


2016

Access and Barriers to Care During Transition from Active Duty to Veteran Status in Veterans with Diabetes: A Look at Health Literacy, Change, and Ongoing Diabetes Self-Management Education

Mark R. Malebranche
University of San Diego

Follow this and additional works at: <https://digital.sandiego.edu/dissertations>

 Part of the [Endocrinology, Diabetes, and Metabolism Commons](#), [Military and Veterans Studies Commons](#), and the [Nursing Commons](#)

Digital USD Citation

Malebranche, Mark R., "Access and Barriers to Care During Transition from Active Duty to Veteran Status in Veterans with Diabetes: A Look at Health Literacy, Change, and Ongoing Diabetes Self-Management Education" (2016). *Dissertations*. 50.
<https://digital.sandiego.edu/dissertations/50>

This Dissertation: Open Access is brought to you for free and open access by the Theses and Dissertations at Digital USD. It has been accepted for inclusion in Dissertations by an authorized administrator of Digital USD. For more information, please contact digital@sandiego.edu.

UNIVERSITY OF SAN DIEGO

Hahn School of Nursing and Health Science

DOCTOR OF PHILOSOPHY IN NURSING

ACCESS AND BARRIERS TO CARE DURING TRANSITION FROM ACTIVE
DUTY TO VETERAN STATUS IN VETERANS WITH DIABETES: A LOOK AT
HEALTH LITERACY, CHANGE, AND ONGOING DIABETES SELF-
MANAGEMENT EDUCATION.

by

Mark R. Malebranche

A dissertation presented to the

FACULTY OF THE HAHN SCHOOL OF NURSING AND HEALTH SCIENCE

UNIVERSITY OF SAN DIEGO

In partial fulfillment of the

requirements for the degree

DOCTOR OF PHILOSOPHY IN NURSING

August 2016

Dissertation Committee

Dr. Joseph Burkard, DNSc, CRNA, Chairperson

Dr. Jane Georges, PhD, RN

Dr. David Bittleman, MD

UNIVERSITY OF SAN DIEGO

Hahn School of Nursing and Health Science

DOCTOR OF PHILOSOPHY IN NURSING

CANDIDATE'S
NAME:

Mark Malebranche

TITLE OF
DISSERTATION:

Access and barriers to care during transition from active duty to veteran status in veterans with diabetes: A look at health literacy, change, and ongoing diabetes self-management education.

DISSERTATION
COMMITTEE:

Dr. Joseph Burkard, DNSc, CRNA, Chairperson

Dr. Jane Georges, PhD, RN

Dr. David Bittleman, MD

Abstract

Background and Rationale: Transition from active duty to veteran status may be a challenging time, especially for veterans with diabetes. These veterans face multiple changes that can cause distress. Most veterans with diabetes have type 2 diabetes, however a diagnosis of type 1 diabetes on active duty is cause for discharge for active duty.

Purposes and Aims: The purpose of this study was to describe the transition experience of veterans diagnosed with diabetes while on active duty from active duty to veteran status. The study describes barriers and facilitators to healthcare and diabetes self-care management. The four aims of the veterans with diabetes transition study of veterans were to 1) Describe the experience of veterans with diabetes during their transition from active duty to veteran status, 2) Describe barriers and facilitators to healthcare access, 3) Describe diabetes self-management and veterans' diabetes self-management education, and 4) To note veteran's health literacy and diabetes distress.

Methods: A qualitative, descriptive study was conducted of the transition experience from active duty to veteran status using a sample of 10 veterans with diabetes. Veterans access and barriers to care and use of diabetes self-management resources were measured by a qualitative questionnaire. Health literacy was measured by S-TOFHLA, and distress during by the DDS. Data were collected in the US southwest. Qualitative data analysis was done by uncovering themes and keywords. Quantitative instruments analysis was per instrument instructions.

Results: Two major and four additional themes were uncovered. Major themes included feeling loss due to undesired end of a military career and feeling prepared to

leave the military. Participants were compliant with diabetes management and had received diabetes education.

Conclusions and Implications: Transition is an inevitable part of military service. The veterans with diabetes transition study provides data regarding transition of healthcare in veterans from active duty healthcare to healthcare in another system previously absent in the literature. Data gathered during the study contains themes indicating veterans have the potential to be extremely compliant participants in their diabetes self-management. The study serves as a starting point for study of the active duty to veteran transition process.

Keywords: Diabetes, veterans, transition

Copyright

Dedication

This dissertation is dedicated to the men and women of the United States Armed Forces and the veterans who have served this country. Our freedom is the result of their steadfast service. In particular, I dedicate this work to the veterans who left active duty with healthcare challenges.

Acknowledgements

This study has to be put in context. No man is an island, and no one achieves results without preparation and assistance. My assistance has come from (in no particular order):

The Jonas Foundation for Nursing and Veterans Healthcare

The immensely talented faculty of the Hahn School of Nursing and Health Sciences

The incredible staff of the Hahn School of Nursing and Health Sciences

Carol Scimone

The quietly effective leadership of the Hahn School of Nursing and Health Sciences

The most amazing cohort a man could hope for

My family, and especially, my wife, Barbara-My PhD is her PhD

Table of Contents

Chapter 1	1
Introduction	1
Description of the Problem.....	1
Purpose	4
Background.....	5
Study Significance.....	11
Chapter 2.....	13
Review of the Literature.....	13
Introduction	13
Transition of Care.....	14
Change.....	15
Health Literacy	16
Background.....	16
Definitions.....	17
Measures of Health Literacy.....	20
Additional Considerations in Health Literacy	22
Access to Care (Barriers and Facilitators).....	25
Diabetes Distress	28
Measuring Diabetes Distress	29
Patient Portal Use	29
The Digital Divide.....	31
Online Educational Resources.....	31
Mandates for use of Technology in Healthcare.....	33

Summary.....	34
Chapter 3.....	36
Methods.....	36
Introduction	36
Study Purpose.....	36
Study Aims	37
Design.....	37
Setting.....	38
Sample	38
Inclusion and Exclusion Criteria.....	38
Data Collection and Security	39
Recruitment.....	39
Qualitative Phase	39
Quantitative Phase.	40
Instrumentation.....	40
Human Subjects Considerations	43
Data Analysis.....	43
Study Strengths and Weaknesses	44
Study Significance.....	45
Chapter 4.....	46
Manuscripts	46
Introduction	46
Summary.....	50

Discussion.....	51
Conclusions	56
Article 1	61
Article 2	76
Article 3	87
Chapter 5.....	110
Instruments	110
Introduction	110
Instruments Used:	110
Qualitative Questions.....	110
S-TOFHLA	110
Diabetes Distress Scale	110
Post hoc considerations	110
References.....	112

List of Tables

Table 1

Chapter 4 Manuscripts 3: The veterans with diabetes transition study

Table 1 104

List of Appendices

Appendix A: USD IRB	129
Appendix B: Naval Medical Center San Diego Approval.....	130
Appendix C: Naval Hospital Camp Pendleton Approval	133
Appendix D: Dr. David Bittleman Approval	134
Appendix E: Participant Flyer	135
Appendix F: Interview Guide and Demographics Questionnaire.....	136
Appendix G: TOFHLA Approval.....	139
Appendix H: STOFHLA Directions for Administering, Scoring & Technical Data	141
Appendix I: DDS Questionnaire and Scoring Sheet.....	148

Chapter 1

Introduction

Description of the Problem

Transition is an inevitable part of the experience of military life. In the context of a military career, service members make the change from civilian status to an introductory indoctrination to the military, which may be boot camp or an officer program. Individuals then transition to another duty station, perhaps many, through schools and promotions until the end of a military career. The final transition is back to civilian life, with the status of veteran. Distress during time of transition is not uncommon in a military population (IOM, 2010; Knight, 2014 ; Morin, 2011). However, the focus of studies to date has been on anticipated or actual difficulties encountered as a result of the physical and mental stresses related to exposure to war and other traumatic events during time spent on active duty in the armed forces.

Healthcare research in transitions has focused on studies examining important changes in two populations. One focus of research is the transition of adolescents whose healthcare is managed by a pediatric primary care provider to reaching adult status requiring a change in provider and in the associated paradigms related to adult healthcare (Peters & Laffel, 2011). Another focus of transition research has been about the circuit a patient undergoes from one place and/or level of care to another, most often related to inpatient care. Patients with acute changes in health status physically move from home to emergency department to hospital setting to a skilled nursing facility and hopefully, back to home. This kind of transition is often focused on progressing from acute care received in a hospital setting to care in an inpatient rehabilitation unit or skilled nursing

facility (Jeffs, Lyons, Merkley, & Bell, 2013; Kim & Flanders, 2013; Naylor, Aiken, Kurtzman, Olds, & Hirschman, 2011). This focus on transitions is reasonable, given the provisions of the Patient Protection and Affordable Care Act of 2010 (ACA) and the American Recovery and Reinvestment Act of 2009 (ARRA) to give incentives and penalties related to hospital readmission (Centers for Medicare & Medicaid Services, 2014; Kocher & Adashi, 2011). A gap in the literature exists concerning transition of healthcare and healthcare systems in either a military or civilian population. This study provides data for further research on healthcare transition in veterans with diabetes.

Change from active duty to veteran status includes a transition of healthcare system. Several options exist, based upon benefits earned by an individual. Three common scenarios are that the service member retires, and one, has eligibility to remain within the Department of Defense (DoD) Military Health System (MHS). Two, the veteran may become eligible for some or all healthcare at the Veterans Administration healthcare system (VA). Or, three, the individual may have private healthcare coverage, most often through an employer. Transition of healthcare may include some delay or interruption in continuity of healthcare. For veterans with diabetes, a delay in access to care may detract from the diabetes management needed to maintain control of their diabetes. Randall (2012) notes there is often a time gap during the transition from active duty healthcare under the DoD MHS to healthcare under the Veterans Administration. Healthcare transition can be further impaired by a lack of electronic connectivity between the DoD and VA healthcare systems (Randall, 2012). Improved patient outcomes for people who have diabetes hinges on diabetes self-management education (DMSE). Ongoing DSME is critical for diabetics seeking knowledge, skills, and ability for

comprehensive self-care (Janiszewski, O'Brian, & Lipman, 2015). Research has shown health literacy is a factor in diabetic self-management as a relationship between health literacy levels and knowledge levels affects health decisions and daily activities (Bohanny et al., 2013; Kandula, Malli, Zei, Larsen, & Baker, 2011; Nutbeam, 2008; Sarkar, Karter, Liu, Moffet, et al., 2010; Wang, Thombs, & Schmid, 2014; Williams, Baker, Parker, & Nurss, 1998). Health literacy impacts patients and caregivers alike.

The Department of Veterans Affairs (VA) is the largest healthcare system in the US serving approximately 9 million beneficiaries, including 700,000 inpatient admissions annually. Prevalence of diabetes in VA patients is estimated at 20 to 25%, over twice that of other Americans. More than half of hospitalization and deaths among patients with diabetes in the VA health system are due to complications of diabetes (Department of Veterans Affairs, 2015b; Kupersmith et al., 2007).

The goals of this study were to describe the experience of transition from active duty to veteran status on access to care, level of DSME, and use of online educational resources in a sample of veterans with diabetes. Their level of health literacy, the impact of the transition on their diabetes distress level, and demographic data were considered factors that would be likely to have an impact upon the transition experience.

This was a qualitative, descriptive study that described common ways in which veterans with diabetes experience the time of transition from active duty to veteran status. The study solicited veterans' stories of their access and barriers to care and diabetes self-management education including use of online educational resources. The study included measurement of health literacy and diabetes distress experienced during their transition from the military. The study was conducted in a sample of veterans with diabetes in the

US southwest, primarily in the San Diego area, with some participants recruited and interviewed in San Antonio, Texas. For ease of reference, the study was named the Veterans with Diabetes Transition Study.

This study indicated this sample experienced one of two main feelings during their transition to veteran status. Either they felt the loss of their military career, or felt prepared to finish their military career. Results of the health literacy assessment showed no variability. Additional research would be needed in this population to determine what, if any, relationship exists between health literacy and DSME. Patient-centered healthcare has the potential to be the setting for health literacy assessment and ongoing DMSE. The DoD MHS and the VA have adopted patient-centered models of care following the patient-centered medical home model (Department of Veterans Affairs, 2015b). By involving veterans in the design of medical components of the transition process, innovative educational interventions or process improvements can be created that have the potential to decrease costs and improve continuity of care for veterans.

Purpose

The purpose of this dissertation study was to describe the factors that act as barriers and facilitators to diabetes care and diabetes self-care management during the transition from active duty to veteran status in veterans. This study a sample of veterans diagnosed with diabetes on active duty included their description of the transition experience.

Specific aims of this study in this sample of veterans with diabetes were to: (1) describe common ways in which veterans with diabetes experience the time of transition from active duty to veteran status, (2) describe barriers and facilitators of access to care

and diabetes self-management during the transition from active duty to veteran status, (3) describe veterans with diabetes' knowledge of traditional and online self-management education, and (4) note the health literacy level and diabetes distress encountered during their transition in a sample of veterans with diabetes.

Background

Reducing the impact of diabetes-related complications among veterans is vitally important to their ongoing health needs, starting with improved diabetes self-management. More than half of hospitalization and deaths among patients with diabetes in the VA health system are due to complications of diabetes including vascular complications, such as stroke and myocardial infarction. This contributes significantly to increased demands for healthcare resources within the VA system, and decreased availability of dollars that could be spent on other VA priorities such as traumatic brain injury, suicide, and care of amputees. Veterans make up only 3% of the US population, but account for nearly 10% of people with diabetes, so they bear a disproportionate health burden regarding diabetes. Death rates among veterans with diabetes are nearly double those in veterans without diabetes (Department of Veterans Affairs, 2011, 2014b).

Diabetes is a progressive disease that causes extensive morbidity, mortality, and expenditure of healthcare dollars. Rates of heart disease and stroke are higher among persons with diabetes than the general population. Diabetes is the leading cause of blindness, kidney failure, and non-traumatic amputation in the US. Compared with those who do not have diabetes, diabetics' healthcare costs are 2.3 times higher. Twenty percent of healthcare dollars are spent on diabetes. Costs of care and complications from diabetes were estimated to be \$245 billion in 2012. Continued growth in the number of

people with diabetes is expected and given the current trend, could result in as many as 1 in 3 adults having diabetes by the year 2050. The Centers for Disease Control and Prevention (CDC) and the American Diabetes Association (ADA) Diabetes Fact Sheets state that nearly 26 million Americans or 8.3% of the population of the United States have diabetes (American Diabetes Association, 2014; Centers for Disease Control, 2011). Recent National Health and Nutritional Examination Survey (NHANES) data show that 8.3% of Americans have diabetes; and, more importantly, that this percentage has doubled since 1988 (Selvin, Parrinello, Sacks, & Coresh, 2014).

Diabetes self-management approaches in the 21st century must take into consideration health literacy levels and increased reliance upon technology for knowledge dissemination. Health literacy impacts diabetic self-management in that health literacy levels are related with knowledge levels. Health literacy is a concern for patients and caregivers alike. The ability to read is not the underlying concern, rather the fact that nearly 90% of Americans are not able to fully understand and fully comply with their primary provider's advice, instructions, and teaching. Skills in reading and writing are necessary as a minimal prerequisite to health literacy, but these skills alone do not guarantee an individual's competency in health literacy (National Committee for Quality Assurance, 2015; Nutbeam, 2000). Nor are they a guarantee of the ability to capably manage their individual health. Veterans are included in this demographic and have a higher than average prevalence of diabetes compared to other Americans.

Preventing or delaying the onset of diabetes and management of risk factors that lead to complications can assist in decreasing onset, severity of complications, monetary costs, and death. Various methods of weight loss, particularly through diet and exercise,

have reduced onset of diabetes in veterans by nearly 60% in a group that adopted a weight loss technique compared to a group that did not adopt lifestyle changes. Even without changes in weight, adoption of the Mediterranean Diet showed decreases in incidence of diabetes. As part of the CDC's Diabetes Prevention Program (DPP), some participants at high risk for developing diabetes were medicated with low doses of metformin. Results showed that metformin can also prevent or delay the onset of diabetes, although the medication only delayed the onset of diabetes in half the participants (Centers for Disease Control, 2014; Esposito, Maiorino, Ceriello, & Giugliano, 2010; Health and Human Services, 1999). Having the ability to better use DMSE for prevention and management is likely to improve outcomes in veterans with diabetes. Data from this study should inform future studies and interventions in this population by providing description of veterans' experiences with transition and its effect on diabetes self-management.

Although this study was not specifically about the use of technology among veterans with diabetes, one cannot ignore the fact that technology use in healthcare has become an accepted practice. Legislation, including the ARRA and the ACA, offer incentives for use of technology in healthcare and disincentives for failure to adopt technological solutions such as an electronic health record (EHR). Included in the ARRA is the Health Information Technology for Economic and Clinical Health Act (HITECH) which promoted the adoption of technology, particularly the EHR, with the goal that the EHR use will be "meaningful use." Meaningful use means using a certified EHR for functions such as e-prescribing. Other uses of EHR technology are for electronic exchange of health information and improved quality of care by electronically submitting

clinical quality reports and similar measures. The US government categorizes meaningful use of EHRs as functions that “improve care coordination, reduce healthcare disparities, engage patients and their families, improve population and public health, and ensure adequate privacy and security.” Included in the concept of meaningful use is the term interoperability, meaning systems are able to share data (Blumenthal, 2010 ; Healthcare Information and Management Systems Society, 2015).

Following this trend, diabetes self-management includes use of online health resources such as web sites and patient portals, to more efficiently and effectively assist diabetic patients with educational needs, provide reminders for self-care, and to act as a repository for personal health information. The VA has developed a comprehensive EHR system consisting of multiple components that include databases able to be mined for patient data. The VA has a patient portal called MyHealtheVet which is used extensively for multiple purposes. However, even though information pertinent to self-management of diabetes and other chronic diseases is available through MyHealtheVet, there is little data regarding use of MyHealtheVet for this purpose. The MyHealtheVet portal is the centralized location for information regarding chronic diseases. The DoD MHS recently contracted McKesson Health as a single-source site or portal for online health resources (HIT.consultant, 2016). Therefore, retired veterans who receive care at DoD healthcare facilities are just being introduced to a centralized portal for online health resources (Cho et al., 2010; Kupersmith et al., 2007; Miller, Safford, & Pogach, 2004; Tsai & Rosenheck, 2012). One negative feature of the VA EHR system is that it does not interface with the DoD healthcare computer system, preventing easy transfer of data on veterans in transition from DoD to the VA. The McKesson Health EHR selected by the

DoD in 2015 has begun an incremental implementation of that EHR across the DoD MHS starting in spring 2016. The system is to be compliant with interoperability mandates between not only the VA, but as much as possible, all American health informatics systems (Healthcare Information and Management Systems Society, 2015).

Patient portals are not used extensively for education. Patients use online portals to view laboratory results, refill medications, contact or email their primary provider, and to make appointments (Sarkar, Karter, Liu, Moffet, et al., 2010). By viewing laboratory results, patients have the opportunity to assess their progress toward meeting mutually agreed upon goals for diabetes self-management. Refilling medications through an online portal may ensure the individual has an uninterrupted supply of prescribed medications. The ability to make appointments online gives patients the ability to meet their scheduling needs while complying with the provider's recommendation for visit frequency. Asking questions via secure email allows for communication and clarification of questions that arise without the requirement of an office visit. Use of each of these components also serves to address individual self-management tasks for patients with diabetes and other chronic conditions. However, research has shown that although veterans use the Internet as much as other Americans, only 20% of veterans use the MyHealthvet portal and the potential for improved self-education and disease management through portal use is yet to be achieved (Cho et al., 2010; Kupersmith et al., 2007).

For two decades, researchers have proposed the concept of a digital divide, or disparity, between those who have the motivation, access, and skills in using a wide variety of online resources and those who do not. The digital divide is defined as

decreased access to online resources or information technologies, specifically the Internet, among groups such as racial and ethnic minorities, people who have disabilities, rural residents, and people of low socioeconomic status (Chang et al., 2004). Research has been conducted in social sciences and healthcare to determine who actually uses online resources (California HealthCare Foundation, 2010). A digital divide between populations and age groups becomes increasingly important as health resources migrate from traditional paper and classroom-based models to electronic ones. People with decreased ability to access or navigate electronic resources are at risk for incurring greater adverse consequences related to their disease process compared to those who can access online resources easily since those without access will not participate in the benefits of having the latest and most useful information (Sarkar, Karter, Liu, Adler, et al., 2010). Some have questioned the ability of those over the age of 65 to accept, access, and apply technological skills or devices. A Pew Research Center report shows that use of the Internet among seniors is lower than younger Americans, but the rate has steadily risen for the past ten years, and currently 74% of those aged 65-69 use the Internet (Smith, 2014). Smith also notes older Americans need to be convinced of the relevance of technology in their life. When they believe technology such as Internet use is relevant, they adopt it and use it on a daily basis. Cho et al. (2010) found that a majority of those in their study of veterans with diabetes (59%) had home access to the Internet. Almost half (47%) had gone online to search for information on diabetes. Also, over one-third (39%) found health information on the Internet (Cho et al., 2010).

Use of technology in the treatment of diabetes is also an established practice. In healthcare, the use of technology in clinical settings has focused on using the EHR to

document and flag abnormalities that require intervention or to send clinical reminders to both clinicians and patients (Byrne et al., 2010). A veteran's individual use of technology in disease management and prevention is not well known. Tsai and Rosenheck (2012) studied veterans' use of the Internet overall, but with a focus on use of the VA's personal health record included in the My HealtheVet application for VA patients using mental health services (Tsai & Rosenheck, 2012). Technology available/used by veterans or their healthcare team includes the EHR, personal health records (My HealtheVet), home patient monitoring, tele-consultation, and non-face-to-face interviews (Jackson et al., 2011).

What is not known is if the health literacy level of veterans with diabetes has an effect upon a veteran's ability to access and utilize traditional and online health resources. If there is an association, what can be done to optimize the healthcare of veterans with diabetes given that electronic health resources are likely to be the single largest medium for self-management of diabetes and other chronic diseases?

Study Significance

The VA estimates that 20 to 25% of veterans have diabetes. This indicates the prevalence of diabetes in the population of veterans is higher than that in the general population. Veterans with diabetes have nearly twice the annual death rate as veterans without diabetes. Most veterans with diabetes have type 2 diabetes and were diagnosed with diabetes after retirement from the armed forces, since diabetes would be a disqualification for military service. Some, however are diagnosed while on active duty. Having diabetes often qualifies veterans for benefits in the VA healthcare system (U. S. Department of Defense, 2010; Kupersmith et al., 2007).

The Healthy People 2020 goal for diabetes is to “Reduce the disease and economic burden of diabetes mellitus (DM) and improve the quality of life for all persons who have, or are at risk for, DM” (Healthy People 2020, 2014). A focus on veterans has the potential to improve the health of a group that has a high diabetic burden. The significance of this study is that it describes the previously undocumented experiences of veterans diagnosed with diabetes while on active duty. Specifically, it describes their transition to veteran status after the diagnosis of diabetes. Exploration of the interplay between access and barriers to care, diabetes self-management, use of traditional and online patient education resources, health literacy, and diabetes distress in this sample gave results that indicate veterans were either ready to leave the military or extremely unhappy that diabetes halted their military career. With this knowledge, future research can focus on designing interventions that increase the ability of veterans with diabetes to take a greater role in self-management and improve their health outcomes, particularly at the time of transition to veteran status. This research study connects with the Healthy People 2020 diabetes goal by providing a starting point toward increasing veterans’ participation in self-care.

Research suggests a disparity in healthcare exists between Americans with adequate functional health literacy and those whose health literacy is measured at the inadequate or marginal level of health literacy (Bennett, Chen, Soroui, & White, 2009; Saha, 2006). Data from this study are intended to inform future research in this population addressing such health disparities in a military population.

Chapter 2

Review of the Literature

Introduction

A combination of stressful events is expected at the time of transition from active duty to veteran status. These events are not necessarily perceived as negative to the individual and the family. However, stress is associated with change, and many changes occur when a service member ends active service. When the individual involved is a veteran with diabetes, changes in self-care management are likely to be one component of the overall stress experienced by that individual. Veterans' options for healthcare include: continued use of TRICARE (the DoD MHS system) which is generally reserved for retirees, transition to the VA healthcare system, transition to private health insurance from an employer, or, in some cases, transition to a government healthcare programs such as Medicare or Medicaid. A number of veterans separating from active duty have temporary transitional health coverage through TRICARE, which essentially extends the healthcare benefit for an additional 180 days of care in the DoD MHS. This results in a confusing set of choices or possibilities the individual must understand and act upon in order to continue their health care (TRICARE, 2015). It is the individual veteran who bears the responsibility for acquiring knowledge regarding their new health plan and manage his/her care, including any required enrollment by a health plan.

Another component expected to influence the stress of the transition to veteran status is health literacy. Because health literacy is related to knowledge and self-care in people with diabetes and other chronic diseases, veterans with diabetes may experience

uncertainty related to changes in management and location of their health care services, often adversely affecting ongoing diabetic self-management (Baker, 2006; IOM, 2013).

Transition of Care

The transition from active duty to veteran status has multiple components, such as change in employment and employer, potential for relocation of domicile, and potential for changes in a primary care provider and healthcare system used. Any or all of these changes can cause distress and can interrupt established management of care for veterans with diabetes. A review of the literature to provide context for military and healthcare transitions revealed a gap in the literature regarding transition of healthcare during this time. Little on these topics had been written previously, and the extant material tends to focus on the transition of those with service-connected disabilities such as traumatic brain injury, amputation, and post-traumatic stress disorder (Committee on Veterans Affairs, 1993; IOM, 2010; Morin, 2011). Knight (2014) studied factors that prepared service members to successfully transition to veteran status. Her study focused on knowledge of resources available to veterans. However, her definition of resources was those programs presented or accessible to an active duty service member who is in the process of transition to veteran status, without providing a definition of the available resources. Therefore no conclusions can be drawn about any one transition resource program (Knight, 2014).

The literature on transition of care consists of studies with an emphasis on a continuation of care moving from one location or setting to a different level of care following an acute episode requiring hospitalization. For example, following hip replacement surgery, a patient spends a relatively short time in the acute setting, followed

by rehabilitation at a lower level of care, often in a skilled nursing facility, with time dictated by progress and insurance coverage. Jeffs et al. (2013) and Naylor (1999) described transitions of care for individuals from an acute care setting to a rehabilitation center and Weissberg-Benchell, Wolpert, and Anderson (2007) researched adolescents who are transitioning from pediatric care to the adult care setting (Jeffs et al., 2013; Naylor et al., 2011; Weissberg-Benchell, Wolpert, & Anderson, 2007). These articles reported on changes within the same healthcare system. No resources on transitions between healthcare systems were noted in the literature. This appears to be a topic which would benefit from further research.

Change

This study was not intended to delve into the psychological issue of depression in veterans with diabetes. Research has shown there is an association between diabetes and depression, but the pertinent issue for this study is that change can initiate distress in an individual (Fisher, Glasgow, Mullan, Skaff, & Polonsky, 2008; Gabbay et al., 2006; Rock, 2003). People desire a measure of control over their lives, and the transition from active duty to veteran status changes the individual's ability to control some of the events incumbent with this transition. Several researchers including Bandura, Lazarus, and Lewin contributed theories of change relevant to this study. Bandura's work on self-efficacy and self-reflectiveness relates belief that one can influence events or their perceived control with motivation to take action in the face of difficulty (Bandura, 1977, 2001). Lazarus explored coping theory and the cognitive-motivational-relational theory of emotion, both of which describe the responses individuals make based upon their interaction with the environment and that the result of coping strategies are judged as

beneficial or detrimental only in context and after evaluation by the individual (Lazarus, 1991, 1993). Lewin's change theory has been widely used and modified. Longo (2009) stated Rogers, Havelock, Reddin, and Lippitt each added elements to the original three stage theory of unfreezing, moving, and refreezing (Longo, 2009). She also stated Rogers included the presence of a change agent as being a key part of the change process (Longo, 2009). Finally, Longo notes Reddin's theory expanded Lewin's three stages to seven techniques (Longo, 2009). These seven techniques are easily relatable to nursing practice, even using the term *diagnosis* as the first part of the model (Longo, 2009). Lewin saw change as a dynamic process that required recognition and action on the part of the individual to effect a change. Even though Lewin writes of rejecting the previous situation, behavior, or thinking, the time of transition is such that the previous reality of being on active duty is no longer possible, and therefore the individual is obliged to change (Miner, 2006; Longo, 2009). Given a loss of control over some life events and the likelihood of an emotional component during time of transition, it is logical to expect that veterans with diabetes will be affected by changes during transition and would benefit from assistance at time of transition.

Health Literacy

Background. Oldfield and Dreher (2010) and Parker, Ratzan, and Lurie (2003) note the first use of the term *health literacy* was in 1974 by Simonds. He took a societal approach arguing that health education affects healthcare, education, and mass communication (Oldfield & Dreher, 2010; Parker, Ratzan, & Lurie, 2003). Health literacy as a topic within healthcare became evident in the early 1990s but was not defined until the year 2000 in documents from the National Libraries of Medicine. The

National Adult Literacy Survey of 1993 and National Adult Assessment of Literacy in 2003 included questions related to health literacy, but were not intended as specific measures of health literacy. Results indicated at least one-third of adult Americans are functionally illiterate. This led medical professionals to research health literacy implications for patient compliance, understanding of instructions, and self-care (Bennett et al., 2009; Paasche-Orlow, Parker, Gazmararian, Nielsen-Bohlman, & Rudd, 2005; Parker, Baker, Williams, & Nurss, 1995; Parker et al., 2003). The literature shows a disparity in healthcare for those with limited health literacy, including worse outcomes in diabetes self-care.

Definitions. As is often the case in healthcare, many definitions of health literacy have been put forward. This creates a difficulty in that different authors may address a fundamentally different concept although each is intending to address health literacy. The end result is differing opinions on health literacy measurement. Fortunately, most definitions of health literacy are fairly similar. As subordinate organizations within the Department of Health and Human Services (HHS), the Health Resources and Services Administration, Health.gov, and HealthyPeople.gov all use the definition taken from Healthy People 2010, which is “Health literacy is defined as the degree to which individuals have the capacity to obtain, process and understand basic health information needed to make appropriate health decisions and services needed to prevent or treat illness” (Healthy People 2010, 2015).

The World Health Organization (WHO) defined health literacy as “the cognitive and social skills which determine the motivation and ability of individuals to gain access

to, understand, and use information in ways that promote and maintain good health.”
(WHO, 2010)

Limited health literacy affects people of all ages, races, incomes, and education, but the impact of limited health literacy disproportionately affects lower socioeconomic and minority groups. It affects people's ability to search for and use health information, adopt healthy behaviors, and act on important public health alerts. Limited health literacy is also associated with worse health outcomes, lower perception of overall health, and higher healthcare costs (DeWalt et al., 2011; Rodriguez et al., 2013; Sarkar, Karter, Liu, Adler, et al., 2010).

Baker (2006) stated that the definition of health literacy used by the AMA in 1999 was “The constellation of skills, including the ability to perform basic reading and numerical tasks required to function in the health care environment.” He further argues that existing definitions describe a set of capacities used by an individual when confronted with new situations and information. Overall, these cognitive abilities are stable over time, but may be influenced by education or the decline that can be associated with the aging process or dementia. Each definition is based upon the perspective of the researcher, and leads to disagreement over measurement and to measurement of the element of health literacy deemed most important by the researcher (Baker, 2006).

Hahn, Choi, Griffith, Yost, and Baker (2011) define health literacy as “the degree to which individuals have the capacity to read and comprehend health-related print material, identify and interpret information presented in graphical format (charts, graphs, tables), and perform arithmetic operation in order to make appropriate health and care decisions.” They present their definition in the context of development of a multimedia

health literacy assessment tool. Having the skill to navigate multiple aspects of the healthcare system is deemed necessary given currently available sources of information and demands upon individuals by healthcare systems to use multimedia sources when searching for information (Hahn et al., 2011).

To provide clarity to the situation surrounding definition and to ultimately improve health literacy, a new, theoretical definition is proposed by the study author: The degree to which individuals possess the set of cognitive and social skills which give them the ability to read, comprehend, identify, and interpret health-related material and information in print or graphical format (charts, graphs, tables), and perform arithmetic operations in order to make appropriate health and care decisions needed to function in the health care environment in ways that promote and maintain good health. This definition draws from the components of all previous definitions. This theoretical definition contains numeracy assessment and has as a goal improved health-related decisions by patients with diabetes and their families. This new theoretical definition will be used in this study. The abstract nature of any theoretical definition emphasizes the need for an accompanying operational definition for the researcher to use an agreed-upon definition for measurement in the clinical setting. In this study, the operational definition of health literacy will be measured by the use of the short form of the Test of Functional Health Literacy in Adults instrument.

Each organization noted above uses an open, conceptual approach to the definition of health literacy. In each case, this leads to an inclusive feeling, but presents difficulty when seeking quantifiable measurement of the health literacy. It is indeed possible to measure the HHS elements of the capability to obtain, integrate, and

comprehend a basic level of health information. Measurement of the ability to make health decisions useful to their individual needs by identifying what meaning these terms have for the individual, including cultural meanings is also achievable. But it is likely that a consensus would not be reached. It will be even more difficult to measure the WHO's definition of skill in cognition and ability to function in the individual's society which then applies to their motivation and individual ability. Not only would individual meanings come into play, but it would be difficult to quantify culture as a global construct. Rudd (2015) notes pertinent issues present as we seek to advance health literacy and health literacy evaluation in healthcare. It is important to keep several things in mind. Health literacy is an evolving concept. Health outcomes are affected by health literacy. There is a need for increasing health literacy at multiple levels. A definition that supports patient engagement, increased information access, and a clear research agenda would serve individuals and allow healthcare professionals to contribute to the advancement of health literacy (Rudd, 2015). If worded to facilitate quantitative measurement, an agreed-upon definition of health literacy would provide a means to advance research across disciplines and allow for meaningful comparison of research results.

Measures of Health Literacy. To determine health literacy, three instruments are currently used for the majority of healthcare research studies. The Newest Vital Sign (NVS), is a screening tool using a nutritional label developed, designed, and tested for use with the NVS. It is short, taking about 3 minutes to complete. This instrument measures the individual's ability to read and comprehend information from the label, such as ingredients causing an allergic response for that person. To evaluate numeracy, a

participant calculates the number of calories per serving listed on the label. Newest Vital Sign scores range from 0 – 6, and are grouped into 0 – 1 likely exhibiting low health literacy, 2 – 3 possibly exhibiting low health literacy, and 4 and above exhibiting adequate health literacy. Osborn et al. (2007) consider the NVS a valid choice for determination of low health literacy. However, scores of participants who were administered both instruments, showed the S-TOFHLA results indicated lower knowledge of cholesterol levels and non-optimal blood pressure control compared with NVS results. Medication adherence was not significantly different between S-TOFHLA and NVS (Osborn et al., 2007).

The Rapid Estimate of Adult Literacy in Medicine (REALM) tests word recognition. Using a list of 66 words progressing from short and easy words to longer and more difficult words common to medicine, REALM assesses the ability to pronounce the medical words, but does not require comprehension on the part of the participant. Scores are categorized as one of three levels: at or below the 6th grade point, the 7th or 8th grade point, and high-school point or above. Many healthcare forms and written instructions are written at the level of high school comprehension, making REALM results a potential measure of health literacy. Like the NVS, REALM can be completed in about 3 minutes. The REALM scores are thought to have a relationship with the individual's knowledge of health rather than a relationship with that individual's ability to process health concepts (Chin et al., 2011; Dumenci, Matsuyama, Kuhn, Perera, & Siminoff, 2013).

The Test of Functional Health Literacy in Adults (TOFHLA) has literacy and numeracy components. For the literacy component, participants read passages that

require them to fill in a word from a list provided. During the numeracy component, participants are asked to determine how many pills they should take as well as whether that pill should be taken at a certain time and with or without meals. The TOFHLA scores place participants in three categories: limited, marginal, or adequate health literacy (Medscape, 2007; Parker et al., 1995). The TOFHLA can take 22 minutes to complete. Parker et al. (1995) noted that when compared to the Wide Range Achievement Test-Revised (WRAT-R), a longstanding measure of literacy from the educational field, TOFHLA showed correlation coefficients of .74 and .84 with the WRAT-R and REALM respectively (Parker et al., 1995) demonstrating sensitivity and specificity for measures of health literacy.

Each of the three instruments has different versions. Some include Spanish and in the case of TOFHLA, a shorter version (S-TOFHLA). The S-TOFHLA contains fewer literacy and numeracy choices. Completion of S-TOFHLA is expected to take 7 minutes. The numeracy scores on the S-TOFHLA correspond moderately (Cronbach's alpha = 0.68) and the reading comprehension scores correspond highly (Cronbach's alpha = 0.97) to scores on the full-length TOFHLA (Parker et al., 1995). The S-TOFHLA was selected for this study as it gives a comprehensive assessment that is not as long as the complete TOFHLA, but assesses more than the NVS and REALM. These instruments are available for purchase, to be funded by the principal investigator. Purchase price includes instructions, the scoring guide, and permission to copy and use the questionnaire.

Additional Considerations in Health Literacy. Research in health literacy has yet to identify one instrument to measure the rather broad definition of health literacy. At

this time, the three instruments described above are the most frequently used measures of health literacy, but other instruments are in use. Pleasant and McKinney (2010) wrote regarding the lack of psychometric testing and questionable generalizability of each test. Validation of the REALM, TOFHLA and NVS was predominantly done using African American women, both Hispanic and African American women, and Hispanic women respectively. In addition, Pleasant and McKinney say current health literacy measures are not based on any theory or framework of health literacy (Pleasant & McKinney, 2011; Pleasant, McKinney, & Rikard, 2011). Such a theory would be a foundation for a unified approach to health literacy research.

Health literacy efforts to date are largely aimed at patients and to a lesser degree, to healthcare providers. Studies by Kelly & Haidet (2007) and Macabasco-O'Connell & Fry-Bowers (2011) noted that both resident physicians and nurses overestimated health literacy levels for patients during provider-patient communication (Kelly & Haidet, 2007; Macabasco-O'Connell & Fry-Bowers, 2011). Sommers and Mahadevan (2010), in a report commissioned by the IOM, notes the federal government has not produced strong legislative actions in support of health literacy (Sommers & Mahadevan, 2010). In the ACA (2010) health literacy is mentioned 7 times in over 900 pages of legislation. These references to health literacy are related to education and research, but no mandates for implementing a program of health literacy at any level are present (Patient Protection and Affordable Care Act, 2010). Authors including Koh et al. (2012), Logan et al. (2015), and Paasche-Orlow et al. (2015) note the progress achieved in the study of health literacy, but indicate that legislation and public policy development have not been realized (Koh et al., 2012; Logan et al., 2015, Paasche-Orlow et al. 2015).

Research on teaching strategies intended to improve health literacy includes the use of multimedia and teach-back in diabetes education. In the same way that asking a yes or no question elicits little information regarding an individual's understanding of a given topic, so does asking "do you have any questions?" when a patient has received instructions. Changing a question from "do you have difficulty with..." to "how often do you have difficulty with..." provides the patient an opportunity to discuss their needs. Better communication on the part of healthcare professionals obliges them to use oral, written, and visual (including multimedia) material when teaching a patient with inadequate or marginal health literacy. It also implies that healthcare organizations take action to assist all patients, but specifically those with inadequate or marginal health literacy in every aspect of care, including signage and directions in facilities, the reading level of printed material, and particularly in the ability of staff to recognize and assist patients with health literacy limitations (Chew, Bradley, & Boyko, 2004; Parker & Hernandez, 2012; Williams et al., 1998).

One multimedia approach to the assessment of health literacy is through use of a "talking touchscreen" tablet laptop known as Health LiTT with software adapted from the TOFHA. Hahn et al. (2011) report on the development and testing of this approach. Participants in the study had visual and audio files presented with answers available as a set of response buttons. When a participant chose to do so, they could touch the screen to receive an oral version of any question. Psychometric evaluation of the instrument was performed as well as a calculation of the Flesch-Kincaid index for the items developed for the instrument. Results were reported as demonstrating reliable measurement of health literacy (Hahn et al., 2011). The Health LiTT adds a new dimension to the field of

testing health literacy and to determine the magnitude of the population at risk due to low health literacy.

Access to Care (Barriers and Facilitators)

The IOM (2013) report “Returning home from Iraq and Afghanistan: Readjustment needs of veterans, service members, and their families” lists five dimensions of access pertinent to veterans with diabetes: geographic, temporal, financial, cultural, and digital. These dimensions of access may facilitate access to care or act as barriers to care (IOM, 2013). Geographic considerations facilitate care for those veterans in urban areas where there is a VA healthcare facility, but for those who are distant from VA facilities, a significant barrier exists. Regarding the temporal dimension, much has been written in the press and online regarding delays in registration for VA services and in the time needed to get an appointment. Reports of veterans dying due to delays have been published (CNN, 2014). Electronic methods and overtime are credited with reducing a backlog of registrations and appointments (Department of Veterans Affairs, 2014a). The financial dimension is a bit more complicated, as costs are dependent upon several factors. The primary factor is the level of disability rating the veteran is assigned when leaving active military service. If the rating is high enough, care is essentially free for that veteran. Income is pertinent for veterans who are seen for conditions not related to their military service and those who do not qualify for either disability compensation or a VA pension. A financial assessment and income verification are required for some veterans to determine if, and how much, they will pay in co-pays. Also, having private medical insurance affects and can even eliminate co-pays (Department of Veterans Affairs, 2015a). Cultural consideration is an area requiring additional research in the

veteran population. As an example, while the Native American, Pacific Islander, Hawaiian, and Alaska Native populations have a high percentage of military service, they may not use VA facilities but often use Indian Health Service facilities. There is an additional cultural component related to military service, in that those associated with the military may often harbor a perception that health conditions, including mental health conditions are weaknesses, and one does not give in to weakness, one overcomes it (IOM, 2013). The digital dimension of access is interesting, in that the VA has robust technological abilities and is seen as a leader in telehealth, but many veterans have not taken advantage of the technology offered due to their limited health literacy or familiarity with technology and computers (Hogan, Wakefield, Nazi, Houston, & Weaver, 2011; IOM, 2013). The main focus of VA telehealth is on behavioral health. Some telehealth work has been among veterans with diabetes (Hawkins, 2010), but this is an area ripe for research since few examples exist in the literature. As regards the veteran with diabetes, digital prowess, as previously noted, influences outcomes.

Fortney, Burgess, Bosworth, Booth, and Kaboli (2011) wrote that we should re-conceptualize the concept of access based on the changing nature of the patient-provider encounter and the advancing ability of online health technology to meet the needs of both provider and patient. They posit a change from face-to-face encounters to virtual encounters of several types. They describe four categories of digital encounters to be added to the traditional in-person visit: (1) synchronous encounters between patient and provider, (2) asynchronous encounters between patient and provider, (3) electronic communications between peers, and (4) synchronous encounters between patients and online health applications. Some of the digital encounters can be through interactive

video. Traditional in-person visits could be reserved for those medical procedures which require a tactile element and/or physical presence. They argue that access should be conceptualized as having had an opportunity to receive care and argue against the traditional measurements of utilization, quality, and outcomes. They also use the geographic, temporal, financial, cultural, and digital dimensions of access in their redefinition (Fortney et al., 2011). Once again, health literacy and computer access are concepts integral to this approach.

Lustria, Smith, and Hinnant (2011) note that Healthy People 2020 recommends more “equitable access to health information and improved health communication” in order to decrease health disparities with the expected result of improved outcomes. Research shows evidence linking improved access to online health information with better health knowledge, daily health choices, collaboration provider recommendations, and improved communication between patient and provider. The goal of enabling better health information and technology access is ultimately to decrease health disparities (Lustria et al., 2011).

The VA healthcare system has worked to improve access to care using its considerable ability to employ virtual medicine while at the same time initiating the patient-centered medical home (PCMH) model. The VA’s version of PCMH is called Patient Aligned Care Teams (PACT). Patient Aligned Care Teams uses a primary care managed team approach. The VA also has two electronic access tools, the Care Coordination Home Telehealth (CCHT) Program and the MyHealtheVet portal. The CCHT is an outreach to those with chronic care needs who are distant or homebound. Videophones and devices such as sphygmomanometers and glucose meters can be

connected so that a provider can receive a snapshot of current vital signs. The MyHealtheVet portal serves as a personal electronic health record in addition to its use in scheduling appointments, communicating with providers, refilling prescriptions, and getting health information (Hawkins, 2010; Hogan et al., 2011).

Diabetes Distress

Diabetes distress denotes one or more problems carried by an individual that are part of managing the sometimes complicated facets of diabetes. Such distress has been shown to have an association with inability to comply with a prescribed medication regimen. Because most research in the area of diabetes distress has been of the self-report variety, little has been written about how distress leads to non-compliant behavior (Fisher et al., 2013; Gonzalez, Shreck, Psaros, & Safren, 2015).

At the time of transition from active duty to veteran status, conditions are in place to cause distress among veterans with diabetes. Hogan et al. (2011) anticipate that coordination of the CCHT and MyHealtheVet resources, when appropriate and tailored to the individual, can increase communication and knowledge needed for self-management of chronic diseases such as diabetes. The time of transition would be an opportune time to incorporate these resources, especially online and other electronic resources, into the tools available to veterans with diabetes. In addition, involving family members and other caregivers and teaching them about VA resources both traditional and electronic, is an effective practice, as they are often those who perform research regarding diabetes and other health issues online. Therefore, having familiarity with MyHealtheVet and other online healthcare resources would be a benefit to the veteran (Fox & Duggan, 2013;

Hogan et al., 2011). Although this study's participants were overwhelmingly familiar with online resources, further research will be needed regarding this aspect of transition.

Measuring Diabetes Distress

As it is expected that some level of distress related to self-care of diabetes is present at the time of transition from active duty to veteran status, it was logical to find an instrument to measure diabetes distress. Diabetic distress was measured using the Diabetes Distress Scale (DDS). Polonsky et al. (2005) described the development of the DDS as a means of overcoming limitations in previously developed diabetes distress measurement instruments. It is described as is a conceptually driven reliable measure useful in research and for screening diabetes-related distress in clinical practice settings. In this study, the DDS measured diabetes-related distress as a proxy for distress encountered by veterans with diabetes at the time of transition from active duty to veteran status (Polonsky et al., 2005). Strengths of the DDS (including the DDS, and to some extent, the Problem Areas in Diabetes (PAID) scale), lie in being recognized as the gold standard instrument(s) for measurement of diabetes distress. Also, a study by Schmitt, et al. (2015) supported the psychometric findings originally reported by Polonsky et al. (2005).

Patient Portal Use

Tsai and Rosenheck (2012) studied the use of the Internet by veterans to determine overall use and specifically use of the MyHealthVet patient portal. Although their interest was in veterans with behavioral health needs, their overall premise was that increased use of online services will improve access to VA healthcare services. Their results showed 67% of those surveyed used the Internet, but only 21% used

MyHealthVet. An encouraging result was that the mean age of respondents was 61 years, indicating substantial numbers of older veterans have the potential to use online resources (Tsai & Rosenheck, 2012). An additional consideration is that previous research on computer use conducted about the turn of the 21st century indicated only 27% of those over 60 years old used computers while 65% of those aged 45-65 used computers. In the 15 years since the study, all those in the 45-60 age group have moved to the over 60 group. One can expect they retained their computer skills (Brodie et al., 2000). It would be useful to conduct a survey to determine current data.

As previously noted, patient portals are used for several common purposes, but less often for education. Patients who use the Internet and have inadequate or marginal health literacy are less likely to use patient portals to view laboratory results, refill medications, contact or email their primary provider, and to make appointments (Sarkar, Karter, Liu, Adler, et al., 2010). The implication is that those who are less likely to use portals will miss the opportunity to review their laboratory results, and will not proactively assess their progress toward meeting diabetes self-management goals. They will not prepare to discuss results with their provider. They may not have an uninterrupted supply of prescribed medications facilitated by refilling medications through an online portal. Patients may need to change or may miss appointments made at the end of a given appointment due to scheduling conflicts. Also, they will miss the opportunity to ask questions via secure email, meaning such questions may be forgotten or not asked in a timely manner.

Research indicates those encouraged to use patient portals do so more often than those who are not. Outcomes for diabetes and other chronic conditions has also been

noted to improve in patients using portals (Goel et al., 2011; Goldzweig et al., 2013; Shaw & Ferranti, 2011). Participants in this study will be asked about their use of the Internet and the MyHealthVet portal as part of the qualitative portion of the study.

The Digital Divide

A gap exists between those who are able to use computers, including their access to computers, and those who are not able to use computers or do not have access. This gap has been labeled the digital divide. The digital divide is defined as decreased access to online resources or information technologies, specifically the Internet, among groups such as racial and ethnic minorities, people with disabilities, rural residents, and people of low socioeconomic status (Chang et al., 2004). Initially thought to be an inequality related to computer access, researchers have noted social, mental, and cultural aspects of the digital divide (van Dijk, 2006). Lower income, race and ethnicity (African American or Latino), living in a rural area, and over age 65 have been factors in defining those experiencing the digital divide. Health literacy is also a factor linked to those affected by the digital divide. A majority of veterans fall into one of the groups most susceptible to the digital divide (Brodie et al., 2000; Chang et al., 2004; Moffet et al., 2009; Sarkar et al., 2011; Yamin et al., 2011).

Online Educational Resources

Many online health resources for patients' use exist. A search in Google for "health information" yielded 679,000,000 results. Topics in the results included advertisements for schools; women's health and HPV education; government sites including NIH, NINR, and the California Department of Public Health; institutionally sponsored sites such as WebMD, Healthline, and the Mayo clinic; and sites for

information on fitness, exercise, and weight loss. A list of suggested related searches included: medical symptoms, health articles, health problems, health questions, health information jobs, health information management, health information definition, and healthcare information. Without guidance, any individual may have difficulty finding the right category, let alone finding a reputable site. Debate has arisen over the difficulty of finding information online when there are so many sites available. Adams (2010) reviewed the literature from the perspective of increased capability of online applications. This technology was made possible by the evolution of interactive online resources, available by the adoption of “web 2.0.” Issues have arisen regarding authorship of content on a specific site, the questionable reliability of sources and user interfaces, and whether the nature of a given site is commercial versus healthcare organization based, or primarily one for social media (Adams, 2010; van Velsen, Beaujean, & van Gemert-Pijnen, 2013). In this environment, a veteran with diabetes needs guidance in order to make good use of online educational resources, including MyHealthVet. A challenge for all healthcare systems is to meet the demand for information in a portable format viewable on smart phones and tablet devices. Consumers face a plethora of choices here, similar to finding a reliable healthcare information website. With as many choices in applications, websites, and social media sources for healthcare information, patients, family members, and others who support veterans with diabetes can become overwhelmed by these choices. van Velsen et al. (2013) suggests the creation of a few reliable gateways, especially for mobile applications. She states that one online store alone has over 650,000 applications available. The same caveat exists regarding the quality of products for sale (or sometimes for free). Except for customer satisfaction

ratings, which are varied, no one has judged the quality of the offerings available in online stores. van Velsen's suggestion is two-fold. The first recommendation is to standardize content through development of true standards for health information. But most importantly, she further urges adoption of open source licensure, which would allow those external to content developers to share and certify content (van Velsen et al., 2013).

Consumers do have preferences when seeking providers, and provider websites are a common source for decision-making regarding choice of a provider. An online survey revealed that close to 75% of those who participated felt that websites need to be more helpful. When an individual seeks to contact a provider, easy contact options were highly favored. But more than one-third of respondents indicated they could not reach providers by email. This was a difficulty for them as 69% found value in receiving communication by email. Mobile healthcare sites were not considered easy to access or navigate (Slabodkin, 2015). Veterans with diabetes face these choices in technology less for choice of a provider, but equally for information gathering.

Mandates for use of Technology in Healthcare

The ARRA includes a provision "to improve American health care delivery and patient care through an unprecedented investment in health information technology." To this end, the ARRA set aside nearly \$38 billion over 10 years in order to assist health systems and providers in purchasing and employing health information technology (ARRA, 2009; Lustria et al., 2011). Health systems, including the VA, are expected to have EHR and other systems in place to improve access for patients. The ARRA includes the HITECH Act, which delivers financial incentives for implementation of EHRs and imposes penalties, particularly in the enforcement of Health Insurance

Portability and Accountability Act (HIPAA) rules and regulations, considered to have been weakly enforced previously (hippasurvivalguide.com, 2014).

The ACA added additional legislation, much of which is not applicable to the VA and DoD healthcare systems. However, provisions that encourage increased integration of healthcare systems, improved transitions for Medicare recipients at the conclusion of an acute care hospital stay, reduction of paperwork and other administrative costs, and work to decrease health disparities apply to these two systems (Patient Protection and Affordable Care Act [ACA], 2010). As the ARRA and ACA legislation began to be implemented, the Agency for Healthcare Research and Quality (AHRQ) developed a health literacy universal precautions toolkit as an online tool to assist healthcare providers at multiple levels, implement actions toward improving health literacy in Americans (Adams, 2010; Agency for Healthcare Research and Quality, 2010). An issue with great relevancy to transitioning veterans is the lack of interoperability of the VA and DoD electronic health records.

Summary

Assessing veterans with diabetes concerning the transition from active duty to veteran status, especially with regard to their health literacy and barriers and facilitators to access to care and DMSE is expected to yield valuable data useful in conducting future research.

There is a gap in the literature regarding the effect of health literacy on veterans with diabetes and their self-management as well as a gap in the literature regarding transition from one health care system to another. Current literature indicates the transition process from active duty to veteran status process does not ensure veterans will

experience a smooth transfer of care from one system to another. While some information regarding use of MyHealthVet is available, there is a gap in the literature regarding veterans' use of MyHealthVet and other online resources for DMSE and/or chronic disease self-management. This study has the potential to contribute valuable data to the literature.

Chapter 3

Methods

Introduction

The literature shows examples of studies describing the transition from active duty military to veteran status (Knight, 2014; IOM, 2010; Morin, 2011). However, the focus has been on difficulties anticipated or experienced secondary to the psychological and physical injuries of war, including adjustments necessary due to post-traumatic stress disorder, traumatic brain injury, amputation, and loss of comrades. No studies have focused on the transition experienced by veterans with diabetes or other chronic diseases. This study was intended to be a starting point for future study of the needs and experiences of veterans with diabetes in order to develop appropriate interventions to assist them in diabetes self-management. The goal of this study was to describe the transition from active duty to veteran status in a sample of veterans diagnosed with diabetes while on active duty. The sample's experience of access and barriers to healthcare, having had some level of DSME, the ability to perform diabetes self-management activities, and veteran's familiarity with and use of online resources during this transition was also to be described. A measurement of each veteran's healthcare literacy level and diabetes distress was included in this study.

Study Purpose

The purpose of this dissertation study was to describe the factors, based on the lived experience of a sample of veterans with diabetes, that acted as barriers and facilitators to diabetes care and diabetes self-care management during the transition from active duty to veteran status.

Study Aims

Specific aims of this study in this sample of veterans with diabetes are to: (1) describe common ways in which veterans diagnosed with diabetes while on active duty experience the time of transition from active duty to veteran status, (2) describe barriers and facilitators of access to care and diabetes self-management during the transition from active duty to veteran status, (3) describe veterans with diabetes' knowledge of traditional and online self-management education, and (4) note the health literacy level and diabetes distress of a sample of veterans with diabetes.

Design

This was a descriptive qualitative study with a quantitative component included. The goal of the study was to determine the barriers and facilitators to access to care faced by veterans with diabetes during transition from active duty to veteran status. In addition, DMSE and diabetes self-management activities were solicited along with use of online patient resources. A measurement of health literacy and diabetes distress was included in the study. The study followed a descriptive approach using a qualitative questionnaire, the S-TOFHLA, and the DDS, administered to veterans with diabetes in a sample of veterans with diabetes. Participant demographics including age, gender, race, length of military service, the year the veteran left the military, education level, type of diabetes, how long the veteran has had diabetes, DMSE, self-care activities, Internet familiarity, use of the Internet in diabetes care, and familiarity with and use of MyHealthVet were collected.

Setting

This study was conducted primarily in the US Southwest, with recruitment of participants from the VA healthcare system, Military healthcare facilities, the non-profit organization Take Control of Your Diabetes (TCOYD), and several veterans' organizations based in San Diego County, CA.

Sample

A sample of veterans was recruited for this qualitative study which reached saturation on the primary question after 10 interviews had been conducted. A convenience sample was selected for this study. This was a feasibility study intended to lead to further research in this population (Leon, Davis, & Kraemer, 2011). It was expected to be a relatively homogeneous group in that the underlying inclusion criterion is that these individuals are all veterans with diabetes. No inferences were intended to be generated from this study.

Inclusion and Exclusion Criteria. Inclusion criteria were having veteran status with a diagnosis of diabetes while on active duty in the US military. Male and female participants with either type 1 or type 2 diabetes were included. Veterans generally have type 2 diabetes and are predominantly male, but in this study, no selection was made on the basis of gender or type of diabetes.

Exclusion criteria were being unable to communicate orally or in written form, being physically unable (i.e. having a prior stroke or behavioral health issue) at a level which prevents oral communication and/or physical movement required to complete a health literacy instrument, and being unable to read and write in English.

Data Collection and Security. Prior to beginning the study, oversight of the institutional review board (IRB) at the University of San Diego was obtained. Quantitative instruments and qualitative interviews were conducted by the study author. Data were entered by the author into a password protected Excel spreadsheet on the author's password-secured computer. All data collected in hard copy were de-identified and stored by the author in a locked file cabinet. Interviews were recorded and transferred to the author's computer into a password protected file. Recordings were transcribed by a professional transcription service, and returned via secure email as Word documents which were then kept in a password protected folder. Transcripts were compared with the recordings and corrected if needed. IRB guidance for maintenance and destruction of data are being followed.

Recruitment. Written permission to advertise the study was obtained from the commanding officers of Naval Medical Center, San Diego (NMCSD), and Naval Hospital Camp Pendleton (NHCP), respectively. Oral and email consent from TCOYD staff and several veterans' organizations was also obtained prior to beginning advertisement for the study. Participants were recruited through personal contact, posters, fliers, and physician advocates, primarily Dr. David Bittleman, a dissertation committee member.

Qualitative Phase. A semi-structured interview guide containing a series of 11 questions and eight demographic items was used to give veterans with diabetes a format to describe common ways in which they experienced the time of transition from active duty to veteran status. The interview guide was developed by the author and included prompts to the study author that ensured consistency from participant to participant. The

questionnaire was reviewed by dissertation committee members and was approved with minor modifications. After obtaining each participant's consent, each interview was recorded. Recordings were transcribed for analysis. Original recordings were compared with the transcripts and minor corrections were made.

Quantitative Phase.

Instrumentation. There are striking differences in estimation of the prevalence of low health literacy in the US. The various studies estimate a range from 26% to nearly 90% of Americans (Baker, Parker, Williams, & Scott, 1998; Parker et al., 1995; Sarkar, Karter, Liu, Moffet, et al., 2010). These estimates have evolved over the past 20 years and may be biased by the original samples from which data were collected. For example, the earliest validation of the two most commonly used measures of health literacy were conducted in largely African American and Hispanic samples (Pleasant et al., 2011). The data change over time as more interest in health literacy is generated. Therefore, careful selection of the instrument was kept in mind.

The TOFHLA has literacy and numeracy components. For the literacy component, participants read passages that require them to fill in a word from a list provided. During the numeracy component, participants are asked to determine how many pills they should take as well as whether that pill should be taken at a certain time and with or without meals. The TOFHLA scores place participants in three categories: inadequate, marginal, or adequate health literacy (Baker et al., 1998; Williams et al., 1998). The TOFHLA can take 22 minutes to complete. Parker et al. (1995) noted that when compared to the WRAT-R, a longstanding measure of literacy from the educational field, TOFHLA showed correlation coefficients of .74 and .84 with the WRAT-R and REALM respectively demonstrating sensitivity and specificity for measures of health

literacy (Parker et al., 1995). The study author obtained permission to administer the TOFHLA. Permission included instructions, the scoring guide, and permission to copy and use the questionnaire.

A shorter version (S-TOFHLA) is included in the purchase of TOFHLA. The S-TOFHLA contains fewer literacy items and eliminates numeracy choices. Completion of S-TOFHLA is timed to take up to 7 minutes. The reading comprehension scores on the S-TOFHLA correspond highly (Cronbach's alpha = 0.97) to scores on the full-length TOFHLA. The numeracy section of the TOFHLA is omitted from the S-TOFHLA. Scores on the S-TOFHLA range from 0 to 36 (Nurss, Parker, Williams, & Baker, 1995; Parker et al., 1995). The S-TOFHLA was used because as it gave a functional health literacy assessment that decreased time of administration, reducing participant burden.

Diabetic distress was measured using the Diabetes Distress Scale (DDS) as a proxy for the distress encountered during the transition from active duty to veteran status in this sample. Polonsky et al. (2005) described the development of the DDS as a means of overcoming limitations in previously developed diabetes distress measurement instruments. It is described as a conceptually driven reliable measure useful in research and for screening diabetes-related distress in clinical practice settings (Fisher, Hessler, Polonsky, & Mullan, 2012; Polonsky & Fisher, 1995; Polonsky et al., 2005). Experts, including nurses, patients, physicians, dieticians, and diabetes-savvy psychologists, were recruited nationwide to review questions included in a previous instrument: The PAID scale. Scores from the PAID scale had been associated with diabetes self-care. The final instrument is a 17-item scale with scores that range from 17 to 102. The total score entered is divided by 17 yielding a mean score for that participant. Scores of 2.0 to 2.9

on the entire instrument are considered moderate distress and scores ≥ 3.0 are considered high distress. Scores on the four subscales have the same score range regarding distress for that subscale. The arithmetic used to derive each subscale score is to divide the score on the corresponding subscale questions by the number of questions contained within that particular subscale. Exploratory factor analysis was performed to uncover factors to include in the DDS scale. Cronbach's alpha was calculated for the whole scale and for the four subscales of emotional burden (EB), physician-related distress (PD), regimen-related distress (RD), and diabetes-related interpersonal distress (ID). Combined scores from all sites were used since there was little variation between sites. The alpha values for the total instrument and the four subscales are as follows: total = 0.93, EB = 0.88, PD = 0.88, RD = 0.90, and ID = 0.88, showing the DDS to be internally consistent. Validity was measured with Pearson correlation coefficients or chi square values, again for the entire scale and for each of the four subscales. The values were also computed against the well-known Center for Epidemiological Studies Depression scale. Results showed a negative correlation with age ($r = -0.29$), showing that young patients reported more diabetes distress than older patients. No correlation with glycemic control was present ($r = 0.01$), but there was a positive association with total cholesterol scores ($r = 0.20$). None of the four subscales showed a relationship with gender, ethnicity, education completed, or duration of having diabetes. All subscales showed a relationship to a depressive affect ($r = 0.33$). Subscales EB and RD showed participants had poorer meal planning ($r = 0.21$ and $.043$ respectively) and did not exercise frequently ($r = 0.12$ and 0.16 respectively). The subscale RD was linked with a lower frequency of self-monitoring of blood glucose ($r = 0.19$). While the subscales did not show a link to hemoglobin A1c, EB, RD, and ID

did have a positive relationship with total cholesterol ($r > 0.16$ for each of the three subscales.) Scores on the DDS were highest for insulin users (39.6 ± 17.1) followed by those on oral medications (35.2 ± 16.2) and those controlled entirely by diet (26.7 ± 12.1). Overall, the instrument has good internal reliability and validity. The DDS was tested for readability and has a Flesch-Kincaid grade level of 7.3, meaning most patients will be able to comprehend the DDS (Fisher et al., 2012; Polonsky et al., 2005). An even shorter version of the DDS with only two questions has been developed as a screening tool. However, the 17-item DDS became the instrument of choice for this study because there was no intention to screen the participants for behavioral health issues, only to describe distress during transition (Fisher, Glasgow, et al., 2008).

Human Subjects Considerations. As in the data collection and security section above prior to any data collection, permission to advertise the study at the NMCS D, NHCP, VA Mission Valley Clinic, TCOYD, and with veterans' organizations was obtained. All data collected were de-identified and stored by the author in password-protected computer files and folders, with hard copy data secured in a locked file cabinet. Data is scheduled to be destroyed according to IRB guidance.

Data Analysis. The four aims of the veterans with diabetes transition study were to:

(a) describe common ways in which veterans diagnosed with diabetes while on active duty experience the time of transition from active duty to veteran status,

(b) describe barriers and facilitators of access to care and diabetes self-management during the transition from active duty to veteran status,

(c) describe veterans with diabetes' knowledge of traditional and online self-management education, and

(d) note the health literacy level and diabetes distress of a sample of veterans with diabetes as measured by the short form of the of the Test of Functional Health Literacy in Adults (S-TOFHLA) and the Diabetes Distress Scale (DDS).

Aim (a). To address aim (a), qualitative data were collected and examined for themes, topics, ideas, concepts, terms, phrases, or keywords. A computer program was considered for analysis but discussion with committee members indicated manual examination was the process of choice.

Aim (b). To address aim (b), qualitative data were collected and examined for themes, topics, ideas, concepts, terms, phrases, or keywords as was done for Aim (a).

Aim (c). To address aim (c), qualitative data were collected and examined for themes, topics, ideas, concepts, terms, phrases, or keywords as was done for Aims (a and b).

Aim (d). To address aim (d), data was entered into an Excel spreadsheet and transferred to the Statistical Package for Social Sciences v. 22 (SPSS) (IBM Corporation) for analysis. Descriptive statistics were derived and are reported in article number three.

Study Strengths and Weaknesses

The year of leaving the military ranged from 1969 to 2014, a 45-year span. Changes in DoD's MHS, the VA healthcare system, and individual memory may cause some bias in the data collected. The study did not include a question regarding level of diabetes control or A1c level. Better or poorer control may influence the individuals' experiences. Results from the S-TOFHLA had no variability, and therefore were not

useful in analyzing the data. These results also deviated from national estimates of health literacy (Koh et al., 2012; Paasche-Orlow et al., 2005; Parker et al., 1995; Parker et al., 2003). Also, the principal investigator for this study is a retired military member subject to bias based upon his military career. The results are not generalizable to another population, particularly due to the homogeneity of this population sample.

Strengths of this study included the homogeneity of the sample and the opportunity to discover information useful to future research studies.

Study Significance

The Healthy People 2020 goal for diabetes is to “Reduce the disease and economic burden of diabetes mellitus (DM) and improve the quality of life for all persons who have, or are at risk for, DM” (Healthy People 2020, 2014). The results of this study on veterans with diabetes produced data with potential for future work to improve the health of a group noted to have a high diabetic burden. The significance of the study is this is the first description of the experience of transition from active duty to veteran status in veterans diagnosed with diabetes while on active duty. Their compliance with diabetes self-care management, surprisingly high level of health literacy, and relatively low diabetes distress during the transition point to the potential for veterans to be extremely successful in diabetes self-management. Future research can focus on designing interventions that increase the ability of veterans with diabetes to take a greater role in improvement of the transition process. This research study connects with the Healthy People 2020 diabetes goal in that it is a starting point toward increasing veterans’ participation in self-care with the goal of decreasing their disease burden.

Chapter 4

Manuscripts

Introduction

The model used in this study follows a format that incorporates three manuscripts rather than the traditional five-chapter dissertation. The specific aims of the veterans with diabetes transition study were to: (1) describe common ways in which veterans with diabetes experience the time of transition from active duty to veteran status, (2) describe barriers and facilitators of access to care and diabetes self-management during the transition from active duty to veteran status, (3) describe veterans with diabetes' knowledge of traditional and online self-management education, and (4) note the health literacy level and diabetes distress encountered during transition in a sample of veterans with diabetes. The following manuscripts put the study in context, critique the instrument used to measure diabetes distress, and summarize and report the conduct and results of the veterans with diabetes transition study.

The first manuscript: *The Transition of Healthcare Management Among Military Personnel with Diabetes from Active Duty to Veteran Status* examines veterans' needs during transition related to barriers and facilitators to healthcare access among veterans diagnosed with diabetes on active duty as these veterans transition their healthcare from the DoD MHS to healthcare as a veteran. This manuscript describes the transition process with attention paid to anticipated healthcare costs, morbidity and mortality, and diabetes distress in this group of veterans with diabetes. A description of the active duty to veteran transition process suggests potential issues a veteran may encounter. The scope and significance of making a transition of healthcare and specifically diabetes

management in veterans with diabetes diagnosed while on active duty is explored. Consequences of healthcare transition in this sample of veterans is discussed including anticipated needs and potential barriers and facilitators to access of healthcare related to transition from the DoD to the VA.

The second manuscript: A critique of the Diabetes Distress Scale (DDS), examines the psychometric properties of this instrument. The DDS has been used mostly by physicians and psychologists and so is not as well known by nurse researchers. The DDS is considered the gold standard for measuring diabetes distress. The manuscript also compares the DDS to its predecessor, the PAID scale. Development of the DDS was intentionally planned as a replacement for the PAID, in order to improve the instrument and correct deficiencies noted in the PAID.

The third manuscript: The Veterans with Diabetes Transition Study summarizes and describes the study as a whole. A qualitative descriptive study was conducted that answered the four study aims. The experience of veterans diagnosed with diabetes while on active duty is reported as two major and four additional themes that emerged via their stories. These veterans' experiences with access and barriers to healthcare, description of diabetes self-management activities, and use of electronic healthcare resources were also elicited during individual interviews. The sample's responses showed better diabetes self-management, use of electronic health resources, and health literacy than those noted in previous research. A description of the sample's health literacy and diabetes distress is included in the manuscript.

Transition is in many ways a given of military service. Active duty service members expect to move, attend schools, and deploy. Healthcare changes are also

expected. Due to expected changes in the duty station or deployment of a service member or change of their primary healthcare provider, there is no expectation to remain under the care of one primary care provider for more than three years. Continuity of diabetes care is thus affected, and continuity of care has been associated with better glucose control in patients with type 2 diabetes, which is the type diagnosed in the majority of veterans with diabetes (Parchman, Pugh, Noël, & Larme, 2002).

Diabetes is often called an epidemic by healthcare professionals (Albright & Gregg, 2013; Lam & LeRoith, 2012; Steinbrook, 2012). An estimated 9.3% of Americans have diabetes (American Diabetes Association, 2014; Centers for Disease Control, 2014). Miller, Stafford, and Pogach (2004) noted that veterans have twice the prevalence of diabetes compared to other Americans. A much smaller prevalence of diabetes is present among active duty military members (Chao, Zarzabal, Walker, & Carnahan, 2013). This small population is considered disqualified for further military service due to their diagnosis (Army, 2011; Department of Defense, 2010; Navy, 2015). Therefore, an inevitable transition from active duty to veteran status takes place. This transition is known to cause stress among members of the military population (IOM, 2010; Knight, 2014; Morin, 2011). The military has recognized those transitioning from the military to civilian life face needs and challenges different from those encountered on active duty. Transition programs are mandated by congress (Department of Defense, 2015) for this very reason. A gap in the literature exists regarding the transition of veterans diagnosed with diabetes on active duty to their current veteran status.

Research on healthcare transitions covers important changes in two populations. The first is the transition of adolescent patients with a pediatric primary care provider to

care as an adult, which frequently requires a change in provider and in the paradigms related to adult healthcare (Peters & Laffel, 2011). The second is a transition from one level of care to another most often related to inpatient care, although this can apply to care changing from a home to an institutional setting. This kind of transition is often from acute care to rehabilitation or skilled nursing (Jeffs et al., 2013; Kim & Flanders, 2013; Naylor et al., 2011).

Few studies on the transition of active duty military members to veteran status have been conducted. Existing studies are focused on difficulties, both actual and anticipated, experienced by service members who have been exposed to war and traumatic events which may or may not be related to exposure to war (IOM, 2010; Knight, 2014; Morin, 2011). A gap in the literature was found regarding the transition of healthcare for active duty service members with chronic conditions, and in particular, those diagnosed with diabetes.

This study's purpose was to determine factors, based upon the lived experience of a sample of veterans diagnosed with diabetes while on active duty, that were noted as barriers and facilitators to receiving diabetes care and which further had influence upon diabetes self-care management during the transition from active duty to veteran status.

The main aim of the study was to describe the experience of a sample of veterans diagnosed with diabetes while on active duty. Additional aims included in the study were veteran-described access and barriers to healthcare, their health literacy level as measured by the S-TOFHLA, a veteran's score on the DDS as a proxy for distress encountered during the transition process, veteran's diabetes self-management education along with their ability to perform diabetes self-management activities, and a veteran's familiarity

and use of online resources related to their healthcare (Fisher et al., 2008; Parker et al., 1995; Polonsky & Fisher, 1995; Polonsky et al., 2005).

Several components of the study were presented in the three articles that comprise chapter four. Article #1, *The Transition of Healthcare Management Among Military Personnel with Diabetes from Active Duty to Veteran Status*, describes veterans' needs and the process of transition from active duty to veteran status. Article #2, *A Critique of the Diabetes Distress Scale (DDS)*, examines psychometric properties of the DDS. Article #3, *The Veterans with Diabetes Transition Study*, presents the results of the qualitative study conducted and describes veteran's experience of the process of transition following active duty diagnosis.

Summary

A sample of veterans diagnosed with diabetes prior to the end of their active duty was recruited in the US southwest, primarily in San Diego County, California. An additional recruitment opportunity arose from interaction with the nonprofit organization TCOYD, a San Diego based entity whose purpose is to assist people with diabetes to live well with diabetes. At a TCOYD conference and health fair in San Antonio Texas, several participants were recruited and interviewed. Participants were recruited until data saturation was achieved which occurred after 10 participants had been interviewed. Interviews were conducted in person using a semi-structured interview guide developed by the principal investigator and validated with a group of military nurse researchers. Participants were interviewed in person at a mutually agreed upon location, which was a coffee shop, take-out restaurant, or the TCOYD conference health fair. Interviews, including the two qualitative instruments, lasted 40 to 45 minutes. Digital recording was

used after obtaining participant consent as part of the consent process. Recordings were transcribed by a professional transcription service and received as word documents by secure email.

Thematic analysis of the transcriptions in combination with a review of the original recordings and field notes uncovered two major themes and four additional themes. The major themes were feeling loss due to an unplanned and undesired end of a military career and feeling prepared to leave the military. Additional themes included feeling an unexpected life change due to the diagnosis of diabetes, feeling a need to personally manage their healthcare, feeling determined to cope with the unexpected health challenges that accompany diabetes, and a feeling of satisfaction with their healthcare provider.

Discussion

The Office of Disease Prevention and Health Promotion, through the Healthy People 2020 program, the American Diabetes Association, and the American Heart Association have each appealed to healthcare providers to prioritize improvement in care for people with diabetes as an ongoing goal (American Diabetes Association, 2013; American Heart Association, 2011; Department of Health and Human Services, 2015; Healthy People 2020, 2014). Veterans diagnosed with diabetes while on active duty faced not only the challenge of managing their diabetes but also an additional change related to their likely transition from the military to civilian life, which may or may not have been planned. The DoD mandates a transition process to be managed by each service to provide assistance for members ending military service (Department of Defense, 2015). Transitioning members have many topics to cover in a relatively short

time in the transition program curriculum. Healthcare is one topic; diabetes care is not. The literature does not contain data on transition between healthcare systems including transition from the DoD MHS to the VA healthcare system. Likewise absent from the literature is data regarding the unavoidable changes in provision of healthcare following a transition from the DoD MHS to the VA or from active duty clinics to retiree clinics. Stories told by veterans participating in this study indicated several things: a desire for excellent preparedness in transition between active duty and veteran status, a desire to serve their country for as long as they desired and determination to succeed by having life skills necessary for coping. Their stories indicated personal composure and maturity gained during their military service which allowed them to address diabetes as a new challenge rather than as condition that could prevent them from living an active life.

Stories are powerful tools for expressing deeper emotions. This study was planned using a qualitative approach in an attempt to uncover the basic feelings of veterans who had experienced a transition that included changes which required specific effort by the veteran in order to achieve success. Their stories add support to the studies on the difficult transition from active duty to veteran status. However, their stories also indicate these veterans were able to find ways to manage the transition along with the generally new diagnosis of diabetes.

The diagnosis of diabetes came as a surprise to the study participants with one exception: a woman who had experienced gestational diabetes during pregnancies, and therefore was more gradually introduced to life with diabetes, the diagnosis of diabetes came as a surprise to the study participants. Five of the participants were planning for the end of their military career, four were retiring from active duty, and one individual had

chosen to leave active duty in order to pursue higher education. Of these five, four simply included provisions for diabetes care and healthcare in general in their transition planning as a matter taken in stride along with the logistics of housing and employment. These four expressed a feeling of preparedness to leave the military. One participant who was eligible for military retirement desired to remain on active duty until mandatory retirement, but was told he would not be allowed to deploy due to his medical needs for diabetes management. He expressed frustration because for him this was “a huge shock when you realize that you can no longer do what you love to do.” He chose to retire about 14 months after learning of his diagnosis. The additional participants who had planned to remain on active duty were displeased with their inability to influence the military’s decision to separate them from active duty and with consequences of leaving the military before they had accumulated enough years to meet career goals and eligibility for retirement.

The two major themes of a feeling loss due to an unplanned and undesired end of a military career and of feeling prepared to leave the military were split nearly evenly among participants (four versus five). The themes can be viewed as two sides of the same coin, which is military service. On one side, it is inevitable that military service will end and thus it is planned for. On the other side, service members would like to decide when they will leave active duty. Even though veterans know that career length is not always under their control, they would like it to be.

The four that were prevented from having a longer military career spent more time discussing the end of their career than did those who had planned for the end of their career. All four of those who felt they were experiencing an undesired end to their

military career made attempts to remain on active duty. Only one of the four had enough time in the service to retire. He expressed his experience as, “the shock of well, you can’t go to sea and you can’t go overseas, which means your career is over.” Two participants said they attempted to delay discharge and avoided sharing their diagnosis with their chain of command because they knew their diabetes was a disqualification for continued military service. A participant who retired in the 1980s shared “There wasn’t a lot of empathy put into transitioning people at that time.”

Although their attempts to remain on active duty ultimately failed, one was able to change his medical evaluation from a process expected to take a week to one that was more thorough and ultimately rendered a decision to medically retire him rather than to release him from active duty with VA eligibility but without any military medical benefits. Another participant shared that he went from diagnosis of diabetes in Iraq to a military hospital in Germany to a military hospital in Maryland to discharge from the Army in less than two months.

The experience of all four cases is summed up by a participant who stated, “I just started my life again, restart everything.” They did not feel the transition process was particularly difficult, they simply did not want to leave active duty. Settling in with a provider the individual considered good provided a positive experience.

Among those who expressed feeling prepared to leave the military, three participants were extremely surprised by their diagnosis of diabetes because they were informed of their diagnosis during their end of service medical screening. All three were among those who decided to manage their diabetes as one more challenge associated with the end of their military career. The other two who had more time to adjust to having

diabetes had already started to manage their diabetes. Four of those who felt prepared to leave the military also felt determined to cope with the unexpected health challenges that accompany diabetes. Only one was less determined to cope and more philosophical, or perhaps, accepting of diabetes as part of life rather than as a specific challenge to be faced.

Those who expressed preparedness to leave the military said being prepared for the transition out of the military helped their access to healthcare as a veteran. Participant number 3 stated, “What helped access to care is preparing before you get out.”

The additional themes of feeling an unexpected life change due to the diagnosis of diabetes, feeling a need to personally manage their healthcare, feeling determined to cope with the unexpected health challenges that accompany diabetes, and a feeling of satisfaction with their healthcare provider were fairly common among participants. All felt an unexpected life change had occurred and with the exception noted above, felt a determination to cope with this life change. The participants indicated they felt a personal need to manage their healthcare which could be an indication of the personal nature of diabetes. Changes in diet, exercise, performing blood glucose monitoring, and taking medications, perhaps being the first ongoing medication regimen for that person, are very personal changes. It is not unusual then, that the participants chose to be proactive and compliant in their diabetes management. This was an extraordinarily compliant group of people.

Several anecdotal items related to the transition process were included, which required knowledge of the DoD MHS for adequate comprehension. One item pertaining to the transition process was the inclusion of comments that were related to the financial

aspect of transition. Under the DoD MHS, active duty service members do not pay for medical visits, durable medical equipment, and medications. Veterans included in this study commented on the need to pay for these either entirely, or as a co-pay for services covered under their health plan. A comment by one participant regarding his insulin pump covered by his health plan was, “I refer to my pump as my Porsche. I don’t have a Porsche, but I do have a pump.” Another aspect of transition relates to beneficiary status in the DoD MHS. Active duty service members are sponsors, as are retired service members. A situation that is less common is when service members are married to other service members which makes each person their own sponsor within the system. When a married service member retires but their spouse remains on active duty, the retiree has a choice to change status to that of dependent of the still active duty service member. As a dependent, the individual has the same financial benefit of not incurring healthcare related costs.

The stories related by the veterans in the veterans with diabetes transition study are also indicative and representative of the composure and maturity often gained by military members. A military paradigm of maturity allows the members of this sample to see diabetes as their next challenge, not a debilitating condition preventing them from living an active life.

Conclusions

Transition has to be considered an inevitable part of service in the US military. Service members experience change from the time they leave civilian status to their entry in the military, through schools and training, programs to work in a career field, to end of service and return to civilian life. Even when planned, change can be accompanied by

distress. Adding the need to manage diabetes care during this process, especially if newly diagnosed, tends to increase personal distress. The process of transition from active duty to veteran status is not always smooth despite work on the part of the DoD to provide information and a variety of contacts veterans can use to make that transition. Given a gap in the literature concerning healthcare transitions in general, and military healthcare transitions specifically, the study of the transition of veterans with diabetes is timely. The themes identified represent powerful feelings which could have either a positive or negative effect upon each individual. The fact that the veterans in this study responded in a positive manner to change that was unexpected and somewhat unwelcome gives cause for encouragement in that several strengths possessed by veterans were noted. Notably, the feeling of readiness to leave the military was generally accompanied by the feeling of ability to meet life's challenges in a positive manner. This leads one to believe military service can be credited for this feeling of confidence.

The sample demonstrated that extremely compliant diabetes self-management is not only possible, but that these veterans are examples of a high level of diabetes self-management. This could be related to a study by Reiber, Koepsell, Maynard, Hass, & Boyko that showed veterans possessing a higher level of having received diabetes education than non-veterans, but is at odds with the studies' reporting of diabetes self-care activities in veterans which was considerably lower than the sample presented from the veterans with diabetes transition study (Reiber et al., 2004). How this sample of veterans has achieved such a high level of diabetes self-care management is unknown, but would be an interesting area for further research because if replicated, it could change current assumptions regarding how veterans with diabetes manage their diabetes care.

The veterans with diabetes transition study serves as a starting point for future study of the transition process for both active duty service members transitioning to veteran status and to begin a discussion of transition between healthcare systems in the private sector. Themes identified can guide future research on military healthcare transition.

Educational demographics were the author's creation, but upon reflection, could have been improved. One participant attended trade school, but that choice was not included. Nor was an associate's degree, each of which could have been included to give participants a more robust choice for their education level. The choice of college graduate versus bachelor's degree seemed a poorer choice as the bachelor's degree is more specific.

Recommendations

The active duty military to veteran transition deserves additional study in collaboration with designers of military transition programs. An opportunity exists for improvement of existing transition programs. Additional research should be conducted to collect comprehensive data leading to identification of points in the transition process which impact a smooth transfer of healthcare. It is likely that transition within the context of military healthcare is the starting point. If the DoD MHS providers were able to identify individual needs and have the ability to communicate with, and transfer data to an identified healthcare system expected to be used by an individual, both patients and providers would continue care, not having to restart or re-implement care. This study included a high percentage of veterans with diabetes who transitioned from the DoD MHS to the VA healthcare system. If additional research reinforces the likelihood of

veterans choosing transition of healthcare from the DoD MHS to VA healthcare, then attention to improvement of communication between DoD MHS and VA providers assisted by interoperable electronic health records should make for a smoother transition. At the same time, the transition programs are managed by entities other than the medical community in the DoD MHS. Politically, collaboration and negotiation for allocation of more time to healthcare matters would need to occur. Changing current time allocation (difficult) and/or provision of optional sessions (possible) of interest to those wanting more information regarding post-service healthcare would be necessary.

Time will tell whether implementation of a DoD MHS system-wide electronic health record scheduled for implementation in 2016 and 2017 will meet the joint DoD-VA goal of seamless health record transfer. A thorough study of the results that follow the implementation of the new electronic health record would be welcome. Military healthcare research commands, including one in San Diego, are positioned to initiate such research. Additional research is needed to demonstrate the effectiveness and impact on provider and patient satisfaction this interoperability will bring. The potential of interoperability and DoD MHS and VA healthcare system providers' collaboration could result in identification of service members about to transition so that uninterrupted healthcare, specifically for those with diabetes, might be accomplished.

In conclusion, the veterans with diabetes transition study provides initial data regarding the transition of healthcare in veterans from the DoD MHS to another healthcare system previously absent in the literature. Data gathered during the study contains themes indicating veterans have the potential to be active, compliant participants in their diabetes care. Given tools that strengthen the connection and collaboration

between DoD MHS and VA healthcare providers, diabetes care can be enhanced in this population. Both the DoD MHS and VA healthcare strive to achieve patient-centered healthcare. Enabling a transition process focused on veteran as individuals should be a positive step toward ensuring veteran-centered care.

The transition of healthcare management among military personnel with diabetes from
active duty to veteran status

Mark Malebranche, PhD(c), RN

Dr. Joseph Burkard, DNSc, CRNA, Chairperson

Dr. Jane Georges, PhD, RN

Dr. David Bittleman, MD

Abstract

The transition from active duty to veteran status is often a challenging period for veterans with diabetes. Veterans face multiple challenges upon leaving active duty such as change in residence, employer, income, and care priority in the military and/or Veterans Administration (VA) system. These challenges in transitioning also include changes in healthcare such as identifying a new primary healthcare provider, locating a new healthcare system, and changing healthcare coverage. The VA estimates that 20-25% of veterans have diabetes, which is over twice the prevalence of diabetes in the US. The changes in healthcare experienced in transitioning from active duty to veteran status have been shown to decrease diabetes care compliance and diabetes self-management, resulting in exacerbations in diabetes symptoms and increased healthcare expenditure. A seamless transition in the healthcare change from active duty to veteran status has the potential to maintain diabetes self-care compliance and self-management among these veterans. This manuscript explores the needs of veterans with diabetes transitioning from active duty to veteran status and lays the groundwork for a study in this area with the goal of developing policies and procedures to facilitate the healthcare transition of personnel with diabetes from active duty to veteran status.

Introduction

The purpose of this manuscript is to describe the current knowledge of needs, barriers, and facilitators among veterans with diabetes as they transition their health care from active duty to veteran status. To that end, this article will explore the transition process from active duty to veteran status and to discuss how this transition impacts the anticipated healthcare costs, morbidity and mortality, and diabetes distress of veterans with diabetes. This purpose will be examined in three sections of this manuscript. The initial section will describe the transition from active duty to veteran status. The second section will examine the scope and significance of transition in healthcare management between active to veteran status in veterans diagnosed with diabetes while on active duty. This section will also describe how this transition may affect care compliance and self-management which directly affect diabetes symptoms and result in increased health care costs (Duncan et al., 2009). In the third section, consequences of transition from active duty to veteran status will be discussed including a brief description of possible needs, barriers and facilitators to transitioning health care between the DoD and the VA. Included in this discussion is a brief description of the state of interoperability of electronic health records at the DoD and VA. A final section summarizing the transition process will examine the next studies that need to be done in order to give direction to research examining the barriers veterans with diabetes experience as they transition from DoD to VA management of their diabetes. Future studies may inform policies and procedures to facilitate the effective health care management of individuals with diabetes from active duty to veteran status.

Transition from active duty to veteran status

Transition is defined as a change from one condition to another (Merriam-Webster, 2013), the specific condition for purposes of this manuscript is the change from active duty to veteran status. Healthcare transition as used in this manuscript is the change from one system of healthcare to another and is a component of transitioning from active duty to veteran status. The DoD mandates a transition process (Department of Defense, 2015) to be managed by each service to provide assistance for members ending military service. Given many topics to cover in a relatively short time, healthcare is one of many topics contained in the transition program curriculum. Diabetes care is not a topic on the agenda.

Healthcare lectures are provided by representatives from the VA and the regional TRICARE healthcare contractor (Department of Veterans Affairs, 2015a; TRICARE, 2015). The VA and TRICARE representatives provide general information, as the audience may or may not plan to use the VA or TRICARE, especially if the individual is not retiring and plans to use healthcare benefits supplied by an employer. Information provided by the VA covers eligibility, registration with the VA healthcare system, and additional resources for disabled veterans (Military.com, 2016). TRICARE representatives explain two important topics, the Continued Health Care Benefits Program (CHCBP) and the Transition Assistance Management Program (TAMP). Transitional healthcare benefits under TAMP extend most TRICARE services to a veteran and his/her family for 180 days. A small difficulty arises when the veteran relocates to an area without a military treatment facility (MTF) nearby, as these veterans and families will incur some costs. The MTF does not charge for most services received

at the MTF (TRICARE, 2015). The CHCBP program is essentially COBRA healthcare coverage purchased for no less than six and no longer than 18 months (TRICARE, 2016).

The process of transitioning healthcare between the DoD and VA systems has resulted in challenges and distress for the veteran transitioning from active duty to veteran status (Goodwill Industries, 2011; Knight, 2014). Among those with diabetes this distress may lead to decreased diabetes self-management (Polonsky et al., 2005). Transition from active duty to veteran status in veterans with diabetes has predictable challenges known to directly affect diabetes self-management. Poorer diabetes self-management has included a decrease in healthy eating and medication adherence (Fisher et al., 2013; Koepsell, Littman, & Forsberg, 2012).

Among the changes that occur at time of transition is a change in healthcare priority for the individual. If the new veteran is a military retiree, they will move from the highest priority for care in the DoD healthcare system, active duty service member, to the lower priority status of retiree. If the healthcare transition is from DoD to VA healthcare, the individual priority is based upon an individual's disability rating and financial need. In either case, a change in primary provider and clinic is expected.

Changes have the potential to cause distress, and multiple changes are occurring at the time of transition from active duty to veteran status. Distress at the time of transition is not unusual in a military population (IOM, 2010; Knight, 2014 ; Morin, 2011). However, current studies are focused on anticipated or actual problems faced by individuals as a result of physical and mental stresses that are the result of exposure to war or other traumatic events experienced during their time on active duty in the armed

forces. A consideration of the needs of veterans with chronic illness, specifically diabetes, is in order.

Significance of transition to veteran status

Recently transitioned veterans including those with diabetes may exhibit disruption in the continuity of healthcare. This disruption may be evidenced by decreased diabetes care compliance and diabetes self-management, exacerbations in diabetes symptoms, and increased health care expenditures (Norris, Lau, Smith, Schmid, & Engelgau, 2002). A gap in the literature regarding transitions between healthcare systems in general and specifically for veterans transitioning to the VA healthcare system frames an examination of the needs of veterans with diabetes as they transition from active duty to veteran status. A literature review using the terms transition, healthcare transition, healthcare systems, and health systems transition resulted in no literature on transition between healthcare systems.

Randall (2012) reported a mean time of transition from DoD to VA healthcare of 3.83 months (range 0-44 months) (Randall, 2012). Medication refills or changes and blood glucose monitoring supplies may be exhausted before a veteran is able to make their first visit at a VA facility. Given the potential for a delay in access to a new primary care provider, diabetes self-management may increase in difficulty at the time of transition from active duty to veteran status.

Diabetes causes extensive morbidity, mortality, and expenditure of health care dollars among active duty and veterans (Kupersmith et al., 2007). Data from the American Diabetes Association (ADA) and the Centers for Disease Control and

Prevention (CDC) Diabetes Fact Sheets show nearly 26 million Americans or 8.3% of the population of the US have diabetes (American Diabetes Association, 2014; Centers for Disease Control, 2014). Estimates from the Department of Veterans Affairs (VA) are that 20 to 25% of veterans have diabetes (Kupersmith et al., 2007; Miller, Safford, & Pogach, 2004). The prevalence of diabetes in veterans is over twice that of the general U.S. population.

Despite administrative challenges of separate facilities geographically separated in a large healthcare system, the VA has a reputation for excellent care for veterans with diabetes (Hunt et al., 2013). Veterans make up only three percent of the total American population, yet they account for almost ten percent of people with diabetes, bearing a disproportionate diabetes health burden (Department of Veterans Affairs, 2015b). The VA expends approximately \$1.5 billion annually on veterans with diabetes (Gold & Briefel, 2007) and monitors laboratory values and provides more services than several managed care organizations (Haas & Watts, 2005; Lynch, Strom, & Egede, 2010). Reducing the impact of diabetes among veterans has the potential to reduce death and disability in this population. Improved diabetes self-management starts with improved diabetes self-management education (DMSE). Those who receive care at the VA are more likely than the general population to receive DMSE. The Healthy People 2020 goal is to increase the level of DMSE from 40% to 60%. Veterans with diabetes receiving care at the VA have already met this goal (Lynch et al., 2010; Norris et al., 2002).

Transition Processes

Transitioning from active duty to veteran status is anticipated to be a smooth, seamless changeover for the person involved. Each branch of the armed services

provides a mandated transition assistance program (TAP) designed to facilitate the transition (Department of Defense, 2015). Transition of healthcare is addressed briefly during the formal transition assistance program, although procedures and systems issues disrupt the smooth transition of healthcare needs among this group. Of the typical four-day TAP class, approximately one to two hours are scheduled for healthcare planning after active duty. Fortunately for those transitioning to healthcare through the VA healthcare system, the focus is on accessing VA benefits (Department of Defense, 2015). Recently, the popular press has noted many access issues for veterans wishing to use VA healthcare (CNN, 2014). Veterans who plan to utilize the VA for their healthcare need know the rules of eligibility and enrollment in order to receive care at the VA. Randall (2012) noted there is often a delay in healthcare services during the transition from active duty healthcare in the Department of Defense (DoD) to healthcare as a veteran under the VA Medical System which acts as a barrier to care. Care transition for those with chronic conditions, including diabetes, can be further impaired by the uncertainty of electronic health record (EHR) connectivity between the DoD and VA patient documentation systems (Randall, 2012). The VA EHR may or may not be able to gather information from DoD EHR systems. Veterans may resort to the time honored practice of hand-carrying their medical records to a new care location.

The DoD and VA have worked to achieve interoperability of electronic systems for as long as two decades. At one time, a joint EHR platform was envisioned. Ultimately, that approach was abandoned, but the desire to succeed in electronic communication between the DoD and the VA continued (Government Accounting Office, 2015). The DoD awarded a contract to Cerner in July 2015 to provide a new

EHR system for their 55 hospitals and approximately 600 clinics worldwide (Conn, 2015). Implementation of the DoD EHR has begun, but has not reached all hospitals and clinics yet (Conn, 2015; Healthcare Information and Management Systems Society, 2015). The strategy by the VA and DoD healthcare systems to improve interoperability of EHRs is ongoing (Saleem, Flanagan, Wilck, Demetriades, & Doebbeling, 2013). VA EHR capabilities are robust, and when the contracted DoD EHR is fully implemented, an opportunity to collaborate regarding patients likely to receive care at the VA will exist. although initial implementation of the DoD EHR has begun, at this point in time, such collaboration has yet to be established.

Conclusion and Recommendations

Transition from active duty to veteran status is an inevitable change for all service members. The VA is a healthcare destination for many veterans, but moving between the DoD and VA healthcare systems may pose difficulties. Among these difficulties are issues with access to VA healthcare as noted in the popular press (CNN, 2014). The number of veterans eligible for VA healthcare and the population of veterans cared for by the VA is increasing. Veterans who plan to receive healthcare at the VA have to know the rules and processes for eligibility and enrollment. Veterans with diabetes also need to plan for some delay in access to care, which can affect their ability to refill medications and obtain supplies for diabetes self-management.

Current processes do not ensure a seamless transition from DoD healthcare to VA healthcare (Randall, 2012). When service members with diabetes are transitioning from active duty to veteran status, continuity of diabetes self-care remains important. Diabetes self-care knowledge assists patients to maintain the continuity of their glycemic diabetes

self-management which helps reduce the risk of complications related to diabetes (Centers for Disease Control, 2014). As previously noted, time delays in accessing primary care appointments can lead to exhaustion of medications and diabetes consumable supplies.

The goal for both the VA and the DoD is to provide a better transition between healthcare systems. Improved healthcare transition is likely to improve continuity of care for veterans with chronic diseases, especially veterans with diabetes. A potential reduction in healthcare expenses may be realized if communication between EHRs requires less manpower to transfer records between systems. The beneficiaries of improved systems communication are not only veterans, but healthcare professionals in the DoD and VA.

Currently, the DoD and VA EHR systems are not compatible for transmission of medical records from the DoD to the VA. The DoD EHR being implemented should facilitate the transfer of data between systems. Use of EHRs that facilitate the transition from active duty to veteran status should enhance the transition experience for veterans and decrease the stress they encounter in the process.

The transition assistance program in each branch of the military prepares many to be veterans and to know their benefits, but is not focused upon the healthcare needs of future veterans. The VA has made progress toward improving many aspects of healthcare registration and access. This is progress, not perfection. The backlog of enrollments has been decreased, waiting times for appointments has decreased, and many personnel changes have been made. These changes should improve access and enhance the transition experience for all involved. A human component of the transition process

that could be implemented is the addition of a joint DoD/VA case manager for those with injuries of war and chronic conditions including diabetes. Officials at the DoD and VA are encouraged to collaborate toward an improved process for healthcare transition from active duty to veteran status.

References

1. Duncan I, Birkmeyer C, Coughlin S, Li Q, Sherr D, Boren S. Assessing the Value of Diabetes Education. *The Diabetes Educator*. 2009;35(5):752-60.
2. Merriam-Webster. Merriam-Webster Online Dictionary. Encyclopedia Britannica; 2013.
3. Department of Defense. DoD Transition Assistance Program 2015 [Available from: <https://www.dodtap.mil/>].
4. Department of Veterans Affairs US. Health Benefits Washington D.C.2015 [Available from: <http://www.va.gov/HEALTHBENEFITS/cost/index.asp>].
5. TRICARE. Transitional Assistance Management Program Washington D. C.2015 [Available from: http://tricare.mil/Plans/SpecialPrograms/TAMP.aspx?sc_database=web].
6. Military.com. Welcome to the Military.com Transition Center. 2016.
7. TRICARE. Continued Health Care Benefits Program 2016 [Available from: http://www.tricare.mil/Plans/SpecialPrograms/CHCBP?sc_database=web].
8. Knight J. A STUDY OF MILITARY PERSONNEL'S PREPARATION for transition from military to civilian life. [Dissertation]. In press 2014
9. Goodwill Industries. From Deployment to Employment
Goodwill's Call to Action on Supporting Military Service Members, Veterans, and Their Families. Rockville, MD 20855: Goodwill Industries, Inc.; 2011.
10. Polonsky WH, Fisher L, Earles J, Dudl RJ, Lees J, Mullan J, et al. Assessing Psychosocial Distress in Diabetes: Development of the Diabetes Distress Scale. *Diabetes Care*. 2005;28(3):626-31.

11. Fisher L, Hessler D, Glasgow RE, Arean PA, Masharani U, Naranjo D, et al. REDEEM: a pragmatic trial to reduce diabetes distress. *Diabetes Care*. 2013;36(9):2551-8.
12. Koepsell TD, Littman AJ, Forsberg CW. Obesity, overweight, and their life course trajectories in veterans and non-veterans. *Obesity (Silver Spring)*. 2012;20(2):434-9.
13. IOM. *Returning Home from Iraq and Afghanistan: Preliminary Assessment of Readjustment Needs of Veterans, Service Members, and Their Families*. Washington D. C.: National Academies Press; 2010.
14. Morin R. *The Difficult Transition from Military to Civilian Life*. Pew Social Trends 2011. p. Report
15. Kupersmith J, Francis J, Kerr E, Krein S, Pogach L, Kolodner RM, et al. Advancing evidence-based care for diabetes: lessons from the Veterans Health Administration. *Health Aff (Millwood)*. 2007;26(2):56-68.
16. American Diabetes Association. *Fast Facts Data and Statistics about Diabetes*. 2014.
17. Centers for Disease Control US. *CDC Diabetes Program- Data and Trends* [Webpage]. U.S. Department of Health and Human Services; 2014 [updated 3/28/2013. Prevalence of Diabetes- Number in Millions].
18. Miller DR, Safford MM, Pogach L. Who Has Diabetes? Best Estimates of Diabetes Prevalence in the Department Computerized Data. *Diabetes Care*. 2004;27(Supp 2):B10 -B21.

19. Hunt KJ, Gebregziabher M, Lynch CP, Echols C, Mauldin PD, Egede LE. Impact of diabetes control on mortality by race in a national cohort of veterans. *Annals of Epidemiology*. 2013;23(2):74-9.
20. Department of Veterans Affairs US. Selected Veterans Health Administration Characteristics: FY2002 to FY2013 Washington, D.C.2015 [Excel Spreadsheet].
21. Gold M, Briefel R. Study of Federal Spending on Diabetes: An Opportunity for Change. Washington, DC Mathematica Policy Research, Inc. ; 2007.
22. Lynch CP, Strom JL, Egede LE. Effect of veterans administration use on indicators of diabetes care in a national sample of veterans. *Diabetes Technology & Therapeutics*. 2010;12(6):427-33.
23. Haas L, Watts S. Diabetes Care in the Veterans Health Administration. *Diabetes Spectrum*. 2005;18(3).
24. Norris S, Lau J, Smith SJ, Schmid C, Engelgau M. Self-Management Education for Adults With Type 2 Diabetes. *Diabetes Care*. 2002;25(7):1159-71.
25. Fisher L, Hessler DM, Polonsky WH, Mullan J. When is diabetes distress clinically meaningful?: establishing cut points for the Diabetes Distress Scale. *Diabetes Care*. 2012;35(2):259-64.
26. Randall MJ. Gap Analysis- Transition of Health Care From Department of Defense to Department of Veterans Affairs -177-pp.pdf>. *Military Medicine*. 2012;117(1):11.
27. CNN. Veterans dying because of healthcare delays New York, N. Y.: Cable News Network; 2014 [Available from: <http://www.cnn.com/2014/01/30/health/veterans-dying-health-care-delays/index.html>].

28. Government Accounting Office US. ELECTRONIC HEALTH RECORDS: Outcome-Oriented Metrics and Goals Needed to Gauge DOD's and VA's Progress in Achieving Interoperability. In: GAO, editor. Washington, D.C.: GAO; 2015.
29. Conn J. Cerner, Leidos and Accenture win massive Defense contract for EHR system Washington, D.C.: Modern Healthcare; 2015 [Available from: <http://www.modernhealthcare.com/article/20150729/NEWS/150729824>].
30. Healthcare Information and Management Systems Society H. DoD awards Cerner, Leidos, Accenture EHR contract. Healthcare IT News; 2015.
31. Saleem J, Flanagan M, Wilck N, Demetriades J, Doebbeling B. The next-generation electronic health record. AJIMA. 2013;20:e175-7.

University of San Diego

Hahn School of Nursing and Health Science

A Critique of the Diabetes Distress Scale (DDS)

Mark Malebranche, MA, RN

Ann Mayo, DNSc, FAAN

Joseph Burkard, DNSc, CRNA

Care of people with diabetes includes physical and behavioral components. A variety of emotional burdens are noted during needs evaluations. These burdens may cause distress in the individual with diabetes. Such distress can negatively affect diabetes self-management. A concise instrument to evaluate diabetes distress can be useful in the clinical setting. Two instruments, the Problem Areas in Diabetes Scale (PAID) and the Diabetes Distress Scale (DDS) measure diabetes distress. This article discusses the development of the DDS as an improvement upon the PAID scale.

KEY WORDS:

diabetes, diabetes distress, diabetes distress scale

Background

Despite a recent New York Times article announcing a decline in the incidence of diabetes from 2008 to 2014¹, diabetes remains a treatment priority for healthcare providers. The burden of diabetes care often affects quality of life for patients and families. The literature suggests^{2,3} that diabetes distress, rather than clinical depression, accounts for many of the challenging behaviors evident in people with diabetes, such as lost work time and decreased self-care behaviors associated with having diabetes. Diabetes distress has been defined as those emotional burdens associated with caring for this difficult chronic disease, particularly the associated stresses and worries that are often encountered by people with diabetes⁴. Distress stemming from the need for daily care and concerns over future disease progression has been shown to impact self-care behaviors of people with diabetes^{2,3,5}.

In order to evaluate the level of distress an individual may be experiencing, healthcare professionals, primarily diabetes psychologists, have developed instruments to measure diabetes distress. Both the Problem Areas in Diabetes Scale (PAID) and the Diabetes Distress Scale (DDS) were developed as self-report instruments to measure emotional response and screens for the presence of diabetes distress. The DDS was developed because of limitations noted in the PAID scale. These limitations include a level of ambiguity in items, an inability to measure patient feelings towards healthcare providers, and an inability to distinguish between various types of diabetes on the basis of emotional distress^{4,6,7}. This manuscript will present a psychometric evaluation of the DDS including instrument development and description, reliability and validity, factor analysis, strengths and weaknesses, and potential benefit of further psychometric testing.

Description of the instrument

The DDS is a conceptually driven reliable measure useful in research and for screening diabetes-related distress in clinical practice settings^{5,7,8}. It consists of 17 items and four subscales. These subscales are emotional burden (EB) consisting of five items, physician-related distress (PD) consisting of four items, regimen-related distress (RD) consisting of five items, and diabetes-related interpersonal distress (ID) consisting of three items. Items from the PAID, the Questionnaire on Stress in Patients with Diabetes-Revised (QSD-R), and the ATT39⁹ which measures psychological adjustment to diabetes were evaluated in construction of the DDS scale⁷. Each item receives a score of 1 to 5 with 1 meaning Not a Problem, 2 meaning A Slight Problem, 3 meaning A Moderate Problem, 4 meaning A Somewhat Serious Problem, 5 meaning A Serious

Problem, and 6 meaning A Very Serious Problem. The 17 item DDS final instrument is a scale with scores that range from 17 to 102.

Scoring. The score for a participant is derived after totaling the scores from the 17 items. The total score obtained is divided by 17 yielding a mean score for that participant. Mean scores of 2.0 to 2.9 on the entire instrument are considered moderate distress and scores ≥ 3.0 are considered high distress. Scores on the four subscales are also calculated as a mean with scores of 2.0 to 2.9 considered moderate distress and scores above 3.0 considered high distress¹⁰. To derive each subscale score, the score on corresponding subscale questions is divided by the number of questions contained within that particular subscale.

Instrument Development

A select group of nurses specializing in diabetes, patients, physicians, dieticians, and diabetes-knowledgeable psychologists were recruited nation-wide to review questions from the PAID scale as well as the QSD-R and the ATT39⁷. Developers formulated a scale with 50 items that was pilot tested in several groups of patients. Feedback received from patient groups resulted in elimination of 22 items judged to be vague, not easily understood, or duplicative. The remaining 28 items were tested in a multi-site study consisting of four study sites. The widely used and well-validated Center for Epidemiological Studies Depression scale (CESD) was administered to participants along with the items developed for the DDS. Statistical analysis was conducted for results from each of the four sites using exploratory factor analysis with Promax rotation. Internal consistency was evaluated using Cronbach's alpha to assess the total score and each subscale's score. A comparison of the DDS with the CESD was performed, again

for the total and for each subscale. Glycolated hemoglobin (HbA_{1c}) and lipid panels (two sites only) were collected as metabolic variables and the HbA_{1c} was used as a validity coefficient ⁷.

Demographic, clinical, and subscale relationships

Demographic results showed a negative correlation with age ($r = -0.29$), showing that young patients reported more diabetes distress than older patients. Clinical results showed no correlation with glycemic control was present ($r = 0.01$), but there was a positive association with total cholesterol scores ($r = 0.20$). None of the four subscales showed a relationship with gender, ethnicity, education completed, or duration of having diabetes. All subscales showed a relationship to a depressive affect ($r = 0.33$). Subscales EB and RD showed participants had poorer meal planning ($r = 0.21$ and $.043$ respectively) and did not exercise frequently ($r = 0.12$ and 0.16 respectively). The subscale RD was linked with a lower frequency of self-monitoring of blood glucose ($r = 0.19$). While the subscales did not show a link to hemoglobin A_{1c}, EB, RD, and ID did have a positive relationship with total cholesterol ($r > 0.16$ for each of the three subscales.) Scores on the DDS were highest for insulin users (39.6 ± 17.1) followed by those on oral medications (35.2 ± 16.2) and those controlled entirely by diet (26.7 ± 12.1). Overall, the instrument has good reliability and validity. The DDS was tested for readability and has a Flesch-Kincaid grade level of 7.3, meaning most patients will be able to comprehend the DDS ⁵.

⁷.

Reliability

Cronbach's alpha was calculated for the whole DDS scale and for four subscales of emotional burden (EB), physician-related distress (PD), regimen-related distress (RD), and diabetes-related interpersonal distress (ID) after data collection at each site. When calculating the total instrument alpha and alphas for each subscale, scores from all four sites were used since there was little variation between sites. The alpha values for the total instrument and the four subscales are as follows: total = 0.93, EB = 0.88, PD = 0.88, RD = 0.90, and ID = 0.88, showing the DDS to be internally consistent. Schmitt et al. (2015) reported similar alpha scores of total = 0.89, EB = 0.87, PD = 0.84, RD = 0.84, and a slightly lower value for ID of 0.71⁴.

Validity

Validity was measured with Pearson correlation coefficients or chi-square values, again for the total instrument scale and for each of the four subscales. The values were also computed against the well-known CESD scale. Total scores from the DDS showed a positive association with symptoms of depression measured by the CESD ($r = 0.56$)⁷. While total scores were associated with demographic values of age, depression, insulin use, higher lipid levels, and poorer self-care, no significant relation was noted between any subscale and age, ethnicity, level of education or duration of having diabetes⁷.

Factor analysis. Exploratory factor analysis was performed to uncover factors in the DDS scale⁷. As this was a multi-site investigation, four within-site factor analyses were performed on the 28 remaining items. Correlation between the 28 items selected for further analysis and the final 17 selected items was notably high ($r = 0.99$).

Correlation of means between the subscales and the 17 item scale was 0.82. Two subscales (EB and RD) had higher correlation, each with an r of 0.88. Subscales ID ($r = 0.76$) and PD ($r = 0.67$) had less strength of association with the 17 item scale. Analysis was performed upon data from each site, and upon the data as a whole. All analyses suggested inclusion of four consistent and interpretable factors. Scree plots from the four site analyses indicated that four or five factors be included in analysis. Similarity of interim correlations noted at each of the four sites allowed the investigators to combine data and to run an exploratory factor analysis with four factor extraction on the entire sample. The four factors matched the investigators' critical content domains of emotional burden, physician-related distress, regimen-related distress, and interpersonal distress ⁷.

Strengths and weaknesses of instrument

The DDS was developed in order to improve upon limitations of the PAID, an instrument developed by diabetes psychologists Polonsky and Fisher ⁷. These limitations included a level of ambiguity of some items, a desire to address patient's feelings towards their healthcare provider, and to distinguish between various types of diabetes related emotional distress.

Strengths include the consideration of the DDS, and to an extent, the PAID, as the current gold standard test for diabetes distress. In addition, results of the study by Schmitt, Reimer, Kulzer, Haak, Erhmann, and Hermanns (2015) coincided with the original psychometric findings of Polonsky et.al. (2005). The methodological analysis of the DDS reveals good reliability and validity in populations reported to date.

Several weaknesses exist. This instrument measures diabetes distress, however, there is not one agreed-upon definition of diabetes distress. This short instrument does not have an instruction manual, instead a set of instructions is included in the instrument itself. The instructions are brief, and do not define diabetes distress. At the same time, Polonsky and Fisher are established researchers and authors regarding diabetes distress. Paradoxically, even though the DDS was designed to replace the PAID, the PAID is more widely used than the DDS. Scores from the PAID have been associated with level of diabetes self-care. The DDS has not demonstrated this association⁴. As a matter of inclusivity for measuring distress in all patients with diabetes, the DDS may fall short. The DDS has detected greater distress in those with Type 2 diabetes, however this may be due to having a population largely composed of those with Type 2 diabetes.

Recommendations for further psychometric testing

Ongoing determination of validity in various populations will give healthcare professionals confidence in their ability to rely upon results received using the DDS. However, a particular area for further testing can be the relationship of the DDS to metabolic findings with regards to validity. Also, since the majority of participants in the initial DDS study (over 83%) had Type 2 diabetes, a study of validity in a predominantly Type 1 population would be welcome.

Conclusion

The DDS was developed to overcome deficiencies in the PAID. Psychometric evaluation of the DDS supports the achievement of this intent. The scores from the PAID have been associated with diabetes self-care^{3,4}. While this has not been the case for the

DDS overall, use of the disease management subscale has been used as an indicator of diabetes self-care and should be examined further ¹¹. As a screening instrument, the DDS shows the ability to detect diabetes distress, at least in Type 2 diabetes, which is valuable in assessment of factors that influence individual diabetes self-care.

References

1. Tavernise S. New Diabetes Cases, at Long Last, Begin to Fall in the United States. *New York Times*. New York, New York: The New York Times Company; 2015.
2. Fisher L, Mullan J, Areal P, Glasgow R, Hessler D, Masharani U. Diabetes Distress but Not Clinical Depression or Depressive Symptoms Is Associated With Glycemic Control in Both Cross-Sectional and Longitudinal Analyses. *Diabetes Care*. 2010;33:23-28.
3. Gonzalez JS, Shreck E, Psaros C, Safren SA. Distress and type 2 diabetes-treatment adherence: A mediating role for perceived control. *Health Psychol*. 2015;34:505-513.
4. Schmitt A, Reimer A, Kulzer B, Haak T, Ehrmann D, Hermanns N. How to assess diabetes distress: comparison of the Problem Areas in Diabetes Scale (PAID) and the Diabetes Distress Scale (DDS). *Diabet Med*. 2015.
5. Fisher L, Hessler DM, Polonsky WH, Mullan J. When is diabetes distress clinically meaningful?: establishing cut points for the Diabetes Distress Scale. *Diabetes Care*. 2012;35:259-264.
6. Welch G, Jacobson A, Polonsky W. The Problem Areas in Diabetes Scale. An evaluation of its clinical utility. *Diabetes Care*. 1997;20:760-766.
7. Polonsky WH, Fisher L, Earles J, et al. Assessing Psychosocial Distress in Diabetes: Development of the Diabetes Distress Scale. *Diabetes Care*. 2005;28:626-631.

8. Fisher L, Hessler D, Glasgow RE, et al. REDEEM: a pragmatic trial to reduce diabetes distress. *Diabetes Care*. 2013;36:2551-2558.
9. Welch G, Dunn S, Beeney L. Adjustment to Diabetes. In: Bradley C, ed. *Handbook of Psychology and Diabetes*. The Netherlands: Harwood Academic Publishers; 1994:425.
10. Polonsky WH, Fisher L. Diabetes Distress Scale 1995.
11. Fisher L, Glasgow R, Strycker L. The Relationship Between Diabetes Distress and Clinical Depression With Glycemic Control Among Patients With Type 2 Diabetes. *Diabetes Care*. 2010;33:1034-1036.

The veterans with diabetes transition study.

Veterans experience of the process of transition following active duty diagnosis.

Mark Malebranche PhD(c), RN

Joseph Burkard DNSc, CRNA

Jane Georges PhD, RN

David Bittleman, MD

Abstract

A diagnosis of diabetes on active duty brings career and lifestyle changes changing event. Transition from active duty to veteran is often a challenging transition for veterans with diabetes. A gap in the literature exists regarding the transition process between healthcare systems, including the DoD and VA. Veterans face challenges upon leaving active duty. Challenges in active duty to veteran status transition include healthcare changes. Changes in healthcare have been shown to decrease diabetes care compliance and diabetes self-management, resulting in exacerbations in diabetes symptoms and increased healthcare expenditure. A seamless transition in the healthcare management change from active duty to veteran status has the potential to maintain or increase diabetes self-care compliance and diabetes self-management among these individuals. This paper describes the transition experience of veterans with diabetes from active duty to veteran status. Two main themes were expressed by participants, unplanned and undesired end of a military career and feeling prepared to leave the military. The sample described a high compliance level in diabetes care. The healthcare transition process would benefit from additional exploration to discover needs and improve processes to facilitate the healthcare management transition of personnel with diabetes from active duty to veteran status.

Introduction

A diagnosis of diabetes while on active duty in the US military is a career changing as well as a lifestyle changing event. Despite case by case review of appeals requesting delay or an exemption from discharge from active duty based upon diagnosis of diabetes, current Department of Defense, Army, Navy, and Air Force regulations list diabetes as a disqualifying condition for service¹⁻³. When an individual is diagnosed with diabetes, transition from active duty to veteran status is likely. This article presents the results of the veterans with diabetes transition study, a qualitative descriptive study of a sample of veterans diagnosed with diabetes while on active duty in the US military and their experience of the transition from active duty to veteran status. This study focused on the transition from healthcare in the Military Health System (MHS) of the Department of Defense (DoD) to healthcare in the Department of Veterans Affairs (VA), healthcare within the DoD as a retiree, or healthcare in another healthcare system.

The transition of healthcare for active duty service members from the MHS to healthcare as veterans in another healthcare systems is largely unexplored. Studies on transitions of care have focused, and rightly so, on movement between levels and settings of care or on the transition of adolescents from pediatric to adult care providers⁴⁻⁷. Transition from one healthcare system to another has not received the level of scrutiny or attention given transitions between levels and settings of care. In particular, the transition of active duty service members diagnosed with diabetes to veteran status has not been explored.

Current literature includes reports of studies describing the experience of active duty military during transition to veteran status⁸⁻¹⁰. Such reports have focused on real or

anticipated difficulties veterans have experienced related to the psychological effects of and physical injuries received in wartime. Notably, veterans have described the necessity to make life adjustments because of their experience of situations that resulted in post-traumatic stress disorder, traumatic brain injury, amputation, and loss of comrades. There were no studies found that focused on the experience of veterans diagnosed with diabetes on active duty during their transition from military to civilian status. The veterans with diabetes study provides data for additional study of the needs of veterans with diabetes. Future research may allow for the generation of interventions which support diabetes self-management in this population.

For individuals diagnosed with diabetes while on active duty in the US military, the transition process includes multiple changes. Some will find they are no longer allowed to deploy and/or to continue their preferred role in the military. Others will no longer be allowed to serve in the military. Still others who are planning for the transition from active duty to veteran will find their planning now to include diabetes management along with practical considerations of where to live, work, and receive healthcare. Following military service veterans with diabetes must continue to manage their diabetes while changing providers, pharmacy, diabetic supplies, and daily routine, each of which may change in their immediate future.

Purpose

The purpose of this study was to describe the transition experience of veterans diagnosed with diabetes while on active duty from active duty to veteran status. Focusing on the experience of that transition described by veterans in the sample, the study describes factors acting as either barriers or facilitators to healthcare and diabetes

self-care management. These factors included health literacy, diabetes self-care management, participation in diabetes self-care management education, and use of online resources in diabetes self-care management.

The four aims of the veterans with diabetes transition study of veterans were to describe 1. the lived experience a sample of veterans with diabetes during their transition from active duty service member to veteran status, 2. to elicit the veteran's described factors acting as barriers or facilitators to healthcare access and ongoing diabetes self-management, 3. veterans with diabetes' experience with traditional (classroom), informal, and online self-management education, and 4. to report the health literacy level of the sample as measured by the short form of the of the Test of Functional Health Literacy in Adults (S-TOFHLA) and their distress measured by the Diabetes Distress Scale (DDS).

Significance

Unexpectedly, a review of the literature on transition revealed a significant gap. While the topic of transition in medical care from active duty to veteran status has been partially explored^{8, 11, 12}, these descriptions have been related to the mental and physical stressors encountered while on active duty and the actual or anticipated consequences an individual may encounter as a result of such stressors. No literature was found exploring the transition between one healthcare system and another in civilian or military setting. This gap leaves unexplored the logistics of change between healthcare systems such as registration, transfer of medical records, finding a primary provider and continuity of care including medication and DME requirements. Notably, the literature suggests veterans do not have the assurance of a smooth transition process either from active duty to veteran status in general. Also there is no seamless process for transfer of healthcare

between active duty care in the MHS and the healthcare system chosen by veterans for care after completing military service.

Because little is known about the transition of veterans from active duty to veteran status, and even less about transition for those diagnosed with diabetes while on active duty, a descriptive exploration of the transition process in this population was warranted.

Methods

Design

This was a qualitative study of the experience of veterans with diabetes who were diagnosed while on active duty. A semi-structured questionnaire developed for the study served to elicit each veteran participant's general description of the transition process. Quantitative measures of health literacy and diabetes distress were used as measurements for potential barriers to diabetes self-management. The Short form of the Test of Functional Health Literacy in Adults (S-TOFHLA) served as a measure for difficulties that individuals might have related to navigating the healthcare milieu. The Diabetes Distress Scale (DDS) was used as a proxy for the potential distress members of the sample might have experienced during their transition process.

Setting

After obtaining IRB oversight and permission to advertise from the institutions involved, participants were recruited from the Naval Medical Center, San Diego, Naval Hospital Camp Pendleton, the VA Mission Valley Primary Care Clinic, the organization Take Control of Your Diabetes (TCOYD), and multiple veteran's organizations within

San Diego County. The study was conducted in the US Southwest, primarily in San Diego County, but several participants were located in San Antonio, Texas through a TCOYD diabetes conference. Individual interviews were conducted in a public setting such as a coffee shop or health fair.

Sample

A convenience sample of 10 veterans diagnosed with diabetes while on active duty was selected for the study. This sample reached saturation regarding the primary question “Tell me about your experience of transition from active duty to veteran status” after the 10 veterans were interviewed. Inclusion criteria included veteran status and having been diagnosed with diabetes while on active duty. Exclusion criteria were being unable to communicate in an oral or written manner, having a physical deficit (such as pre-existing stroke or behavioral health issue) preventing oral communication or physical movement required to complete the quantitative instruments, and inability to read and write in English.

Procedures

After obtaining written consent from the commanding officers of Naval Medical Center San Diego and Naval Hospital Camp Pendleton, respectively, as well as oral and email consent from TCOYD staff and several veteran’s organizations, advertising was begun. Flyers and e-newsletter notices were distributed. Personal contact by the study author was made in several cases. Data collected were analyzed according to the nature of the data. The semi-structured interview guide was transcribed and field notes were reviewed after each interview. The S-TOFHLA and DDS quantitative instruments were

scored according to their instructions. Demographic and quantitative results were entered into a password protected spreadsheet, and all papers were maintained in a locked file cabinet. Materials are securely maintained in accordance with IRB procedures, and will be destroyed according to those procedures.

Instrumentation

A semi-structured qualitative questionnaire consisting of 11 questions and eight demographic items was developed by the study author. Questions contained prompts with potential follow-up questions dependent upon the participant's response. The questionnaire was reviewed by dissertation committee members and was approved with minor modification. All interviews were recorded following consent of each participant. Each recording was transcribed for analysis. Transcripts were compared with the original recordings and minor corrections were made.

The S-TOFHLA was selected despite disagreement over which of the currently available health literacy instruments is most useful¹³, as it has been accepted as an effective measure of health literacy in the US^{14, 15}. Low health literacy has been estimated to be between 26% and 90 % in the US depending on the study¹⁵⁻¹⁷. Low health literacy has also been noted to be a barrier to healthcare and compliance with diabetes self-management^{18, 19}. S-TOFHLA contains 36 questions grouped into two passages. The first passage concerns a patient who has an X-ray ordered, and the second passage concerns applying for health benefits. The instrument uses a modified close technique approach of sentences containing a blank that give the participant four response choices for each blank. Scores of 0 to 16 on the S-TOFHLA are indicative of inadequate

health literacy, scores of 17 to 22 are indicative of marginal health literacy, and scores of 23 or above are indicative of adequate health literacy.

The DDS was selected as a proxy for the distress encountered by veterans with diabetes during transition. The DDS was developed to improve upon a previous measure, the Problem Areas in Diabetes scale. Both instruments were developed by the same authors as measures of distress related to diabetes for clinical practice and research purposes. The DDS contains 17 items that result in an individual score between 17 and 102. The total score for each participant is divided by 17 to find the mean score for that individual. Mean DDS scores of 2.0 to 2.9 are considered moderate diabetes distress, and scores greater than or equal to 3.0 are considered high diabetes distress^{20, 21}.

Human Subjects Protection

Prior to conducting the study, permissions were obtained as above. Consent was obtained from each participant prior to conducting an interview. Interviews were conducted in public settings, but privacy was maintained at all times. All data collected was de-identified and stored by the principal investigator in a password-protected spreadsheet, with hard copy data secured in a locked file cabinet. Transcribed interviews were also password protected.

Data Analysis

To address the qualitative aims of describing the experience of veterans with diabetes during the process of transition to veteran status, their barriers and facilitators in accessing healthcare, and their experience of diabetes self-care management during their transition, recordings, transcripts of the recordings, and field

notes were examined for themes, topics, ideas, concepts, phrases, and keywords. Use of a qualitative analysis computer program was considered. Discussion with an expert qualitative researcher who is a dissertation committee member led to analysis of themes, etc. manually.

Results

Overall, veterans participating in this study were over 50 years of age, better educated than the average military member, and used the VA healthcare system for care of their diabetes. They were compliant with diabetes self-management activities and had been formally educated in diabetes self-care management. Most frequently, they used the internet in many aspects of life, and their internet use for healthcare most often was used to secure online resources for communication with their provider.

Demographic Data

The sample of veterans in the study were slightly different than the demographic composition of the US military, according to 2012 statistics from the Defense Manpower Data Center (DMDC). The small sample size is the most likely reason for differences in percentages between the sample and the US military. Females represented 20% of the sample versus 14.6% of active duty service members. Blacks were somewhat overrepresented at 30 of the sample versus 16.8% of active duty service members. Asians also were overrepresented at 10% versus 3.7% of active duty service members. This sample had a slightly higher education level than current active duty service members as 30% had a Master's degree versus 7.3% on active duty, 20% were college

graduates versus 11.7% on active duty, and 50% had an education level of high school or some college versus 78.6% on active duty ²².

Most veterans with diabetes have type 2 diabetes ²³. The DoD, Army, Navy, and Air Force regulations disqualify those with diabetes from entering military service ¹⁻³. The sample participating in this study contained a significantly higher percentage of veterans with type 1 diabetes than expected, as half were type 1, and half type 2. Four of the five veterans in the sample diagnosed with type 2 diabetes were noted to have 20 years or more of military service, which aligns with data describing the onset of type 2 diabetes at a relatively older age. All but one of those diagnosed with type one diabetes were much earlier in their military career, and relatively younger at onset of diabetes.

Theme Summary

Two main themes and four additional themes were identified during analysis of transcripts, recordings, and field notes. Major themes were:

- Feeling loss due to an unplanned and undesired end of a military career
- Feeling prepared to leave the military

Participants showed two overall responses to their transition from active duty to veteran status categorized as major themes. Some were unhappy about leaving the military when they had planned to have a longer military career. Participant number one stated “and then the shock of well, you can’t go to sea and you can’t go overseas, which means your career is over.” And, “That was a huge shock when you realize that you can no longer do what you love to do.” Others had planned to end of their military career and were able to add diabetes management to the plans they had already made regarding their

expected transition. Participant number three said “What helped access to care is preparing before you get out.”

Three participants were surprised to learn they had a diagnosis of diabetes because it was first communicated to them during the process of leaving active duty. In the case of participant number four, he was told of his diagnosis during his last week on active duty, and he was referred to the VA for treatment. He was hospitalized at the VA just weeks later with a blood glucose of 1200. A review of his military medical records showed “indications that maybe medical, like, that my blood sugars were elevated but nobody ever told me...” Each of these veterans expressed determination to cope with the unexpected health challenge that they now faced.

Of the five participants who were distressed over loss of a military career, two attempted to delay discharge or avoid sharing with their chain of command their diagnosis simply because they realized that they would be disqualified for further military service.

Additional themes were:

- Feeling an unexpected life change due to the diagnosis of diabetes
- Feeling a need to personally manage their healthcare
- Feeling determined to cope with the unexpected health challenges that accompany diabetes
- Feeling of satisfaction with provider

The additional themes were shared by at least two-thirds of the sample and all participants felt the consequences related to the unexpected life change that accompanied

their diagnosis of diabetes and felt satisfied with the provider who is their primary diabetes resource. Although their current provider may not be the first provider collaborating in managing their diabetes, all participants expressed their confidence in, and plan to continue receiving care with their current diabetes care provider. Two-thirds of the sample expressed a need to personally manage their diabetes and nearly all expressed determination to cope with unexpected health challenges that accompany diabetes. Those who expressed a need to manage their own care were emphatic in stating that they felt they received better care when that stayed informed and proactive regarding their healthcare and they felt they received better care and gave better attention to their diabetes care than if they were not vigilant in their attention to diabetes care.

Health Literacy

Previous studies have shown that veterans have health literacy equal to or below the US average^{24,25}. Put another way, over 25% of veterans are noted to have low health literacy. The sample in this study all scored at the adequate health literacy level, making further conclusions about the relationship of health literacy to any characteristic of the sample moot. This was unexpected and raises questions regarding the measurement of health literacy in general.

Choice of healthcare

A majority of the study participants chose the VA for their diabetes care. Although a majority of the sample were eligible to receive care in either the DoD MHS or from private providers through private medical insurance or Medicare, they felt they received high quality care at the VA. Several participants discussed the potential for

delays and difficulty in scheduling appointments that have been items in the news. In their current situation, none felt the VA was failing to provide their appointments in a timely manner and are all registered for care in the VA system, and so were no longer subject to delays in receiving eligibility for care from the VA.

Diabetes education and use of electronic resources

All participants except one had attended a formal diabetes self-management class, usually in a group, from a diabetes educator. The exception was a veteran diagnosed during the late 1960's when diabetes education was undertaken primarily by clinic nurses. The American Association of Diabetes Educators was not founded until 1973. Providers added informal diabetes education during scheduled visits to over half of this sample. Responses indicated that this sample was particularly compliant with diabetes self-management activities. All participants adhered to prescribed medication regimens, periodic laboratory testing, provider visits, and all but one in having their blood pressure monitored. That participant stated "No blood pressure. My blood pressure is like 102 over 50. I don't get blood pressure; I give it."

Participants were asked about familiarity with, and use of, electronic resources such as online patient portals to assist in their diabetes self-management. All but one said they use the internet frequently, usually more than once daily. However, they did not consistently use online resources for diabetes self-management. Thirty percent stated they prefer to use the telephone to order medication refills and not a patient portal. Sixty percent of the sample used online secure portals to communicate with their provider, generally in order to ask a question or questions.

Discussion

Improvement in care for people with diabetes is a priority for healthcare providers²⁶⁻²⁸. Veterans diagnosed with diabetes face the challenge of managing their diabetes but often have an additional aspect of change related to transition from the military which may or may not be planned. The DoD has mandated each service to provide a transition process²⁹ for members ending military service. Healthcare, particularly diabetes care, is not the primary topic contained in the transition program curriculum. Transition from one healthcare system such as the DoD MHS to the VA has not been noted in the literature. Changes in provision of healthcare incumbent with a transition from the DoD MHS to the VA, and to a lesser extent from active duty clinics to retiree clinics are likewise absent from the literature. The stories told by the veterans who participated in this study indicate a desire for excellent preparedness in transition and a desire to be able to serve their country despite the potential limitations imposed by a diagnosis of diabetes. Their stories also indicate the composure and maturity gained by military member which allows them to see diabetes as their next challenge, not a debilitating condition preventing them from living an active life. The active duty military to veteran transition deserves additional study and in collaboration with designers of military transition programs and can be an opportunity for improvement of existing transition programs.

Conclusions

Limitations

The year of leaving the military ranged from 1969 to 2014, a 45-year span. Changes in DoD's MHS, the VA healthcare system, and individual memory may cause

some bias in the data collected. The study did not include a question regarding level of diabetes control or A1c level. Better or poorer control may influence the individuals' experience. Results from the S-TOFHLA had no variability, and therefore were not useful in analyzing the data. These results also deviated from national estimates of health literacy^{15, 30-32}. Also, the principal investigator for this study is a retired military member subject to bias based upon his military career.

Summary

The purpose of this study was to describe the transition experience of veterans from active duty to veteran status who had been diagnosed with diabetes while on active duty. A qualitative design was used to elicit factors acting as either barriers or facilitators to healthcare and diabetes self-care management. Six themes emerged from participant interviews. Feelings of loss of a military career versus being prepared to finish their military career were nearly equally expressed. As most of the sample found their diagnosis of diabetes unexpected, it was not surprising to have the participants relate their feeling an unexpected life change due to the diagnosis of diabetes. The skills obtained and attitudes fostered by the military make the feelings of a need to personally manage their healthcare and feeling determined to cope with the unexpected health challenges that accompany diabetes fairly predictable. It was not expected that all of the participants had a feeling of satisfaction with their provider. Overall, the stories shared by these veterans indicate an attitude of capability to manage their diabetes and to function well in daily living. The qualitative measures of health literacy and diabetes distress lacked variability, and as such were not meaningfully measurable. Diabetes self-care

management, participation in diabetes self-care management education, and use of online resources in diabetes self-care management proved to be strengths of the sample.

Among the study aims was to describe factors acting as either a barrier or as a facilitator to healthcare access. Few interviewees expressed the process of registering with the VA as a barrier, although one participant described the process as arduous. Most did not feel they had encountered barriers to care. The main facilitator of access to care in participant's stories was their attitude. They felt that they would succeed, and their stories indicate they feel they have been successful. The ongoing diabetes self-management activities described by veterans in the study were examples of extremely compliant diabetes management.

Recommendations

As a follow-up to the veterans with diabetes transition study, it would be useful to collaborate with transition assistance program personnel to devise a larger study of the transition process. Study results should be communicated to the medical centers where participants were solicited as well as to the veteran's groups involved in recruitment for the study and TCOYD.

Acknowledgements

I would like to acknowledge professors Ann Mayo, DNSc, FAAN, and Robert Topp, PhD, the Jonas Foundation for Nursing and Veteran's Healthcare, and the organization TCOYD for contributions essential to completion of this study

Table 1 Descriptive statistics for demographics from the Veterans with Diabetes Transition Study		
		%
Age		
21-40		10
41-60		50
61-70		40
Gender		
Male		80
Female		20
Race		
Black		30
White		50
Latino/Hispanic		10
Asian		10
Education		
High school or less ^a		20
Some College		20
College graduate		20
Master's degree or above		30
Other		10
Length of Service		
4 years or less		20
5-9 years		10
10-19 years		20
20 years or more		50
Years post service (median; range) ^b		
		(13.5; 2-45)
Diabetes Type		
1		50
2		50
Length of diabetes diagnosis		
2-5 years		10
6-10 years		10
11-20 years		30
21 years or more		50
Uses Insulin		
Yes		70
No		30
Place of care for diabetes		
VA		70
MTF		22
Private		10
a: one participant attended trade school b: median and range for this demographic		

Themes identified during analysis of transcripts, recordings, and field notes						
<i>Participant</i>	Feeling loss due to an unplanned and undesired end of a military career	Feeling prepared to leave the military	Feeling an unexpected life change due to the diagnosis of diabetes	Feeling a need to personally manage their healthcare	Feeling determined to cope with the unexpected health challenges that accompany diabetes	Feeling of satisfaction with provider
1	Yes	No	Yes	Yes	Yes	Yes
2	Yes	No	Yes	No	No	Yes
3	No	Yes	Yes	Yes	Yes	Yes
4	No	Yes	Yes	Yes	Yes	Yes
5	No	Yes	Yes	No	Yes	Yes
6	Yes	No	Yes	Yes	Yes	Yes
7	Yes	No	Yes	Yes	Yes	Yes
8	No	Yes	Yes	Yes	Yes	Yes
9	No	Yes	Yes	No	No	Yes
10	Yes	No	Yes	Yes	Yes	Yes

References

1. Department of Defense US. DOD Instruction 6130.3. In: Department of Defense US, ed. Washington, D. C.2010.
2. Army Dot. Army Regulation 40-501. In: Army U, ed. Washington, DC: Department of the Army; 2011.
3. Navy U. Medical Disqualifications. Vol 2016. Washington, DC2015.
4. Naylor MD, Aiken LH, Kurtzman ET, Olds DM, Hirschman KB. The care span: The importance of transitional care in achieving health reform. *Health Aff (Millwood)*. 2011;30:746-754.
5. Kim, Flanders. Transitions of Care.
6. Anthony S, Kaufman M, Drabble A, Siefert-Hansen M, Dipchand A, Martin K. Perceptions of Transitional Care Needs and Experiences in Pediatric Heart Transplant Recipients. *American Journal of Transplantation*. 2011;9:614-609.
7. Peters, Laffel. Diabetes Care for Emerging Adults: Recommendations for Transition From Pediatric to Adult Diabetes Care Systems. *Diabetes Care*. 2011;34.
8. Knight J. A STUDY OF MILITARY PERSONNEL'S PREPARATION for transition from military to civilian life. Nashville: Argosy University; 2014
9. IOM. Returning Home from Iraq and Afghanistan: Assessment of Readjustment Needs of Veterans, Service Members, and Their Families. Washington D. C.2013.
10. Morin R. The Difficult Transition from Military to Civilian Life. *Pew Social Trends*. Washington D. C.: Pew Research Center; 2011.
11. IOM. Returning Home from Iraq and Afghanistan: Preliminary Assessment of

Readjustment Needs of Veterans, Service Members, and Their Families. Washington D.

C.: National Academies Press; 2010.

12. Morin R. The Difficult Transition from Military to Civilian Life. *Pew Social Trends* 2011:Report
13. Pleasant A, McKinney J. Coming to consensus on health literacy measurement: an online discussion and consensus-gauging process. *Nurs Outlook*. 2011;59:95-106 e101.
14. Nurss JR, Parker RM, Williams MV, Baker DW. TOFHLA: Test of Functional Literacy in Adults. Hartford, MI: Emory University; 1995.
15. Parker RM, Baker DW, Williams MV, Nurss JR. The test of functional health literacy in adults: a new instrument for measuring patients' literacy skills. *J Gen Intern Med*. 1995;10:537-541.
16. Baker DW, Parker RM, Williams MV, Scott AC. Health Literacy and the risk of hospital admission. *Journal of General Internal Medicine*. 1998;13:791-798.
17. Sarkar U, Karter AJ, Liu JY, Moffet HH, Adler NE, Schillinger D. Hypoglycemia is more common among type 2 diabetes patients with limited health literacy: the Diabetes Study of Northern California (DISTANCE). *J Gen Intern Med*. 2010;25:962-968.
18. Persell, Osborn, Richard, Skripkauskas, Wolf. Limited Health Literacy is a Barrier to Medication Reconciliation in Ambulatory Care. *Journal of General Internal Medicine*. 2007;22:1523-1526.
19. Yin, Dreyer, Vivar, MacFarland, van Schaick, Mendelsohn. Perceived Barriers to Care and Attitudes Towards Shared

Decision-making Among Low Socioeconomic Status Parents: Role of Health Literacy.

Vol 2016: National Institutes of Health; 2012.

20. Fisher L, Hessler DM, Polonsky WH, Mullan J. When is diabetes distress clinically meaningful?: establishing cut points for the Diabetes Distress Scale. *Diabetes Care*. 2012;35:259-264.
21. Polonsky WH, Fisher L, Earles J, et al. Assessing Psychosocial Distress in Diabetes: Development of the Diabetes Distress Scale. *Diabetes Care*. 2005;28:626-631.
22. Department of Defense U. 2012 Demographics: Profile of the Military Community. In: Defense Do, ed. Washington, DC: Government Printing Office; 2012.
23. Department of Veterans Affairs US. Diabetes QUERI Center Strategic Plan 2011. Ann Arbor, MI: VA; 2011:67.
24. Artinian, Lange, Templin, Stallwood, Hermann. Functional Health Literacy in an Urban Primary Care Clinic. *Internet Journal of Advanced Nursing Practice*. 2001;5.
25. Rodriguez V, Andrade AD, Garcia-Retamero R, et al. Health literacy, numeracy, and graphical literacy among veterans in primary care and their effect on shared decision making and trust in physicians. *J Health Commun*. 2013;18 Suppl 1:273-289.
26. Healthy People 2020. Diabetes Data: healthypeople.gov; 2014.
27. American Diabetes Association. Economic Costs of Diabetes in the U.S. in 2012. *Diabetes Care*. 2013;36:1033-1046.

28. American Heart Association. American Heart Association Annual Report 2011-2012. Dallas, Texas 2011:32.
29. Department of Defense. DoD Transition Assistance Program. Vol 2015 2015.
30. Paasche-Orlow MK, Parker RM, Gazmararian JA, Nielsen-Bohlman LT, Rudd RR. The prevalence of limited health literacy. *J Gen Intern Med.* 2005;20:175-184.
31. Parker RM, Ratzan SC, Lurie N. Health Literacy A Policy Challenge For Advancing High-Quality Health Care. *Health Affairs.* 2003;22.
32. Koh HK, Berwick DM, Clancy CM, et al. New federal policy initiatives to boost health literacy can help the nation move beyond the cycle of costly 'crisis care'. *Health Aff (Millwood).* 2012;31:434-443.

Chapter 5

Instruments

Introduction

This section presents the instruments used in the Veterans with Diabetes Transition Study. In addition, some thoughts in hindsight about how the study might have been developed are noted.

Instruments Used:

Qualitative Questions: See Appendix

S-TOFHLA: See Appendix

Diabetes Distress Scale: See Appendix

Post hoc considerations

Upon reviewing the demographic information collected during the study, further explanation of some decisions made during the study design seem necessary. By developing a semi-structured interview guide, freedom of choice was available. Therefore, different demographic measurements could have been chosen. As a retired service member, the author's familiarity with military structure led him to divide length of service into unequal but useful segments. The time frame of four years or less was equivalent to a veteran who had served only one enlistment. Service of five to nine years is equivalent to two enlistment periods. Service of 10-19 years is equivalent to service beyond two enlistments, but shorter than retirement, an important distinction, as a service member within this time frame would be conscious of the proximity to a 20-year retirement that they might achieve and may have planned to reach. Disqualification for further military service in this time frame could lead to distress. Service of 20 years or

longer qualifies a member for retirement benefits, including healthcare, unless misconduct interferes.

References

- Adams, S. A. (2010). Revisiting the online health information reliability debate in the wake of "web 2.0": An inter-disciplinary literature and website review. *International Journal of Medical Informatics*, 79(6), 391-400. doi:10.1016/j.ijmedinf.2010.01.006
- Agency for Healthcare Research and Quality. (2010). Universal precautions toolkit. Retrieved from <http://www.ahrq.gov/professionals/quality-patient-safety/quality-resources/tools/literacy-toolkit/index.html>
- Albright, & Gregg. (2013). Preventing type 2 Diabetes in communities across the U.S: The national diabetes prevention program. *American Journal of Preventive Medicine*, 44(4).
- American Diabetes Association. (2013). Economic costs of diabetes in the U.S. in 2012. *Diabetes Care*, 36, 1033-1046.
- American Diabetes Association. (2014). *Fast facts data and statistics about diabetes*. Alexandria, VA: Author.
- American Heart Association. (2011). American Heart Association annual report 2011-2012. Retrieved from https://www.heart.org/idc/groups/heart-public/@wcm/@adt/documents/downloadable/ucm_449081.pdf
- American Recovery and Reinvestment Act of 2009 (ARRA), Pub. L. No. 111-5, 123 Stat. 115 (2009).
- Baker, D. W. (2006). The meaning and the measure of health literacy. *Journal of General Internal Medicine*, 21(8), 878-883. doi:10.1111/j.1525-1497.2006.00540.x

- Baker, D. W., Parker, R. M., Williams, M. V., & Scott, A. C. (1998). Health literacy and the risk of hospital admission. *Journal of General Internal Medicine, 13*, 791-798.
- Bandura, A. (1977). Self-efficacy: Toward a unified theory of behavioral change. *Psychology Review, 84*(2), 191-215.
- Bandura, A. (2001). Social cognitive theory: An agentic perspective. *Annual Review of Psychology, 52*, 1-26.
- Bennett, I. M., Chen, J., Soroui, J. S., & White, S. (2009). The contribution of health literacy to disparities in self-rated health status and preventive health behaviors in older adults. *The Annals of Family Medicine, 7*(3), 204-211. doi:10.1370/afm.940
- Blumenthal, D. (2010). Launching HITECH. *New England Journal of Medicine, 362*(5).
- Bohanny, W., Wu, S. F., Liu, C. Y., Yeh, S. H., Tsay, S. L., & Wang, T. J. (2013). Health literacy, self-efficacy, and self-care behaviors in patients with type 2 diabetes mellitus. *Journal of the American Association of Nurse Practitioners, 25*(9), 495-502. doi:10.1111/1745-7599.12017
- Brodie, M., Flournoy, R. E., Altman, D. E., Blendon, R. J., Benson, J. M., & Rosenbaum, M. D. (2000). Health information, the Internet, and the digital divide. *Health Affairs, 19*(6), 255-265. doi:10.1377/hlthaff.19.6.255
- Byrne, C. M., Mercincavage, L. M., Pan, E. C., Vincent, A. G., Johnston, D. S., & Middleton, B. (2010). The value from investments in health information technology at the U.S. Department of Veterans Affairs. *Health Affairs, 29*(4), 629-638. doi:10.1377/hlthaff.2010.0119
- California HealthCare Foundation. (2010). *Consumers and Health Information Technology: A National Survey*. Retrieved from

<http://www.chcf.org/publications/2010/04/consumers-and-health-information-technology-a-national-survey>

Centers for Disease Control and Prevention. (2011). *National Diabetes Fact Sheet, 2011*.

Retrieved from https://www.cdc.gov/diabetes/pubs/pdf/ndfs_2011.pdf

Centers for Disease Control and Prevention. (2014). *CDC diabetes program- data and trends*. Atlanta, GA: Author.

Centers for Medicare & Medicaid Services. (2014). Readmissions reduction program.

Retrieved from <https://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/AcuteInpatientPPS/Readmissions-Reduction-Program.html>

Chang, B. L., Bakken, S., Brown, S. S., Houston, T. K., Kreps, G. L., Kukafka, R., . . .

Stavri, P. Z. (2004). Bridging the digital divide: Reaching vulnerable populations.

Journal of the American Medical Informatics Association, 11(6), 448-457.

doi:10.1197/jamia.M1535

Chao, S., Zarzabal, L., Walker, S., & Carnahan, D. (2013). Estimating diabetes

prevalence in the military health system population from 2006 to 2010. *Military Medicine, 178*, 986-993.

Chew, L., Bradley, K., & Boyko, E. (2004). Brief questions to identify patients with

inadequate health literacy. *Family Medicine, 36*(8), 588-594.

Chin, J., Morrow, D. G., Stine-Morrow, E. A., Conner-Garcia, T., Graumlich, J. F., &

Murray, M. D. (2011). The process-knowledge model of health literacy: Evidence from a componential analysis of two commonly used measures. *Journal of Health Communication, 16*(Suppl. 3), 222-241. doi:10.1080/10810730.2011.604702

- Cho, A. H., Arar, N. H., Edelman, D. E., Hartwell, P. H., Oddone, E. Z., & Yancy, W. S. (2010). Do diabetic veterans use the Internet? *Telemedicine and e-health*, 16(5). doi:10.1089=tmj.2009.0164
- CNN. (2014). Veterans dying because of healthcare delays. Retrieved from <http://www.cnn.com/2014/01/30/health/veterans-dying-health-care-delays/index.html>
- Department of Defense. (2015). DoD Transition assistance program. Retrieved from <https://www.dodtap.mil/>
- Department of Defense. (2010). DOD Instruction 6130.3.
- Department of the Army. (2011). *Army Regulation 40-501*. Washington, DC: Author.
- Department of Health and Human Services, Office of Disease Prevention and Health Promotion. (1999). Physical activity and health. Retrieved from <https://health.gov/paguidelines/>
- Department of Veterans Affairs. (2011). *Diabetes QUERI center strategic plan 2011*. Ann Arbor, MI: Author.
- Department of Veterans Affairs. (2014a). Disability claims backlog reduced by 44 percent since peaking one year ago. Retrieved from <http://www.blogs.va.gov/VAntage/13577/disability-claims-backlog-reduced-by-44-percent-since-peaking-one-year-ago/>
- Department of Veterans Affairs. (2014b, 2/14/2014). National Center for Veterans Analysis and Statistics (NCVAS). Retrieved from <http://www.va.gov/vetdata/>
- Department of Veterans Affairs. (2015a). Health benefits. Retrieved from <http://www.va.gov/HEALTHBENEFITS/cost/index.asp>

- Department of Veterans Affairs. (2015b). Veterans Health Administration. Retrieved from <http://www.va.gov/health/>
- DeWalt, D. A., Broucksou, K. A., Hawk, V., Brach, C., Hink, A., Rudd, R., & Callahan, L. (2011). Developing and testing the health literacy universal precautions toolkit. *Nursing Outlook*, *59*(2), 85-94. doi:10.1016/j.outlook.2010.12.002
- Dumenci, L., Matsuyama, R. K., Kuhn, L., Perera, R. A., & Siminoff, L. A. (2013). On the validity of the rapid estimate of adult literacy in medicine (REALM) scale as a measure of health literacy. *Communication Methods Measures*, *7*(2), 134-143. doi:10.1080/19312458.2013.789839
- Esposito, K., Maiorino, M. I., Ceriello, A., & Giugliano, D. (2010). Prevention and control of type 2 diabetes by Mediterranean diet: A systematic review. *Diabetes Research and Clinical Practice*, *89*(2), 97-102. doi:10.1016/j.diabres.2010.04.019
- Fisher, L., Glasgow, R. E., Mullan, J. T., Skaff, M. M., & Polonsky, W. H. (2008). Development of a brief diabetes distress screening instrument. *The Annals of Family Medicine*, *6*(3), 246-252. doi:10.1370/afm.842
- Fisher, L., Hessler, D., Glasgow, R. E., Arean, P. A., Masharani, U., Naranjo, D., & Strycker, L. A. (2013). REDEEM: A pragmatic trial to reduce diabetes distress. *Diabetes Care*, *36*(9), 2551-2558. doi:10.2337/dc12-2493
- Fisher, L., Hessler, D. M., Polonsky, W. H., & Mullan, J. (2012). When is diabetes distress clinically meaningful? Establishing cut points for the diabetes distress scale. *Diabetes Care*, *35*(2), 259-264. doi:10.2337/dc11-1572
- Fisher, L., Skaff, M. M., Mullan, J. T., Arean, P., Glasgow, R., & Masharani, U. (2008). A longitudinal study of affective and anxiety disorders, depressive affect and

- diabetes distress in adults with type 2 diabetes. *Diabetic Medicine*, 25(9), 1096-1101. doi:10.1111/j.1464-5491.2008.02533.x
- Fortney, J. C., Burgess, J. F., Jr., Bosworth, H. B., Booth, B. M., & Kaboli, P. J. (2011). A re-conceptualization of access for 21st century healthcare. *Journal of General Internal Medicine*, 26(Suppl. 2),639-647. doi:10.1007/s11606-011-1806-6
- Fox, S., & Duggan, M. (2013). *Health Online 2013*. Retrieved from http://www.pewInternet.org/files/old-media//Files/Reports/PIP_HealthOnline.pdf
- Gabbay, R. A., Lendel, I., Saleem, T. M., Shaeffer, G., Adelman, A. M., Mauger, D. T., . . . & Polomano, R. C. (2006). Nurse case management improves blood pressure, emotional distress and diabetes complication screening. *Diabetes Research and Clinical Practice*, 71(1), 28-35. doi:10.1016/j.diabres.2005.05.002
- Goel, M. S., Brown, T. L., Williams, A., Hasnain-Wynia, R., Thompson, J. A., & Baker, D. W. (2011). Disparities in enrollment and use of an electronic patient portal. *Journal of General Internal Medicine*, 26(10), 1112-1116. doi:10.1007/s11606-011-1728-3
- Goldzweig, C. L., Orshansky, G., Paige, N. M., Towfigh, A. A., Haggstrom, D. A., Mlake-Lye, I., . . . & Shekelle, P. G. (2013). Electronic patient portals: Evidence on health outcomes, satisfaction, efficiency, and attitudes: A systematic review. *Annals of Internal Medicine*, 159(10), 677-687. doi:10.7326/0003-4819-159-10-201311190-00006
- Gonzalez, J. S., Shreck, E., Psaros, C., & Safren, S. A. (2015). Distress and type 2 diabetes-treatment adherence: A mediating role for perceived control. *Health Psychology*, 34(5), 505-513. doi:10.1037/hea0000131

- Hahn, E. A., Choi, S. W., Griffith, J. W., Yost, K. J., & Baker, D. W. (2011). Health literacy assessment using talking touchscreen technology (Health LiTT): A new item response theory-based measure of health literacy. *Journal of Health Communication, 16*(Suppl. 3), 150-162. doi:10.1080/10810730.2011.605434
- Hawkins, S. Y. (2010). Improving glycemic control in older adults using a videophone motivational diabetes self-management intervention. *Research and Theory for Nursing Practice, 24*(4), 217-232. doi:10.1891/1541-6577.24.4.217
- Healthcare Information and Management Systems Society, H. (Producer). (2015). DoD awards Cerner, Leidos, Accenture EHR contract. Retrieved from <http://www.healthcareitnews.com/news/dod-names-ehr-contract-winner>
- Healthy People 2010. (2015). Health literacy online. Retrieved from <http://health.gov/healthliteracyonline/index.htm>
- Healthy People 2020. (2014, 10/9/2014). *Diabetes data*. Retrieved from <https://www.healthypeople.gov/2020/topics-objectives/topic/diabetes>
- Hersey, P., Blanchard, K., & Johnson, D. (2001). *Management of organizational behavior* (8th ed.). Upper Saddle River, NJ: Prentice Hall.
- hippasurvivalguide.com. (2014). HITECH act summary. Retrieved from <http://www.hipaasurvivalguide.com/hitech-act-summary.php>
- HIT.consultant. (2016). McKesson lands \$139M DoD contract for RelayHealth's patient engagement, secure messaging. Retrieved from <http://hitconsultant.net/2016/04/07/mckessons-relayhealth/>
- Hogan, T., Wakefield, B., Nazi, K. M., Houston, T. K., & Weaver, F. (2011). Promoting access through complementary eHealth technologies: Recommendations for VAs

home telehealth and personal health record programs. *Journal of General Internal Medicine*, 26(Suppl. 2), 628-635. doi: 10.1007/s11606-011-1765-y.

Institute of Medicine (IOM). (2010). *Returning Home from iraq and afghanistan- preliminary assessment of readjustment needs of veterans, service members, and their spouses*. Retrieved from http://deploymentpsych.org/system/files/member_resource/Returning%20Home%20From%20Iraq%20and%20Afghanistan.pdf

Institute of Medicine (IOM). (2013). *returning home from iraq and afghanistan: assessment of readjustment needs of veterans, service members, and their families*. Retrieved from <http://www.nap.edu/search/?term=Readjustment+needs+and+gaps+related+to+the+conditions+most+frequently+diagnosed+in+returning+OEF+and+OIF+active-duty+personnel+and+veterans>

Jackson, G. L., Krein, S. L., Alverson, D. C., Darkins, A. W., Gunnar, W., Harada, N. D., . . . & Bosworth, H. B. (2011). Defining core issues in utilizing information technology to improve access: evaluation and research agenda. *Journal of General Internal Medicine*, 26(Suppl. 2), 623-627. doi:10.1007/s11606-011-1789-3

Janiszewski, D., O'Brian, C. A., & Lipman, R. D. (2015). Patient experience in a coordinated care model featuring diabetes self-management education integrated into the patient-centered medical home. *Diabetes Educator*, 41(4), 466-471. doi:10.1177/0145721715586577

- Jeffs, L., Lyons, R., Merkley, J., & Bell, C. (2013). Clinicians' views on improving inter-organizational care transitions. *BMJ Health Services Research, 13*.
- Kandula, N. R., Malli, T., Zei, C. P., Larsen, E., & Baker, D. W. (2011). Literacy and retention of information after a multimedia diabetes education program and teach-back. *Journal of Health Communication, 16*(Suppl. 3), 89-102.
doi:10.1080/10810730.2011.604382
- Kelly, P. A., & Haidet, P. (2007). Physician overestimation of patient literacy: A potential source of health care disparities. *Patient Education and Counseling, 66*(1), 119-122. doi:10.1016/j.pec.2006.10.007
- Kim, & Flanders. (2013). Transitions of Care. *Annals of Internal Medicine 158*(5).
- Knight, J. (2014). *A study of military personnel's preparation for transition from military to civilian life (dissertation)*. Argosy University. Nashville.
- Kocher, R. P., & Adashi, E. Y. (2011). Hospital Readmissions and the affordable care act. *Journal of the American Medical Association, 306*(16).
- Koh, H. K., Berwick, D. M., Clancy, C. M., Baur, C., Brach, C., Harris, L. M., & Zerhusen, E. G. (2012). New federal policy initiatives to boost health literacy can help the nation move beyond the cycle of costly 'crisis care'. *Health Affairs, 31*(2), 434-443. doi:10.1377/hlthaff.2011.1169
- Kupersmith, J., Francis, J., Kerr, E., Krein, S., Pogach, L., Kolodner, R. M., & Perlin, J. B. (2007). Advancing evidence-based care for diabetes: Lessons from the Veterans Health Administration. *Health Affairs, 26*(2), 56-68.
doi:10.1377/hlthaff.26.2.w156

- Lam, & LeRoith. (2012). The worldwide diabetes epidemic. *Current Opinion in Endocrinology, Diabetes & Obesity, 19*(2).
- Lazarus, R. S. (1991). Coping theory and research: Past present and future. *Psychosomatic Medicine, 55*, 234-247.
- Lazarus, R. S. (1993). Progress on a cognitive-motivational-relational theory of emotion. *American Psychologist, 46*(8), 819-834.
- Leon, A. C., Davis, L. L., & Kraemer, H. C. (2011). The role and interpretation of pilot studies in clinical research. *Journal of Psychiatric Research, 45*(5), 626-629.
doi:10.1016/j.jpsychires.2010.10.008
- Logan, R. A., Wong, W. F., Villaire, M., Daus, G., Parnell, T. A., Willis, E., & Passche-Orlow, M. K. (2015). Health literacy- A necessary element for achieving health equity. Retrieved from <http://www.nam.edu/perspectives/2015/Health-literacy-a-necessary-element-for-achieving-health-equity>.
- Longo, A. (2009). Change, Complexity and Creativity. In Roussel, L. Editor (5th Ed.) *Management and leadership for nurse administrators* (pp. 112-120.) Sudbury, MA: Jones and Bartlett.
- Lustria, M. L., Smith, S. A., & Hinnant, C. C. (2011). Exploring digital divides: An examination of eHealth technology use in health information seeking, communication and personal health information management in the USA. *Health Informatics Journal, 17*(3), 224-243. doi:10.1177/1460458211414843
- Macabasco-O'Connell, A., & Fry-Bowers, E. K. (2011). Knowledge and perceptions of health literacy among nursing professionals. *Journal of Health Communication, 16*(Suppl. 3), 295-307. doi:10.1080/10810730.2011.604389

- Medscape. (2007) Health literacy in clinical practice. Retrieved from http://www.medscape.org/viewarticle/566053_5 20 August 2015
- Miller, D. R., Safford, M. M., & Pogach, L. (2004). Who has diabetes? Best estimates of diabetes prevalence in the department computerized data. *Diabetes Care*, 27(Suppl. 2), B10 -B21.
- Miner, J. B. (2006). *Organizational Behavior 1 : Essential Theories of Motivation and Leadership*. London: Routledge
- Moffet, H. H., Adler, N., Schillinger, D., Ahmed, A. T., Laraia, B., Selby, J. V., . . . & Karter, A. J. (2009). Cohort profile: The diabetes study of northern California (DISTANCE)--objectives and design of a survey follow-up study of social health disparities in a managed care population. *International Journal of Epidemiology*, 38(1), 38-47. doi:10.1093/ije/dyn040
- Morin, R. (2011). The difficult transition from military to civilian life. Retrieved from <http://www.pewsocialtrends.org/2011/12/08/the-difficult-transition-from-military-to-civilian-life/>
- National Committee for Quality Assurance. (2015). Addressing the quality gaps in diabetes prevention and care. Retrieved from <http://www.ncqa.org/PublicationsProducts/OtherProducts/QualityProfiles/FocusonDiabetes/AddressingtheQualityGaps.aspx>
- Navy. (2015). Medical Disqualifications. Retrieved from <http://navy.army.com/info/join/medical>

- Naylor, M. D., Aiken, L. H., Kurtzman, E. T., Olds, D. M., & Hirschman, K. B. (2011). The care span: The importance of transitional care in achieving health reform. *Health Affairs*, 30(4), 746-754. doi:10.1377/hlthaff.2011.0041
- Naylor, M.D., Brooten, D., Campbell, R., Jacobsen, B.S., Mezey, M.D., Pauly, M.V., & Schwartz, S.J. (1999). Comprehensive discharge planning and home follow-up of hospitalized elders: A randomized clinical trial. *Journal of the American Medical Association*, 281(7), 613-620. doi: 10.1001/jama.281.7.613.
- Nurss, J. R., Parker, R. M., Williams, M. V., & Baker, D. W. (1995). *TOFHLA: Test of functional literacy in adults*. Peppercorn Books & Press: Hartford, MI.
- Nutbeam, D. (2000). Health literacy as a public health goal. *Health Promotion International*, 15(3), 259-267.
- Nutbeam, D. (2008). The evolving concept of health literacy. *Social Science & Medicine*, 67(12), 2072-2078. doi:10.1016/j.socscimed.2008.09.050
- Oldfield, S. R., & Dreher, H. M. (2010). The concept of health literacy within the older adult population. *Holistic Nursing Practice*, 24(4).
- Osborn, C. Y., Weiss, B. D., Davis, T. C., Skripkauskas, S., Rodrigue, C., & Bass III, P. F. (2007). Measuring adult literacy in health care performance of the newest vital sign. *American Journal of Health Behavior*, 31(Suppl. 3), S36-S46.
- Paasche-Orlow, M. K., Parker, R. M., Gazmararian, J. A., Nielsen-Bohlman, L. T., & Rudd, R. R. (2005). The prevalence of limited health literacy. *Journal of General Internal Medicine*, 20(2), 175-184. doi:10.1111/j.1525-1497.2005.40245.x

- Parchman, M., Pugh, J., Noël, & Larme, A. (2002). Continuity of care, self-management behaviors, and glucose control in patients with type 2 diabetes. *Medical Care*, 40(2), 137-144.
- Parker, R. M., Baker, D. W., Williams, M. V., & Nurss, J. R. (1995). The test of functional health literacy in adults: a new instrument for measuring patients' literacy skills. *Journal of General Internal Medicine*, 10(10), 537-541.
doi:10.1007.BF02640361
- Parker, R. M., & Hernandez, L. M. (2012). What makes an organization health literate? *Journal of Health Communication*, 17(5), 624-627.
doi:10.1080/10810730.2012.685806
- Parker, R. M., Ratzan, S. C., & Lurie, N. (2003). Health literacy: A policy challenge for advancing high-quality health care. *Health Affairs*, 22(4).
- Patient Protection and Affordable Care Act (ACA), 42 U.S.C. § 18001 et seq. (2010).
- Peters, & Laffel. (2011). Diabetes care for emerging adults: Recommendations for transition from pediatric to adult diabetes care systems. *Diabetes Care*, 34.
- Pleasant, A., & McKinney, J. (2011). Coming to consensus on health literacy measurement: An online discussion and consensus-gauging process. *Nursing Outlook*, 59(2), 95-106 e101. doi:10.1016/j.outlook.2010.12.006
- Pleasant, A., McKinney, J., & Rikard, R. V. (2011). Health literacy measurement: A proposed research agenda. *Journal of Health Communication*, 16(Suppl. 3), 11-21. doi:10.1080/10810730.2011.604392
- Polonsky, W. H., & Fisher, L. (1995). Diabetes Distress Scale.

- Polonsky, W. H., Fisher, L., Earles, J., Dudl, R. J., Lees, J., Mullan, J., & Jackson, R. A. (2005). Assessing psychosocial distress in diabetes: Development of the diabetes distress scale. *Diabetes Care*, 28(3), 626-631. doi:10.2337/diacare.28.3.626
- Randall, M. J. (2012). Gap analysis: Transition of health care From Department of Defense to Department of Veterans Affairs. *Military Medicine*, 117(1), 11.
- Reiber, G., Koepsell, T., Maynard, C., Hass, L., & Boyko, E. (2004). Diabetes in nonveterans, veterans, and veterans receiving Department of Veterans Affairs health care. *Diabetes Care*, 27(Suppl. 2), B3-B9.
- Rock, M. (2003). Sweet blood and social suffering: Rethinking cause-effect relationships in diabetes, distress, and duress. *Medical Anthropology*, 22, 131-174. doi:10.1080/01459740390203454
- Rodriguez, V., Andrade, A. D., Garcia-Retamero, R., Anam, R., Rodriguez, R., Lisigurski, M., . . . & Ruiz, J. G. (2013). Health literacy, numeracy, and graphical literacy among veterans in primary care and their effect on shared decision making and trust in physicians. *Journal of Health Communication*, 18(Suppl. 1), 273-289. doi:10.1080/10810730.2013.829137
- Rudd, R. E. (2015). The evolving concept of health literacy: New directions for health literacy studies. *Journal of Communication in Healthcare*, 8(1), 7-9. doi:10.1179/1753806815z.000000000105
- Saha, S. (2006). Improving literacy as a means to reducing health disparities. *Journal of General Internal Medicine*, 21, 893-895
- Sarkar, U., Karter, A. J., Liu, J. Y., Adler, N. E., Nguyen, R., Lopez, A., & Schillinger, D. (2010). The literacy divide: Health literacy and the use of an Internet-based

patient portal in an integrated health system-results from the diabetes study of northern California (DISTANCE). *Journal of Health Communication*, 15(Suppl. 2), 183-196. doi:10.1080/10810730.2010.499988

Sarkar, U., Karter, A. J., Liu, J. Y., Adler, N. E., Nguyen, R., Lopez, A., & Schillinger, D. (2011). Social disparities in Internet patient portal use in diabetes: Evidence that the digital divide extends beyond access. *Journal of the American Medical Informatics Association*, 18(3), 318-321. doi:10.1136/jamia.2010.006015

Sarkar, U., Karter, A. J., Liu, J. Y., Moffet, H. H., Adler, N. E., & Schillinger, D. (2010). Hypoglycemia is more common among type 2 diabetes patients with limited health literacy: The diabetes study of northern California (DISTANCE). *Journal of General Internal Medicine*, 25(9), 962-968. doi:10.1007/s11606-010-1389-7

Schmitt, A., Reimer, A., Kulzer, B., Haak, T., Erhmann, D., & Hermanns, N. (2015). How to assess diabetes distress: Comparison of the Problem Areas in Diabetes Scale (PAID) and the Diabetes Distress Scale (DDS). *Diabetic Medicine*, 33(6), 835-843. doi: 10.1111/dme.12887

Selvin, E., Parrinello, C. M., Sacks, D. B., & Coresh, J. (2014). Trends in prevalence and control of diabetes. *Annals of Internal Medicine*, 160(8), 517-252.

Shaw, R. J., & Ferranti, J. (2011). Patient-provider Internet portals--patient outcomes and use. *Computers Informatics Nursing*, 29(12), 714-720.
doi:10.1097/NCN.0b013e318224b597

Simonds, S. K. (1974) Health education as social policy. *Health Education Monograph*, 2, 1-25.

- Slabodkin, G. (2015). Provider websites, mobile offerings coming up short. Retrieved from <http://www.healthdatamanagement.com/news/Provider-Websites-Mobile-Offerings-Coming-Up-Short-51023-1.html>
- Smith, A. (2014). *Older Adults and Technology Use*. Retrieved from <http://www.pewinternet.org/2014/04/03/older-adults-and-technology-use/>
- Sommers, S. A., & Mahadevan, R. (2010). *Health literacy implications of the affordable care act*. Retrieved from <http://www.chcs.org/resource/health-literacy-implications-of-the-affordable-care-act/>
- Steinbrook, R. (2006). Facing the diabetes epidemic-Mandatory reporting of glycosylated hemoglobin values in New York City. *New England Journal of Medicine*, (354),545-548.
- TRICARE. (2015). Transitional assistance management program. Retrieved from http://tricare.mil/Plans/SpecialPrograms/TAMP.aspx?sc_database=web
- Tsai, J., & Rosenheck, R. A. (2012). Use of the Internet and an online personal health record system by US veterans: Comparison of veterans affairs mental health service users and other veterans nationally. *Journal of the American Medical Informatics Association*, 19(6), 1089-1094. doi:10.1136/amiajnl-2012-000971
- U.S. House of Representatives Committee on Veterans Affairs. (1993). *Implementation and Effectiveness of the Montgomery GI Bill and Transition Assistance Program*. Retrieved from GPO's Federal Digital System <https://www.gpo.gov/fdsys/pkg/GPO-CPRT-103HPRT67135/content-detail.html>
- van Dijk, J. A. G. M. (2006). Digital divide research, achievements and shortcomings. *Poetics*, 34(4-5), 221-235. doi:10.1016/j.poetic.2006.05.004

- van Velsen, L., Beaujean, D., & van Gemert-Pijnen, J. (2013). Why mobile health app overload drives us crazy, and how to restore the sanity. *BMC Medical Informatics and Decision Making*, *13*. doi: 10.1186/1472-6947-13-23
- Wang, J., Thombs, B. D., & Schmid, M. R. (2014). The Swiss Health Literacy Survey: Development and psychometric properties of a multidimensional instrument to assess competencies for health. *Health Expectations*, *17*(3), 396-417.
doi:10.1111/j.1369-7625.2012.00766.x
- Weissberg-Benchell, J., Wolpert, H., & Anderson, B. J. (2007). Transitioning from pediatric to adult care: A new approach to the post-adolescent young person with type 1 diabetes. *Diabetes Care*, *30*(10), 2441-2446. doi:10.2337/dc07-1249
- WHO. (2010). Track 2: Health literacy and health behavior. Retrieved from <http://www.who.int/healthpromotion/conferences/7gchp/track2/en/>
- Williams, M. V., Baker, D. W., Parker, R. M., & Nurss, J. R. (1998). Relationship of functional health literacy to patients' knowledge of their chronic disease. *Archives of Internal Medicine*, *158*(2), 166-172.
- Yamin, C., Emani, S., Williams, D., Lipsitz, S., Karson, A., Wald, J., & Bates, D. W. (2011). The digital divide in adoption and use of a personal health record. *Archives of Internal Medicine*, *171*(6), 568-574.

Appendix A



Institutional Review Board Project Action Summary

Action Date: January 22, 2016 *Note: Approval expires one year after this date.*

Type: New Full Review New Expedited Review Continuation Review Exempt Review
 Modification

Action: Approved Approved Pending Modification Not Approved

Project Number: 2016-01-113

Researcher(s): Mark R. Malebranche Doc SON
Dr. Joseph Burkard Fac SON

Project Title: Access and Barriers to Care during Transition from Active Duty to Veteran Status in Veterans with Diabetes: A Look at Health Literacy, Change, and Ongoing Diabetes Self-management Education

Note: We send IRB correspondence regarding student research to the faculty advisor, who bears the ultimate responsibility for the conduct of the research. We request that the faculty advisor share this correspondence with the student researcher.

Modifications Required or Reasons for Non-Approval

None

The next deadline for submitting project proposals to the Provost's Office for full review is N/A. You may submit a project proposal for expedited review at any time.

Dr. Thomas R. Herrinton
Administrator, Institutional Review Board
University of San Diego
herrinton@san Diego.edu
5998 Alcalá Park
San Diego, California 92110-2492

Office of the Executive Vice President and Provost
Hughes Administration Center, Room 214
5998 Alcalá Park, San Diego, CA 92110-2492
Phone (619) 260-4553 • Fax (619) 260-2210 • www.sandiego.edu

Appendix B



DEPARTMENT OF THE NAVY
 NAVAL MEDICAL CENTER
 34800 BOB WILSON DRIVE
 SAN DIEGO, CALIFORNIA 92134-5000

IN REPLY REFER TO:
 6500

Ser 14IV/0254
 29 MAR 2016

From: Commanding Officer, Naval Medical Center San Diego
 To: Mark R. Malebranche PhD, RN
 University of San Diego, Hahn School of Nursing
 5998 Alcalá Park, San Diego, CA 92110-2492

Subj: PERMISSION TO POST RESEARCH FLYERS AT NAVAL MEDICAL CENTER SAN
 DIEGO IN CONNECTION WITH USD-IRB APPROVED PROTOCOL

Ref: (a) Your request re: USD-IRB approved project 2016-01-113

1. I have reviewed your request, reference (a) and understand that this research has been reviewed and approved by University of San Diego's (USD) Institutional Review Board (IRB). USD has a current Assurance for Compliance with Human Research Protections, FWA 00000583 (expiration date 12/05/2018) and a DOD Addendum N-A3084 expiration date 12/05/2018). The research will be conducted in compliance with all relevant federal regulations and state laws for the protection of human research subjects.
2. It is understood that, on this protocol, Naval Medical Center San Diego (NMCS D) is not engaged in research with human subjects and its role is limited to allowing you as the research Investigator to post flyers at NMCS D in connection with the study titled "Access and Barriers to Care During Transition from Active Duty to Veteran Status in Veterans with Diabetes: A Look at Health Literacy, Change, and Ongoing Diabetes Self-management Education".
3. USD and its IRB are responsible for conducting any ongoing monitoring of the research. You are responsible for cooperating with the IRB and its requirements.
4. NMCS D's IRB will be notified immediately of any unanticipated problems, events, or incidents in connection with the recruitment activity at NMCS D.
5. I have reviewed reference (a) and give permission for you to post research study flyers at NMCS D.
6. My point of contact is Sal Doria, IRB Administrator (619)532-9927 or via e-mail salvador.i.doria.civ@mail.mil


 J.A. ACOSTA

Copy to:
 USD IRB



Memorandum

Naval Medical Center San Diego
 Clinical Investigation Department (14IV)
 34800 Bob Wilson Drive, Suite 5
 San Diego, CA 92134-1005
 Tel: 619/532-9927; FAX: 619-532-8137

6500
 14IV
 07 March 2016

From: IRB Chairman, Naval Medical Center San Diego
 To: Commanding Officer, Naval Medical Center San Diego

Subj: NMCS D IRB Letter of Support

1. I reviewed the University of San Diego IRB approved protocol Project Number: 2016-01-113, titled "Access and Barriers to Care During Transition from Active Duty to Veteran Status in Veterans with Diabetes: A Look at Health Literacy, Change, and Ongoing Diabetes Self-management Education" submitted by Mark R. Malebranche, PhD, RN, USN Retired. The purpose of the study is to interview veterans with diabetes regarding their transition from active duty to veteran status. There will be no activity at NMCS D except the opportunity to post PAO approved flyers for recruitment purposes only.
2. I find the study to be minimal risk, as approved. NMCS D's role is limited to posting study flyers to recruit prospective research subjects.
3. University of San Diego's IRB holds a current Federal Wide Assurance.
4. The study will not be conducted at NMCS D; NMCS D is not engaged in this study and does not have to be evaluated or reviewed in accordance with Department of the Navy and Department of Defense Human Research Protection rules and regulations.
7. My point of contact is Sal Doria, Supervisory Program Analyst, 619-532-9927 or salvador.i.doria.civ@mail.mil.

DENNIS SPENCE, CDR, NC, USN
 IRB Chairman

Enclosure: 1. USD IRB approved Protocol

Copy to: USD IRB

REQUEST FOR CLEARANCE OF AUTHORED WORKS PREPARED FOR PUBLICATION OR PRESENTATION

A. AUTHOR

A1. Name (Last, First, MI) Malebranche, Mark R.	A2. Grade / Rank Civ (CDR, NC, USN ret.)	A3. Title PhD(c), RN
A4. Department / Directorate University of San Diego/ CID	A5. Email Address mrmalebranche@sandiego.edu	A6. Phone Number (including Area Code) 619-838-7218

B. AUTHORED WORK

B1.1 Authored Work Title
Access and Barriers to Care During Transition from Active Duty to Veteran Status in Veterans With Diabetes: A Lool

B1.2 Protocol # (If appropriate)
2016-01-113 (Assigned by the University of San Diego Insti

B1.3 Type of Authored Work
Original Research

B2.1 Name of Journal or Conference
N/A

B2.2 Date of Event

B2.3 Submission Deadline

B3 Intended Audience
Veterans with diabetes

Other
Dissertation study

B4.1 Is the Event/Conference Open to Media?
N/A

B4.2 Summary of Provocative Subject Matter (If applicable)
N/A

B5. Author's Signature
Mark R. Malebranche Digitally signed by Mark R. Malebranche
Date: 2016.03.31 10:07:47 -07'00'

B6. Department Head's Signature
MALONE.JOHN.D.1076201028
Digitally signed by MALONE JOHN D. 1076201028
DN: cn=US, o=U.S. Government, ou=DOD, ou=PKI, ou=USN,
c=US, email=JOHN.D.1076201028@usn.mil
Date: 2016.04.13 15:56:33 -07'00'

B7. Director's Signature
KING.HEATHER.CUNIFF.1177123494
Digitally signed by KING HEATHER CUNIFF 1177123494
DN: cn=US, o=U.S. Government, ou=DOD, ou=PKI, ou=USN,
c=US, email=HEATHER.CUNIFF.1177123494@usn.mil
Date: 2016.03.14 14:36:04 -07'00'

B8. Medical Editor's Signature
AVALOS.ELISEA.ESTELA.1381576082
Digitally signed by AVALOS ELISEA ESTELA 1381576082
DN: cn=US, o=U.S. Government, ou=DOD, ou=PKI, ou=USN,
c=US, email=ELISEA.ESTELA.1381576082@usn.mil
Date: 2016.05.10 12:51:35 -07'00'

B9. OPSEC's Signature
JARMER.RYAN.FRANCIS.128363853
Digitally signed by JARMER RYAN FRANCIS 128363853
DN: cn=US, o=U.S. Government, ou=DOD, ou=PKI, ou=USN,
c=US, email=RYAN.FRANCIS.128363853@usn.mil
Date: 2016.05.10 12:51:35 -07'00'

C. LOCAL / REGIONAL PUBLIC AFFAIRS OFFICER (PAO)

- I have reviewed this authored work and request a BUMED/PAO review and approval.
- This work has been cleared by the local Public Affairs Officer.

C1. PAO's Signature
WIENER.MICHAEL.T.1139048420
Digitally signed by WIENER MICHAEL T. 1139048420
DN: cn=US, o=U.S. Government, ou=DOD, ou=PKI, ou=USN, cn=WIENER.MICHAEL.T.1139048420
Date: 2016.05.10 15:48:14 -07'00'

C2. Legal Department Contacted?

C3. Legal Department POC's Signature
KLANT.ROBERT.CHRISTOPHER.1065987950
Digitally signed by KLANT ROBERT CHRISTOPHER 1065987950
DN: cn=US, o=U.S. Government, ou=DOD, ou=PKI, ou=USN, cn=KLANT.ROBERT.CHRISTOPHER.1065987950
Date: 2016.05.10 09:05:57 -07'00'

D. BUMED PUBLIC AFFAIRS

D1. Approval

D1.1 BUMED Public Affairs has approved for submission/presentation	Date
D1.2 BUMED Public Affairs has forwarded for higher review	Date
D1.3 BUMED Public Affairs has received from higher review	Date
D1.4 BUMED Public Affairs has notified sender	Date

D2. BUMED Public Affairs Officer

D2.1 Name	D2.2 Grade / Rank	D2.3 Phone Number (including Area Code)
D2.4 Email Address	D2.5 Signature	

Appendix C



DEPARTMENT OF THE NAVY
 NAVAL HOSPITAL
 BOX 555191
 CAMP PENDLETON, CA 92055-5191

IN REPLY REFER TO
 6500
 Ser 00/324

- 4 MAY 10

From: Commanding Officer, Naval Hospital Camp Pendleton
 To: Mark R. Malebranche, PhD(c), Hahn School of Nursing and Health Sciences, University of San Diego, Principal Investigator of 2016-01-113
 Subj: PERMISSION POST RECRUITMENT FLYERS AT NAVAL HOSPITAL CAMP PENDLETON FOR PROTOCOL 2016-01-113
 Ref: (a) Protocol 2016-01-113
 (b) University of San Diego Institutional Review Board approval of protocol 2016-01-113
 Encl: (1) Recruitment flyer for protocol 2016-01-113

1. I have reviewed the information provided in references (a) and (b). I give permission for the distribution of recruitment flyers (enclosure 1) at Naval Hospital Camp Pendleton (NHCP) for the referenced protocol titled, "Access and barriers to care during transition from active duty to veteran status in veterans with diabetes: a look at health literacy, change, and ongoing diabetes self-management education".
2. I understand that this study has been approved by the University of San Diego (USD) Institutional Review Board (IRB). The approved recruitment process and study flyer must be used. NHCP is not engaged in research and enrollment of study participants will take place off-site.
3. Study flyers may be placed in NHCP Internal Medicine, Family Medicine, and Endocrinology clinical spaces between 15 April and 31 August 2016. All questions that potential participants may have about the study will be referred directly to the study team, as per the study flyers.
4. My point of contact on this issue is Ms. Maria Devore, 760-719-3663, or email maria.d.devore.civ@mail.mil.


 L. P. MULLIGAN

Copy to:
 Director of Medical Services
 Clinical Investigation Program Office

Appendix D



To: Institutional Review Board, University of San Diego
From: David Bittleman, MD
Re: Dissertation Research

I have discussed the dissertation study entitled, "Access and barriers to care during transition from active duty to veteran status in veterans with diabetes: a look at health literacy, change, and ongoing diabetes self-management education" with Mark Malebranche, who is a candidate for the PhD degree in Nursing Science at the University of San Diego. I have also communicated with his Chairperson, Dr. Joseph Burkard, regarding this study.

Mr. Malebranche may use the VA Mission Valley Primary Care Clinic as a recruitment site for his study. I will be happy to assist him by distributing recruitment flyers and placing them at our reception desk.

If you have any questions, please do not hesitate to contact me at (858) 552-8585 or david.bittleman@va.gov.

Sincerely,

A handwritten signature in blue ink, appearing to read "DB", followed by a horizontal line.

David Bittleman, MD
VA Mission Valley Primary Care Clinic



DEPARTMENT OF VETERANS
AFFAIRS
VA San Diego Health Care System
3350 La Jolla Village Dr.

Appendix E

Attention Veterans!

Did you have diabetes on active duty?

Participate in a 1 hour interview about your transition to healthcare as a veteran

Who is eligible?

Veterans with diabetes at the time of transition from active duty to veteran

What is involved?

An in-person interview about transition from active duty to veteran and your diabetes care

Contact Mark Malebranche PhD(c), RN

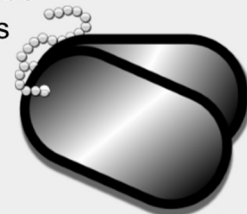
mrmalebranche@sandiego.edu

619-838-7218

\$15 Starbucks Gift Card will be given to qualified participants

Approved: University of San Diego
Institutional Review Board

Project number 2016-01-113



Appendix F

Semi-structured Interview Guide with Demographic Data for the Transition in Veterans With Diabetes Study

1. Tell me about your experience of transition from active duty to veteran status.

2. How did your diabetes self-management change during transition?

3. What barriers to care did you run into?

4. What helped access to care?

5. Where do you go most often for care and management of your diabetes?

VA MTF Private provider Other government provider
Emergency Department

6. What are your choices in where you receive health care?

What do you know about your health care choices?

7. Do you receive care from providers other than at the VA?

Yes No

If yes, where do you go and what reasons do you have for going there?

8. What diabetes self-care activities do you do?

e.g. take medicine Check blood sugar Get lab work results See provider Check
BP

How often?

9. What education have you had in diabetes self-management?

e.g. formal DM class self-education informal education with provider none

10. How familiar are you with using the internet?

Not at all slightly familiar familiar very familiar expert

(If any familiarity) How often do you use the internet?

Never monthly weekly daily more than once a day

(If any familiarity) What do you use the internet for?

(If any familiarity) What diabetes self-management do you use the internet for?

Appointments lab results diabetic education ask provider questions
refill medications

11. How Familiar are you with MyHealthVet?

(If any familiarity) What do you use MyHealthVet for?

(If any familiarity) Has your provider or other clinic staff educated you on use of MyHealthVet?

Demographic questions

1. Age

20 or younger 21-40 41-60 61-70 71-80 81 and older

2. Race

Black White Latino/Hispanic Asian

Native American

3. Length of military service

4 years or less 5 – 9 years 10 – 19 years 20 years or more

4. What year did you leave the military?(open ended)

5. What is your highest level or education?

High school or less Some college College graduate

Master's degree or above

6. Type of diabetes

Type 1 Type 2 Unsure

7. How long have you had diabetes?

1 year or less 2 – 5 years 6 – 10 years 11 – 20 years 21 year or more

8. Do you use insulin?

Yes No

Appendix G

PEPPERCORN BOOKS & PRESS INC

TOFHLA TEST OF FUNCTIONAL HEALTH LITERACY IN ADULTS

LICENSE TO REPRODUCE THE TOFHLA
FOR USE IN TESTING OR RESEARCH

Permission is granted to:

Mark Malebranche

To reproduce the TOFHLA for use in personal testing or research program, using the photocopy masters of the TOFHLA supplied with this order.

Reproduction for other purposes such as teaching, grant or funding applications, or general lending is not permitted and is covered by separate agreements. For information about these uses please contact the publisher.

License Number: 89/15
Issued: August 1, 2015

For further information, contact:

Peppercorn Books & Press Inc
68158 Red Arrow
Hartford, MI 49057

Phone: (269) 621-2733
Fax: (269) 621-2709

Email: post@peppercornbooks.com
Website: www.peppercornbooks.com

Peppercorn Books & Press
Information Sheet

TOFHLA: TEST OF FUNCTIONAL HEALTH LITERACY IN ADULTS

Authors: Joanne R. Nurss, Ph.D.
Ruth M. Parker, M.D.
Mark V. Williams, M.D.
David W. Baker, M.D., M.P.H.

TOFHLA is used to measure functional health literacy--both numeracy and reading comprehension--using actual health-related materials such as prescription bottle labels and appointment slips. It is designed to assess adult literacy in the health care setting:

- ✓ by health care providers, to determine the adequacy of their patients' reading and understanding of health care materials needed for their health care or health education;
- ✓ by researchers, to assess patient health literacy as a variable in their research.

TOFHLA was developed at Georgia State University under a grant to Emory University from the Robert Wood Johnson Foundation and was first published in 1995. It is now available from Peppercorn Books.

TOFHLA is presented in a three-ring notebook for ease of use. You may photocopy the instruments for use in your own research or testing, within your department or organization only. The TOFHLA package includes:

- Full versions in English and Spanish, in regular (12 pt.) and large font (14 pt).
- A short version in English and Spanish in large font (14pt).
- Directions for administration and scoring and the technical manual for each.
- A bibliography of published articles concerning the development and validation of the instrument and research studies for using it.

ISBN: 1-928836-11-9
Published: August 2001
PBP Title #: 100-0014
Price: \$70.00 plus shipping & handling

Available from:
Peppercorn Books & Press, 68158 Red Arrow Hwy Hartford, MI 49057
Phone: (269) 621-2733 - Fax: (269) 621-2709
Email: post@peppercornbooks.com
Website: www.peppercornbooks.com

Updated January 2006

Appendix H



Test of Functional Health Literacy in Adults

Short Test of Functional Health Literacy in Adults (STOFHLA)

STOFHLA Directions for Administration, Scoring & Technical Data

STOFHLA - English & STOFHLA - Spanish

Directions For Administration & Scoring

I. Introduction

A. Background

A review of existing literacy assessment instruments shows that most concentrate on word recognition or narrative text comprehension skills. To answer the need for a more comprehensive evaluation of literacy, and a different conceptual framework for understanding the impact of low literacy on health status and/or health care delivery, the Literacy in Health Care Project developed the Test of Functional Health Literacy in Adults (TOFHLA). TOFHLA is a functional literacy assessment tool designed to evaluate adult literacy in the health care setting. The instrument measures functional literacy on the assumption that more than classroom reading ability is necessary to understand and negotiate the health care system adequately. TOFHLA is especially directed toward capturing numeracy and reading comprehension skills in the middle to low levels of literacy ability.

B. Short TOFHLA

Initial use of the TOFHLA indicated that healthcare professionals found a need for a shorter version for screening patient literacy in clinical and educational settings. While the full TOFHLA provides a more complete estimate of patients' functional health literacy, the Short TOFHLA is a quicker, more efficient way of determining patient functional health literacy. It measures understanding of functional health literacy tests, a more effective measure of literacy than simple word recognition. It decreases administration time to 7 minutes (from 22 minutes for the full TOFHLA) and eliminates the need for visual acuity screening. Administration is also simplified as the tasks involve no manipulatives and may be given as a group test.

C. Special Considerations for Testing Low Literate Patients

An important part of health literacy features personal ability. Those with few or reduced skills often feel vulnerable when literacy inability is brought to their attention or to the attention of those around them. The force of this vulnerability is heightened by peer and social pressure. Consequently, low literate persons employ sophisticated mechanisms to conceal their literacy skill level and to prevent subsequent discovery or embarrassment, not to mention outright anger.

You very likely will encounter some of these low literacy behaviors:

- pointing to the text with a finger, while reading
- lifting the text closer to be read
- claiming "the light's not good"

- complaining about “having trouble seeing”
- expressing fatigue
- explaining that they don’t have time
- stating that they don’t think the material is interesting

When you encounter low literacy, soften the impact of unmasking by stating compassionately, “I am not here to embarrass you, frustrate you, or make you feel uncomfortable. I am willing to stop if you want to, but the information you can give me is very special and valued highly by all of us here. (PAUSE) May I continue?” Honor the dignity to which every human is entitled.

II. Preliminary Procedures

A. Informed Consent

Your hospital or health-care setting may require you to obtain a signed Informed Consent from the patient before testing may begin. Your institution may have a standard form and/or a procedure for developing one. The informed consent must be read orally verbatim. Paraphrasing is allowed, but not as a substitute for verbatim reading. When the respondent signs the consent, in effect he/she gives you permission to ask them questions, but they do not commit themselves to answering the questions. It is normal, however, for the respondent to answer all questions asked. Typically, the informed consent provides the respondent with information about procedures, risks and discomforts, expected benefits, withdrawal of consent, confidentiality and project disclaimer of financial reliability in the event of injury. Manage the consent procedure with the same diligence you use to administer a data collection tool.

B. Visual Acuity

Routinely, low literate persons will mask reading problems by saying that they cannot see the materials they are given. This test is printed in 14 point font (large print) appropriate for persons with visual acuity at least 20/50. If the respondent wears glasses, ask them to put them on for this test.

C. Language Preference

If the patient’s dominant language is Spanish, administer the Spanish-version of Short TOFHLA (STOFHLA-Spanish). However, it is important to remember this gives information on the patient’s literacy in Spanish, not English. The health care facility needs to provide written material in Spanish as well as English for these patients.

III. STOFHLA: Reading Comprehension

A. Description

STOFHLA (Reading Comprehension) tests a patient's ability to read passages using real materials from the health care setting. The test of 36 items uses a modified Cloze procedure. Passages are selected from instructions for preparation for an upper GI series and the patient rights and responsibilities section of a Medicaid application form. Readability levels on the Gunning Fog index are grades 4.3 and 10.4 respectively. The passages are ordered by increasing difficulty.

B. Directions for Administration

It is important to present the reading comprehension section verbatim from the scripted introduction. Once introduced, fold the preceding pages back so that the respondent sees only the text passages. Turn one or two pages to show the respondent what you mean, and turn them in a way that only shows the text passages. If the respondent asks about the score columns, tell them that the boxes are for use in the office. Do not tell the respondent that they are score columns. This is a timed test and should be stopped at the end of 7 minutes. Do not inform the respondent in advance that the test is timed. When 7 minutes have elapsed, tell the respondent that "That should give us what we are looking for. Thank you for your cooperation." and remove the test materials.

C. Directions for Scoring STOFHLA: Reading Comprehension

Score the results immediately on the spot, after the respondent has left. You will need to do six things to confirm and transcribe respondent data to appropriate boxes in the column of boxes appearing on the page opposite the text:

1. For each blank, circle the letter in the box corresponding to the letter selected by the respondent.
2. Compare the answers by page and variable name to the appropriate scoring key provided below.
3. In the score box, circle "1" for correct or "0" for incorrect for each blank.
4. Sum correct answers for each page, and record total at bottom of page.
5. Sum the subtotals for all pages and record total on the last scoring column page as the Reading Comprehension Raw Score. Record in the appropriate box on the back cover of the test booklet (STOFHLA Total Score).

STOFHLA: Reading Comprehension

Score Keys for English (Large Font)

STOFHLA: Reading Comprehension Score Key
English: 14 Point Font

Passage A	Passage A	Passage A	Passage B	Passage B	Passage B
A1 a	A6 a	A12 c	B17 c	B24 d	B33 d
A2 b	A7 c	A13 b	B18 a	B25 b	B34 c
A3 d	A8 b	A14 c	B19 d	B26 c	B35 b
A4 a	A9 d	A15 d	B20 b	B27 d	B36 b
A5 c	A10 b	A16 a	B21 d	B28 d	
	A11 c		B22 c	B29 a	
			B23 a	B30 c	
				B31 b	
				B32 a	

STOFHLA: Reading Comprehension

Score Keys for Spanish (Large Font)

STOFHLA: Reading Comprehension Score Key
Spanish: 14 Point Font

Passage A	Passage A	Passage B	Passage B	Passage B
A1 b	A10 c	B17 a	B24 a	B34 a
A2 a	A11 a	B18 b	B25 c	B35 d
A3 c	A12 c	B19 a	B26 b	B36 b
A4 c	A13 a	B20 b	B27 c	
A5 a	A14 b	B21 a	B28 b	
A6 d	A15 a	B22 d	B29 b	
A7 c	A16 a	B23 c	B30 a	
A8 c			B31 a	
A9 b			B32 d	
			B33 c	

IV. STOFHLA: Functional Health Literacy Level

A. Functional Health Literacy Level

Look up the Total STOFHLA Score on the table below. Record the patient's Functional Health Literacy Level on the back cover of the test booklet.

TOFHLA Functional Health Literacy Levels

Level	TOFHLA Score	Functional Health Literacy Description
Inadequate Functional Health Literacy	0-16	Unable to read and interpret health texts.
Marginal Functional Health Literacy	17-22	Has difficulty reading and interpreting health texts.
Adequate Functional Health Literacy	23-36	Can read and interpret most health texts.

B. Functional Interpretation of STOFHLA Scores

1. Patients who have **Adequate Functional Health Literacy** should be able to read, understand, and interpret most health texts.
2. Patients who have **Marginal** or **Inadequate Functional Health Literacy** will have difficulty reading, understanding, and interpreting most health materials. They are not going to be able to read and understand directions for their health care. They are likely to take their medications incorrectly or to fail to follow prescribed diets or treatment regimens. Modifications must be made in the health care setting in order to accommodate these persons. Recommendations include the following:
 - Suggest the person bring someone along with them to read and interpret health texts.
 - Suggest the person use someone at home to read and interpret health texts.
 - Rewrite health materials, including prescription bottle labels at a lower literacy level (below 5th grade readability level).
 - Use pictures, graphic directions, symbols to indicate directions, information, and procedures.

- Have staff available to assist patients whose functional health literacy level is low.
- Provide important information on audio-tape and/or video-tape.

Remember that persons with low functional health literacy often are ashamed of their literacy status. They will be unlikely to volunteer that they can not read or to ask for assistance. Low literacy does not mean low intelligence. Treat them with dignity and respect, offering literacy help but not talking down to them.

V. STOFHLA: Technical Report

The STOFHLA (English & Spanish) consists of two functional health reading comprehension passages. In a group of 211 patients given the STOFHLA at the Urgent Care Center and Medical Clinic at Grady Memorial Hospital in Atlanta, Chronbach's Alpha (internal consistency) was 0.97 (0.94 for passage A & 0.97 for Passage B). The correlation (Spearman) with the REALM was 0.81 and with the full TOFHLA 0.91. For further information on the development of the Short TOFHLA, see Baker, Williams, Parker, Gazmarian, & Nurs, 1998.

When Should You Use:

Short TOFHLA

- Screening patients in a medical clinic.
- Determining literacy level for a health variable in education program.
- Including literacy level as a descriptive variable.

Full TOFHLA

- Including literacy as a dependent or independent research.

Appendix I

DDS

DDS

DIRECTIONS: Living with diabetes can sometimes be tough. There may be many problems and hassles concerning diabetes and they can vary greatly in severity. Problems may range from minor hassles to major life difficulties. Listed below are 17 potential problem areas that people with diabetes may experience. Consider the degree to which each of the 17 items may have distressed or bothered you DURING THE PAST MONTH and circle the appropriate number.

Please note that we are asking you to indicate the degree to which each item may be bothering you in your life, NOT whether the item is merely true for you. If you feel that a particular item is not a bother or a problem for you, you would circle "1". If it is very bothersome to you, you might circle "6".

	Not a Problem	A Slight Problem	A Moderate Problem	Somewhat Serious Problem	A Serious Problem	A Very Serious Problem
1. Feeling that my doctor doesn't know enough about diabetes and diabetes care.	1	2	3	4	5	6
2. Feeling that diabetes is taking up too much of my mental and physical energy every day.	1	2	3	4	5	6
3. Not feeling confident in my day-to-day ability to manage diabetes.	1	2	3	4	5	6
4. Feeling angry, scared and/or depressed when I think about living with diabetes.	1	2	3	4	5	6
5. Feeling that my doctor doesn't give me clear enough directions on how to manage my diabetes.	1	2	3	4	5	6
6. Feeling that I am not testing my blood sugars frequently enough.	1	2	3	4	5	6
7. Feeling that I will end up with serious long-term complications, no matter what I do.	1	2	3	4	5	6
8. Feeling that I am often failing with my diabetes routine.	1	2	3	4	5	6

DDS

	Not a Problem	A Slight Problem	A Moderate Problem	Somewhat Serious Problem	A Serious Problem	A Very Serious Problem
9. Feeling that friends or family are not supportive enough of self-care efforts (e.g. planning activities that conflict with my schedule, encouraging me to eat the "wrong" foods).	1	2	3	4	5	6
10. Feeling that diabetes controls my life.	1	2	3	4	5	6
11. Feeling that my doctor doesn't take my concerns seriously enough.	1	2	3	4	5	6
12. Feeling that I am not sticking closely enough to a good meal plan.	1	2	3	4	5	6
13. Feeling that friends or family don't appreciate how difficult living with diabetes can be.	1	2	3	4	5	6
14. Feeling overwhelmed by the demands of living with diabetes.	1	2	3	4	5	6
15. Feeling that I don't have a doctor who I can see regularly enough about my diabetes.	1	2	3	4	5	6
16. Not feeling motivated to keep up my diabetes self management.	1	2	3	4	5	6
17. Feeling that friends or family don't give me the emotional support that I would like.	1	2	3	4	5	6

DDS17 SCORING SHEET

INSTRUCTIONS FOR SCORING:

The DDS17 yields a total diabetes distress score plus 4 subscale scores, each addressing a different kind of distress.¹ To score, simply sum the patient's responses to the appropriate items and divide by the number of items in that scale.

Current research² suggests that a mean item score 2.0 – 2.9 should be considered 'moderate distress,' and a mean item score ≥ 3.0 should be considered 'high distress.' Current research also indicates that associations between DDS scores and behavioral management and biological variables (e.g., A1C) occur with DDS scores of ≥ 2.0 . Clinicians may consider moderate or high distress worthy of clinical attention, depending on the clinical context.

We also suggest reviewing the patient's responses across all items, regardless of mean item scores. It may be helpful to inquire further or to begin a conversation about any single item scored ≥ 3 .

Total DDS Score:	a. Sum of 17 item scores:	_____
	b. Divide by:	_____ 17 _____
	c. Mean item score:	_____
	Moderate distress or greater? (mean item score > 2)	yes__ no__
A. Emotional Burden:	a. Sum of 5 items (2, 4, 7, 10, 14)	_____
	b. Divide by:	_____ 5 _____
	c. Mean item score:	_____
	Moderate distress or greater? (mean item score > 2)	yes__ no__
B. Physician Distress:	a. Sum of 4 items (1, 5, 11, 15)	_____
	b. Divide by:	_____ 4 _____
	c. Mean item score:	_____
	Moderate distress or greater? (mean item score > 2)	yes__ no__
C. Regimen Distress:	a. Sum of 5 items (6, 8, 3, 12, 16)	_____
	b. Divide by:	_____ 5 _____
	c. Mean item score:	_____
	Moderate distress or greater? (mean item score > 2)	yes__ no__
D. Interpersonal Distress:	a. Sum of 3 items (9, 13, 17)	_____
	b. Divide by:	_____ 3 _____
	c. Mean item score:	_____
	Moderate distress or greater? (mean item score ≥ 2)	yes__ no__

1. Polonsky, W.H., Fisher, L., Esarles, J., Dudl, R.J., Lees, J., Mullan, J.T., Jackson, R. (2005). Assessing psychosocial distress in diabetes: Development of the Diabetes Distress Scale. *Diabetes Care*, 28, 626-631.

2. Fisher, L., Hessler, D.M., Polonsky, W.H., Mullan, J. (2012). When is diabetes distress clinically meaningful? Establishing cut-points for the Diabetes Distress Scale. *Diabetes Care*, 35, 259-264.