Investigating Relationships between Diabetes Distress, Diabetes Self-Care Behaviors, Intention to Use and Actual Use of a Personal Health Record within 30 Days of Hospital Discharge in Persons with Type 2 Diabetes

Khaliah Fisher-Grace

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INVESTIGATING RELATIONSHIPS BETWEEN DIABETES DISTRESS, DIABETES SELF-CARE BEHAVIORS, INTENTION TO USE AND ACTUAL USE OF A PERSONAL HEALTH RECORD WITHIN 30 DAYS OF HOSPITAL DISCHARGE IN PERSONS WITH TYPE 2 DIABETES

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Duquesne University

In partial fulfillment of the requirements for the degree of Doctor of Philosophy

By
Khaliyah Fisher-Grace

December, 2021
INVESTIGATING RELATIONSHIPS BETWEEN DIABETES DISTRESS, DIABETES SELF-CARE BEHAVIORS, INTENTION TO USE AND ACTUAL USE OF A PERSONAL HEALTH RECORD WITHIN 30 DAYS OF HOSPITAL DISCHARGE IN PERSONS WITH TYPE 2 DIABETES

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ABSTRACT

INVESTIGATING RELATIONSHIPS BETWEEN DIABETES DISTRESS, DIABETES SELF-CARE BEHAVIORS, INTENTION TO USE AND ACTUAL USE OF A PERSONAL HEALTH RECORD WITHIN 30 DAYS OF HOSPITAL DISCHARGE IN PERSONS WITH TYPE 2 DIABETES

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December 2021

Dissertation supervised by Dr. Melanie T. Turk

**Background:** Diabetes distress (DD) is defined by emotional and behavioral challenges caused from diabetes and its management. Diabetes self-care behaviors can be compromised by DD. Personal Health Record (PHR) use has been associated with improvements in HbA1c, blood pressure, and LDL-C, but the relationship between DD and PHR use is unknown. **Aims:** 1) to determine differences between sociodemographic variables and intention to use and actual use of PHR in hospitalized persons with Type 2 Diabetes Mellitus (T2DM), 2) to investigate the relationship between DD, intention to use a PHR and actual use of a PHR within 30 days of hospital discharge, 3) to investigate the relationship between DD, self-care behaviors, and clinical indicators of diabetes self-management, and 4) to investigate the relationship between DD and PHR-related
performance expectancy, effort expectancy, social influence, and facilitating conditions.

**Method:** Using a cross-sectional survey design, 99 inpatients reported their level of DD, self-care behaviors, and intention to use a PHR. **Results:** The mean intention to use the PHR score was 3.4; however, 85.9% did not use the PHR after discharge. Higher levels of DD were associated with higher HbA1c, rho= 0.26, \( p = 0.01 \), but DD was not related to intention to use or actual use of a PHR, \( p = 0.26 \) and \( p = 0.66 \). **Limitations and Implications:** The small number of PHR users and possible recall or social desirability biases are limitations. Nurses should recognize that hospitalization might contribute to DD. **Conclusion:** Future research is needed to understand associations between diabetes distress and PHR use.
DEDICATION

To my friends and Diva Cohort thank you for all your support and encouragement along the way. To my boss Karen Boyd, I cannot thank you enough for promising me a work environment that would allow me to pursue this degree. To my oldest brothers Dalsegno Fisher and Dacee Fisher, Sr. your lives have inspired this work. To my John and LaTonya, and the rest of my siblings, this is a part of our lived experience. This is for us.
ACKNOWLEDGEMENT

I would like to acknowledge Dr. Melanie T. Turk for serving as my committee chair. Without your patience and guidance, I would not be at this point today. To my committee members, thank you for feedback and guidance. Your wisdom and scholarship have helped me conduct a better study and better articulate my findings. To the Nursing Staff at University Hospitals thank you for allowing me to conduct my research on your units and all the assistance that you provided.
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Use of Personal Health Records to Support Diabetes Self-Management: An Integrative Review

More than 30 million persons in the United States (US) have diagnosed or undiagnosed diabetes, and the prevalence is increasing\(^1\). Persons with chronic types of diabetes (i.e. Type 1 Diabetes Mellitus or Type 2 Diabetes Mellitus) must learn self-management principles and techniques, and perform self-care behaviors to reduce the risk of complications associated with this illness. Professional associations have identified self-management, treatment, and quality standards for diabetes.\(^1,2\) In addition to the identification of these standards, there has been an explosion in the use of various types of technology to support diabetes self-management. An electronic Personal Health Record (PHR) is one type of technology commonly used to support diabetes self-management.\(^3\) In the US, health policy and financial incentives set forth in the Promoting Interoperability Program, formerly known as the Meaningful Use Program, encourage the use of Personal Health Records, also called a Patient Portal (PP).

BACKGROUND and SIGNIFICANCE

Definition of Diabetes

While there are three main types of diabetes affecting adults, two are a chronic and require lifelong self-management. Type 1 Diabetes Mellitus (T1DM) is a condition in which insulin is not produced by the pancreas.\(^1\) Over one million American adults have T1DM.\(^5\) In Type 2 Diabetes Mellitus (T2DM), the pancreas does not produce enough insulin to manage glucose levels in the bloodstream.\(^1\) T2DM is the most common type of diabetes, affecting over 23 million adults in the US\(^1\). In addition to the 30.3 million American adults with diabetes, 84.1 million US adults have prediabetes.\(^1\)

Problem Identification

Unmanaged, T1DM or T2DM can cause physical complications to the eyes, feet, heart,
nerves, skin, and may lead to death. Cardiovascular disease is the primary cause of mortality in persons with diabetes. Psychological issues, such as depression and diabetes distress, as well as increased morbidity and mortality, may also occur from poorly controlled diabetes or a diagnosis of diabetes. The high cost of diabetes treatment is another concern associated with increasing prevalence. In addition to the increasing prevalence of diabetes, and the morbidity and mortality associated with unmanaged diabetes is the high cost of diabetes treatment. In the US, the cost of treatment of this illness is estimated to be $404 billion annually. The International Diabetes Federation estimates by the year 2040, 642 million people will have diabetes worldwide. The rising incidence and cost of diabetes combined with the serious complications associated with poor self-management indicate the need for solutions to decrease the burden of this disease.

National organizations such as the American Diabetes Association, and the Centers for Medicare and Medicaid Services (CMS) have identified quality of care standards for diabetes which include care processes and physiological outcomes indicative of good glycemic control. Commonly assessed physiological measures indicative of diabetes self-management include low density lipoprotein cholesterol (LDL-C), blood pressure, and hemoglobin A1C (HbA1c).

Through self-care behaviors, patients can achieve effective self-management of diabetes, which is often assessed by lower or controlled hemoglobin A1C. The American Association of Diabetes Educators identified seven self-care behaviors necessary for effective diabetes self-management. Eating healthy, physical activity, glucose monitoring, medication taking, solving problems, healthy coping, and risk reduction are the seven self-care behaviors contributing to diabetes self-management.

The American Diabetes Association’s (ADA) position statement changed to incorporate the need for psychosocial care in diabetes management, and the 2017 ADA Standards of Care
were updated to reflect this need in self-management and all other facets of diabetes care.9 An element of psychosocial care involves recognition of diabetes distress. Diabetes distress is defined as “the emotional and behavioral challenges generated by diabetes and its management”.10 According to the ADA Standards of Care, high levels of diabetes distress significantly impact medication-taking behaviors and are linked to higher hemoglobin A1C, lower self-efficacy, and poorer dietary and exercise behaviors.9 Understanding diabetes distress is an important factor in knowing how to improve diabetes self-management.

**Use of Personal Health Records**

Over the past decade, several studies have explored or explained the relationships between PHR use and diabetes self-management. PHRs are software applications healthcare consumers can use to manage and share their health information.11,12 The 2009 Health Information Technology for Economic and Clinical Health (HITECH) Act, aimed to increase use of electronic medical records by incentivizing hospitals and healthcare providers. Over a period of 10 years, $67 billion in incentive payments from CMS was initially budgeted for disbursement for demonstrating compliance with standards that reflected the Promoting Interoperability Program. These standards include providing patients with access to personal health records or patient portals (PP).13,14

Initial Promoting Interoperability Program regulations specific to PHR use included capabilities which allowed provision of a clinical summary to the patient and provider after each visit; secure messaging between patients and providers; viewing, downloading, and transmitting PHR data; provision of patient-specific education; reminders for services related to preventative care; and medication reconciliation.14 The features and function of the PHR combined with the clinical information available in the PHR may support diabetes self-care behaviors essential for diabetes self-management.
Purpose and Specific Aims

The purpose of this integrative review (IR) is to synthesize empirical literature about the use of PHRs to support diabetes self-management and to identify opportunities for further research. Specifically, the IR will include research on how PHRs incorporate or address (1) American Association of Diabetes Educators (AADE) self-care behaviors, (2) diabetes-related psychosocial concerns, and (3) the diabetes-related clinical quality of care measures of hemoglobin A1C, Low Density Lipoprotein-cholesterol (LDL-C), and blood pressure (BP).

METHODS

Design

We used the methodology established by Whittemore and Knafl to conduct this integrative review of the literature. The method includes five stages: identification of the problem, a literature search, evaluation of data, analysis of data, and presentation of the results. Use of this specific well-established methodology and strict adherence to inclusion and exclusion criteria helped reduce the risk of bias in this review. Integrative reviews are unique among the four common methods of literature reviews because they allow experimental and non-experimental study designs to be included in the review of a topic.

Literature Search and Search Strategy

A comprehensive search of the literature was performed under the guidance of a health sciences librarian to identify studies related to PHR use to support diabetes self-management. The first author assessed the studies for inclusion and reviewed the literature; data analysis and synthesis were regularly discussed with co-authors. The electronic databases of CINAHL®, Embase®, Ovid Medline®, PubMed®, and APAPsyCInfo®, were searched for relevant literature. We chose these databases in an effort to capture all of the disciplines that might publish on this
topic. Key search terms used in the database search included *diabetes mellitus, type 1 diabetes mellitus, type 2 diabetes mellitus, personal health record, patient portal, electronic medical record, self-care, self-management, psychosocial, stress, distress, and depression*. Table of Contents of journals frequently publishing articles about technology and diabetes were reviewed for relevant articles including *CIN: Computers Informatics Nursing, The Journal of Internet Medical Research (JMIR), JMIR Diabetes, and Diabetes and Science Technology*. We also reviewed reference lists from articles Reference lists from articles found in the literature search were also reviewed to find empirical studies related meeting the eligibility criteria.

**Inclusion and Exclusion Criteria**

Because diabetes is a prevalent illness with a rich body of literature, addressing the purpose and specific aims of this integrative review required discrete inclusion and exclusion criteria. Articles published in academic journals, from 2005 to present with study participants ≥18 years of age were eligible for inclusion in this review. Due to the interest in diabetes-related psychosocial concerns, specifically diabetes distress, studies from earlier than 2005 were excluded because an updated screening measure for diabetes distress was introduced at that time.\(^{10}\) Dissertations, conference abstracts, gray literature, and pediatric studies and were also excluded from this integrative review.

Using Boolean logic, AND OR search functions, 228 articles were considered for review. Duplicates (12) were removed, and 216 article abstracts were reviewed for their relevance and inclusion. Upon further review, 182 articles did not meet eligibility criteria, and thirty-four full text articles were further assessed for eligibility. Of these 34 articles, some did not explicitly describe PHR or PP use for diabetes self-management. Other articles did not exclusively focus on diabetes self-management, some focused on PHR function or design, or patient activation and engagement. Twenty-three articles were excluded, and eleven articles were
chosen for final inclusion in this integrative review. Results of the search strategies are displayed in Figure 1.16

DATA EVALUATION

The studies identified as relevant to this review utilized qualitative, quantitative, and mixed methods research designs. The 16-item Quality Assessment Tool for Studies of Diverse Designs (QATSDDD) was chosen to evaluate the quality of each article. This tool has face validity and good inter-rater reliability ($K = 71.5\%$).17 Qualitative and quantitative studies are evaluated against 14 items, with two items being unique and specific to the type of study being reviewed. All 16 items in the QATSDDD are used to evaluate mixed method studies.

Each article is scored using a 0-3 scoring system. Scores reflect the degree to which the article includes each of the quality criteria, e.g., having an explicit theoretical framework, including a statement of the aims and objectives in the main body of the report, incorporating a clear description of the research setting. Zero indicates no mention of the criterion, 1 reflects a slight reference to the criterion, 2 corresponds to moderate coverage of the criterion, and 3 means complete inclusion of the quality criterion in the article. Scores from each criterion are summed and divided by the total possible points for all criteria, then each article is awarded a total quality score as a percentage. The total score of each article is summed together and divided by highest possible score of the total number of articles reviewed. A cumulative score in a percentage reflective of the quality of the body of literature is then assigned.17 The overall quality score given to the body of literature in this review was 78% out of a possible 100%.17 Cut points specific to level of quality are not established, but percentages are used to provide an overall evaluation of the rigor of research. No articles were excluded from the review based on quality scores. See Table 1 for each study’s quality score.
Data Extraction and Analysis

We extracted common data elements from each article to organize the content and enable comparative analysis to be conducted.\textsuperscript{15} Data elements included the author and year of publication, the study purpose, design, sample size and setting, data collection methods, and the results.\textsuperscript{18} Table 1 shows the common data elements extracted for this integrative review. Using a matrix table, we further organized data by categories according to how PHRs used to support diabetes self-management incorporated 1) AADE self-care behaviors, 2) diabetes-related psychosocial concerns, and 3) the clinical quality of care measures: hemoglobin A1C, LDL-C, and/or blood pressure. Through the iterative process of data evaluation, extraction, and analysis, synthesis of the literature provided insight into how PHR are used to support diabetes self-management as reported below.

RESULTS

Incorporation of AADE Self-Care Behaviors

Six of the eleven studies reviewed related to PHR or PP use for diabetes self-management explicitly investigated self-care behaviors, medication-taking, and diabetes-related distress. We present our analysis of studies related to self-care behaviors first, followed by studies examining medication-taking behaviors, diabetes distress, and physiological measures of diabetes self-management.

Self-care behaviors. Utilization of PHR by patients with T2DM was examined in a qualitative study of 59 patients treated in endocrinology and internal medicine clinics.\textsuperscript{19} Themes emerging from this study included positive and negative experiences with the PHR. Positive experiences included having access to medical information, awareness of blood glucose levels, and being able make behavior changes based on that information. PHR use highlighted areas for self-care improvement, which led some participants to make behavioral changes such as
adjusting insulin dosages, monitoring blood pressure and blood glucose levels as well as exercising and losing weight. Negative feedback included participants with optimal blood glucose control who did not identify a need to use the PHR, uncertainty about the security of health information, computer and health literacy issues, lack of provider encouragement of PHR use, financial concerns about the cost of internet services and concerns about the burden of tracking health information in more than one place. This study showed PHR use enhanced awareness of diabetes self-management and may be a catalyst for self-care behavior change, supporting PHR use for persons with T2DM.\(^{19}\)

**Medication-taking.** Three quantitative studies examined medication-taking behaviors in persons with diabetes who use a PHR. Each study examined this behavior in a different way. In a randomized controlled trial (RCT) conducted with patients from 11 primary care practices, the effect of using a diabetes-specific PHR on diabetes clinical quality measures of hemoglobin A1C, BP, and LDL-C was evaluated. Participants in the intervention group were signed up for a diabetes-specific PHR with diabetes-specific education, secure messaging and clinical decision support based on their blood glucose levels. Participants in the control group had access to the PHR that was not specific to diabetes. Patients in the intervention arm who used the diabetes PHR module and submitted a diabetes care plan prior to their primary care visits (n=82) were more likely to have their hyperglycemia (29% vs 15%; P=.10), hypertension (13% vs 0%; P=.02), and hyperlipidemia (11% vs 0%; P=.03) medications adjusted than patients enrolled in the control arm (n=41) who used a different PHR module.\(^{20}\)

A five-year retrospective cohort study of veterans with T2DM registered for the MyHealth eVet PHR examined the relationship between secure messaging and web-based medication refills.\(^{21}\) Included veterans were registered to use the MyHealth eVet PHR and had at least one diabetes clinical quality or physiological measure (HbA1c, BP, or LDL-C) out of range.
Results revealed better glycemic control in veterans who used the PHR for prescription refills after 3 or more years (OR = 1.07, CI: 1.01-1.14) and better BP control after two (OR=1.06, CI: 1.01-1.12) or three or more (OR = 1.05, CI: 1.00-1.11) years of use than veterans with T2DM who did not use the PHR. Secure messaging and web-based prescription refills were both associated with statistically significant improvements in LDL-C in PHR users compared to non-users.\textsuperscript{21}

In a retrospective cohort study of racial and ethnic minorities with T2DM receiving care at Kaiser Permanente of Northern California, researchers evaluated prescription refill patterns to determine if using the PP refill function resulted in similar changes in statin adherence over time compared with Whites.\textsuperscript{22} Among 17,760 patient records, data from Whites (58%), Blacks (7%), Latinos (9%), Asians (10%), Filipino (9%), and mixed/other/unknown races (9%) showed exclusive online medication refill users (n=3,287) had significantly higher medication adherence from baseline across all racial and ethnic groups. Results from these three studies examining medication-taking behavior and PHR use demonstrated an association between PHR use and improvements in this aspect of diabetes self-management.\textsuperscript{20-22}

**Diabetes-related distress: a psychosocial concern impacting coping.** Healthy coping is another diabetes self-care behavior necessary to achieve self-management examined in two quantitative studies. In both studies, a diabetes self-management education program with access to clinical outcome measures was contained within a PHR with features such as secure messaging. Conducted in primary care settings, both studies used reminders for patients to log in to the portal, and evaluated diabetes-related distress using the Problem Areas in Diabetes (PAID) Screening Tool.\textsuperscript{23,24} While the outcomes of each study differed, both offered recommendations for further research to better understand how the patient’s psychosocial needs are best met using a PHR.
The RCT by van Vugt and colleagues used a PHR which provided access to diabetes education, personal diabetes related outcome measures and behavioral goals, e.g., smoking cessation, diet, exercise, and medication taking, from which participants could choose. Participants were randomized into the coaching group (CG, n=66) and received feedback on their chosen behavioral goals and messages reminding them to use the PHR self-management support program, or they were a part of the non-coaching group (NCG, n=66). Researchers obtained measures of diabetes self-care behaviors, diabetes-related distress, emotional well-being, and health status (HbA1C, BP, LDL-C, BMI, smoking) at baseline and at six-month follow-up.

There were no statistically significant differences in outcomes measures from baseline to follow up between the two groups. Additional findings from this study showed low provider engagement seemed to impact patient engagement with the PHR, and patients who had an overall positive health status did not seem have a need to use the PHR.

The second study addressing coping behaviors specific to diabetes self-management used an internet-based care model with a diabetes education model embedded inside a patient portal. Results from this 12-month study demonstrated a relationship between lower levels of diabetes-related distress and use of the PHR care model. There was also an association between achieving glycemic control followed by decreased levels of diabetes distress. Additional findings from this study concluded persons with lower initial diabetes distress engage more with the PHR. Of the eleven studies included in this integrative review, only two explicitly investigated psychological issues related to diabetes.

**Physiological Measures**

Another aim of this integrative review was to explain how PHR addressed diabetes related physiological measures. Nine of the eleven included studies addressed one or more of the three commonly assessed physiological measures of HbA1c, LDL-C, and BP.
**Hemoglobin A1c.** HbA1c was evaluated as the only physiologic outcome in mixed methods, qualitative, and quantitative studies related to the use of PHR in diabetes self-management. Results from a qualitative study exploring patient communication with providers using the PP showed 82% of patients using the portal had an HbA1c at or below target. In a mixed methods study exploring how adults with T2DM use the secure messaging function of a PHR, a link was noted between patient self-reports of secure messaging use and achieving glycemic control as measured by HbA1c.

A second mixed methods study exploring themes in secure messaging with providers about AADE self-care behaviors found patients who sent messages about glucose monitoring or medication demonstrated a decrease in HbA1c of 0.62 and 0.72 percentage points (P=.03 and P=.01), respectively. Sending messages about healthy eating, glucose monitoring, or medication together contributed to a decrease in HbA1c of 0.54 percentage points compared to not sending messages about these three self-care behaviors (P=.045).

In a retrospective cohort study, Devkota and colleagues assessed the effectiveness of online PHR use (described as no use, read only, or read and write) on HbA1c in persons with T2DM receiving care in primary care clinics. Results showed patients who read their portal information and wrote messages back to their providers had significantly better HbA1c values than nonusers (P < 0.001). Patients who only read their portal information had significantly lower HbA1c values than those who were nonusers (P < 0.05). Results from all studies reflect an improvement in HbA1c for persons with diabetes who use PHRs.

**HbA1C, BP, and LDL-C.** Hemoglobin A1C, blood pressure, and LDL cholesterol were measured together in four studies examining the impact of PHR use on T2DM outcomes. The effect of patient use of an online portal on diabetes outcomes was assessed in a retrospective observational study of patients with T2DM in a university hospital private practice setting in
Vancouver, British Columbia. Results from this study showed that portal users tended to have lower HbA1C at baseline (mean difference 0.89%, \( P < 0.01 \)), and follow-up (6-24 months) HbA1c tended to be lower for users than non-users (mean difference 0.75%, \( P < 0.01 \)); users were significantly more likely to have HbA1c < 7% at last follow-up visit (\( P=0.010 \)). No significant difference in LDL-C and BP were observed at baseline or follow-up.\(^{29}\)

In an RCT, patients in the intervention arm were invited to enroll in a patient portal with diabetes-specific modules for medications and asking providers questions, and patients in the control arm were invited to enroll in a non-diabetes specific PHR.\(^{20}\) Results demonstrated study participants in both arms had good baseline glycemic control, blood pressure and LDL-C, but among persons with HbA1c > 7.0%, patients in the intervention arm were more likely to reach HbA1c goal at study completion (45% vs 25%, \( P=.07 \)). Patients with elevated LDL-C or BP in the intervention arm tended to show improvements in these measures, however the differences were small.\(^{20}\)

As discussed previously under medication taking, use of secure messaging and prescription refill through the My Health eVet (MHV) portal was studied to determine if diabetes outcomes are improved for persons with T2DM compared to those with T2DM who do not use it.\(^{21}\) Sustained use of the secure messaging and prescription refill portal features had an impact on HbA1c, BP and LDL-C with significantly greater odds of achieving glycemic control, blood pressure control and LDL-C level below 100 mg/dL noted in the portal users compared to the non-users at several long-term time points, e.g., two years and after 3 or more years.\(^{21}\)

A retrospective study of 10,746 adults with diabetes mellitus was conducted to examine the use of PHR on physiological measures which included in part HbA1C, blood pressure, and LDL-cholesterol.\(^{30}\) Results from this large study demonstrated that persons who used the PHR
had better diabetes-related physiological measurements than those who did not. In all studies where multiple diabetes-related physiological measures were examined, patients who used the PHR or PP tended to display better physiological measures of diabetes control.\textsuperscript{20,21,29,30}

**DISCUSSION**

The purpose of this IR was to synthesize empirical literature about the use of PHRs to support diabetes self-management in adults with T2DM, and to identify opportunities for further research. This review explored how 11 studies incorporated the use of PHRs to address AADE self-care behaviors, diabetes distress, and diabetes related physiological outcomes. In the majority of studies, participants showed improvement in the self-care behavior (i.e. medication taking) or physiological outcome (i.e. HbA1c, BP, LDL-C) examined. This suggests there is significant benefit to using PHRs to support self-care behaviors and achieve diabetes self-management. Only two studies addressed diabetes-related distress as a secondary outcome of a PHR intervention and results were mixed.

Synthesis of the literature also revealed three major gaps in the literature. First, a paucity of studies have been conducted about PHR use and diabetes-related psychosocial issues or coping. This gap is an important one because diabetes-related distress can negatively impact self-care behaviors and subsequently physiological indicators of diabetes self-management. A second major gap identified in this review is the lack of studies available exploring the use of PHRs for diabetes self-management in recently hospitalized persons. This finding is important because persons with diabetes are more likely to be admitted to a hospital and to have a longer length of stay than those without diabetes.\textsuperscript{31} The third gap revealed in this review is the lack of evidence of patient specific factors influencing intention to use a PHR for management of T2DM. Most studies collected demographic data and published sociodemographic differences; however, they
did not fully explore factors specific to an individual with diabetes which may influence their intention to use a PHR. Among patients with diabetes some characteristics found to be associated with portal use included being young, white, and male. These demographic characteristics have been noted, but how they influence intention to use a PHR has not been discussed in the literature. Without knowledge of what characteristics influence decisions to use a PHR, the ability to promote its use for diabetes self-management is limited.

Limitations

Limitations of this review are related to the quality evidence of the body of literature based on QATSDD criteria, narrow scope of the review, and the limited number of study reviewers. Eight of the eleven studies did not mention, or made only a slight mention of, use of a theoretical framework to guide the study. Only two studies provided a complete description of the statistical assessment of the reliability and validity of the measurement tools used in quantitative and mixed methods studies. The QATSDD tool for evaluation of study quality assesses for the inclusion of participants in the design. This criterion contributed to a lower quality score for the body of literature reviewed because nine articles made no mention of user involvement in the study design, and only two articles made slight mention of user involvement in design. The scope of this review was narrow. Its focus was limited to adults with T2DM who used a PHR to support self-management with a specific emphasis on AADE self-care behaviors, diabetes distress, and physiological outcomes. Finally, there was only one reviewer evaluating studies for inclusion and the quality of evidence of the literature reviewed. Future reviews should include multiple reviewers to identify articles and rate the quality of the evidence.

Implications for Practice and Policy

Despite evidence PHR use improves diabetes self-management, they are underutilized.
The implications for practice include understanding what influences intention to use a PHR. Understanding persons with T2DM intention to use a PHR will increase awareness of barriers to use or facilitators of PHR use. If diabetes distress influences persons with T2DM intention to use a PHR, it is imperative that diabetes distress is treated. This increased awareness of barriers and facilitators to PHR use can be the catalyst for new discoveries that may further promote the use of this technology.

Future health policy research should aim to understand intention to use the PHR, prioritizing the T2DM population as an area of focus. Because the prevalence of T2DM and prediabetes is so large in the U.S. studying intention to use a PHR in this population can provide insight and direction for other chronic diseases requiring lifelong self-management. The low utilization of PHRs despite financial incentives to organizations and providers suggest there is still significant opportunity to address the reasons for this gap. Starting with understanding intention to use the PHR is a necessary first step in closing this gap.

CONCLUSION

Synthesis of the studies presented in this review reflect limited or unspecified incorporation of nationally recognized diabetes self-management standards in PHRs, and highlights the need for multipronged, or multiple solutions to address the complexities of how diabetes self-management is supported through PHRs. The most important finding of this review is the empirical evidence linking PHR use to improved diabetes self-management, measured by diabetes-related self-care behaviors and physiological outcomes. This finding supports use of the PHR in adults with T2DM and to further explore relationships with the major gaps identified from this review. Because the ADA’s 2017 recommendation calls for diabetes-related distress to be recognized in the care and treatment of persons with diabetes, there is a need for further
research describing the use of a PHR and its effect on diabetes distress. The findings of this review reveal preliminary evidence supporting the use of a PHR among patients with T2DM and suggest future research is needed to further explore the potential benefits of PHR use in this patient population.
References


11. Tang PC, Ash JS, Bates DW, Overhage JM, Sands DZ. Personal health records: definitions,


Figure 1 PRISMA 2009 Flow Diagram

Records identified through database searching (n = 226)

Records after duplicates removed (n = 216)

Records screened (n = 216)

Full-text articles assessed for eligibility (n = 34)

Studies included in review (n = 11)

Additional records identified through other sources (n = 2)

Records excluded (n = 182)

Full-text articles excluded (n=23):
- Patient experience/engagement only (n=8)
- No exclusive focus on PHR use for diabetes self-management (n=6)
- App/PHR Design (n=5)
- PHR not used in study (n=3)
- Study incomplete (n=1)

Table 1 Description of Studies Reviewed

<table>
<thead>
<tr>
<th>Author(s)</th>
<th>Purpose and Design</th>
<th>Sample and Setting</th>
<th>Data Collection Methods</th>
<th>Results and Discussion related to PHR Use in Diabetes Self-Management</th>
<th>Data Evaluation</th>
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</thead>
<tbody>
<tr>
<td>Devkota et al.²⁸</td>
<td>To assess the effect of online use of a patient portal on improvement of HbA1c in patients with T2DM in primary care clinics. Retrospective cohort design</td>
<td>1510 patients from 3 family medicine and 3 internal medicine clinics in St. Louis University School of Medicine, St. Louis, MO PHR Used: MyChart</td>
<td>E-mail use, diagnosis, social history, laboratory, and demographic data were obtained from the Primary Care Patient Data (PCPD) Registry.</td>
<td>73% were nonusers, 6% enrolled for e-mail but only read and did not write e-mails (readers), and 21% enrolled and read and wrote e-mails (readers and writers). Patients who read and wrote e-mails had significantly (P &lt; 0.001) lower average HbA1c values compared to nonusers. Patients who only read email also had significantly (P &lt; 0.05) lower mean HbA1c values compared to nonusers.</td>
<td>QATSDD Quality Evaluation Score: 33/42 = 79%</td>
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<tr>
<td>Fonda et al.²⁴</td>
<td>To investigate whether changes in diabetes distress were associated with participation in a 12-month</td>
<td>104 adults with diabetes treated at the Boston</td>
<td>Diabetes Distress measured</td>
<td>People who had lower baseline diabetes distress tended to be</td>
<td>QATSDD Quality</td>
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<tr>
<td>Fuji, Abbot, &amp; Galt.</td>
<td>Internet based care model delivered using a patient portal. Also assessed changes in glycemic control or HgbA1C. Quantitative study, RCT.</td>
<td>Veterans Administration Health System, 99% of sample were men, PHR My HealtheVet Randomized to intervention (n=52) and treatment (n=52) groups Intervention groups received internet based patient portal.</td>
<td>using the PAID scale. Scores obtained at study enrollment and every 3 months for 1 year including HbA1c, and PHR log in.</td>
<td>the same people who used the technology. A causative relationship could not be determined between IBCM PHR use, diabetes distress, and changes in HgbA1C.</td>
<td>Evaluation Score: 34/42 or 81%</td>
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</table>

<p>| Fuji, Abbot, &amp; Galt. | To explore how patients with type 2 diabetes use PHR to manage health information for self-care. Qualitative study, prospective design, patient interviews. | 59 participants were interviewed 3–6 months after receiving initial training on a Web-based PHR. | Interviews were audio-recorded, transcribed, and analyzed using an iterative process of | Nine themes. 3 were related to positive experiences and 6 were related to negative experiences. An example of a positive experience includes having full access to medical | QATSDD Quality Evaluation Score: 37/42 = 88% |</p>
<table>
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<tr>
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<tr>
<td>Grant et al.</td>
<td>The purpose of this study was to identify if a diabetes specific PHR intervention with secure messaging, access to medications, and labs would result in more effective treatment of diabetes-related risk factors (hyperglycemia, hypertension, and hyperlipidemia), in comparison to patients not using a diabetes specific PHR. Another goal of the study was to examine demographic and clinical variations between the intervention and control group. Design: Quantitative, RCT</td>
<td>Midwest, metropolitan city, 2 internal medicine practices and 1 endocrinology practice</td>
<td>Coding, categorization, and theme development. Information, and negative experiences ranged from not thinking about the PHR to concerns over privacy and security.</td>
<td>Patients in the control and intervention arm had a 7-14% utilization rate of the PHR. Persons who used the PHR were younger and had lower baseline HgbA1C. Patients who used the PHR more frequently had an increased percentage of medication adjustments which is reflective of better diabetes management.</td>
<td>QATSDD Quality Evaluation Score: 23/42 = 55 %</td>
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<tr>
<td>Lau et al.</td>
<td>To assess the effect of online patient portal use on diabetes outcomes,</td>
<td>157 participants, (n=50 portal</td>
<td>Log-in and lab value data was collected from</td>
<td>Users achieved A1C &lt;7% at follow up</td>
<td>QATSDD Quality</td>
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<td>Author(s)</td>
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<tr>
<td>Study</td>
<td>Objective</td>
<td>Participants</td>
<td>Methods</td>
<td>Results</td>
<td>Evaluation Score</td>
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<td>Lyles et al.²²</td>
<td>To examine the influence of using the online refill function on changes in medication adherence across racial/ethnic groups. Retrospective cohort design.</td>
<td>17,760, Northern California Kaiser Permanente patients with T2DM prescribed statins</td>
<td>Data collected retrospectively from MyChart. Patient portals were linked to better medication adherence across all racial/ethnic groups.</td>
<td>82% of study participants had HgbA1C at target, diabetes management concepts examined, 3 major themes:</td>
<td>35/42 = 83%</td>
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<tr>
<td>Peremislov²⁵</td>
<td>The purpose of this study was to explore electronic communication between patients with type 2 diabetes and their providers within a patient portal. An aim of the study was to examine characteristics of patients that used the PHR for</td>
<td>Sample size included 90 participant records of patients receiving care in primary or</td>
<td>A purposive random sample of 90 electronic medical record charts of</td>
<td>82% of study participants had HgbA1C at target, diabetes management concepts examined, 3 major themes:</td>
<td>35/42 = 83%</td>
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<td>56% vs. 32% (p = 0.031) for non users.</td>
<td>32/42 = 76%</td>
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Notes:
- HbA1C: Hemoglobin A1C
- T2DM: Type 2 Diabetes
- PHR: Personal Health Record
- EMR: Electronic Medical Record
- BC Diabetes
- MyChart
- QATSDD: Quality Assessment Tool for Service Databases
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<tbody>
<tr>
<td>Quinn et al. 27</td>
<td>To identify patient engagement themes in diabetes messaging with diabetes providers, and determine if differences in engagement in the Mobile Diabetes Intervention Study influenced changes in HbA1c over a 1-year treatment period. Mixed methods study design.</td>
<td>163 patients enrolled in a mobile diabetes intervention study. Persons who were uninsured or had Medicare or Medicaid insurance were excluded. This study was conducted over a 1-year treatment period.</td>
<td>Data was collected from all participants, including demographic information, health history, current health status (including HbA1c) and any medical or medication history.</td>
<td>Sending any messages about healthy eating, glucose monitoring, or medication combined led to a decrease in HbA1c of 0.54 percentage points compared to not sending messages in these themes (P=.045).</td>
<td>QATSDDD Quality Evaluation Score: 41/48 = 85%</td>
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<td>Shimada et al. 21</td>
<td>To evaluate the association between sustained use of specific patient portal features (Web-based prescription refill and secure messaging-SM) and physiological measures important for the management of T2DM. Quantitative study with a retrospective cohort design.</td>
<td>Sample size included 111,686 medical records of patients who received care in the Veterans Health Administration health care system.</td>
<td>Retrospective data collected on persons with T2DM registered for the My HealtheVet portal over a five year time period. persons registered for the patient portal.</td>
<td>HgbA1c at baseline of persons who used SM were significantly more likely than nonusers to achieve glycemic control if they used SM for 2 years or 3 or more years. No significant association between Web-based refill use and glycemic control. Persons with uncontrolled BP at baseline who used Web-based refills were significantly</td>
<td>QATSSD Quality Evaluation Score: 36/42 = 85%</td>
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<tr>
<td>Tenforde et al. 30</td>
<td>To measure the association between use of an advanced electronic medical record-linked PHR and diabetes quality measures in adults with diabetes mellitus (DM). Quantitative study, using retrospective record review.</td>
<td>10,746 adults 18–75-year of age with DM seen at least twice by their Internal Medicine PCP between July 2008 and June 2009 were included in the study using the MyChart PHR in primary practice settings in</td>
<td>Queried EMR data warehouse for clinical quality data and queried PHR to obtain PHR usage data.</td>
<td>more likely than nonusers to achieve control with 2 more years of Web-based refill use. SM and web based refills were both significantly associated with improvements in LDL.</td>
<td>QATSDD Quality Evaluation Score: 28/42 = 67%</td>
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<tr>
<td>Wade-Vuturo, Mayberry, &amp; Osborn</td>
<td>To explore how adults with T2DM use and benefit from secure messaging (SM) within a patient portal. Also to examine use of portal features with glycemic control. Mixed Methods Design</td>
<td>Cleveland, Ohio.</td>
<td>Qualitative data collected through patient surveys and quantitative data extracted from the electronic health record.</td>
<td>3 themes emerged from the qualitative analysis: benefits, barriers, and providers perceptions of SM. Higher self-reporting of secure messaging utilization was significantly associated with glycemic control.</td>
<td>QATSDD = Quality Assessment Tool for Studies of Diverse Designs</td>
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Introduction

Diabetes is a chronic disease present in an estimated 463 million adults worldwide and over 34 million people in the US (International Diabetes Federation [IDF], 2021; American Diabetes Association [ADA], 2021). Further, estimates project that 700 million people worldwide will have diabetes by the year 2045 (IDF, 2021). Each year, an estimated 1.5 million US adults are diagnosed with diabetes, and over 88 million US adults are living with prediabetes, which increases the risk for developing diabetes (ADA, 2021). There are multiple types of diabetes and Type 2 Diabetes Mellitus (T2DM) is the most common. The pancreas produces insulin, which helps drive glucose into the cells to be used for energy. In T2DM, the pancreas does not produce enough insulin to manage excess glucose in the blood or the cells are resistant to the insulin produced (ADA, 2021, CDC, 2021). This may require a person with T2DM to be treated with medications such as insulin and oral antihyperglycemic agents. Management of chronic illnesses, such as T2DM, can be a financial burden, e.g., an estimated $327 billion is spent annually in the US on diabetes management (CDC, 2020). Most of the direct costs of diabetes is attributable to care in the inpatient setting (CDC, 2020).

Diabetes Self-Management and Complication Prevention

Health care professionals assist persons in managing diabetes; however, individuals must also take action to prevent complications associated with the disease. Blindness, lower limb amputations, and kidney failure can occur as complications from diabetes (CDC, 2017). Persons with diabetes are also at increased risk for developing retinopathy, periodontal disease, depression, and acute illnesses such as influenza and pneumonia. Complications from diabetes can progress in severity and lead to death; diabetes is the 7th leading cause of death in the US.
Persons with diabetes can prevent or delay complications associated with this illness by performing self-care behaviors that will support effective diabetes self-management. The American Association of Diabetes Educators (AADE) has defined “healthy eating, being active, monitoring, taking medication, problem solving, healthy coping, and reducing risks” as the self-care behaviors that contribute to effective diabetes self-management (American Association of Diabetes Educators [AADE], 2014, p.1). These self-care behaviors reflect measurable outcomes of diabetes self-care activities. In addition to the AADEs recommendation that healthy coping is an essential diabetes self-management behavior, the ADA Standards of Medical Care also recognizes the need for psychosocial care in persons with diabetes, which includes the recognition of diabetes distress (ADA Standards of Medical Care, 2017).

**Diabetes Distress (DD) is a Psychosocial Component of Self-Management**

Diabetes distress is defined by emotional and behavioral challenges caused from diabetes and its management (Fisher, Hessler, Polonsky et al, 2012). Inadequate self-care and the concern associated with progression of illness are linked to diabetes distress (ADA Standards of Medical Care, 2017). Diabetes distress is estimated to occur in 40% of persons with diabetes (Diabetes Distress Assessment and Resource Center, 2021). Health care team members are encouraged to screen for diabetes distress on a routine basis, when patient and provider established diabetes-specific targets are not met, and when complications from diabetes are first identified (Young-Hyman, Groot, Hill-Briggs. et al, 2016). Diabetes self-care behaviors can be compromised by diabetes distress. It is prudent to identify a patient centered, innovative tool that can assist persons with diabetes in their efforts to engage in self-care behaviors and mitigate high levels of diabetes distress. One such tool may be a personal health record.

**Personal Health Records (PHR) Overview**
Personal Health Records (PHR) are a technological tool used by consumers to manage and share their health information (Tang, Ash, Bates, Overhage, & Sands, 2006; Centers for Medicare & Medicaid Services, 2017). PHRs may be connected, or tethered, to an electronic health record (EMR) or they may be managed by an individual. Lab results, allergies, and other patient information usually transmit from the EMR to a PHR if the PHR is tethered (Irizarry, DeVito Dabbs, & Curran, 2015). The 2009 Health Information Technology for Economic and Clinical Health (HITECH) Act aimed to increase use of electronic medical records by incentivizing hospitals and healthcare providers. Over a period of 10 years, $67 billion in incentive payments from the Centers for Medicare and Medicaid Services was budgeted for disbursement for demonstrating compliance with Promoting Interoperability Program standards which reflected the meaningful use (MU) of electronic health records. These standards include providing patients with access to PHRs, uploading clinical information in the PHR, and measuring PHR use (Blumenthal & Tavenner, 2010; ONC, 2017).

**Diabetes Self-Management and PHR**

Measurement of diabetes self-management generally incorporates evaluating clinical and behavioral outcomes (Beck et al., 2017). Examples of behavioral outcomes include reports from individuals about self-care activities and diabetes distress; examples of clinical outcomes include incorporation of physiological data and biomarkers such as hemoglobin A1c (HbA1c), hypertension, hyperlipidemia, and body mass index (Beck, et al., 2017). Several studies have been conducted that examined the relationship between PHR use and diabetes related clinical outcome measures. Overall, these studies show that portal use is associated with improvements in HbA1c, blood pressure (BP) and low-density lipoprotein cholesterol (LDL—C) (Shimada,

Fewer studies have been conducted that examined the relationship between PHR use and self-care activities and diabetes distress. Results of one study examining diabetes distress, self-care behaviors, and PHR use demonstrated a link between portal use, achieving glycemic control and decreasing diabetes distress although it was unable to determine factors that contributed to portal use (Fonda et al., 2009). A second study investigated usage of a PHR with an embedded diabetes self-management support program on diabetes self-care activities, diabetes distress, and emotional well-being over six months. Forty six percent of study participants only logged into the PHR one time. Of the remaining participants that logged in, only five used the embedded self-management program. No significant relationships of PHR use with any of the study variables were shown (van Vugt et al., 2016).

Gaps in Knowledge

Evidence from studies conducted about PHR use in T2DM suggest improved clinical outcomes, which largely reflect improved diabetes self-management. What remains unknown is the impact of diabetes distress on intention to use and actual use of a PHR. The limited research and conflicting results found in the two studies that examined diabetes distress and PHR use have shaped the purpose of this study, which is to explore relationships between diabetes distress, diabetes self-care behaviors, clinical indicators of diabetes self-management, intention to use and actual use of a PHR among patients admitted to an acute care setting.

Importance to Nursing and Health

Education and skill acquisition are immediate needs for persons who have any type of diabetes (AADE, 2014). Without the proper knowledge and skills, diabetes self-care activities
cannot be performed, and health-related complications may be unmanaged and progress. Nurses in the acute care setting provide education and teach self-care skills to persons with diabetes; they prepare patients to transition from inpatient to outpatient care (American Association of Clinical Endocrinologist [AACE], 2017). Because diabetes requires lifelong self-management, nurses have an integral role in identifying sustainable solutions that can meet the immediate and long-term educational and behavioral needs of persons with this illness. PHRs are commonly used by patients, families, and the healthcare team to manage health information and health status (Tang, 2006, & The Office of the National Coordinator, 2021). This study will explore the PHR and determine its relationship to behaviors and diabetes distress essential to achieve diabetes self-management. This is in alignment with the mission and strategic plan of the National Institute of Nursing Research ("National Institute of Nursing Research," 2017), specifically the scientific focus area of self-management of chronic conditions.

**Theoretical Framework**

The Unified Theory of Acceptance and Use of Technology (UTAUT) (Venkatesh, Morris, Davis, & Davis, 2003) was used to examine intentions to use technology and determinants of usage behavior. Four of the main constructs of the theory include performance expectancy, effort expectancy, social influence and facilitating conditions. *Performance expectancy* reflects how much an individual believes using the system will help him/her in job or task performance. *Effort expectancy* represents the degree of ease associated with use of the system. *Social influence* is how much an individual believes that persons who are important to them think that they should use the new system or technology. *Facilitating conditions* represent the existence of an organizational and technological infrastructure to support use of the system or device. Performance expectancy, effort expectancy, and social influence are direct determinants
of usage intention and usage behavior, facilitating conditions are determinants of user behavior (Venkatesh, Morris, Davis, & Davis, 2003). See Figure 1. The specific aims of the study that were examined, the independent and dependent variables of interest, and how they were measured are represented through the conceptual model displayed in Figure 2.

Among hospitalized persons with T2DM, the specific aims of this study are: 1) to determine if sociodemographic variables, such as race, age, sex, and level of education are associated with intention to use and actual use of a PHR, 2) to investigate the relationship between diabetes distress and a) intention to use a PHR and b) actual use of a PHR within 30 days of hospital discharge, 3) to investigate the relationship between diabetes distress and a) self-care behaviors and b) clinical indicators of diabetes self-management (HbA1c, BP, LDL-C), and 4) to investigate the relationship between diabetes distress and PHR related performance expectancy, effort expectancy, social influence, and facilitating conditions.

![Figure 1. Constructs of the UTAUT Framework](image-url)
Methods

Design

Using a descriptive correlational research design, this study explored associations between diabetes distress, self-care behaviors, clinical indicators of diabetes self-management, intention to use, and actual use of a PHR within 30 days of hospital discharge in persons with Type 2 Diabetes Mellitus (T2DM). A priori estimation using G*Power indicated that 108 participants were needed to achieve .80 power with a medium effect size of 0.30 and a common significance level of 0.05 to examine the relationship between levels of diabetes distress and PHR use (Faul, Erdfelder, Buchner et al., 2009). Ninety-nine inpatients with T2DM were surveyed during their hospital stay to determine their level of diabetes distress, evaluate their participation in self-care behaviors, and assess their intention to use a PHR using the Diabetes Distress Scale (DDS17) (Fisher, 2012), Summary of Diabetes Self-Care Activities Scale (SDSCA) (Toobert, Hampson & Glasgow, 2000), and the adapted Use of Technology
Questionnaire, respectively (Ma, Xiao, & Blonstein, 2013). Actual PHR use was assessed at 30 days post discharge as to whether the participant viewed, downloaded, or transmitted his/her clinical summary report.

**Setting and Population**

The study was conducted in the inpatient setting of an academic medical center in Cleveland, Ohio, where 600-700 persons with diabetes are discharged each month according to internal diabetes metrics. Five inpatient units with the specialties of cardiology, cardiothoracic surgery, infectious disease, orthopedics, and internal medicine were used for recruitment, providing an opportunity for a diverse sample of study participants.

**Inclusion and Exclusion Criteria**

Persons aged 18 years or older with a diagnosis of T2DM admitted to one of the five designated inpatient medical-surgical units were eligible to be included in the study. Participants had to be able to read and comprehend the English language and provide written or verbal answers to survey questions. Two of the survey instruments asked patients to reflect on times when they were not sick, on actions they performed during a seven-day period, or on feelings they had over the course of one month. Due to the amount of recall required, patients who were hospitalized for eight or more days, as well as patients with dementia or diagnosed cognitive limitations were excluded from the study. Patients were only allowed to participate in the study one time, so participants who were readmitted were ineligible to participate in the study again.

**Recruitment**

A partial waiver of HIPAA was obtained so that the PI could identify patients with a diabetes diagnosis through the EMR as potential study participants. Recruitment flyers were available on the designated nursing units. Through convenience sampling, potential participants
were also identified by RNs from the five designated units. Registered Nurses caring for patients on each inpatient unit informed potential participants about the purpose of the study, and if they expressed an interest in participation, provided them with the Principal Investigator’s (PI) contact information. The RNs also asked potential participants for permission for the investigator to contact them and notified the PI through text or phone call of potential participants if the individuals agreed.

**Informed consent procedures**

Upon initial contact with the potential participant, the investigator reviewed the inclusion criteria to determine their eligibility to participate in the research study. Informed consent procedures were performed in accordance with both the Duquesne University and health system IRB. After consent was provided, participants were provided with a packet that included the three survey instruments, a sociodemographic form and an informational flyer describing the health system’s PHR. HbA1c, BP, LDL-C, age, race, admission diagnosis, and PHR usage within 30 days of discharge were obtained from the electronic medical record (EMR) and a PHR use report. Participants who completed the study questionnaires received a $15 gift card as nominal compensation for their time. RN gatekeepers were entered into a monthly drawing for a $25 gift card as compensation for their help with recruitment.

**Variables and Instruments**

Diabetes distress, diabetes related self-care behaviors, clinical indicators of diabetes self-management, sociodemographic factors, performance expectancy, effort expectancy, social influence, facilitating conditions, intention to use a PHR, and actual use of a PHR are the variables that were explored in this study, as described in further detail below.
**Sociodemographic variables.** Sociodemographic information was collected from research participants using an investigator developed data collection tool. Participants were asked to provide the number of years diagnosed with diabetes, educational level, and employment status. Age, sex, and race were collected from the participant’s electronic medical record to decrease the amount of information that the participant was asked to provide.

**Diabetes distress.** Study participants were screened for Diabetes Distress using the publicly-available 17-item Diabetes Distress Scale (DDS17) (Fisher, 2012). The DDS17 is categorized into four subscales that specifically identify what may cause an individual’s distress. Emotional burden (EB), physician-related distress (PD), regimen-related distress (RD), and interpersonal distress (ID) are the four subscales of the diabetes distress scale (Polonsky et al., 2005). Examples of DDS17 items include the following: 1) feeling that diabetes controls my life, 2) not feeling confident in my day-to-day ability to manage diabetes, and 3) feeling that I don’t have a doctor who I can see regularly enough about my diabetes.

Total DDS score, the mean score of all 17 items, was used to analyze the data for this variable. A score of < 2.0 reflects little or no distress, a score between 2.0 and 2.9 reflects moderate distress, and a score > 3.0 reflects high distress (Fisher, 2012). The survey instrument demonstrated high reliability and internal consistency (α = 0.87) among the DDS-17 subscales (Fisher, 2012). In the current study, the Cronbach’s alpha for the 17 item DDS was .94. The DDS has four subscales. The Cronbach alpha for the DDS subscales are as follows: Emotional burden .90, Physician Distress .90, and Interpersonal Distress .87 and Regimen Distress .87.

**Diabetes self-care activities.** The Summary of Diabetes Self-Care Activities (SDSCA) Questionnaire was used to assess participant’s performance of diabetes self-care activities. The SDSCA is an 11-item instrument. The five regimen areas or subscales of the SDSCA tool are
diet, exercise, blood glucose-testing, foot care and smoking (Toobert, Hampson, & Glasgow, 2000). Examples of questions from the SDSCA are as follows: 1) how many of the last seven days have you eaten a healthful diet, 2) on how many of the last seven days did you participate in the at least 30 minutes of physical activity, and 3) on how many of the last seven days did you check your blood sugar the number of times recommended by your healthcare provider?

Participants responded to the questionnaire items by indicating the number of days, from 0-7, they completed a self-care activity or by responding with yes or no answers to questions about smoking. Permission was granted from the Oregon Research Institute to use the SDSCA. Each subscale represents a domain of self-care and was scored individually using the mean number of days reported for that subscale. The smoking status subscale was scored as a dichotomous outcome, yes/no. According to Toobert, et al., the SDSCA tool “average inter-item correlation within scales were acceptable (mean r = 0.47), with the exception of specific diet; test-retest correlations were moderate (mean r = 0.40, r = -0.05 [for medications] to 0.78 [for glucose testing])” (Toobert, Hampson, & Glasgow, 2000 p. 944). Activity Scale. Correlations with other measures of diet and exercise generally supported the validity of the SDSCA subscales (mean = 0.23) (Toobert, Hampson, & Glasgow, 2000). In this current study, inter-item correlation resulted in a value of (r = .14) with smoking included and (r = .20) with smoking excluded, indicating low inter item correlation amongst the items on the Summary of Diabetes Self Care

Clinical indicators of diabetes self-management. Measuring physiological variables in addition to patient reported self-care behaviors provides a more comprehensive picture of diabetes self-management and can shed light on ones’ risk for serious comorbid conditions (Toobert, Hampson, & Glasgow, 2000). HbA1c within the last three months, BP at the time of
the participant’s admission, and LDL-C within the last 12 months were obtained from the participant’s EMR. HbA1c is indicative of blood glucose control over a period of two to three months. Blood pressure and cholesterol are indicators of cardiovascular health. All three of these measures have been identified as necessary elements of clinical assessment to support comprehensive diabetes care (Cardiovascular Disease and Risk Management: Standards of Medical Care in Diabetes, 2018). The American Diabetes Association recommendations for HbA1c is < 7.0%, BP is <140/90, and LDL-C ≤ 100 for persons without cardiovascular disease, and ≤ 70mg/dL in persons with cardiovascular disease (American Diabetes Association, 2018).

**Use of technology.** Performance expectancy, effort expectancy, social influence, facilitating conditions, and intention to use a PHR are dependent variables that were explored using the adapted Use of Technology Questionnaire (UTOQ). The UTOQ is a 33-instrument item. Authors of the UTOQ adapted measures from five constructs of the UTAUT framework and two constructs of the Technology Acceptance Model and the Computer Self-Efficacy Scale (Ma, Xiao, & Blonstein, 2013). The subscales of the UTOQ align with the theoretical constructs in parentheses: 1) perceived usefulness (*performance expectancy*), 2) perceived ease-of-use (*effort expectancy*), 3) social influence (*social influence*), 4) self-efficacy (*facilitating condition*), 5) compatibility (*facilitating condition*), and 6) intention to use (*behavioral intention*). There are six items in the performance expectancy subscale, four items in the effort expectancy subscale, four items for social influence, ten items for self-efficacy, five items for compatibility, and four items in the intention to use subscale.

Examples of the survey items are as follows: 1) the tool enables me to manage my health better, 2) I find the tool easy to use, and 3) people who influence me think I should use the tool. All constructs were measured on a 5-point Likert scale, with 1 = strongly disagree, 2 = disagree, 3
= neither disagree nor agree, 4 = agree, and 5 = strongly agree. The adapted UTOQ was scored as the mean of the items for each construct subscale. Raw score ranges for the constructs are 6-30 for performance expectancy (6 items), 4-20 for effort expectancy (4 items), 4-20 for social influence (4 items), 5-25 for compatibility as a facilitating condition (5 items), 10-50 for self-efficacy as a facilitating condition (10 items), and 4-20 for intention to use (4 items). Higher mean scores in any construct are associated with a higher likelihood of intention to use and actual use of the PHR. Permission to use the Use of Technology Questionnaire was granted by the instrument’s developer.

Results of a previous study revealed high internal consistency with the constructs of performance expectancy (α = .95), effort expectancy (α = .94), social influence (α = .94), and facilitating conditions/computer self-efficacy (α = .78) (Ma, Xiao, & Blonstein, 2013). In the current study, Cronbach alphas were performance expectancy (α = .94), effort expectancy (α = .78), social influence (α = .93), and the facilitating conditions of compatibility (α = .94), and self-efficacy (α = .90) as well as user intention (α = .92).

Actual use of a PHR. PHR use 30 days after discharge from a hospital is another dependent variable that will be measured in this study as a dichotomous outcome. The Allscripts Clinical Performance Management (CPM) View, Download, Transmit (VDT) report was reviewed to determine if a patient accessed their clinical summary within 30 days of discharge.

Data Collection

Questionnaire data were collected in the patient rooms during their hospital admission. Upon completion of demographic forms and survey instruments, participants placed their completed responses in an envelope, returned the envelope to their nurse, and the envelope was locked on the inpatient unit for the PI to later retrieve. At the participant’s request, the
investigator was available to read the information on the demographic form and survey instruments to the participant and record their responses on the tools; 53% of the questionnaire data was recorded by the participants and 47% was recorded by the investigator. Envelopes and survey data were labeled with a unique participant ID to de-identify the data. A codebook was developed to categorize variable, survey questions and instrument items and their associated responses. Raw and coded data were inspected for outliers’ errors, and missing data as described in the data analysis plan (Polit, 2010).

Data Analysis

Pre-analysis. Missing values were assigned a code of -1. Only 4% of the overall data was missing in this study. While most variable data were present, 10% of the HbA1c values and 42% of the LDL-C variables were unavailable. According to Polit, data are rarely “missing completely at random (MCAR) but may be missing at random (MAR) if the missingness is unrelated to the value of the variable itself, but it is related to other variables that can be identified” (Polit, 2010 p. 367). Missing data were tested for MCAR, MAR, and missing not at random (MNAR). Participants in this study had a variety of admission diagnoses that may not require obtaining HbA1c, and LDL-C laboratory testing for acute treatment, so these data are considered MAR. Based on the pattern of missingness, mean imputation of missing values was performed on missing variable data to maintain an adequate sample size for analysis and statistical power, except HbA1c and LDL-C. To assess the impact of the large number of missing data for HbA1c and LDL-C on the results, pairwise deletion was performed. Therefore, analyses using the HbA1c, and LDL-C variables were performed both with mean imputation and only available data. No difference was noted in the results between the mean imputation and only available data; thus, results are reported using the full data set with mean imputation.
Assumptions of normally distributed variables were assessed for the continuous variables in each aim prior to data analysis. Normality was assessed using SPSS and analyzing the output of the kurtosis and skewness analyses and inspecting the histogram and scatterplots. Assumptions of normality were violated for some of the major study variables. This is discussed below. Statistical significance was set at $p < .05$, and all tests were two-tailed.

**Statistical analyses.** Using univariate descriptive statistics for each aim, the mean and median, with standard deviation and interquartile ranges, as appropriate, were calculated for continuous variables. Percentages and frequencies were calculated for categorical variables. Using IBM® SPSS® Statistics 27 (IBM Corp., 2020), inferential statistical analysis was performed to examine relationships between variables.

**Aim One.** To determine if differences exist between sociodemographic variables, such as race, age, sex, and level of education) and intention to use and actual use of PHR in persons with T2DM.

Assumptions were tested for age and intention to use a PHR. Skewness and kurtosis results for age were -.05 and -.92 respectively. Skewness and kurtosis results for intention to use were -3.4 and 2.1. A Shapiro-Wilk test was performed. Results of the analysis for age and intention to use were $p = .67$ and $p < .01$ respectively. Data for intention to use a PHR were not normally distributed on the histogram, and the scatterplot revealed non-linearity. Assumptions of normality were violated; therefore, a Spearman rho test was performed to examine the association between age and intention to use a PHR.

A Mann Whitney U test was performed to assess differences between intention to use a PHR with race, sex, and level of education. Level of education was collapsed into two categories (less than high school; high school, GED, or college) for analysis to eliminate cell sizes with zero
as a value. Chi square testing or Fisher’s Exact tests with contingency tables was used to
determine relationships between categorical independent variables (sex, race, educational level,
and the dependent variable, actual use of a PHR (yes/no).

**Aim Two. To investigate the relationship between diabetes distress and 1) intention to
use a PHR and 2) actual use of a PHR within 30 days of hospital discharge among persons with
T2DM.**

Assumptions were tested for diabetes distress and intention to use a PHR. Skewness and
kurtosis for diabetes distress and intention to use a PHR were 3.3 and -.82 and -3.4 and 2.1
respectively. A Shapiro-Wilk test was performed. Results of the analysis for intention to use and
diabetes distress were $p < .01$ and $p < .01$ respectively. Data for diabetes distress and intention to
use a PHR were not normally distributed on the histograms, and the scatterplot revealed non-
linearity Assumptions of normality were violated for diabetes distress and intention to use a
PHR. This aim was analyzed using Spearman rho correlation to explore the relationship between
diabetes distress and intention to use a PHR. Point biserial correlation was used to analyze the
relationship between diabetes distress and actual use of a PHR.

**Aim Three. To investigate the relationship between diabetes distress and 1) self-care
behaviors and 2) clinical indicators of diabetes self-management (HbA1c, BP, LDL-C) among
persons with T2DM.**

Assumptions of normality were evaluated for diabetes distress and diabetes related self-
care behaviors. Skewness and kurtosis for DD, general diet, specific diet 1 specific diet 2,
exercise, blood glucose testing, and foot care were 3.3 and -.82, 1 and 1.86, -.40 and -2.6, -.82
and -1.8, 4.16 and -.18, -9.6 and -3.3, and 0.8 and -2.2 respectively. A Shapiro-Wilk test was
performed. Results of the analysis for DD, general diet, specific diet 1, specific diet 2, exercise,
blood glucose testing, and foot care were $p < .01$, $p < .01$, $p < .01$, $p < .01$, $p < .01$, $p < .01$, respectively. Data were not normally distributed on the histogram, and the scatterplot revealed non-linearity. Based on the results of this analysis assumptions of normality were violated. Spearman rho correlation was used to explore associations between diabetes distress and diet, specific diet 1, specific diet 2, exercise, blood glucose testing and foot care. Point biserial correlation was used to analyze the relationship between diabetes distress and smoking.

Assumptions of normality were tested for diabetes distress, HbA1c, LDL-C, systolic and diastolic blood pressure. Skewness and kurtosis for DD, HbA1c, LDL-C, Systolic and Diastolic BP were 3.3 and -.82, 3.9 and 1.36, 7.6 and 12.5, 1.9 and .73, 4.4 and 8.6 respectively. A Shapiro-Wilk test was performed. Results of the analysis for DD, HbA1c, LDL-C, systolic and diastolic blood pressure were $p < .01$, $p < .01$, $p = .21$, and $p < .01$, respectively. Data were not normally distributed on the histogram, for all variables except systolic blood pressure, and the scatterplots revealed non-linearity. Based on this the assumptions of normality for these variables were violated for all variables accept systolic blood pressure. Spearman rho correlation was also used to explore associations between diabetes distress and HbA1c, systolic and diastolic BP, and LDL-C.

**Aim Four.** To investigate the relationship between diabetes distress and PHR related performance expectancy, effort expectancy, social influence, and facilitating conditions among hospitalized persons with T2DM.

Assumptions of normality were tested for diabetes distress, performance expectancy (PE), effort expectancy (EE), social influence (SI), and the facilitating conditions of compatibility (C-FC) and self-efficacy (SE-FC). Skewness and kurtosis for DD, PE, EE, SI, C-FC, and SE-FC were 3.3 and -.82, 3.8 and 2.1, -.83 and 4.1, -.2.7 and .78, and -3.3 and 2.1, and -
4.1 and 3.6. A Shapiro-Wilk test was performed. Results of the analysis for DD, PE, EE, SI, C-FC, and SE-FC were $p < .01$, $p < .01$, $p < .01$, $p < .01$, $p < .01$, and $p < .01$, respectively. Data were not normally distributed on the histogram, and the scatterplot revealed non-linearity. Based on the results of this analysis the assumption of normality was not met. Spearman’s rho bivariate analyses were performed to identify association between diabetes distress and effort expectancy, performance expectancy, social influence, compatibility, and self-efficacy.

**Findings**

**Sample Characteristics, Demographics, and Key Variables.** One hundred and fourteen participants consented to participate in the study; however, only 99 participants returned their surveys. Of the 99 participants, the average distress score was 2.2 (SD = 1.03) indicating a moderate level of distress, and most participants agreed that they had intention to use the PHR ($M = 3.4$, $SD = 0.9$); however, 86% of the sample did not actually use the PHR. Nearly half of the participants were African American (48.5%). The majority were female (59.6%) and unemployed or retired (73.7%). The average age of the participants was 61.2, and the average years with Type 2 Diabetes Mellitus was 14.2. Most participants had a high school diploma or higher (81.8%). Table 1 displays the demographic data.

**Aim One.** There was no association between race and intention to use a PHR ($U = 1234.5$, $p = .95$), sex and intention to use a PHR ($U = 1138.5$, $p = .77$), or level of education and intention to use a PHR ($U = 843$, $p = .30$). There was also no association between age and intention to use a PHR ($\rho = -.158$, $p = .12$).

Only 15% ($n=7$) of the African American participants were PHR users, and 14% ($n=7$) of white participants used the PHR. There is no significant relationship between race and actual use of a PHR user ($r = .02$, $p = .90$). There was no correlation between actual PHR use and age ($r$
14% (n = 8) of the female participants used a PHR, and 15% of male (n = 6) participants were PHR users. There was no significant association between sex and actual use of a PHR ($X^2 = .04, p = 1.0$). There was no significant association between level of education and actual use of a PHR with Fisher’s exact test ($p = .75$). See Table 2.

**Aim Two.** Bivariate analyses indicated that there was no relationship between diabetes distress and intention to use a PHR, ($\rho = -.12, p = .26$), and no relationship between diabetes distress and actual use of a PHR ($r = -.05, p = .66$). See Table 3.

**Aim Three.** The Summary of Diabetes Self-Care Activities instrument scores participant responses to items according to the average number of days per week a participant performs a self-care activity. The range of days is from 0-7. On average, study participants reported following a healthful diet that was low in fat 4 days out of a 7-day week (SD = 2.1) when not in the hospital. Participants reported following a specific diet 3.7 days per week (SD= 1.6). Participants reported an exercising an average of 2.1 days per week (SD = 2.2), and blood glucose testing as recommended by their healthcare provider 4.0 days per week (SD = 2.9), and most participants reported that they had not smoked a cigarette in the past 7 days (n = 92). Participants reported performing foot care on an average of 3.1 days out of the week (SD = 2.7) There were three amputees in the study who did not complete foot care questions and were excluded from the foot care analysis.

Diabetes distress was not significantly associated with any self-care behaviors: general diet ($\rho = -.13, p = .22$), specific diet 1 ($\rho = -.10, p = .32$), specific diet 2 ($\rho = -.03, p = .78$), exercise ($\rho = -.15, p = .19$), blood glucose testing, ($\rho = -.11, p = .28$), or smoking ($r = -.04, p = .67$). The relationship between diabetes distress and foot care approached a significant positive
association ($\rho = .20, p = .05$) with the correlation suggesting a small to moderate effect size, (Cohen, 1992). See Table 4.

Diabetes distress was positively correlated with one clinical indicator of diabetes self-management, HbA1c, such that higher levels of diabetes distress were associated with higher levels of HbA1c, ($\rho = .26, p = .01$). Diabetes distress was not associated with systolic blood pressure ($\rho = -.01, p = .93$), diastolic blood pressure ($\rho = .11, p = .28$), or LDL-C ($\rho = .14, p = .32$). See Table 5.

**Aim Four.** Spearman’s rho bivariate analyses indicated a statistically significant negative association between diabetes distress and effort expectancy, such that as diabetes distress increased, performance expectancy decreased, ($\rho = -.21, p = .04$). No significant associations were found between diabetes distress and effort expectancy ($\rho = -.08, p = .38$), social influence ($\rho = .01, p = .96$), compatibility ($\rho = -.19, p = .06$), or self-efficacy ($\rho = -.09, p = .39$). See Table 6.

**Discussion**

The purpose of this study was to explore relationships between diabetes distress, diabetes self-care behaviors, intention to use and actual use of a PHR within 30 days of hospitalization in adults with T2DM. Key findings were revealed through analysis of the four specific aims. Neither sociodemographic variables nor diabetes distress were associated with intention to use, or actual use of the PHR. Diabetes distress was not associated with any self-care behaviors, but diabetes distress was associated with HbA1c and the construct effort expectancy.

Specific aim one was to determine if race, age, sex, and level of education were associated with intention to use and actual use of a PHR in persons with T2DM. Results of this study revealed no significant association between race, age, sex, or education level and intention
to use a PHR or actual use of a PHR. Characteristics of PHR users in several other studies where majority white, female, and college educated (Goldzweig, 2013, Lau, 2014, Lyles et al., 2015, Cunningham et al, 2019, Conway, 2018, Azizi et al., 2016). PHR users in our study were closely split between race and gender, but all the PHR users were high school, high school equivalent, or college educated. See Table 1.

Our study revealed a mean intention to use score (3.4) indicating an above average intention to use the PHR after discharge; however, more than 4 out 5 participants did not use the PHR. Other researchers who used the UTAUT constructs to explore the use of a self-tracking website for weight loss demonstrated that high intention to use scores were initially correlated with use of the website, but intention scores and website usage declined over time (Ma, Xiao, & Blonstein, 2013). While our study demonstrated no use of the PHR among many participants, “decreasing technology use is commonly reported in e-health intervention studies” (Ma, Xiao, & Blonstein, 2013 p. 744), so our finding seems to be in alignment with what has been seen in other studies.

Results of this study show that there was no relationship between diabetes distress and intention to use a PHR or actual use of a PHR. As discussed previously, only two studies examined the relationship between diabetes distress and PHR use (Fonda et al., 2009; van Vugt et al., 2016). Of the studies that examined diabetes distress and PHR use, one suggested that diabetes-related distress was decreased with PHR use (Fonda et al., 2009), and the other study had inconclusive results based on attrition (van Vugt et al., 2016). The results of our study contrast with the study by Fonda et al., 2009, because diabetes distress levels were not related to actual PHR use, nor were they related to intention to use a PHR. This study by Fonda discussed that the factors that contribute to engagement with a PHR or patient portal were not clear or
examined in their study. Our study adds to the existing literature the need to better understand factors that contribute to PHR used specifically for hospitalized persons with moderate diabetes distress. A larger sample size with more PHR users might have detected a similar association of lower distress scores with increased PHR use.

Two studies about diabetes distress were conducted outside of the US and focused on patients within a hospital setting (Wolde & Wondim, 2020; Sasi, Kodali, Burra et al., 2013), and one of these enrolled outpatients in a hospital system (Sasi, Kodali, Burra et al., 2013). Aims of both studies were to examine diabetes distress and other factors related to diabetes self-management. Both studies used the DDS-17 to measure diabetes distress and demonstrated that hospitalized patients and patients with frequent outpatient hospital visits demonstrated moderate levels of diabetes related distress. These findings are like the findings of our study where participants demonstrated moderate distress. Results of our study demonstrated that regimen-related distress was the highest-ranking distress subscale for the participants in this study. Although the two comparison studies did not address the diabetes distress subscales, our findings of moderate distress especially related to the managing the diabetes regimen may indicate an area of intervention for hospitalized patients with diabetes related distress.

Fisher (2006) described two possible reasons for diabetes distress to be associated with poorer diabetes self-management, including clinical indicators of self-management. One reason is that distress may stimulate cortisol production and contribute to insulin sensitivity. Another is that distress may make participating in diabetes related self-care activities difficult. Findings from our study demonstrated an association between diabetes distress and HbA1c, where higher levels of distress were associated with higher levels of HbA1c. This finding is consistent with other studies where distress and A1C are examined (Fonda et al., 2009, Sasi et al., 2013).
study did not find significant associations between diabetes distress and other clinical indicators of diabetes self-management, such as BP and LDL-C. The correlation between DD, BP, and LDL-C has not been examined in the literature.

Results of our study did not reveal an association with diabetes distress and self-care behaviors, such as following a healthful diet, participating in exercise, conducting blood glucose testing, or smoking. There was a small-to-moderate correlation between diabetes distress and foot care such that, where diabetes distress levels increased, self-reports of foot care decreased, but this relationship was not significant. This finding contrasts with Sasi’s 2013 study of 546 patients that examined self-care, diabetes distress and other factors affecting glycemic control, which demonstrated that glycemic control was impacted by diabetes distress, diet, exercise, and medication taking (Sasi et al., 2013). It is possible that the conflicting results are due to the small sample size of this study or the sample characteristics.

One study that used structural equation modeling to link diabetes distress, self-care medication adherence and diabetes related quality of life used the Problem Areas in Diabetes (PAID) tool to examine self-care and the SDSCA tool (Jannoo, Wah, Lazim, et al., 2017). This study identified a statistically significant relationship between an SDSCA construct and diabetes distress, as measured by the PAID; however, it is not reported if a specific construct was associated with DD, or if the constructs of blood sugar testing and smoking were included in the structural equation model. It is unclear what construct was associated with diabetes distress in that study.

Another study examined psychological distress and diabetes self-care activities using the Kessler Psychological Distress Scale and the SDSCA tool (Bala, Srivastava, Potsangbam, Anal et al., 2020). These researchers found no relationship between psychological distress and
diabetes related self-care activities. Based on the conflicting results of these two studies and the paucity in existing literature about the relationship between diabetes distress and diabetes self-care activities using the DDS-17 and SDSCA instruments, more research is needed to draw a conclusion about the relationship between these variables.

The results of this study demonstrated a negative association between diabetes distress and performance expectancy related to the use of technology. Performance expectancy is a construct of the UTAUT theory that reflects how much an individual believes using the system will help him/her in job or task performance, in this case the system is a PHR. No studies have examined the constructs of the UTAUT theory with diabetes distress; however, some studies explored UTAUT constructs and diabetes in general. Results of those studies show that effort expectancy, performance expectancy and social influence are the most important determinants of the intention to use diabetes self-management technology (Zhang, Liu, & Lou et.al, 2019, Petersen & Panther, 2020). Technology has emerged as a convenient tool to support diabetes self-management (Fisher-Grace, Turk, Anthony, et al., 2021), and our finding about performance expectancy suggests promoting information about how beneficial the PHR is for self-management may assist with diabetes distress.

Strengths and Limitations

Strengths of this study are that the sample contained a balanced distribution Black and White, and male and female participants, allowing the study’s results to be more representative and applicable to multiple races and sexes. This was the first study to examine diabetes distress and subsequent PHR use among hospitalized patients with T2DM. Additionally, this study was conducted across five in-patient units, which allowed patients with various admitting diagnoses,
for whom diabetes may have been a secondary diagnosis, to be included. Thus, our study can be generalized to hospitalized patients with a variety of acute diagnoses.

One limitation of this study is its sample size. While 114 participants enrolled in the study, only 99 completed the questionnaires measuring study variables, and in-person recruitment of patients ended due to the COVID-19 pandemic. Not achieving the necessary sample size may have impacted the power to detect relationships among the variables examined. Other limitations of the study are that hospitalized patients were asked to recall information about their self-care behaviors over a 7-day period and their thoughts about how diabetes had impacted them over a 30-day time. Participant responses may have been impacted by recall and social desirability biases. The cross-sectional design of the study also impacts the ability to determine causation, so the results of the study are associations only. Two of the key study variables had a large percentage of missing data likely due to the lab values not being pertinent to the patient’s reason for admission. However, statistical analysis was performed using both mean imputation and by using pairwise deletion for these two variables, and the results did not show a difference.

**Recommendations for Future Research**

Future research in this area is needed to understand the associations between diabetes distress and PHR use. Data collected from this study provides a unique opportunity to further examine this phenomenon from several perspectives. One perspective is to examine a larger sample of PHR users with T2DM and explore their levels of diabetes distress. The purpose of that study could be to investigate if persons with T2DM who use the PHR have less distress, and to examine how they use the PHR to manage their health. Additional research can be done to further understand the factors that prevented actual PHR use in the participants with diabetes.
distress who had moderate to high intentions to use the PHR. That study could identify possible barriers to PHR use for this patient population. Another area for future nursing research is to further explore different aspects of diabetes distress in hospitalized patients with T2DM. Results of such a study may provide more insight into the highest distress subscale in hospitalized patients and highlight areas for nursing intervention in the inpatient setting.

**Nursing Implications**

Diabetes Self-Management Education has been shown to effectively treat diabetes distress (Fisher, Hessler, Glasgow et al., 2013, Kreider, 2017), and nurses have an integral role in supporting self-management through patient education. One implication for nursing because of this study is to recognize that patients with diabetes may be experiencing diabetes-related distress due to their hospitalization and additional changes in their diabetes management during their hospital stay. Another implication for nursing leaders and providers is to implement policies, plans, and/or processes to screen for diabetes distress in hospitalized patients. A final implication for nursing is to identify how PHRs and other technologies can be used to implement nursing interventions for hospitalized patients with diabetes related distress.

**Conclusion**

This study examined relationships between diabetes distress, sociodemographic variables, clinical indicators of diabetes self-management and diabetes related self-care behaviors. It also explored relationships between diabetes distress, intention to use a PHR and actual use of a PHR, using the UTAUT framework as a guide. Results of the study demonstrated relationships between diabetes distress and 1) HbA1c and 2) the theoretical construct of effort expectancy. Results revealed that hospitalized patients had moderate levels of overall diabetes distress and regimen-related diabetes distress. Hospitalized patients also had an above average intention to
use a PHR, but their actual PHR use within 30 days of hospitalization was low. The results of this study add more information to the literature about the clinical and psychosocial status of patients hospitalized with T2DM and suggest that further research is needed to promote the use of the PHR as a self-management tool for this patient population.
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Table 1.
Sample Characteristics and Variables of Interest (N=99)

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<th>Characteristic</th>
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<td>African American</td>
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<td></td>
</tr>
<tr>
<td>Yes</td>
<td>14 (14.1%)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>85 (85.9%)</td>
<td></td>
</tr>
<tr>
<td>Characteristic</td>
<td>N (%)</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>--------------------------------------------</td>
<td>-----------</td>
<td>-----------</td>
</tr>
<tr>
<td><strong>Self-Care Behaviors (days/week)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>General Diet</td>
<td>4.0 (2.1)</td>
<td></td>
</tr>
<tr>
<td>Specific Diet</td>
<td>3.7 (1.6)</td>
<td></td>
</tr>
<tr>
<td>Exercise</td>
<td>2.1 (2.2)</td>
<td></td>
</tr>
<tr>
<td>Blood Sugar Testing</td>
<td>4.0 (2.9)</td>
<td></td>
</tr>
<tr>
<td>Foot Care</td>
<td>3.2 (2.5)</td>
<td></td>
</tr>
<tr>
<td>Smoker</td>
<td>8 (8.1%)</td>
<td></td>
</tr>
<tr>
<td>Non-smoker</td>
<td>91 (91.9%)</td>
<td></td>
</tr>
<tr>
<td><strong>Clinical Indicators of Self-Management</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HbA1c (%)</td>
<td>8 (2.1)</td>
<td></td>
</tr>
<tr>
<td>LDL-C (mg/dL)</td>
<td>98 (38.7)</td>
<td></td>
</tr>
<tr>
<td>Systolic BP (mm Hg)</td>
<td>131.7 (26.8)</td>
<td></td>
</tr>
<tr>
<td>Diastolic BP (mm Hg)</td>
<td>72.1 (14.2)</td>
<td></td>
</tr>
<tr>
<td>Intention to Use (range = 1-5)</td>
<td>3.4 (0.9)</td>
<td></td>
</tr>
<tr>
<td>Performance Expectancy (range = 1-5)</td>
<td>3.6 (0.9)</td>
<td></td>
</tr>
<tr>
<td>Effort Expectancy (range = 1-5)</td>
<td>3.5 (0.9)</td>
<td></td>
</tr>
<tr>
<td>Social Influence (range = 1-5)</td>
<td>3.5 (0.9)</td>
<td></td>
</tr>
<tr>
<td>Compatibility (range = 1-5)</td>
<td>3.4 (0.9)</td>
<td></td>
</tr>
<tr>
<td>Self-Efficacy (range = 1-5)</td>
<td>3.6 (0.8)</td>
<td></td>
</tr>
</tbody>
</table>
Table 2.

*Sociodemographic Variables, Intention to Use a PHR, and Actual PHR Use (N=99)*

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Intention to Use a PHR</th>
<th>Actual PHR Use</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$r = .02, p = .90$</td>
<td>$n = 7 (15%)$</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
</tr>
<tr>
<td>African American</td>
<td>$U = 1234.5, n = 48, p = .95$</td>
<td>$n = 7 (15%)$</td>
</tr>
<tr>
<td>Caucasian</td>
<td>$U = 1234.5, n = 51, p = .95$</td>
<td>$n = 7 (14%)$</td>
</tr>
<tr>
<td>Age</td>
<td>$r = -.01, p = .95$</td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td>$X^2 = .04, p = 1.0$</td>
<td>$n = 8 (14%)$</td>
</tr>
<tr>
<td>Female</td>
<td>$U = 1138.5, n = 59, p = .77$</td>
<td>$n = 8 (14%)$</td>
</tr>
<tr>
<td>Male</td>
<td>$U = 1138.5, n = 40, p = .77$</td>
<td>$n = 6 (15%)$</td>
</tr>
<tr>
<td>Level of Education</td>
<td>$p = .75$</td>
<td></td>
</tr>
<tr>
<td>Less Than High School</td>
<td>$U = 843, n = 18, p = .30$</td>
<td></td>
</tr>
<tr>
<td>High School Diploma,</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Equivalent or College</td>
<td>$U = 843, n = 81, p = .30$</td>
<td></td>
</tr>
</tbody>
</table>

$U = $ Mann Whitney U, $r =$ point biserial correlation, $X^2 =$ chi square
Table 3.

*Diabetes Distress Intention to Use a PHR and Actual PHR Use (N = 99)*

\[ \rho = \text{Spearman rho}, r = \text{point biserial correlation} \]

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Intention to Use a PHR</th>
<th>Actual PHR Use</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes Distress</td>
<td>( \rho = -.12, p = .26 )</td>
<td>( r = -.05, p = .66 )</td>
</tr>
</tbody>
</table>

Table 4.

*Diabetes Distress and Self-Care Behaviors (N=99), (N = 96, foot care, 3 persons with amputations excluded)*

\[ \rho = \text{Spearman rho}, r = \text{point biserial correlation} \]

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>General Diet</th>
<th>Specific Diet 1</th>
<th>Specific Diet 2</th>
<th>Exercise</th>
<th>Blood Sugar Testing</th>
<th>Foot Care</th>
<th>Smoking</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes Distress</td>
<td>( \rho = -.13, p = .22 )</td>
<td>( \rho = -.10, p = .32 )</td>
<td>( \rho = -.03, p = .78 )</td>
<td>( \rho = -.15, p = .19 )</td>
<td>( \rho = -.11, p = .28 )</td>
<td>( \rho = .20, p = .05 )</td>
<td>( r = -.04, p = .67 )</td>
</tr>
</tbody>
</table>
Table 5.

*Diabetes Distress and Clinical Indicators of Diabetes Self-Management (N=99)*

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>HbA1C</th>
<th>LDL-C</th>
<th>Systolic Blood Pressure</th>
<th>Diastolic Blood Pressure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes Distress</td>
<td>$\rho = .26, p = .01$</td>
<td>$\rho = .14, p = .32$</td>
<td>$\rho = - .01, p = .93$</td>
<td>$\rho = .11, p = .28$</td>
</tr>
</tbody>
</table>

$\rho = \text{Spearman rho}$

Table 6.

*Diabetes Distress and UTAUT Constructs (N=99)*

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Performance Expectancy</th>
<th>Effort Expectancy</th>
<th>Social Influence</th>
<th>Facilitating Condition: Compatibility</th>
<th>Facilitating Condition: Self-Efficacy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes Distress</td>
<td>$\rho = -.21, p = .04$</td>
<td>$\rho = -.08, p = .38$</td>
<td>$\rho = .01, p = .96$</td>
<td>$\rho = -.19, p = .06$</td>
<td>$\rho = -.09, p = .39$</td>
</tr>
</tbody>
</table>

$\rho = \text{Spearman rho}$