximately thirty minutes. During the interviews, the researchers also took notes on points that were emphasized by the HCPs. These records were incorporated as *field notes* into data analysis (Merriam & Tisdell, 2015). Three members of the research team (TK + LS + KA) developed the semi-structured interview guide (Table 3.1) to ensure key themes and questions were covered during the interviews. The guide consisted of open-ended questions to understand HCPs' perspectives about the challenges faced by patients and practitioners surrounding DSM and the necessary and extant supports to overcome these barriers. The questioning route was developed using best practices for semi-structured interviews, which allows for flexibility with order and wording of the questions (Merriam & Tisdell, 2015). The interview guide used a mix of open-ended and structured questions of varying types: experience, values, feelings, knowledge, and background (Merriam & Tisdell, 2015; Sullivan-Bolyai et al., 2005).

Data analysis

We recorded all interviews and used a paid transcription service for verbatim transcripts. We used thematic analysis to analyze transcripts and field notes (hereafter referred to as *documents*). We sorted data into codes and themes using NVIVO qualitative analysis software

(QSR International, Melbourne, Australia). We used an inductive approach to analysis, meaning that the codes and themes were driven by the content of the data with minimal interpretation. Below are the specific steps that were taken during data analysis according to the 6 strategies for thematic analysis as outlined by Braun and colleagues (2014).

1) *Familiarize yourself with the data*. Authors LS and TK first read and considered the documents as a whole to gain a preliminary sense of the data. They engaged in open coding, a process which began with reading the documents as a whole and making comments about relevant bits of data (Merriam & Tisdell, 2015). Then, they read and discussed the documents to get a sense of the major takeaways from the interviews.
2) *Generate initial codes.* At this point, LS and TK began systematic data analysis. Once again, they read through the documents. This time, they developed initial codes and applied these to chunks of data that were relevant to the research question. These codes described the contents of the data, while staying close to the content and participant meaning (Braun et al., 2014). They met weekly during this process to discuss emerging codes, ensuring that there were enough codes to capture the diversity of content, but also that the codes each appeared across multiple data items. They also used a "miscellaneous" code to capture any data that did not fit into other categories (Merriam & Tisdell, 2015).
3) *Search for themes*. At this point in the analysis, the analysis team's focus shifted from identifying codes to shaping codes into themes. These initial themes were the product of an iterative process of analysis and discussion that took place between LS and TK. LS and TK created a table to display each theme alongside the relevant data extracts (Braun et al., 2014).

4) *Review potential themes.* Next, TK engaged in a quality check consisting of two stages: first, she checked the themes against the collated data, and second, she checked the themes against the entire data set. She re-read each of the documents to determine if themes adequately portray the data set (Braun et al., 2014). During this phase, she reshaped, added, and discarded themes, and re-established thematic boundaries based upon how themes fit into the overall picture (Merriam & Tisdell, 2015). She incorporated these changes into the thematic table. Although TK led this step of data analysis independently, she checked in often with LS for feedback. TK presented the thematic table to experienced qualitative researchers CC and KA for feedback. After receiving feedback, TK adjusted and finalized the themes.
5) *Define and name themes.* Next, TK compared the themes again to the collated data and the entire data set, confirming congruence between the data and themes as well as among the different themes. This process ensured that each theme had a clear focus, scope, and purpose and contributed useful insight to the overall research questions (Braun et al., 2014).
6) *Produce the report.* In this phase, TK selected the most representative excerpts and analyzed, then related them back to research questions and background literature. The final product of this research is a dissertation chapter for submission to an academic journal (Braun et al., 2014).

Study trustworthiness

We chose three main strategies to enhance trustworthiness of the study: peer review, reflexivity, and maximum variation sampling (Merriam & Tisdell, 2015). First, two experienced qualitative researchers (authors CC and KA) served as peer reviewers and helped ensure the themes were well-defined and plausible based upon the raw data. Additionally, a novice qualitative researcher (LS) analyzed data, aided in consensus-building, and provided additional checks along the way. Second, TK engaged in the practice of reflexivity prior to beginning data analysis by critically examining assumptions, experiences, and values related to management of T2DM. Lastly, we used maximum variation sampling to obtain the participant sample, which consists of a variety of occupational roles (e.g., physician, pharmacist, social worker). This action increases transferability by making the qualitative findings applicable to a wider range of the study's consumers (Merriam & Tisdell, 2015).

Results

Participants were 6 HCPs in a safety-net primary care clinic, each representing a different field of practice. The average time working with individuals with T2DM was 12 years (range = 5-21 years) (See Table 3.2). Three themes arose from the data regarding the perspectives of HCPs in a safety- net primary care clinic (See Figure 3.1). First, the HCPs described their perceptions of patient experiences with DSM. Second, the HCPs described barriers and strategies they have encountered when working with individuals with T2DM toward better health. Third, HCPs described services and supports they believe would be beneficial to those who are trying to better manage T2DM.

Theme One: Provider perceptions of Patient DSM

HCPs offered three sub-themes related to the experience of DSM for patients from the safety-net primary care clinic. First, HCPs perceived that patients have limited access to health resources. Second, HCPs understood that patients have multiple obstacles to DSM. Third, HCPs believed that DSM requires the patient take an active role.

Patients have limited access to resources. HCPs indicated that patients were often unable to access the supplies, medications, and services required to successfully manage T2DM, due to inadequate finances or insurance coverage. As one provider stated, "…one of the biggest problems seems to be that you can get a good glucometer from just about anybody free, but then you don't have the money to cover the test strips, which can be really, really expensive (P 1)." Other HCPs also recognized the difficulty faced by patients with T2DM to obtain and correctly use medications. One provider mentioned the prescription copay for a Medicaid patient, though "nominal", was a "significant challenge for some of them (P 6)." These prescription copays forced some patients to self-adjust medication dosages. One HCP said, "I think a lot of people choose. It's like, 'do I need this medication every single month, or is it important for me to take it every day?' So maybe they skip some days (P 2)." In addition to the medication needs of patients with T2DM, some HCPs described restricted access to auxiliary appointments due to insurance status. For example, one participant reported, "being able to see what you're doing is a huge part of [managing T2DM], and there are so many people that can't get a regular eye exam because most insurances for adults don't cover regular eye exams (P 1)." She added, "another specialist they aren't going to get to see is endocrinology" due to restrictions in number of uninsured and Medicaid patients they will see each month.

Patients have multiple obstacles to participation in DSM. HCPs described "chaotic life circumstances" (P 5) as a major barrier for patients to engage in DSM. One provider stated, "Their socioeconomic status has to be such that they can prioritize lifestyle, because it's hard for people to prioritize lifestyle when they don't have the things [they] need... It just doesn't rise high on the hierarchy (P 3)." To describe the thought processes that can influence a person's ability to prioritize health, one HCP noted:

> [Some patients have] an in-the-moment mentality that I think is hard to fathom for people that don't have to deal with those issues… getting to the pharmacy… when you're worried about your next meal or where you're going to sleep… I think a survival mentality is [why] some of the planning or future thinking is not as robust as it would be for you and I (P 6).

In addition to "chaotic life circumstances (P 5)", HCPs felt that decreased health literacy negatively impacted patients' abilities to understand health information and discouraged patients from attending group education events. One provider recounted:

> There are lots of people that go to [diabetic] education classes, but they might be people from the [local senior club], and sometimes our patients…they say, "I look different, they're dressed really nicely, they ask all these really smart questions… I feel like I'm too dumb to be there (P 1).

Patients must take an active role in DSM. Despite the recognition that patients in safety-net clinics may have limited access to resources and multiple obstacles to a healthy lifestyle, some HCPs considered patient motivation and responsibility as key to DSM. One provider claimed that "personal responsibility is first and foremost (P 2)", while another HCP similarly stated, "first they've got to want to be better. It's got to be important to them to want to be healthier and want to have things under control because if they don't… you're not going to get anywhere (P 5)."

Theme two: Insights into Current Practice

HCPs in this study identified two sub-themes related to the experience of providing care to individuals with T2DM in a safety-net clinic. First, because they work with a patient group who often experienced difficulty with DSM, they used methods, like motivational interviewing and “meeting a patient where they’re at (P 6)”, to facilitate connections with patients. Second, these providers encountered barriers to the type of treatment they would like to give, including time to spend on direct patient care and poor participation in programming.

Providers identify ways to facilitate connections. Patients from safety-net primary care clinics have unique needs because they face multiple, varied obstacles to DSM related to both health and SES which may not be present for patients who seek care elsewhere. Because of the complexity of these cases, HCPs in our study needed to use empathy, understanding, and respect to build relationships with their clients. For some HCPs, empathy was most important. One provider said, “it’s really important to have empathy, and yes, it’s a manageable illness, but it’s not a fun illness to have (P 1).” Another HCP stated the importance of understanding a patients needs and values, “you have to understand the person’s value-based milieu; like where they live, and what’s important to them, before you can try to motivate them (P 3)”. One provider described the process of first establishing himself as an ally before addressing DSM:

> I think that approach of trying to work with a person [by] coming in with your own agenda and saying ‘you’ve got to do it this way or you’re not doing it right, here’s how you do it’, it just is not very effective. You’ve got to start with meeting the patient where they’re at and if their priority is food or housing or some of the basic needs, we’ve got to have a way to come alongside with that… Meanwhile, we’ve got an agenda in our mind that yes we want to get to the diabetes management, but we’ve got to build a relationship with a person first (P 6).

Another HCP used motivational interveiwing to empower patients to identify their own health goals. She spoke about the importance of “respecting that [the patients] are the expert in their life (P 5).” She continued to say that “9.5 times out of 10, people can tell me pretty much exactly where they need to start [making behavioral changes] (P 5)." Sometimes these changes were small; patients chose to discontinue soda consumption, or switched from flour tortillas to corn tortillas, or added one glass of water to daily intake. These changes were often more acceptable to patients than making "that huge jump to mostly fruits and vegetables (P 4)."

Providers encounter barriers to ideal treatment.

Time for patient care. Two HPCs in this study experienced tension between providing an ideal standard of care to patients and time constraints in the given setting. Time for direct patient care was the most frequently mentioned barrier in this study. One participant lamented, "I think it's [key] to get a sense of what's important to that person, and then having them identify, based on what's important to them, what are they actually willing to do? The fundamental problem is that takes time (P 3)." Limited time forced HCPs to prioritize some elements of care while diminishing others. As one provider described, "In the context of working with patients, there are too many things to worry about and the diabetes will often get pushed aside because it's the hardest to deal with (P 3)." After taking the time to devise and deliver a treatment plan for a newly-diagnosed patient, providers had little time to ensure patient understanding. One provider decried this lack of time:

> I think in the healthcare world, we're caught up in meeting metrics of the patient as a diabetic; they have an A1C, they have lipids, we just need to put them on these meds… but we don't ever talk to patients about it… More time needs to be spent upfront with people before we just give them a barrage of meds and changes (P 4).

Poor participation in programming. This safety-net clinic is unique because they provide services not typical of primary care. For example, the clinic operates a food pantry where patients can come and shop for free, and they provide comprehensive behavioral health services. However, one theme that surfaced repeatedly in the discussions was the low rate of participation in clinic-sponsored programming for patients with T2DM. To provide comprehensive, efficient care for patients with T2DM, this clinic once offered supplementary T2DM management programs including foot checks with a podiatrist and group physician visits. For different reasons, these programs did not succeed. One provider mentioned, “it would be great to have a podiatry clinic here… we’ve tried that before,” however, this service was discontinued because there were “too many no-shows (P 1).” Another program that failed was a group diabetes appointment, where patients with T2DM could receive education and physician consultation to improve efficiency and education. One HCP postulated that these group appointments failed because “people don’t want to be that person that asks the question because they don’t want to look stupid, but they honestly just don’t know the answer and so they won’t speak up (P 4).” These failures seemed to perplex some HCPs; when we asked one provider how to best increase engagement, the provider replied, “If I knew the answer to that, I would have a Nobel Prize, so I don’t really know (P 3).”

Theme three: Recommendations to Improve DSM.

We asked HCPs to identify services and supports that were missing or limited in current primary care practice, as well as ideal components of a comprehensive DSM program. We identified four sub-themes in this line of questioning: first, engaging patients in their home and community; second, including family members in DSM education; third, comprehensive case management; and fourth, providing DSM education in the clinic.

Engage patients in the home/community. Five of 6 HCPs suggested home visits for patients with T2DM. They cited two primary reasons: first, HCPs could observe patient circumstances firsthand, and second, HCPs could gauge patients’ understanding of education received in the primary care clinic. One HCP wondered, "How much did they really understand when they left the doctor's office? Because we can tell them, and we can feel like they understand, but we don't know what it's like when they're home trying to draw their insulin (P 1)." Some HCPs viewed home visits as a way to see "what we're not going to see at the doctor's", and continued on to say, "when someone is in their house, you'll be able to see all of the Coke bottles lined up… when they say 'I don't drink any soda' and then all they have is soda in their house (P 4)." Other HCPs saw home visits as a way to collaborate and teach the patient to apply the information learned in the primary care clinic. One provider commented, "if the patient learns that 'I should be getting forty-five grams of carbohydrate in a meal' and you have somebody that can say 'okay, let's look in your pantry, what's your favorite meal, let's do this together' (P 5)."

Another provider suggested educational sessions held on-location at the grocery store. This HCP stressed that these educational sessions "can't just be about fruits and vegetables. That's not the option for most of our patients." She emphasized the importance of being realistic and considering patients' resources:

> We need to be able to show them how to eat smarter with cheaper food options, whether that's having to buy frozen vegetables and those kinds of things, …most nutritionists that I've worked with are not thinking about cost and we need to think about that (P 5).

Include family members. HCPs readily identified the influence of social support on DSM, but interestingly, their examples were related to the importance of involving female partners in the care of male patients for motivation and information-sharing. One HCP commented that a recent patient had drastically improved his health partially due to the "support he received from his wife (P 2).” Another HCP commented on her male patients’ tendency to exclude family in health management:

> I think we need to… involve families. If you look at it from a male/female perspective, most female diabetics are actually more likely to want to make changes because they are the ones, typically, that do the cooking. If you have a male newly-diagnosed diabetic, he’s fine taking the meds but he doesn’t always share things he learns with the household… So I think for males sometimes we need to think about involving family members (P 4).

Provide needs-based case management. HCPs emphasized the importance of providing needs-based case management for the patients in the clinic with complex health care needs. One provider identified case-management teams as a way to improve care and decrease health care costs:

> “[We should have] a needs-based case-management program focused more on motivational interviewing and coaching… What you want is to have a team of people who are following evidence-based treatment guidelines. Honestly, for diabetes, you don’t need the doctor. We cost too much (P 3).”

One HCP commented that, for these multidisciplinary teams to be successful, coordinated care would be key. To truly provide coordinated care, the practitioner suggested, the teams would have to discuss patients and treatment plans during regular case management meetings. The provider lamented that typically in these situations, “…it’s just you’re doing your thing, I’m doing my thing (P 5).”

Clinic-based DSM education. HCPs mentioned clinic-based DSM education to decrease patient stress associated with seeking education elsewhere. At the time of interviews, most patients received referrals to DSM classes at the local hospital, but many either chose not to attend or were not able to attend. As previously described, the stigma associated with having lower income and education levels may have kept some patients from going. One provider commented, “I think the [DSM classes at the local hospital are] a good thing. But sometimes our patients don’t feel like they fit in there. They really don’t (P 1).” In addition to feeling out of place, HCPs believed that other patients chose not to go because it was “overwhelming” or they were “afraid of the cost (P 2).” To mitigate these negative feelings and promote attendance, HCPs recommended that the clinic offer no-cost, clinic-based DSM education.

Discussion

The purpose of this study was to explore and describe the perceptions of HCPs in a safety net clinic regarding the patient experience of DSM, insights into current practice, and to outline providers’ recommendations for services and supports to enhance DSM. To understand the insights and recommendations of the HCPs, we first sought to understand their position regarding patients’ experience of DSM. Theme one illustrated the beliefs of this group of HCPs about the barriers to engaging in DSM with limited health resources. Within our interview guide, there were no questions that specifically prompted HCPs to discuss individuals with low SES and limited health resources. However, discussion of the unique challenges for individuals with low-SES happened naturally. The HCPs at this safety-net clinic were attuned to the challenges their patients’ faced; when we asked general questions about their patients (i.e., what are the greatest challenges for the person with diabetes?), the sub-themes of “limited access to resources” and “multiple obstacles” rose to the top. Although all patients who seek care at this safety-net clinic do not experience the same economic and social barriers, the HCPs felt that majority do have this experience. Research by Bernheim, Ross, Krumholz and Bradley (2008) supports our findings. Physicians in this study noted that patients with low SES were often uninsured or unemployed, had low educational achievement, faced barriers to transportation, and lived chaotic lives.

In the present study, HCPs described the importance of individual responsibility for DSM: noted one provider, "personal responsibility is first and foremost (P 2)." This attitude is pervasive amongst the general population in the United States; most believe that individual health behavior (e.g., smoking, unhealthy diet, lack of exercise) and access to medical care are the strongest determinants of health (Robert, Booske, Rigby, & Rohan, 2008). However, recent research showed that individual health behaviors were only partially to blame for racial and SES-related health inequities (Braveman, Egerter, & Williams, 2011). The social determinants of health (SDH) framework offers a counter-perspective to the narrative of personal responsibility. SDH are non-medical factors that influence the management and trajectory of T2DM: economic stability, educational level, access to health care, social support, and community infrastructure (Braveman, Egerter, et al., 2011; Clark & Utz, 2014). In an extensive scoping review of current literature, Walker, Strom Williams and Egede (2016) found that SDH have more of an impact on DSM than individual health behaviors. In a study by Bernheim and colleagues (2008), physicians described situations in which patients' SES impacted the type of care they received (e.g., less aggressive treatment, postponement of laboratory testing). The physicians believed these changes were in the best financial interest of the patient, but they may unknowingly have contributed to widening gaps in health equity. Our research supports the influence of SDH on engagement in DSM. The dueling concepts of personal responsibility and the influence of the greater context on health both emerged in the providers' narratives. It is unclear which factors had a greater impact on how our HCPs make decisions and provide care.

Individuals who access care in safety-net clinics often live below the poverty line and may struggle to obtain basic human needs, like secure housing and adequate food supplies (Nguyen et al., 2016). HCPs in this study have stated that the ability to prioritize health is based on a hierarchy similar to Maslow's Hierarchy of Needs (Maslow, 1943), where biological and safety needs supersede the higher order needs of a healthy lifestyle. Some of these HCPs regard addressing these more basic needs, like food security and housing, as fundamental to successful DSM. One provider discussed the importance of "coming alongside (P 5)" the patient to address their concerns related to food and housing before introducing DSM. These HCPs believed that only after addressing basic needs will an individual have the capacity to focus on improving health behaviors.

Contrarily, other HCPs in our study found success by starting small. Two providers commented on building success with small goals, like adding water to their diet or switching from flour to corn tortillas. Self-efficacy theory (Bandura, 1977) supports this approach: setting small goals can build confidence to tackle larger challenges such as long-term employment or stable housing. Self-efficacy is a well-established predictor of ability to undertake health behaviors (Grembowski et al., 1993; O'Hea et al., 2004; Schwarzer & Renner, 2000; Strecher, McEvoy DeVellis, Becker, & Rosenstock, 1986). Recently, Gunstzviller, King, Jensen and Davis (2017) linked increases in self-efficacy with improved fruit and vegetable consumption and weekly exercise in a low SES population (Guntzviller, King, Jensen, & Davis, 2017). In addition to building a repertoire of success, one strategy used by our HCPs to enhance self-efficacy and build momentum for behavior change is motivational interviewing (MI) (Rollnick, 2002). MI is a client-centered dialogic method manifested through reflective listening and shared patient-provider decision making that enhances motivation for change by encouraging clients to find their own solutions (Walpole, Dettmer, Morrongiello, McCrindle, & Hamilton, 2011). One HCP discussed her strategies for guiding patients toward smaller, more achievable goals:

> If somebody says "gosh, I really need to exercise. Well I'm going to exercise every day for an hour," [I may] work with them using MI… to get them okay to see maybe an hour is too much. I always do things very time limited…what do you think you can do… just for this month (P 5).

These differences in approach, whether starting big (with housing, employment) or starting small (with discrete, measurable goals and building self-efficacy), underscore the idea that HCPs can build understanding and confidence fundamental to DSM by multiple means. As one HCP declared, "there are many ways to skin a cat (P 3)."

Nearly every HCP mentioned that patients would benefit from having access to DSM education and training in the home or community. Particularly salient in these responses was that, by entering the home, HCPs would be able to observe what is not apparent in the clinic, thereby helping the patient identify individualized goals and strategies. A recent home-based program to increase physical activity in individuals with T2DM improved physical functioning and mental health at six months by providing one-on-one, tailored training in the home and community (Collins et al., 2011). One additional benefit of the home-based exercise intervention was the decreased patient burden of scheduling and transportation, an issue also noted by the participants of the present study.

Although interviewed HCPs indicated that home-based interventions were in the patients' best interest, the acceptability of this approach for DSM is not yet clear. We identified only one previous study that suggested the acceptability and feasibility of home-based interventions for patients with T2DM (Keogh et al., 2011). Research from another complex patient group – those with Alzheimer's disease – suggested that the acceptability of a home-based intervention depended upon a trusting relationship between the care provider and recipient (Mahoney, Trudeau, Penyack, & MacLeod, 2006). While individuals with T2DM are certainly different from individuals with Alzheimer's, we might expect that this holds true across populations. The desirability of home-based interventions for individuals with T2DM is also unclear. In qualitative research studies exploring effective patient-identified strategies for DSM (Anderson-Loftin & Moneyham, 2000; Booth et al., 2013; Nagelkerk et al., 2006), patients have not identified home-based training and education. However, it is possible that these patients were unaware of the possibility of home-based services. Future research should explore acceptability and desirability of home-based interventions for patients with T2DM.

HCPs also recommended incorporating family and the family context into DSM. Previous research suggested that family support can be a help or a hindrance. For example, traditional gender roles (i.e., women's dominance in the kitchen) may constrain the ability of men to make dietary adjustments (Carbone et al., 2007). On the other hand, male patients in another study felt that their wives took their needs into account (Gallant, Spitze, & Prohaska, 2007). In a large meta-analysis, DiMatteo (2004) found that social support benefited patients' health by buffering stress, changing affective states, increasing self-efficacy, and influencing change in negative health behaviors across diagnostic categories (DiMatteo, 2004a). However, in a study of individuals with T2DM, some individuals felt that inclusion of family members contributed to "criticizing" or "nagging" to increase adherence to DSM (Carter-Edwards, Skelly, Cagle, & Appel, 2004). The decision to include family members in DSM education should be individualized based on patient circumstances and family relationships: *quality* of family interactions may be a more important factor than simply presence of an individual in a social network (DiMatteo, 2004a).

Despite providers' convictions about strategies to improve care related to DSM, HCPs in this study described barriers to providing ideal care. First, they identified time limitations. Previous research examining physician time-use indicated that physicians spend only 55% of the 8.6 hour workday in face-to-face patient care (Gottschalk & Flocke, 2005). However, another study suggested that, to meet clinical practice recommendations for chronic disease, physicians would need to spend 10.6 hours per day in direct patient care (Østbye et al., 2005). The HCPs in our study expressed frustration with time constraints; as one provider stated, "there are too many things to worry about [in patient care] and the diabetes will often get pushed aside (P 3)." HCPs also identified patients' limited resources throughout the interviews, especially when discussing barriers to ideal practice. The study by Bernheim and colleagues (2008) described previously, suggests that, by accounting for patients' SES in clinical decision-making, providers may unwittingly re-enforce health disparities. The perspectives of HCPs in our study reflect a tense balancing act between what is realistic and what is ideal.

While not often identified as a barrier by clinicians in our study, financial and systemic conditions in this clinic may also have prevented ideal care. The recommendations made by HCPs in this study to ameliorate barriers (i.e., home/community visits, engaging family members, clinic-based DSM education, and team-based case management), could likely only exist in a health system that uses a coordinated framework of specialized, non-physician providers who provide monitoring and management for DSM (Milani & Lavie, 2015). However, the current fee-for-service medical system discourages care coordination (Schroeder & Frist, 2013). One provider seemed especially cognizant of this barrier. The provider noted that the suggested practices would require a fundamentally different type of health care system: “We have a pretty good sense of what we need to do [for chronic conditions] but we don’t have a system that’s funded to do that work. We have a system that’s funded to chop off legs, treat wounds, and inject things (P 3).” This sentiment is echoed by a recent article calling for the reorganization of health care in the United States from reactive, episodic care to integrated, multidisciplinary care for better management of chronic conditions, the chief medical crisis of the 21st century (Milani & Lavie, 2015).

Limitations

We present several limitations to consider. First, there are inherent problems with asking the view of HCPs about the experience of their patients. Though they do have the experience and interaction with patients, providers can be subject to implicit biases that can shape their communications and behavior toward a group of people (Chapman, Kaatz, & Carnes, 2013). These implicit biases may operate without conscious awareness but may still influence HCP treatment decisions. To reduce the impact of implicit biases, we presented beliefs about the patient experience of DSM in theme one in order to position HCPs’ insights and recommendations. Additionally, while patients in a safety-net clinic tend to be of lower SES, more than 35% of all safety-net primary care visits in the United States between 2006 and 2010 were among adults with primary insurance other than Medicaid, suggesting higher SES (Nguyen et al., 2016). If this pattern endured in the safety-net clinic where we conducted this study, it is possible that at least a third of patients may not experience the same social and economic barriers described by the HCPs. The HCPs in our study made generalizations about their patients as a whole; however, these findings cannot be transferred to all patients in safety-net clinics. A further limitation is the number of participants and the isolation to a single clinic.

The study included six participants all from a single safety-net primary care clinic. We included a variety of occupational roles in our study, thus obtaining a variety of perspectives. However, there is only one HCP from each discipline, therefore, these findings may not be representative of all professionals in a certain field. Given that we only had one HCP from each discipline and our study was limited to six HCPs, we likely did not meet saturation of ideas. Future researchers should include more participants to improve saturation and interpretation of data.

Conclusion

In this study, we presented the perspectives of six HCPs working in a safety-net primary care clinic regarding the patient experience of DSM, insights from current practice, and recommended services and supports for patients with T2DM. Our findings suggested that HCPs felt that patients in their clinic had more obstacles to DSM relative to individuals who seek primary care elsewhere. These obstacles lead the HCPs to use approaches of empathy, non-judgement, and connection to facilitate behavior change. Despite this, HCPs experienced barriers to ideal care based on limited time for patient care and poor participation in patient programming. Lastly, HCPs in this clinic believed patients would benefit from training and education in the home/community, engaging family members in educational sessions, clinic-based DSM education and team-based case management. HCPs believed these recommendations would provide a more efficient, integrated, and comprehensive care experience for the patient. However, these recommendations have barriers to implementation in the United States' current health care system.

Figures and Tables

Table 3.1 *List of questions and probes for HCP interviews*

Opening Question (2-3 min)

Who are you, what is your experience in working with people with diabetes? What is your role in the clinic?

Transition Question (5-7 min)

What are the essential components that people with diabetes need to do to manage their diabetes well?

- Where do they struggle most?
- Why do you think they struggle with that?

Key Questions (15-20 min)

What are the supports and barriers to good diabetes self-management program?

- Services or resources that are missing or limited?
- What are the greatest challenges for the person with diabetes?
- How might we get around these barriers? What would you recommend to people working with this population?
- What are the challenges you (as the provider/nurse) experience in working with these patients towards better health goals?
- What have you seen that works?

If you could create a program for diabetes self-management, what would it entail?

- What type of patient would most benefit from this type of intervention?

Exit Questions (3-5 min)

Is there anything else that is important for us to know?
Is there anything else we can do to help the staff?

Table 3.2 *Characteristics of study participants*

Participant number	Occupation	Years in field
P 1	Social worker	21
P 2	Nurse	5
P 3	Physician	18
P 4	Pharmacist	12
P 5	Lifestyle educator	10
P 6	Case manager	6

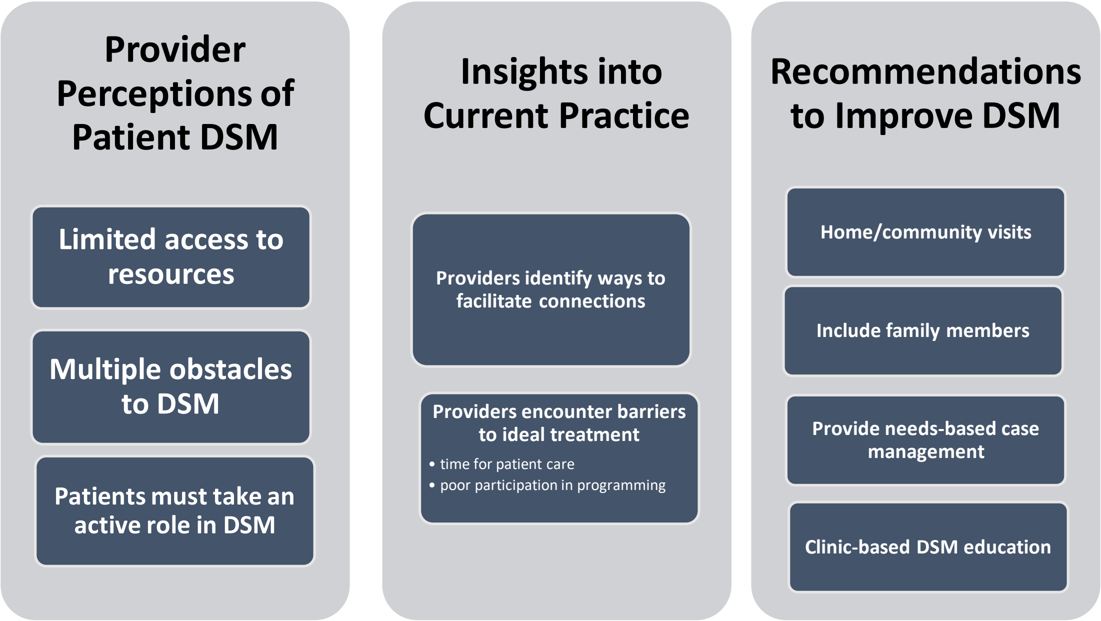

Figure 3.1. Themes from interviews with HCPs.

CHAPTER FOUR: DISCUSSION

The purpose of this dissertation was to advance understanding of the experience and management of type 2 diabetes (T2DM) for adults. To achieve this purpose, I conducted three studies that will result in three manuscripts to be submitted for publication to academic journals. The results of these studies complement one another and provide a picture of the experience of T2DM using both qualitative and quantitative methods, from the perspectives of the individual with T2DM and their health care providers (HCPs). In this section of the dissertation, I will bring together the findings of these three studies in an attempt to draw attention to commonalities amongst the research, and highlight a potential path for future research and service provision.

Common Threads throughout the Three Studies

In the first chapter, I present Study 1, which used multiple regression to predict instrumental activities of daily living (IADL) performance based on demographic and health variables for individuals with T2DM. In this study, we found that having present-moment depression and history of depression/anxiety, increased number of daily medications, and increased healthcare utilization significantly predicted lower IADL performance. IADL performance, though not a direct measure of diabetes self-management (DSM), encompasses many important activities of DSM (e.g., physical activity, meal preparation, and medication management).

In the second chapter, Study 2, participants discussed ways DSM was influenced by the four components of the Model of Human Occupation (MOHO): volition, habituation, performance capacity, and the environment. The most resonant findings from this study were 1) the barriers to DSM originating from the social environment, 2) the importance of consistent habits and routines for DSM, and 3) how decreased performance capacity impedes motivation for exercise. This study demonstrated the intricate and multi-faceted nature of the occupation of DSM, as well as the utility of using MOHO for exploring this occupation.

In the third chapter, Study 3, HCPs discussed the patient experience of DSM, provided insights into current practice in safety-net primary care, and recommendations for services and supports to improve management of T2DM. From this study, we learned that HCPs believed their patients experienced increased barriers to DSM than patients from non-safety-net primary care clinics. We also learned that HCPs used specific strategies to build understanding with their patients, who often have chaotic lives. These HCPs also experience barriers to providing ideal care. Finally, HCPs offered recommendations for services and supports that would provide an improved care experience for their patients. These recommendations included: providing visits in the home/community, engaging family members in DSM training, providing needs-based, coordinated case management, and providing clinic-based DSM education. However, as noted, these recommendations are difficult to implement in the current health care system. In the following sections, I will discuss common threads across the three studies.

Complexity of Diabetes Self-Management

Within qualitative Studies 2 and 3, there was a depiction of DSM from two different perspectives: the individual with T2DM and HCPs from a safety-net clinic. In both of these studies, the complexity of DSM was highlighted, though through different lenses. In this section, I discuss the common themes through both studies: 1) family dynamics/social support was a major influence for DSM, 2) consistent habits and routines upheld DSM, and 3) health behavior is a matter of personal responsibility.

First, participants in both studies discussed the importance of the family and social environment on DSM. In Study 2, the familial dynamic was referred to both as a help and a hindrance to DSM. When family members were receptive to the self-care needs of the individual with T2DM, they were supportive, but when family members did not understand, or social environments were unsupportive, there were negative feelings and activity avoidance. Similarly, in Study 3, HCPs discussed the importance of involving family members in learning opportunities, thus increasing information sharing in the household. HCPs believed that increased information sharing amongst family members would improve motivation and diet adherence. These findings emphasize an important point: DSM does not occur in a vacuum. If individuals with T2DM needed only to consider themselves and their own self-care, DSM would be much less complicated. This was particularly salient in the comment from Jamie in Study 2 regarding how caring for her father with dementia and hypoglycemia impacts her engagement in DSM. Referring to their different glycemic needs, she said, "…so I'm trying to deal with him and deal with me." This provides a poignant example of the enormous pressure some individuals feel to care for family members even though it interferes with lifestyle behaviors. In agreement with previous research, the quality of family and social support is likely more important than mere presence of an extended family or social network (Carter-Edwards et al., 2004; DiMatteo, 2004a).

The second common thread throughout Studies 2 and 3 was the idea that consistent performance of lifestyle behaviors upheld DSM. In Study 2, we used the MOHO concept of habituation to conceptualize the consistent patterns of behavior associated with DSM. Many participants indicated that even though the rigidity of routines was "frustrating" at times, they were viewed as important to maintaining health. In this study, DSM habits and routines were motivated by both positive and negative subjective feelings, and were found to be interdependent with the environment. In Study 3, habits and routines were not addressed so explicitly, however, HCPs were quick to point out the survival mentality often experienced by individuals with low SES is a hindrance to prioritizing lifestyle. The chaotic life circumstances experienced by many patients at the safety-net clinic do not naturally support consistent participation in DSM, but past research examining DSM routine development in similarly complex groups has shown that, not only is this possible (Fritz, 2014), establishment of DSM routines has powerful effects for glycemic control (Pyatak et al., 2018).

Third, in both studies, personal responsibility for health behavior, or the idea that individuals are responsible for their own health, was discussed. In Study 2, this discussion surrounding the need for willpower and self-control, and in Study 3, HCPs pointed out that patients have to "want to be better… or you're not going to get anywhere". Although in both studies there was recognition that outside factors also impact a person's ability to engage in DSM, personal responsibility was viewed as equally important. In Study 2, Belinda shared, "the idea is self-control… Which is so important with diabetics…If you have a lot of self-control, you're a better person." This quote not only illustrates the perceived importance of self-control, but also the perception that lack of self-control was a moral problem. This statement reflects the power of societal judgement, which people with T2DM have felt intensely (Youngson, 2019). Rose also weighed in, "[managing T2DM] takes a lot of willpower, and sometimes we don't have it." In Study 3, HCPs recognized the difficulty of managing T2DM, especially given low SES and other attendant problems (e.g, low health literacy, chaotic lives), however, there was an undercurrent of personal responsibility that ran through many of the interviews. For example, one HCP argued that "we are giving individuals personal responsibility, but we know that individuals just aren't responsible (P 3)." HCPs also discussed ways to motivate patients to seek better health rather than ways of augmenting public policy to better support individuals with chronic conditions. However, this may be due to the nature of the interview, which was to identify services and supports, not highlight public policy matters. Overall, the convergence of findings from Studies 2 and 3 confirm the complexity and multi-faceted nature of DSM. In order to engage in DSM, individuals must contend with many influences within and outside of personal control, however, there is a buffering effect of positive family support and consistent performance of health-supporting habits and routines.

Impact of Life Chaos on Daily Activity and DSM

The previous section highlighted the complexity of DSM, and in this section, I discuss how life chaos further complicates daily activity and engaging in DSM. Life chaos, in recent literature, has been defined as "variability in daily routine" (O'Conor et al., 2018, p. 2). In the present research, life chaos was an impendence to performing both IADL and DSM from the perspectives of individuals with T2DM and HCPs. In study 1, individuals who spent more nights in the hospital had decreased levels of IADL performance. Life chaos was recently shown to be a barrier to seeking regular medical care (M. D. Wong, Sarkisian, Davis, Kinsler, & Cunningham, 2007), therefore, increased use of urgent health care (i.e., hospital overnights) is a potential indicator of greater life chaos.

In study 2, individuals with T2DM found greater control of T2DM when they consistently participated in DSM behaviors. Consider the way Brett steadfastly recorded each meal he ate for review at the end of the day. He perceived this practice as giving him increased control over his condition. Brett's daily routine, as a middle-class, retired man, allowed him to take the time to record his dietary intake as well as organize the local T2DM information classes.

This level of dedication to DSM may not be available to someone with more pressing demands on their time and more day-to-day variability.

In Study 3, the "chaotic lives" of patients were often-mentioned by HCPs as a barrier to DSM. One provider emphasized that the life chaos experienced by many patients in safety-net clinics goes beyond SES and limited access to resources, "there are ways to get medicines [with prescription assistance], there are ways to get food..." Though social and economic hardship make engaging in a consistent daily routine difficult, there are any number of other stressors that are potentially contributing to unpredictability, including housing instability, trauma, mental illness, violence, unsupportive employment, poor physical health, and competing demands on time (O'Conor et al., 2018). Taken together, the findings from three studies, alongside previous research, illustrate the deleterious impact of a high amount of day to day variability on DSM as well as the positive influence of predictability in daily routines. However, life chaos and its relationship to DSM have not received enough attention; future research should work to understand the sources of life chaos as well as the impact of life chaos on DSM.

Directions for Future Research

Together, these three studies provide preliminary evidence for the need for further research examining the existence and impact of life chaos on management of T2DM. One way to increase understanding of life chaos in this context is to explore non-diabetes-related stressors, a concept theorized based on the findings of this dissertation. This concept is closely related to diabetes distress, an important determinant of long-term glycemic control (Fisher et al., 2010). Diabetes distress can arise from diabetes and related management, as well as from everyday life (familial, home, and work environments, etc.); both types of distress can negatively impact the ability to successfully manage T2DM (Fisher, Gonzalez, & Polonsky, 2014). Current methods of assessing diabetes distress understand well the burdens of T2DM, but lack comprehensive assessment of the sources of distress and related impacts on DSM (Fisher et al., 2014). Therefore, qualitative research is needed to begin to operationally define these non-diabetes-related stressors and understand their impact on DSM. In the present research, individuals with T2DM and HCPs identified the following non-diabetes-related stressors as having an impact on DSM: caregiving responsibilities, poorly defined DSM routines, chaotic lives, limited access to resources, mental health concerns, physical limitations, and low health literacy.

Each of these stressors are amenable to intervention that is patient-centered and holistic. Occupational therapists have expertise and ability to have real impact on the lives of individuals with T2DM. Occupational therapists can aid in development of daily routines that support different roles (e.g., caregiving, mother) and integrate DSM behaviors, thus helping the individual bring order to chaos (Fritz, 2014; Pyatak, 2011). Also in the scope of occupational therapy practice is the adaptation or modification of physical activity and occupations of DSM to accommodate limitations of the physical body (American Occupational Therapy Association, 2014). Further, occupational therapists are prepared to individually tailor intervention to individuals with limited health literacy to empower and increase self-efficacy (Levasseur & Carrier, 2012). Developing a deeper understanding of everyday, non-diabetes-related stressors and their subsequent impact on DSM will enhance clinical decision-making and identify potential inroads for occupational therapy intervention for this population with complex health care needs.

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APPENDIX

Participant #__________ Date ____________ Session 1 2 3 Reviewer _________

Hospital Anxiety and Depression Scale

The TODAY Project
Department of Occupational Therapy, Colorado State University

Please circle one answer which describes your current feelings

Score:

1. I feel tense or 'wound up':
    a. Most of the time
    b. A lot of the time
    c. From time to time, occasionally
    d. Not at all

2. I still enjoy the things I used to enjoy:
    a. Definitely as much
    b. Not quite so much
    c. Only a little
    d. Hardly at all

3. I get a sort of frightened feeling as if something awful is about to happen:
    a. Very definitely and quite badly
    b. Yes, but not too badly
    c. A little, but it doesn't worry me
    d. Not at all

4. I can laugh and see the funny side of things:
    a. As much as I always could
    b. Not quite so much now
    c. Definitely not so much now
    d. Not at all

5. Worrying thoughts go through my mind:
    a. A great deal of the time
    b. A lot of the time
    c. From time to time, but not too often
    d. Only occasionally

6. I feel cheerful:
    a. Not at all
    b. Not often
    c. Sometimes
    d. Most of the time

7. I can sit at ease and feel relaxed:
    a. Definitely
    b. Usually
    c. Not often
    d. Not at all

Please continue to the other side

Score:

8. I feel as if I am slowed down:
   a. Nearly all the time
   b. Very often
   c. Sometimes
   d. Not at all

9. I get a sort of frightened feeling like butterflies in the stomach:
   a. Not at all
   b. Occasionally
   c. Quite often
   d. Very often

10. I have lost interest in my appearance:
   a. Definitely
   b. I don't take as much care as I should
   c. I may not take quite as much care
   d. I take just as much care as ever

11. I feel restless as if I have to be on the move:
   a. Very much indeed
   b. Quite a lot
   c. Not very much
   d. Not at all

12. I look forward with enjoyment to things:
   a. As much as I ever did
   b. Rather less than I used to
   c. Definitely less than I used to
   d. Hardly at all

13. I get a sudden feeling of panic:
   a. Very often indeed
   b. Quite often
   c. Not very often
   d. Not at all

14. I can enjoy a good book or radio or TV program:
   a. Often
   b. Sometimes
   c. Not often
   d. Very seldom

Total Evens (3-0): ______

Total Odds (0-3): ______

Adapted from the Hospital Anxiety and Depression scale

Participant #__________ Date ____________ Session 1 2 3 Reviewer _________

The Frenchay Activities Index
The TODAY Project
Department of Occupational Therapy, Colorado State University

In the last 3 months how often have you undertaken:

1. Preparing main meals (circle <u>one</u> of the following):
    0 = Never
    1 = Less than once a week
    2 = 1-2 times per week
    3 = Most days

2. Washing up after meals (circle <u>one</u> of the following):
    0 = Never
    1 = Less than once a week
    2 = 1-2 times per week
    3 = Most days

3. Washing clothes (circle <u>one</u> of the following):
    0 = Never
    1 = 1-2 times in 3 months
    2 = 3-12 times in 3 months
    3 = At least weekly

4. Light housework (circle <u>one</u> of the following):
    0 = Never
    1 = 1-2 times in 3 months
    2 = 3-12 times in 3 months
    3 = At least weekly

5. Heavy housework (circle <u>one</u> of the following):
    0 = Never
    1 = 1-2 times in 3 months
    2 = 3-12 times in 3 months
    3 = At least weekly

6. Local Shopping (circle <u>one</u> of the following):
    0 = Never
    1 = 1-2 times in 3 months
    2 = 3-12 times in 3 months
    3 = At least weekly

7. Social occasions (circle <u>one</u> of the following):
    0 = Never
    1 = 1-2 times in 3 months
    2 = 3-12 times in 3 months
    3 = At least weekly

Participant #__________ Date ____________ Session 1 2 3 Reviewer _________

Participant Information Sheet

The TODAY Project

Department of Occupational Therapy, Colorado State University

The information obtained in this questionnaire will be kept confidential and in a secure area.

DO **NOT** WRITE YOUR NAME ON THIS SHEET

Participant Number:	Date:	Reviewed by:
Date of birth:	Height:	Weight:
Do you have? ☐Smart phone ☐Tablet ☐Laptop computer ☐Desktop computer ☐Other computer access (e.g., public library) ☐Email address	**Where do you access the internet?** ☐Home ☐Work ☐School ☐Other (e.g., library, business) ☐Do not access internet	**Have you attended diabetes education sessions through Family Medicine Center or Poudre Valley Hospital?** ☐Yes ☐No

Health Care Use

In the past 6 months, how many times did you visit a physician? *(Do not include visits while in the hospital or the hospital emergency room)*	
In the past 6 months, how many times did you go to a hospital emergency room?	
How many of these visits were related to symptoms or secondary complications of diabetes?	
How many total nights did you spend in the hospital in the last six months?	
How many times per year do you go to the dentist?	
When was your last dental appointment?	
Did you get a flu shot this year?	
If not, did you get one last year?	
When was the last time you had your eyes examined?	
In the past 6 months, have your feet been examined by a doctor or a nurse?	
In the past 6 months, have you had any wounds that are slow to heal?	

Have you recently fallen? ☐ Yes ☐ No ☐ Do not remember

If 'Yes,' how often? ☐ *Daily* ☐ *Weekly* ☐ *Monthly* ☐ *Just once* ☐ *Other* __________

Were you injured? ☐ Yes ☐ No ☐ Do not remember ☐ N/A

Do you think the fall was related to diabetes? ☐ Yes ☐ No ☐ Not sure

If yes, please explain below…

____

Please continue to the other side

Health History

Have you ever been told by a doctor that you have any of the following?

Kidney problems?	Yes ☐	No ☐
Neuropathy (nerve damage)?	Yes ☐	No ☐
Heart disease or stroke?	Yes ☐	No ☐
Eye disease?	Yes ☐	No ☐

If yes, circle all that apply: Cataracts Retinopathy Glaucoma

Periodontal (gum) disease?	Yes ☐	No ☐
Frequent infections of the skin, feet, lungs, or other body parts?	Yes ☐	No ☐
Depression or anxiety?	Yes ☐	No ☐

Current Medications

Name of medication?	Reason for medication?	Times taken per day?	Taken for how long?

Health Measures

A1C ____________

Cholesterol ____________

BMI ____________

Blood pressure ______/______

Other:

What is your ethnicity?

☐Hispanic or Latino ☐Non-hispanic or Latino

What is your race?

☐White
☐Black or African American
☐American Indian or Alaska Native
☐Asian
☐Native Hawaiian or Pacific Islander
☐Two or more races

Do you work or volunteer in the community? ☐Yes ☐No; ☐work ☐volunteer ☐both
If "yes", how many hours per week do you work/volunteer? ______________

What is your total annual household income?

☐Less than $10,000	☐$40,000-49,999	☐$80,000-89,999
☐$10,000-19,999	☐$50,000-59,999	☐$90,000-99,999
☐$20,000-29,999	☐$60,000-69,999	☐$100,000-149,999
☐$30,000-39,999	☐$70,000-79,999	☐$150,000 +