ABSTRACT

Objective: The purpose of this study was to investigate the relationship between type 1 diabetes duration and uncertainty. According to the Reconceptualized Uncertainty in Illness Theory, it was hypothesized that longer duration would be associated with less uncertainty.

Research Design and Method: A sample of 379 people with type 1 diabetes recruited from the T1D Exchange completed an online survey. The online survey measured disease duration, uncertainty, and demographic characteristics. Multiple variable linear regression was calculated to test for an association between diabetes duration (in years) and uncertainty in diabetes self-management. Post hoc one-way analysis of variance with Tukey’s HSD test was calculated to investigate uncertainty at five and ten-year disease duration intervals.

Results: With adjustment for age, gender, and education, diabetes duration was negatively associated with uncertainty (b = -0.15, p = .03; 95% CI = -0.28, -0.01). Uncertainty was lowest among the 64 participants with a duration equal to or greater than 40 years (M=63.53, SD=15.04). In Tukey’s HSD post hoc test, the mean difference on the uncertainty scores for 5 to < 10 years diabetes duration (n=38, M=72.66, SD=14.51) and 40 or more years diabetes duration was significant (p = 0.02, 95% CI = 0.81, 17.44).

Conclusions: Individuals with longer disease duration reported less uncertainty related to self-management, and uncertainty varied by duration interval. These findings provide preliminary information about where to place behavioral interventions designed to reduce uncertainty among individuals with type 1 diabetes.
INTRODUCTION

Uncertainty, defined as the inability to determine the meaning of illness-related events [1], characterizes the chronic illness experience [2, 3]. Uncertainty is important because it relates to self-management behaviors among those with chronic conditions [4]. For example, higher levels of uncertainty have been associated with worse self-management behaviors, resulting in poorer outcomes [4].

Type 1 diabetes mellitus (T1D) demands complex self-management behaviors [5]. Due to the need for intensive biological, behavioral, and medication monitoring, uncertainty may be particularly relevant in T1D management [6-8].

Diabetes duration is one factor that could be relevant to uncertainty among those with T1D as uncertainty is not steady across the duration of the disease. For example, uncertainty may be very high among individuals who have very recently received a T1D diagnosis [9]. It is possible that as diabetes duration increases, skills in metabolic management and control mature, and uncertainty decreases. This idea is theoretically grounded; according to the Reconceptualized Uncertainty in Illness Theory (RUIT) [3], uncertainty decreases the longer an individual lives with a chronic condition, such as T1D.

Mishel’s RUIT explains how uncertainty changes over time. Uncertainty in early stages of chronic disease is considered a threat. Over time, the view of uncertainty shifts from disruption to adaptation. Individuals learn to cope with the ongoing uncertainty of long-term disease. It is possible that the association between disease duration and uncertainty could vary across disease duration. For example, King and Mishel (1986) found that illness-related uncertainty decreased over time [10].

Currently the evidence is sparse regarding the relationship between T1D duration and uncertainty, and it is not known if there is a linear association between diabetes duration and uncertainty. Further, to our knowledge there are no published tests assessing this among people with T1D.

Understanding the relationship between duration and uncertainty could be useful for helping those with T1D improve disease self-management. If it was known when across the duration of disease that individuals with T1D are most likely to experience uncertainty, this information could be used to tailor, guide, and target interventions to reduce uncertainty and promote metabolic control.

The purpose of this study was to conduct a theoretically grounded investigation of the relationship between diabetes duration and uncertainty. According to the Reconceptualized Uncertainty in Illness Theory, it was hypothesized that longer duration would be associated with less uncertainty. Uncertainty was also examined by five and ten-year duration intervals to test for differences in uncertainty across the disease duration.

RESEARCH DESIGN AND METHODS

Participants

A total of 379 participants were recruited from T1D Exchange’s online patient community, Glu [11]. The target sample size for this analysis was 89, which was determined from a power analysis for a fixed model linear multiple regression with a medium effect size (r=.3) and 0.95 power [12]. Emails were sent to registered Glu users who previously indicated a preference to be contacted about research studies. Eligible participants were required to be at least 18 years old, with a self-reported diagnosis of T1D. Each participant signed an electronic informed consent form prior to participating in the study.

Participants completed an online, cross-sectional questionnaire designed to identify demographic characteristics of adults with T1D, diabetes duration, and experiences of uncertainty reported by the individuals.

Measures

Dependent Variable

Uncertainty: Uncertainty in diabetes self-management was measured using the 4-factor Mishel Uncertainty in Illness Scale – Form A (MUIS-A) [13]. The measure examines ambiguity (cues about the illness are vague and tend to blur and overlap), complexity (cues about treatment and the system of care are multiple and vary), inconsistency (information changes frequently or does not agree with information previously received), and unpredictability (lack of contingency between illness and treatment cues and illness outcome) [13]. The scale has a reported Cronbach α of
For this study, items were modified for diabetes self-management in collaboration with the T1D Exchange. For example, “It is difficult to know if the treatment or medications I am getting are helping” was reworded to “It is difficult to know if my insulin doses are helping.” Six items were excluded because they were not relevant to diabetes self-management. Response categories were set to a 5-point Likert scale (1 = strongly agree; 5 = strongly disagree). Items were summed to generate a total uncertainty score; higher scores indicated more uncertainty. Total uncertainty was used to capture all aspects of uncertainty.

Independent Variables

Diabetes Duration: First, diabetes duration was treated as a continuous variable calculated by subtracting age at diagnosis from self-reported age [15]. Second, diabetes duration was recoded into 6 categories including <5 years duration, 5 to <10 years, 10 to <20 years, 20 to <30 years, 30 to <40 years, and 40 or more years to test uncertainty at duration intervals [16].

Demographic Characteristics: Demographic characteristics included age (in years), gender, and education level (less than a college degree and college degree or more).

Statistical Analysis

Descriptive statistics were calculated on demographic and independent variables. Multiple variable linear regression was calculated to test for an association between diabetes duration (in years) and uncertainty in diabetes self-management, adjusted for demographic characteristics. Post hoc one-way analysis of variance with Tukey’s HSD test was calculated to investigate uncertainty at five and ten-year duration intervals. Cases with missing data were excluded. Data analyses were conducted using SPSS statistics software 23.0. All study materials were approved by the University of Tennessee Institutional Review Board (UTK IRB # 14-01905 XP).

RESULTS

A total of 379 individuals participated in this study (which was 290 more participants than was needed based on power calculations). A majority of the sample (n=379) was female (70.90%) and had a college or university degree or higher (81.20%). The mean age was 42.94 (SD=14.89), and participants had diabetes for an average of 22.81 years (SD=15.69) (Table 1).
Table 2b summarizes uncertainty at all duration intervals. Uncertainty was lowest among the 64 participants with a duration equal to or greater than 40 years (M=63.53, SD=15.04). In Tukey’s HSD post hoc test, the mean difference (9.13) on the uncertainty scores for 5 to <10 years diabetes duration (n=38, M=72.66, SD=14.51) and 40 or more years diabetes duration (n=64, M=63.53, SD=15.04) was significant (p = 0.02, 95% CI = 0.81, 17.44) (Table 2b).

<table>
<thead>
<tr>
<th>Table 2b. Uncertainty at 5 and 10 year intervals of T1D duration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Uncertainty</td>
</tr>
<tr>
<td>F (378) = 2.58; p = 0.026</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;5 years</td>
<td>70.31</td>
<td>14.80</td>
</tr>
<tr>
<td>5 &lt; 10 years</td>
<td>72.66</td>
<td>14.51</td>
</tr>
<tr>
<td>10 &lt; 20 years</td>
<td>67.01</td>
<td>12.93</td>
</tr>
<tr>
<td>20 &lt; 30 years</td>
<td>66.53</td>
<td>14.49</td>
</tr>
<tr>
<td>30 &lt; 40 years</td>
<td>66.91</td>
<td>13.33</td>
</tr>
<tr>
<td>&gt;= 40 years</td>
<td>63.53</td>
<td>15.04</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>67.38</td>
<td>14.32</td>
</tr>
</tbody>
</table>

**CONCLUSIONS**

According to the Reconceptualized Uncertainty in Illness Theory (RUIT) [3], longer diabetes duration should be associated with less uncertainty because individuals are thought to become more skilled in chronic illness self-management. However, the published evidence is sparse regarding the association between duration and uncertainty in T1D self-management. We tested and found evidence of the RUIT. As theorized by Mishel [3], we found that individuals with longer T1D duration reported less uncertainty related to self-management. This finding is consonant with recent evidence by Gafvels [17] who reported that individuals with a shorter diabetes duration reported more concern about self-management than individuals with a long duration. It was not clear from Gafvel's [17] findings how uncertainty may vary by duration interval.

We also found differences in uncertainty at different duration intervals. In our study, uncertainty increased 5 to <10 years after diagnosis, decreased and then plateaued between 10 to <40 years duration. After 40 years of disease duration, uncertainty was the lowest of all duration intervals. It is not clear from the current evidence why individuals who had T1D diabetes for 5 to <10 years reported the highest uncertainty. It is possible that during this interval uncertainty is highest because individuals are somewhat near diagnosis and have not yet developed the self-management skills needed to reduce uncertainty.

Individuals with T1D for 40 years or more reported the lowest uncertainty. This finding is in line with the Reconceptualized Uncertainty in Illness Theory that suggests individuals adapt to uncertainty over time [3].

This study provides a first step toward understanding the relationship between T1D duration and uncertainty in self-management. This is important because it provides information about where to place behavioral interventions designed to reduce uncertainty among individuals with T1D. For example, individuals with diabetes for 5 to <10 years could be targeted with uncertainty management interventions. These findings could also be used to tailor interventions to specific uncertainty-related issues for individuals at different intervals. For example, if it were determined that individuals in the 5 to <10 year interval needed information about diabetes-related complications, interventions could be built around those issues. Intervention content might be different for individuals with T1D for less than 5 years. Future research should explore the unique experiences, needs, and uncertainty among individuals at distinct intervals.

This study had limitations. First, a cross-sectional study design was used, which limited casual inferences and limits our ability to explore uncertainty experiences across a longitudinal period. Second, the sample was primarily female and highly educated, limiting the generalizability of our findings to the full population of people with T1D. Third, convenience sampling was used; participants were sampled from Glu of the T1D Exchange, and it is possible that our findings suffer from the healthy volunteer effect [18] where the healthiest individuals involved with Glu participated in our survey.

This study also has notable strengths. Participants were recruited from the nation’s only research-based online community of individuals with T1D [10]. This is important because although T1D registries that could provide a population-based sample do not exist, a 2013 report of the T1D Exchange showed it is probable that Glu members provide a high-quality representation of people with T1D [19]. Finally, this study is theoretically grounded.
ACKNOWLEDGEMENTS

The authors have no funding or conflicts of interest to report. LMA contributed the literature review, research design, questionnaire development, data analysis, and manuscript writing. JMJ provided support for research design, questionnaire, and data analysis, as well as manuscript revisions. The authors wish to thank the T1D Exchange and the participants who completed the survey.

CONFLICT OF INTEREST DISCLOSURES

The authors have completed and submitted the ICMJE Form for Disclosure of Potential Conflicts of Interest. The authors report no potential conflicts of interest relevant to this article.

REFERENCES