

PSYCHOSOCIAL NEEDS OF U.S. ACTIVE-DUTY MILITARY SERVICE MEMBERS AND
SPOUSES WITH CANCER: A QUALITATIVE STUDY

by

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A DISSERTATION

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ABSTRACT

Current United States active-duty military (AD) service members and spouses are at an increased risk of developing various types of cancer at a higher rate reported than their military predecessors (Defense Health Research Programs, 2017; Zhu et al., 2009; Steinmaus et al., 2004). Active-duty service members and spouses also face challenges not faced by their civilian counterparts because of the military lifestyle and “mission first” culture. These challenges can include being geographically separated from families, friends, along with deployments, frequent moves, and the lack of consistent support systems. Therefore, when AD service members and spouses are diagnosed with cancer, psychosocial needs may not be met. The research and literature surrounding the psychosocial needs of AD military service members and spouses with cancer are limited as the current research focuses mainly on non-military affiliated groups or veterans.

The purpose of this qualitative research was to understand the psychosocial needs of U.S. AD service members and spouses diagnosed with cancer. Data from semi-structured interviews provided insight that facilitated understanding these psychosocial needs. Participants discussed support systems, relationships, psychological and emotional responses, and ways the military environment both supported and lacked support during their cancer journey. Participants further noted that some of the barriers included not knowing what support systems were available and that availability depended upon geographic location and how “close” the community was; not

having to pay any out-of-pocket costs; and that chains of command inconsistently supported their service members and families.

The results of this study have implications for social workers who work within the military structure as well as civilian providers. Ensuring that AD service members and spouses know the available resources, both through the military and in the civilian community, is one area that can improve the psychosocial outcomes of AD service members and spouses with cancer. The results also show the importance in understanding the stressors that cause additional mental and physical barriers, unique to the military environment, during treatment and into survivorship. Participants were eager to have their voices heard and wanted to ensure that fellow AD service members and spouses with cancer have improved experiences with health care systems and support.

DEDICATION

I would like to dedicate this dissertation to my grandparents, John and Buena Walters. Neither are living, but both had a profound impact on my life from a very young age. My granny was a very simple woman but told the best stories from her childhood. My grandfather was a hardworking man, who owned a peach orchard in Ashland, AL. When I was diagnosed with cancer, he would go to the library and research everything about my specific cancer so he would be informed. He was also one of my biggest supporters when I decided to start my PhD journey. I wish that he was here to see me finish, but I know that he was proud and knew I would finish. I miss both of you every day.

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MILITARY TERMS GLOSSARY

AD	Active Duty: Full-time duty in the active military service of the United States
AGR	Active Guard Reserve: National Guard and Reserve members who are on voluntary active duty providing full-time support to National Guard, Reserve, and Active Component organizations for the purpose of organizing, administering, recruiting, instructing, or training the reserve component.
ARMED FORCES	A term used to denote collectively all components of the Army, Marine Corps, Navy, Air Force, and Coast Guard (when mobilized under Title 10, U.S. Code, to augment the Navy).
BASE	A locality from which operations are projected or supported. An area or locality containing installations which provide logistics or other support.
BRANCH	An arm or service of the Army.
CoC	Chain of Command: The succession of commanding officers from a superior to a subordinate through which command is executed.
COMBAT STRESS	The expected and predictable emotional, intellectual, physical, and/or behavioral reactions of an individual who has been exposed to stressful events in military operations.
COMMAND	The authority that a commander in the armed forces lawfully exercises over subordinates by virtue of rank or assignment; A unit or units, an organization, or an area under the command of one individual.
DEERS	Defense Enrollment and Eligibility Reporting System: A database containing information for each uniformed service member, US sponsored foreign military, DoD and uniformed civilians, other personnel directed by the DoD, and their eligible family members.
DoD	Department of Defense: The Office of the Secretary of Defense, the Military Departments, the Chairman of the Joint Chiefs of Staff and the Joint Staff, the combatant commands, the Office of the Inspector General

of the Department of Defense, the Department of Defense agencies, the Department of Defense field activities, and all other organizational entities in the Department of Defense.

DEPENDENT	An employee's spouse; children who are unmarried and under age 21 years or who regardless of age, are physically or mentally incapable of self-support; dependent parents, including step and legally adoptive parents of the employee's spouse; and dependent brothers and sisters, including step and legally adoptive brothers and sisters of the employee's spouse who are unmarried and under 21 years of age or who, regardless of age, are physically or mentally incapable of self-support.
DEPLOYMENT	The movement of forces into and out of an operational area.
EFMP	Exceptional Family Member Program: A mandatory enrollment program that works with other military and civilian agencies to provide comprehensive and coordinated community support, housing, educational, medical, and personnel services to families with special needs.
FRG	Family Readiness Group: A command-sponsored organization of family members, volunteers, military members, and civilian employees associated with a particular unit. They provide activities and support to enhance the flow of information, increase the resiliency of unit soldiers and their families, provide practical tools for adjusting to military deployments and separations, and enhance the wellbeing and spirit de corps within the unit.
MH	Mental Health
MHS	Military Health System: Provides direction, resources, health care providers, and other means necessary to foster, protect, sustain, and restore health to service members and other beneficiaries.
MOS	Military Occupational Specialty: A job classification.
MTF	Medical Treatment Facility: A facility established for the purpose of furnishing medical and/or dental care to eligible individuals.
NG	National Guard: The National Guard of the United States is a reserve military force composed of National Guard military members or units of each state and the territories of Guam and the Virgin Islands plus the Commonwealth of Puerto Rico and the District of Columbia under federally recognized active or inactive Armed Force service for the United States.

NIH	National Institutes of Health
NCO	Non-commissioned Officer: An officer who has not been given a commission, usually obtains their position of authority by promotion through the enlisted ranks.
OCONUS	Outside the Continental United States
PA	Physician Assistant
PAO	Public Affairs Officer: An officer that works within communication activities with external and internal audiences.
PCM	Primary Care Manager: A civilian network provider or military treatment facility provider who provides primary care service to TRICARE beneficiaries.
PCS	Permanent Change of Station: The official relocation of an active-duty military service member, including family, to a different duty location.
PRIME	Managed care option of TRICARE
PTSD	Post-Traumatic Stress Disorder
SELECT	Fee-for-service option of TRICARE
SGLI	Servicemembers' Group Life Insurance: A term insurance policy for active-duty service members, Ready Reservists, National Guard members, members of the Commissioned Corps of the National Oceanic and Atmospheric Administration and the Public Health Service, cadets and midshipmen, and Reserve Officer Training Corps (ROTC) members. Maximum coverage is currently \$400,000.
SM	Service Member
SP	Spouse
SQUADRON	A organization consisting of two or more divisions of ships or two or more divisions (Navy) or flights of aircraft; The basic administrative aviation unit of the Army, Navy, Marine Corps, and Air Force; Battalion-sized group or aviation units.
TDY	Temporary Duty: An assignment at a location other than the military member's permanent station, usually of relatively short duration.
TRICARE	The health care program for military, retirees, and dependents.

UNIT	Any military element whose structure is prescribed by competent authority.
U.S.	United States: Includes the land area, internal waters, territorial sea, and airspace of the United States, including a. United States territories; and b. Other areas over which the United States government has complete jurisdiction and control or has exclusive authority or defense responsibility.
VA	Department of Veterans Affairs
WTU	Warrior Transition Unit (also referred to as Warrior Transition Battalion): A system of support and advocacy to guide and assist the wounded, ill, and injured service members and family or designated caregiver through treatment, rehabilitation, return to duty, or military retirement into the civilian community. Each military department has a unique wounded warrior program that addresses its service members' needs.

Terminology provided by the DoD Dictionary of Military and Associated Terms (2021)

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CHAPTER 1: INTRODUCTION

Problem Statement

Active-duty military service members (AD) and spouses are at an increased risk of developing various types of cancer because of many factors including environmental exposures during deployments, training exercises, and exposures on and around military installations (Defense Health Research Programs, 2017; Zhu et al., 2009; Steinmaus et al., 2004). It is difficult to pinpoint when the rise in case rates began because many cancers present in later years, but exposure cancers can be traced as far back at WWII (Zhu et al., 2009). Toxic environmental exposures have been discovered at U.S. military installations throughout the world and contribute to higher rates of cancer among AD service members and spouses (Copp, 2018). These environmental exposures include chemical weapons (or storage of such), ionizing radiation, herbicides, electromagnetic fields, jet fuel, organic materials, biological agents, ultraviolet radiation, firefighting foam, and open-air trash burning pits (known as burn pits), perfluorooctane sulfonate (PFOS) and perfluorooctanoic acid (PFOA); this list is not all inclusive (U.S. Army Medical Research and Material Command, 2017). Tests were conducted at military installations of the potable water in 2017. These tests showed there are 401 active and Base Realignment and Closure (BRAC) installations where PFOS/PFOA has been released into the water supply, with half being at Air Force installations (Sullivan, 2018).

Although not all toxic exposure risks that AD service members experience during deployments and from duty station locations are risks that are shared with spouses, many toxicities from duty locations are shared and increase the risk of cancer significantly for both compared to civilian counterparts (Goldberg et al., 2020). There is speculation that the previous studies were not asking the right questions and therefore were not identifying the increased risk or attempting to understand the increasing rates (Copp, 2019). It is difficult to pinpoint the exact incidence of cancer in the AD military force, but the Veterans Health Administration reported more than 12 million unique visits to treat cancer and diagnoses, approximately 45,000 new cases per year (Dasgupta et al., 2019).

Previous research either combines military service members and military spouses as one entity, either not distinguishing between the two groups or omitting military spouses altogether. Much of the published research centers around the effect of global conflicts, depression, limited resources, and other factors primarily focusing on the military service members (Verdeli et al., 2011). Some research conducted with military spouses shows that they often take on the main parental role in the family and a supportive role to their service member spouse (Verdeli et al., 2011). Military spouses often neglect their own health and forego positive health behaviors, such as healthy eating and physical activity, because of the competing priorities in supporting their military member and family (Mailey et al., 2018; Joseph & Afifi, 2010; Tanofsky-Kraff et al., 2013). With the different roles that the military service members have versus military spouses, the focus on the 'mission' first for the military service members and the uneven concentration of resources available for the military service members demands that the research distinguish between the two. However, the readiness and resilience of the military spouse, in supporting the military mission of their service member, plays a large part in the retention of the military

service member (Corry et al., 2019; Willerton et al., 2011). In addition, military spouses have their own unique histories and difficulties that may influence their experiences with serious illness such as cancer (Kees et al., 2015).

The AD military is primarily composed of service members and spouses under the age of 40, the cohort identified by the Department of Defense (DoD) as having unique needs during cancer (Murtha Cancer Center Annual Report, 2018). Some of the challenges include the lack of a support system of extended family, periodic geographical moves, mental health problems stemming from multiple deployments, the need to continue to put mission first, childcare, etc. Active-duty service members and spouses are often geographically separated from their families, friends, and support systems and move more than the average civilian (Godfrey & Albright, 2019). An average of 1,000 AD service members are diagnosed with some form of cancer annually (Murtha Cancer Center Annual Report, 2018). Cancer diagnoses are also prevalent among their spouses (US Army Medical Research and Material Command, 2017).

In addition to the need for specialty medical care, cancer patients have psychosocial needs including the need to manage daily life activities, including job responsibilities, while undergoing cancer treatments. This is often challenging depending on the severity of the diagnosis and treatment prescribed (McIllmurray et al., 2001). Other challenges to psychosocial well-being may include access to consistent specialized health care, reliable and available family and friend support networks, emotional, spiritual, and mental health support, adequate financial resources, practical daily living support, and maintaining a sense of identity during and after treatment (McIllmurray et al., 2001). When AD service members or spouses are diagnosed with cancer, it is likely that the psychosocial needs may not be fully met or inadequately met because of the uncertainty of these needs or the lack of continuity in care. This can be because of the

stressors of the military lifestyle such as frequent deployments and moves of residence along with a lack of a consistent support system.

Having unmet psychosocial needs during cancer treatment can lead to poor outcomes in both physical and mental health (Adler & Page, 2008). Because of psychological and physical health problems, created or intensified, patient and family distress ultimately affect the course of the disease or outcome of treatments (Adler & Page, 2008). While understanding the psychosocial needs of AD service members and spouses diagnosed with cancer and who are receiving, or have received, treatment may improve the outcomes and well-being, limited research exists that addresses these needs. The research that does exist focuses on the medical/biological aspects of oncology, issues related to survivorship, and the veteran population (rather than AD military service members and spouses). One of the differences between the AD military population and the veteran population is that there is no longer a contractual obligation to the military or a requirement to be where the military tells you to be and when. This likely creates differences in available resources and the support systems between the veteran and the AD member. Veterans are seen, for medical issues, through the Department of Veterans Affairs (VA) and in the community clinics not related to the VA (Albright et al., 2020). Active-duty military and spouses are seen, for medical issues, both at military treatment facilities on military installations and at civilian community clinics.

Significance of the Study and Relevance to Social Work

The military community is a unique and often vulnerable population because of its hierarchy, undue influence, and lack of control over many aspects of their lives (Clay, 2010; Griffith & Bryan, 2015; Cogan et al., 2018). Therefore, their psychosocial needs when receiving a cancer diagnosis and undergoing treatment could be different than the civilian population. The

military is unique in that it is more than a job, it is a lifestyle. When you are an AD service member, the military decides what you do, where you live, when you move, when you can take vacation, when you go to medical appointments, etc. (Stiehm, 2012). Because of the lack of continuity in one location, with friends and family, military service members and military families often essentially start over every six months to three years, depending on the assignment and length at each station. Although the cancer incidence surveillance research is limited for AD, there is an increased occurrence of cancer in VA patients. For example, there was a 96 percent increase in pancreatic cancer from 2000 to 2018, and bladder, kidney, and ureter cancer increased by 61 percent over the same period (Wood, 2019). Based on these reports, it seems plausible to assume an increasing number of AD service members and spouses who are diagnosed with cancer annually.

Although the military devotes resources to addressing the psychosocial needs of AD service members and their spouses when receiving a cancer diagnosis at some locations, such as the Murtha Cancer Center in Bethesda, Maryland, few AD service members are stationed in the Washington, D.C. area and therefore must seek treatment elsewhere if the appropriate resources exist where they are stationed. Some of the potential services offered include support groups, educational groups, health groups such as yoga, counseling services, end of life and bereavement counseling, stress management, play therapy, cutting edge therapies and diagnostic technologies, community service and outreach activities, etc., along with all medical treatments provided on-site. Understanding the psychosocial needs of AD service members and spouses that are stationed throughout the world is essential so that oncology social workers, working with patients who utilize care both from military treatment facilities and civilian health care providers, can effectively intervene to address their needs. By understanding and addressing psychosocial

along with medical needs, improved physical and mental health outcomes such as lower reoccurrence rates, better compliance with treatment plans and long-term follow-ups, and the ability for retention of trained military service members may result.

Although this research focuses mainly on AD military service members and spouses who are receiving ongoing treatments and in survivorship, the results of this research may also be useful to hospice social workers, as death from cancer does occur among AD service members and spouses. Social workers who work with the AD service members and spousal oncology population should understand the uniqueness of the military lifestyle and how it may affect the individual and the family's psychosocial needs regarding the cancer diagnosis, treatment decisions, death, and grief/bereavement.

This research is a beginning that will, ideally, better inform oncology social workers, behavioral health social workers, and hospice social workers who may work with the AD military population in a variety of physical and mental health settings regarding the population and their needs due to the unique AD military lifestyle.

Study Purpose

The primary objective of this pragmatic qualitative study is to provide a better understanding of the psychosocial needs of U.S. AD service members and spouses who currently have or had cancer and to recognize their difficulties and gaps in resources with these psychosocial needs. Research on the psychosocial needs of AD service members and spouses who have cancer has been very limited to date, with more focus on the veteran population and on the medical aspects of cancer in the military rather than the psychosocial needs. This study establishes the need for additional qualitative, quantitative, and mixed-methods research on the topic to address the psychosocial needs from diagnosis through survivorship.

Research Questions

1. What are the psychosocial needs of U.S. AD military service members or spouses with cancer?
2. What psychosocial difficulties did those diagnosed with cancer encounter during the experience with cancer?

Research Design

A pragmatic qualitative design was utilized to gain an understanding of the way in which AD service members and spouses experience cancer in relation to psychosocial needs in the context of AD military service. Individual semi-structured interviews were conducted with (n=13) AD (or previous AD) service members and spouses (n=6 service members and n=7 spouses) to understand experiences of AD service members and spouses with a current or previous cancer diagnosis that occurred while serving on AD or being an AD spouse to better recognize the psychosocial needs. Participants were recruited from Facebook groups for active and retired (longevity and medically) military service members and spouses. Interviews were conducted by Zoom using video and audio. Therefore, it was very similar to doing an in-person interview.

Interviews were recorded using Zoom and transcribed verbatim using Otter.ai through the Zoom platform. Interviews were then edited to remove filler words and correct grammar. Field notes were handwritten as interviews were conducted and transcribed. These notes were put into Microsoft Word after each interview and reviewed before the next interview took place to aid in emerging themes and possible additional questions. Data was coded using In Vivo for first cycle coding, subcoding was done and, finally, pattern coding for second cycle coding.

Military Context and Conceptualization of Terms

Active Duty

There are six branches of military service, including the recent addition of the Space Force, but only five located within the Department of Defense and housed at the Pentagon (Stiehm, 2012). Each military branch has a different mission and has its own identity. There is also a distinction between AD, National Guard, and Reserve forces. The National Guard (NG) is organized by each of the fifty states and in the territories consisting of the Army NG and the Air NG. National Guard members have service obligations, but it is not their full-time job (Stiehm, 2012). Typically, NG train one weekend a month, two weeks during the summer, and deploy when ordered (Stiehm , 2012). National Guard members live wherever they choose and have civilian jobs. The Reserve force consists of the Army Reserve, the Air Force Reserve, Navy Reserve, and Marine Corps Reserve with similar military obligations as the NG but are federally controlled rather than state administered (Stiehm , 2012).

Members of the AD force are enlisted and officer members of the regular military whose profession or full-time job is the military. Active-duty service members do not hold a civilian job with their military career as a part time job, as NG and Reserve members (Stiehm, 2012). There are almost 1.4 million AD members stationed both within the continental United States (CONUS) and overseas, or outside the continental United States (OCONUS). Active-duty military service members are required to live in the geographical location of their duty station as defined by their military orders and based on the needs of the service. Although NG and Reserve members may also be diagnosed with cancer and have their own psychosocial needs, this research focuses solely on AD due to their unique lifestyle and the fact that they are typically

geographically separated from their families and/or informal or formal support systems (Stiehm, 2012).

Military Spouse

Although the composition of the American military family is changing, including who service members consider to be either family or part of a support system, for the purpose of this research, I followed the DoD's definition of a military spouse, which is defined in Title 37, Section 401, of the U.S. Code. The DoD defines a military spouse as someone whom the service member is legally married, with this definition expanding to same-sex marriages following the ruling by the Supreme Court in 2013 (Gribble et al., 2018). These spouses are eligible for enrollment in the Defense Enrollment Eligibility Reporting System (DEERS), which is the system that processes military benefits enrollment. Only spouses eligible for DEERS enrollment are considered dependents and afforded the benefits of a spouse. An unmarried significant other or common law spouse is not eligible for DEERS enrollment and, therefore, is not recognized as a spouse by the U.S. military (Gribble et al., 2018). This is the definition that is followed when defining a military spouse for the purposes of this research. Members of a dual-military couple can choose to be defined as either a military spouse or military service member but will be noted in the demographics for reporting purpose and possible generalizability.

Cancer and Psychosocial Needs

The National Cancer Institute (2015) defines cancer as a name given to a collection of diseases where cells become abnormal, old, or damaged but survive. For this exploratory study, any type of cancer diagnosis was eligible. Therefore, for this research, cancer is defined as someone who has been medically diagnosed with a specific disease that falls under the collective terminology of cancer.

“Psychosocial” is a term utilized in describing the influences of social factors on mental health and behavior (Vizzotto et al., 2013). According to the Oxford English Dictionary (2012), “Psychosocial means pertaining to the influence of social factors on an individual’s mind or behavior, and the interrelation of behavioral and social factors.” Typically, in an oncological setting, a social worker completes a psychosocial assessment for the purpose of assessing strengths and needs of the patient. Within the context of this study, the needs were identified through participant interviews and researcher data analysis. Psychosocial needs can include emotional and mental health, financial stress, lack of or inadequate health care, and reduced income; physical stressors and social support needs often exacerbate these needs (Adler & Page, 2008).

Epistemology, Theories, and Models

The philosophical underpinning for my study is pragmatism. This approach is more focused on real-world practice and using the method that works to answer the research question posed (Creswell & Plano Clark, 2018). Pragmatism allows for the research problem to be central to the research and for all approaches to be based on understanding the problem (Savin-Baden & Major, 2013). This approach allows for the combination of research methodologies to solve a problem and is the more balanced approach to answer the research question (Savin-Baden & Major, 2013).

The theoretical foundations utilized for this research were the social cognitive theory and the social ecological model. The social cognitive theory is that self-efficacy, or a person’s confidence in his or her ability to act and persist in that action despite obstacles or challenges, is especially important for influencing health behavior change efforts (Graves, 2003). In the social ecological model, creating an environment conducive to change is important to making it easier

to adopt healthy behaviors (Sorensen et al., 2003; Glanz, n.d.). Bronfenbrenner's 1979 ecological theory examines the relationship of people to the settings and interactions in which they are actively involved (Harkonen, 2008).

These theoretical models apply to cancer patients who are attempting to remain engaged within other facets of their lives and psychosocial functions. Active-duty military service members and spouses often have many other obligations within their daily sphere, such as career, family, social, etc. Self-efficacy and having an environment that accounts for other relationships while examining the psychosocial needs of this unique population are important because they are not experiencing cancer within a silo.

Theories and Models Applied

Within the interviews, I attempted to examine how each participant's confidence in their ability to navigate the military lifestyle affected their cancer journey. My observation was that each participant had a different perspective, but most were confident in their own ability irrespective of hurdles they faced. This self-efficacy may lie within everyday challenges they had with the military lifestyle which were carried over positively into their cancer journey. Both the military service members and military spouses had a sense of self-efficacy and many stated that they had this prior to joining the military or becoming a military spouse. Future research would allow for utilizing this model and examining if the military environment helped to adopt healthy behaviors and provided protective factors of self-sufficiency. This confidence seemed to allow for the participants to advocate for themselves, to continue to seek care, and to finish their treatments even if they had obstacles with their primary care manager (PCM), TRICARE, or the various military entities.

In relation to the ecological theory, with its relationship of people to the settings and interactions in which they are actively involved, the interviews with the participants showed that being a military member or military spouse pushed them to not only actively participate in their medical treatment, but to continue daily activities. The military lifestyle places expectations of excellence on military service members and this often carries over to military spouses. With frequent moves, deployments, and other fast-paced and ongoing changes in the military life, participants often stated that they continued to do everything they normally would, on top of cancer treatments, because that is just what they do and what they are expected to do. The military environment culture in which they lived created a place of not only support, but an expectation of taking care of themselves and their responsibilities.

The Researcher

My interest in this specific topic developed because I was once an AD military spouse with cancer. During this time, I lived at Fort Hood, Texas, and had limited support systems. I continued to work my full-time job, as did my spouse. My mother had to put her life on 'pause' for seven weeks to come live with me so that I could go to treatments, continue to raise an elementary-school-aged child, and work because my spouse had military obligations with a brigade that was deployed. I later moved from Fort Hood and had to change oncologists. I saw firsthand the difficulties that I experienced with resources and having to change care providers. My assumption, based on my personal experience, was that AD military service members and spouses who have cancer have unique psychosocial needs that are assumed to be the same as the civilian population.

CHAPTER 2

LITERATURE REVIEW

Military Life

In 1973, the United States stopped conscription and the U.S. military became an all-volunteer force. As of July 2020, there are six branches of active military service, with only five classified as armed services as the Coast Guard falls under the control of the Department of Homeland Security. These branches are Army, Navy, Marine Corps (which is part of the Department of the Navy), Air Force, and the newly formed Space Force (which is part of the Department of the Air Force) (Council on Foreign Relations, 2020). There are also Reserve and National Guard components to the branches, but these will not be discussed as they are not the target of this research study.

As of 2018, there were approximately 1.3 million AD service members, with the Army being the largest branch (Council on Foreign Relations, 2020). The numerical strength of the military fluctuates based on the needs and allocations by Congress but is typically around one percent of the general population. The military is made up of enlisted service members, warrant officers, and officers (Pryce, Pryce, & Shackelford, 2012). In the civilian world, rank and hierarchy often do not matter. However, within the military, rank matters and details the levels of responsibility, experience, and supervision (Stiehm, 2012). Within both enlisted and officer ranks, there are junior and senior level ranks. The enlisted ranks range from E-1 to E-9 (there is a senior enlisted E-9 in each branch and one who serves as Senior Enlisted Advisor to the Chair of the Joint Chiefs of Staff); the officer ranks range from O-1 to O-10 (Stiehm, 2012). Each rank

has a corresponding title such as sergeant or captain, but these vary throughout the different branches of service (Stiehm, 2012). The more junior the rank (both enlisted and officer), the less experience and less responsibility the person has; there are exceptions for this with officers who have enlisted time prior to becoming an officer. All branches of the military, apart from the Air Force and Space Force, have warrant officers (Sherman 2020). All warrant officers begin their careers as enlisted non-commissioned officers, become specialized in a particular field, and take the same oath of office that a commissioned officer does (Sherman 2020). In most branches that utilize the warrant officer rank, the rank ranges between W-1 to W-5 (U.S. Department of Defense, 2021).

Approximately 88 percent of the AD force is based within the United States or within its territories, with around 67 percent of the 88 percent based within 10 states including California, Colorado, Florida, Georgia, Hawaii, North Carolina, South Carolina, Virginia, and the Washington D.C. capital region (National Academies of Sciences, Engineering, and Medicine, 2019). This is important based on where services are concentrated for both AD service members and spouses.

The military has diversity in its composition. It includes people from all fifty states, the District of Columbia, and US territories. The military is also racially diverse, although the diversity is less noticeable in the higher ranks (Council on Foreign Relations, 2020). Most military service members are under the age of 44, with the Marine Corps having a majority under 24 years of age and the Coast Guard having majority over the age of 24 (Council on Foreign Relations, 2020). Sixty-one percent of the total military force is under the age of 30. This is important, as the age distribution of the AD military population is vastly different than the general civilian population, having a minimum enlistment age of 17 with very few members over

the age of 60 because of retirements or mandatory retirement restrictions (Zhu et al., 2009). Most of the military service members come from middle class families, but a wide span of income brackets is represented (Council on Foreign Relations, 2020). The military also has gender diversity, with females now making up 16 percent of the enlisted force and 19 percent of the officer force (Council on Foreign Relations, 2020). Openly gay, lesbian, bisexual, and transgendered people have been permitted to serve within the U.S. AD military even though this policy has experienced multiple changes and challenges due to political changes and court challenges (National Academies of Sciences, Engineering, and Medicine, 2019). Because of the short time that the approval has been in place and the political and court challenges, there is little data on the number of gay/lesbian/bisexual and transgendered AD service members or spouses with cancer.

The military is a profession and a way of life. It has a different culture than that of the general civilian population (Hall, 2012; Redmond et al., 2015). This culture is formed through a combination of beliefs and practices, some of which are already in place prior to joining the military and some through military indoctrination (Hunter, 2018; McCormick et al., 2019). Although there is not one singular military culture, there are similar experiences and influences such as language, symbols, rituals, and practices (Grassman, 2013; Hunter, 2018). Just as it is important to understand the demographics of the military, it is important to understand the culture of the military. Many who join the military do so to find a sense of service and belonging, and ultimately take on the warrior identity of “duty and mission first” (Stiehm, 2012). The military is characterized with frequent separations and relocations; a “mission first” mentality; the effects of rank on the family; a general lack of control of increases in salary since it is based on rank and performance, promotion, and benefits; and the constant changes, deployments, or

moves that are more commonly known as permanent change of station (PCS), etc. (Hall, 2012). The military is an authoritarian structure that requires discipline and conformity of its service members (Hall, 2012). This authoritarian structure often trickles down into family life and into the homes and family identity of the military service members. This may likely create a strain or create a commitment to mission, duty, and service in the spouse and children as well (Hall, 2012).

The military has its own “all-encompassing” community. This community consists of housing, schools, shopping facilities, grocery stores, childcare, golf courses, restaurants, entertainment such as bowling alleys and theaters, and medical facilities which are all located on secure military installations and require a military identification card to access (U.S. Department of Defense, 2020). Although not all military service members and their families live on the installations where these “military only” services are located, most utilize them on a regular basis. Most military installations require a military identification card to access the installation, and all require it when accessing the services. To obtain a military identification card, the person must be the military service member (known as the sponsor) or enrolled in DEERS by the sponsor (usually their spouse or child) (Stiehm, 2012). Eligibility for enrollment in DEERS is clearly defined by the Department of Defense and usually extends to a married spouse, biological, adopted, or step children, and dependent family members such as parents; some former spouses can remain in enrolled in DEERS if they meet certain eligibility criteria (Absher, 2021).

Military service members and spouses have access to health care through the Military Health System (MHS), which is separate from the Veterans Health Administration (Hutchinson et al., 2016). The MHS is overseen by TRICARE health insurance and, while MHS and

TRICARE are often used interchangeably, they are different entities. The MHS is a federal health care system that is comprised of medical personnel from the Army, Air Force, Navy, Defense Health Agency, and Office of the Assistant Secretary of Defense. The main purpose of the MHS is to ensure troop readiness and support operational medical requirements (Tanielian & Farmer, 2019). Private sector care is coordinated through a managed care program known as TRICARE that covers care utilized off the military installation at civilian health care providers. TRICARE got its name because, at its original conception, it had three separate levels of benefit packages, which have been condensed into two as of 2018 (Tanielian & Farmer, 2019).

The MHS is regularly screened for effectiveness and meets benchmarks in all areas except for children with pharyngitis, cervical cancer screening, breast cancer screening, diabetes screening, and controlling diabetes with HbA1c at or under 9 (Tanielian & Farmer, 2019). The MHS is also screened for patient satisfaction and falls below civilian benchmarks in all groups, with those who utilized TRICARE experiencing better satisfaction than those who utilized the direct MHS care on installations (Tanielian & Farmer, 2019).

One program specific to military family members, is the Exceptional Family Member Program (EFMP), which as of 2018 had approximately 104,697 family members enrolled (Meadows et al., 2021; National Academies of Sciences, Engineering, and Medicine, 2019). This program provides resources for family members with special medical or educational needs and helps coordinate assignments to ensure that family members are not located where services are unavailable for their specific need (Meadows et al., 2021; National Academies of Sciences, Engineering, and Medicine, 2019). Spouses with cancer can enroll in EFMP, but many choose not to because enrollment could possibly affect their spouse's career (duty posts and promotion based on career development). In addition, failure to enroll could be because of spouses' lack of

education regarding the program, spouses' beliefs that the program is flawed and will not serve their best interests, or the program not being implemented as intended (Meadows et al., 2021).

The identity of military service members and military families is often important and well defined with honor and sacrifice, but also exhibits the stereotypical male dominance (Hall, 2012). As Dahn (2008) stated, "Military service members are expected to 'soldier up' and get through the rough times on their own." This mentality is often very different than what is seen in the civilian world, as seeking help is seen as a sign of weakness and can affect the promotions and career potential of the military member (Hall, 2012). Each branch has its own unique identity, which includes specialized norms, customs, ways of unification, loyalty, and commitment (Exum & Coll, 2008). These expectations are required for military service members to complete their jobs and be effective and resilient. The military places a strong emphasis on resilience and has programs dedicated to it for both military service members and their families (Hendricks-Thomas & Albright, 2018; Coll et al., 2012).

Another important sub-culture embedded within the military is the culture of combat (Grassman, 2013). The United States military has been in a constant state of war since the George W. Bush administration began military operations in October 2001, in response to the September 11th attacks, with the launch of Operation Enduring Freedom in Afghanistan (Torreon, 2020). The culture of combat has different influences and reasons, but most military service members are fighting for a purpose greater than themselves and are willing to die for their brother/sister-in-arms (Grassman, 2013). Grassman (2013) offers insight into the mindset of the culture of combat and how it affects military service members seeking help for anything that will take them away from their unit: "Downplaying their suffering and feeling shame about 'weak' feelings often confuses stoicism with courage."

Since 2001, more than 2.7 million U.S. troops have been deployed in support of the various operations in both Iraq and Afghanistan (Lee & Dursun, 2018). These deployments have created a constant state of pre-deployment, deployment, and post-deployment cycles for which the military service members and their families are always in preparation. This has created a great burden due to separations, mental health issues, physical health issues, and others (Lee & Dursun, 2018).

The military is also made up of military spouses. A little over one-half of the military service members are married (Department of Defense, 2020; Martin et al., 2017; Gribble et al., 2018). Although these spouses are not part of the official end-strength of the military, they have come to be considered the backbone of the military and provide support that allows military service members to complete their jobs both in the U.S. and abroad (Everson & Perry, 2012). Most military spouses are female, with only approximately seven to eight percent being male (Southwell & MacDermid Wadsworth, 2016; National Academies of Sciences, Engineering, and Medicine, 2019). Military spouses, just like military service members, are a very diverse group, with some maintaining a separate identity while others are completely engaged in their military spouse's career and success. Although military spouses are a source of support for military service members, they also face their own stressors. These include deployments, family finances and household management (with and without military member), parenting, maintaining a relationship with their military spouse while he or she is deployed, and constant fear of injury or death of their military spouse (Everson & Perry, 2012; National Academies of Sciences, Engineering, and Medicine, 2019).

Many military service members are single parents providing a caregiving role for their minor children while also serving their country. There is not as much known about the needs of

this sub-population of the military and what their needs are in relation to their military service and caregiving obligations (Kelley, Doane, & Pearson, 2011). Even for many of these single parent service members, who are required to have a mission first attitude, family is a priority (Southwell & Wadsworth, 2016).

One of the most important factors when examining AD military service members and spouses is the characteristics that make up the multiple identities this subpopulation has, including intersects with non-military characteristics such as religion, native culture, prior socio-economic status, and status as foreign or domestic born, etc., that have an impact on the overall makeup of each service member and spouse (National Academies of Sciences, Engineering, and Medicine, 2019). The overall military identity creates commonality and an umbrella of needs and resources that are similar, but the intersectionality of these additional characteristics can assist in explaining the self-identification as a cancer patient or the lack of utilization of psychosocial services.

Military and Increased Mental Health Issues

Active-duty military service members and spouses have an increased risk for mental health problems, predating a cancer diagnosis (Mailey et al., 2018; Green et al., 2013; Lin et al., 2016). Military spouses often put their physical and mental health on hold because they are the “backbone” of their family, including serving as the main support system for their AD military spouse (Mailey et al., 2018). Combined with the major life stressors that come with the military lifestyle such as deployments, constant moves, changes in employment, changes in friends and support systems, changes in schools and care for their children, and the demands of the military culture, has caused military spouses to show an increased risk and level of stress, depression, anxiety, and other negative psychological health markers (Mailey et al., 2018; Green et al.,

2013). These tendencies toward poor mental health often go unnoticed until the service member needs clinical intervention. Unrecognized or poor mental health problems can also lead to negative physical health consequences (Green et al., 2013).

Active-duty military service members often have higher levels of stress, anxiety, depression, post-traumatic stress disorder (PTSD), and even suicidal ideations (Lin et al., 2016; Waitzkin et al., 2018; Novotney, 2020). Treatment of mental health problems for AD military service members is sought both on and off the military installation. A stigma associated with seeking mental health treatment and limitations to the programs provided on the military installation leads to seeking mental health care in the larger community (Waitzkin et al., 2018). Active-duty service members have 24% greater odds of attempting to commit suicide due to mental health problems than veterans who are no longer serving, especially as deployments increased after 2001 (Lin et al., 2016). This is important in the association between mental health and cancer diagnosis and treatment since civilians may not have an increased risk of a preexisting suicidal ideations or attempts (Villatte et al., 2015).

Many of these mental health stressors increase in the AD military service member and spouse population because of the military lifestyle and culture (Lin et al., 2016; Green et al., 2013; Lazar 2014). Although some conditions may be preexisting from before entrance into AD military status, they can all have negative impacts on the overall mental and physical health of AD military service members and spouses and can be exacerbated by a cancer diagnosis and treatment (Whitney et al., 2015; McDaniel et al., 2019).

Increased Cancer Risk and Problems Fully Understanding the AD Cancer Numbers

Although much of the current research on cancer and the military focuses on veterans and the Veteran's Health Administration, growing literature exists regarding increased cancer risk

and diagnosis among AD military service members and spouses. In the Veterans Affairs (VA) Central Cancer Registry from 1995 to 2010, there was almost a 20,000 person increase in annual cancer cases in veterans (McDaniel et al., 2019). Although there is more publicly available data and published research for veterans with cancer than for AD service members and spouses, this helps paint the picture of more military connected persons being diagnosed annually with cancer than in previous decades. Another limitation to fully understanding the rates of cancer among military members and spouses is the ability to receive care both on military installations at military treatment facilities and in civilian facilities. This is often a factor for geographically displaced AD military service members and spouses who are not within a 40-mile radius of a military treatment facility (Chaudhary et al., 2017).

One of the suggestions for both higher overall survival rates and early diagnosis of cancer among AD service members is the higher screening rates. For example, with colorectal cancer, the second most common cancer in the U.S., the national screening rate is 50 to 65 percent, whereas within the military health system it is approximately 71 percent (Stahlman & Oetting, 2017). There are certain medical readiness requirements of all AD military service members, and although cancer screenings are not required, they are highly encouraged (Stahlman & Oetting, 2017).

Women are both increasing in total force numbers and in the roles they hold within the military, to include front-line combat jobs (Committee on Health Care for Underserved Women, 2012). Many women, serving in the AD military, receive their health care away from the military treatment facilities and may not identify to their primary physician or care team that they are AD military service members. This may, in turn, conceal some of their health needs related to cancer screening and cancer prevention as their prolonged exposure to environmental toxins at military

installations and during deployments creates an increased risk (Committee on Health Care for Underserved Women, 2012). This can also be true with military spouses who are veterans themselves. They may also have an increased risk due to their exposures and may not identify their previous AD status.

There is current evidence that some cancer increases are connected to the ‘burn pits’ that many service members are exposed to during deployments, especially in the Middle East (Hickman, 2016). During the tenure of the conflicts in Iraq and Afghanistan, trash was disposed of through open-air burn pits and included toxic and medical waste. Just as veterans of the Vietnam-era experienced illnesses now linked to the use of agent orange, current veterans are facing illnesses, including cancer, from the burn pits (Hickman, 2016). Representative Tulsi Gabbard introduced H.R. 663 (2019), “Burn Pits Accountability Act” to evaluate members of the military and their exposure to open air burn pits or toxic airborne chemicals. Senator Dan Sullivan also introduced S.437 (2021), “Veterans Burn Pits Exposure Recognition Act of 2021” to make concessions about exposure to burn pits as early as August 2, 1990. These burn pits are already affecting veterans and AD service members and will continue to affect both populations, as symptoms can be delayed (Hickman, 2016).

Psychosocial Needs from Diagnosis to Survivorship

Psychosocial needs during the diagnosis, treatment, and survivorship of cancer are just as important as treating the disease itself. Within the civilian community, attention to this essential aspect of treatment has been the recommendation of researchers and medical practitioners alike for many years now, especially as they begin to understand whole person cancer care (McIllmurray et al., 2001). Understanding the psychosocial needs of cancer patients is frequently done through an assessment, and often by an oncology social worker (Blum et al., 2001). The

screening and assessment of psychosocial needs should continue throughout treatment as the patient's needs change and as the treatments themselves take a physical toll on the patient (Blum et al., 2001). Understanding that each patients' experience is different, some of the stressors patients experience include inadequate social supports; insufficient financial support and other material resources (such as transportation) to support the patient in treatment adherence and overall well-being; emotional distress and mental health problems; developmental problems; inadequate insurance; lack of information or skills to handle the disease or adhere to treatment; and lack of support from their health care system (Adler & Page, 2008). Patients can also experience a disruption in social and personal relationships due to the mental anxiety from the diagnosis, the fatigue and difficulties from the treatments, and side effects from both the cancer and the treatments on physical and mental health (Tamagawa et al., 2012).

In many patients, a religious belief is also identified as a significant factor in their psychosocial needs (Krok et al., 2019; McIllmurray et al., 2003). Although there is limited research on the connection between religious coping and psychological well-being in cancer patients, the literature is growing and shows that many cancer patients and survivors benefited from their religious beliefs and counseling services from their clergy (Trevino et al., 2011; Krok et al., 2019). A survey was conducted from July 1 to July 16, 2009, known as the Religious Identification and Practices Survey (RIPS) as a part of the Defense Equal Opportunity Climate Survey (DEOCS), which consisted of 14,769 military participants, and of which only 38 percent (6,384) participated in RIPS (Military Leadership Diversity Commission, 2010). Two of the thirty RIPS questions addressed self-identified religious affiliation, with approximately 25 percent of the respondents claiming no religious preference (Military Leadership Diversity Commission, 2010). While this data could be skewed if participants are not part of an organized

religion and because of the small overall sample size, it shows that religion is an important part of many service members' lives and can play a role in their psychosocial needs when faced with cancer.

Financial need is an extreme burden and psychosocial problem for many cancer patients, especially patients under the age of 40, and can have an impact on their treatment and medication choices, their personal finances, and their overall mental and physical well-being (Landwehr et al., 2016). Financial burdens can increase based on their ability to maintain employment, whether they are insured or underinsured, and whether they have access to multiple treatment options (Delgado-Guay et al., 2015).

In a synthesis of the literature, Abrahamson et al. (2010) point to many cancer patients having unmet needs in relation to emotional distress, decision-making support, financial assistance, and other daily needs such as transportation and childcare. These unmet needs often lead to emotional and psychological distress and poor adherence to medical and self-care (Abrahamson et al., 2010). One of the ongoing issues with addressing the psychosocial needs of oncology patients is that the unmet needs of cancer patients are often not known by practitioners and, even at times, the patients themselves have a misperception of their need (Howell et al., 2012). The connection between the perceived needs of the patient, the knowledge of resources, and routine psychosocial screening often leads to a disconnect and needs going unmet. Clinicians need to be aware of resources available to specific patient populations to make connections and reduce unmet needs (Howell et al., 2012).

Social Determinants of Health

The United States is a developed nation and is characterized by multiple levels of wealth and poverty. Those with less wealth often have more illness, which is an important factor leading

to social injustice (Wilkinson & Marmont, 2003). Some of the social risks for military service members and their spouses include the following: economic stress because of limited financial literacy; the deployment cycle and a loss of social systems; behavioral health care stigma and social isolation; quality of housing and environmental hazards; food insecurity (some military families are on food stamps); inadequate health care systems; trauma, including PTSD; and the transition from military service to civilian jobs (Grissom et al., 2019). Many military service members have poor mental and physical health, including sleep issues, chronic pain, alcohol misuse or abuse, and anxiety (Grissom et al., 2019).

Military service members and dependents have access to medical care through a universal health care system known as the military health system (MHS). MHS is managed by TRICARE and is not equal to the civilian health care options. Military service members (and often spouses) do not have a choice in where they receive their medical care or from whom and may receive unequal care, compared to civilians, based on location and the skills of MHS providers (Kellerman, 2017). With behavior and environment contributing to around 70% of all premature adult deaths in the United States, understanding the social determinants of health within the military population can be vital in all health research, including cancer occurrences within the population of military service members and spouses (Padden et al., 2011). The influences or determinants of health have an impact on the behaviors and health outcomes of the service members and spouses (West & Jeffery, 2018).

Military Health Systems do not have the same racial health disparities that are frequently seen within civilian medical care (Kellerman, 2017). One of the main purposes of the MHS is maintaining the preventive care and protecting the health of the military force. The MHS does not come without its barriers of “mission first” and “the warrior mentality” taking center stage

with military service members (Kellerman, 2017). The military lifestyle and the MHS can be both a protective factor and an element in the social determinants of health. While many service members and spouses aspire to maintain regular exercise and healthier lifestyles through eating and meditation, the stresses, environmental factors, deployment cycles, and combat exposures are unavoidable and potential negative determinants of health for military service members and spouses because of the “mission first” mentality of the military (West & Jeffery, 2018). Many service members and spouses often take on the “suck it up” mentality when it comes to their own physical and mental health (West & Jeffery, 2018).

Another known social determinant of health that can create health disparities and barriers in the United States is being a person of color (Davey et al., 2016). Within the United States, there are certain types of cancer that have a higher mortality rate for Black/African American persons, and stress levels are often higher in this subpopulation as well (Davey et al., 2016). There is specific literature that outlines the need for having minority-specific psychosocial interventions for cancer patients in order to make a difference, as many psychosocial supports are often underutilized by persons of color as they were mostly developed for a white population (Davey et al., 2016; Traeger et al., 2014). Black males and female service members have a higher diagnosis rate than white service members for cancers such as colon, lung, prostate, and breast (Zhu et al., 2009). As the military has a diverse racial makeup and persons of color are diagnosed at a higher rate, it is important to take ethnic background and culture into consideration as it relates to oncology psychosocial programs and the barriers to accessing the programs.

Social Cognitive Theory

The main concepts of social cognitive theory focus on self-efficacy or a person's beliefs in their own capabilities, outcome expectancies, goals, perceived impediments, and opportunity structures (Bandura, 1986). Social cognitive theory is one of the most widely utilized theories of health behaviors and health related outcomes (Riley et al., 2016). Social cognitive theory can explain the differences in behavior and outcomes among people, as well as interpersonal variations such as motivation, self-evaluation, and self-regulation (Riley et al., 2016; Andersen & Chen, 2002). A cancer diagnosis can impact every area of a person's life, including physical, psychological, interpersonal, career, and spiritual (Hoffman et al., 2012). The ability and choice to disclose the cancer diagnosis and treatments to others can affect access to social and emotional support, thereby influencing the cancer patient's perceived impediments (Hoffman et al., 2012). Self-efficacy can be demonstrated in health behaviors and in navigating through difficulties during deployments, moves, changes, and stressors, all of which can have an impact on physical and mental health.

Social Ecological Theory

The social ecological theory within social work practice explains the interactions between a person and their environment (Ungar, 2002). A person, a cancer patient, an AD service member, or a spouse are all individuals, but also exist within the context of a family unit, a military unit, and a community. Engagement within all the various environments affect behavior, including health seeking and adherence behaviors (Ungar, 2002). Patient and community level issues can influence health behaviors and health outcomes (Rodriguez et al., 2018).

The social cognitive theory and the social ecological model share the person-in-environment theory of health behaviors and outcomes. However, there has been more of a

struggle to determine the application of using the social ecological model in health promotion, as multiple levels must be addressed, which can cost money and create complications in interventions (Golden & Earp, 2012; Fernandez et al., 2019). Within the context of this research, the social ecological model was applied to gain insight as to how an AD service member or spouse within, the military environment, affected health behaviors and outcomes impacted within the military environment and whether it may influence psychosocial needs.

Gaps in Knowledge

There is limited research on the military and veteran cancer, in relation to psychosocial needs, but research involving veterans has begun over the past decade, especially those who seek their oncology care through the VA (Beehler et al., 2013). Although this research and growing literature has been evolving in the veteran space, a gap remains regarding the research within the AD military service member and spouse population. In addition, many AD military members and spouses experience psychosocial stressors that stem specifically from being in the military environment and experiencing multiple combat deployments, outside of cancer; this is not addressed in the oncology psychosocial literature (Lazar, 2014).

Specific psychosocial needs associated with the cancer diagnosis and treatment, or the exacerbation of these needs because of the military lifestyle, are unknown, with a gap in the literature. It may be assumed that the psychosocial needs are the same for all patients and that AD military service members and spouses should be treated the same as any other oncology patients. However, this assessment practice does not account for the differences in military and civilian life. Most current psychosocial screenings and interventions may inadequately account for the impact of military life. Additionally, there are no current studies that examine the psychosocial needs of U.S. AD military service members and spouses with cancer. Therefore,

my research questions had the aim of identifying the psychosocial needs of AD military service members or spouses diagnosed with cancer and attempted to understand whether these needs are the same or different than those of their civilian counterparts.

Another gap in knowledge that may play a role in the psychosocial needs of AD service members and spouses is their identity as a cancer patient. Active-duty service members and spouses already take on a unique identity as military members and spouses that their civilian counterparts do not have. This identity is unique to their role in serving their country, their social circles, and their frequent employment changes and moves both within the continental United States and overseas. If AD service members and spouses do not identify as a cancer patient to themselves or others, including social workers, it is uncertain if they would articulate their psychosocial needs in the same manner as their civilian counterparts. There is little to no research on the overlap of identity as an AD military service member or spouse and their self-identity as a cancer patient and cancer survivor. This could play an important role in the self-identification and professional screening of psychosocial needs of AD military service members and spouses with cancer.

Finally, there is no found literature on military-specific psychosocial resources for persons of color diagnosed with cancer. It has been shown in previously examined literature that culturally and ethnically competent psychosocial programs are important to reduce the barriers to access by people of color. These considerations need to be examined within the military population and include both AD service member and spouse resources and access to ensure utilization is equitable and sufficient since most studies and resources are based on predominantly white populations.

CHAPTER 3

METHODS

Research Approach

This study utilized a pragmatic qualitative research approach, drawing upon practical and real-world methods (Savin-Baden & Major, 2013) to present an understanding of the experiences of AD military service members and spouses with a cancer diagnosis. My research focused on the psychosocial needs of a heterogeneous group of AD military service members and/or spouses with cancer.

The pragmatic research design (Savin-Baden & Major, 2013) allowed me to bring comprehensive descriptions and meaning to the experiences of AD service members or an AD spouse with cancer, while allowing the research question and the data to drive the design rather than the design limiting the data. The participants were asked to speak about their experiences of being a cancer patient as an AD service member or spouse. The goal of this research was to better understand the psychosocial needs of this specific group. Requirements for participation included being a U.S. AD service member or spouse who has or had cancer during their time on AD status.

With increasing cancer rates in AD military service members and spouses, thus more individuals with potential for increased psychosocial problems, a better understanding of their specific needs is necessary. A pragmatic qualitative research inquiry allowed an exploration into the experiences to better understand the psychosocial needs. This can help establish the need for additional research, guide resources and appropriate interventions, and help future research

methods such as quantitative assessments. To assess if the psychosocial needs of this population are being met, the unique and met or unmet psychosocial needs first needed to be discovered. A pragmatic qualitative research inquiry provided this by allowing the research question to be answered without being stifled by methodology that does not allow for a unique approach.

Participants were recruited utilizing purposive sampling with a snowball technique. This allowed people who knew others who fit the inclusion criteria, that I may not otherwise reach, to be included. To be eligible to participate, the participants had to meet specific conditions.

Participants could be a current AD military service member or spouse with cancer, a former AD service member or spouse who had cancer on AD, or the spouse of an AD service member who died or AD service member whose spouse died. All races, genders, and anyone over the age of 18 were considered for the study. Participants were between the ages of 25 and 57 at the time of diagnosis.

Epistemological Framework

Since the beginning of my doctoral program, I have explored and reviewed different epistemological approaches. In many ways, I have identified with the social constructionism theory that meanings are developed from building upon experiences (Galbin, 2014). However, this was not specific to how I viewed meaning and identified my epistemological stance.

Through examining many other epistemological views, I realized that pragmatism best fit the way I viewed meaning and the theory of knowledge.

My theoretical worldview best aligned with the pragmatism. With my life experience and experiences in social work, it is often hard to make practical sense of the complexities of knowledge and how it is gained without being socially constructed and through the human experience. Thomas Kuhn (1970) introduced pragmatism to discuss generalizations, beliefs, and

values of a specific community within reality and knowledge. Pragmatism is often strongly associated with social justice and fits well within the social work model and code of ethics and this exploratory study (Kaushik & Walsh, 2019).

Within this study, the pragmatism was utilized throughout in the sense that the knowledge of the psychosocial needs of the participants was based on their experiences with cancer. The interviews allowed me to gain knowledge regarding the psychosocial needs and make sense of the interviews based on the shared experience every participant had, even if their individual experiences varied. I also used my own experience of being an AD military spouse with cancer to make meaning out of their experiences.

Researcher Role and Reflexivity

In this study, as the principal investigator, I had the following roles: (a) collecting data from participants using semi-structured interviews, (b) transcribing and analyzing the data using In Vivo coding and pattern coding, and (c) creating meaning from the data to understand the psychosocial needs of AD military service members and spouses with cancer to better inform social work practice and other multi-disciplinary professionals who may work with this subpopulation. I choose this topic to study because of my own personal experiences. I was an AD military spouse who was diagnosed with cancer and went through cancer treatments while in the AD military lifestyle. This information was disclosed to all participants to help them understand why I was doing this research, why I wanted to hear their story, and to allow them to speak freely (many military members and their families are wary of civilian “outsiders” because they think that civilians do not understand their experiences). This also allowed me to consider my bias, which is a part of the qualitative inquiry process (Creswell, Plano, & Clark 2018).

Based on the examination of bias recommended by Creswell (2013), I believed that it was an important part of this process to journal my biases based on my own experiences. First, it is hard for me to set aside my identity as a military child and previous military spouse as it is embedded in my identity and helped shape me and my thinking. I spent approximately 20 years of my life as a military dependent and continued as a Department of Defense employee and military and veteran researcher. However, when I had cancer, I struggled with many things within the military environment and with the leadership's response regarding the lack of available resources or those I was unaware existed. Therefore, I have a bias that the military, as an entity including the environment and leadership, is not providing the necessary psychosocial resources to military service members and families when they have cancer. To help alleviate this bias, all questions in my semi-structured interviews are open ended and are neutral in tone. I also do not provide my specific experience beyond informing participants that I had cancer while my former spouse was on AD.

I believe that I was able to recruit effectively and that participants felt comfortable being open and honest in their interviews because I was military-affiliated and because I had cancer as an AD spouse. I was likely able to reach people that others may not because I have many friends and family who are military and veteran-related and because I moderate a Facebook page for military members and spouses who are retiring or retired. It could be more difficult for someone who does not have military connections to access this population and connect with people from multiple duty locations.

Although I experienced cancer as an AD military spouse, I do not believe there was any bias in the analysis of the interviews. Although I experienced some of the same positive and

negative feelings that participants stated in their interviews, I strictly utilized their interviews and not my own experience to code and analyze the data.

Study Design

The study included the use of a semi-structured, informal, and interactive interview with each participant relying upon open-ended questions to get an in-depth understanding of the experiences. Each interview was followed up with a member-checking session after transcription and first level coding was complete. The first interview focused on participants' life histories with the military, the details of their experiences with cancer while being AD military service members or an AD military spouse, and what they believed their psychosocial needs to be or have been. The member checking session allowed for inquiry regarding my accurate interpretation of their experiences and allowed me to ask additional questions that arose after beginning the analysis or obtaining additional information. The interviews were from 60 to 95 minutes in length.

Demographic data was collected from each participant. This data included branch of service, education completed, identified gender, age at diagnosis and current age, identified race or ethnicity, the type of cancer, diagnosis date, military status at diagnosis, installation assigned to at time of diagnosis (since there are variations in medical care based on location), marital status at time of diagnosis, familial status (has children or does not) at time of diagnosis, rank of the service member at diagnosis, and their remission status. This information allows for characteristics of the group to be described due to the many varying ranks, branches, etc.

Data Collection

Participant Selection

Participants in this study only represent the Army, Air Force, Navy, and Marine Corps. There were no participants from the newly formed Space Force or the Department of Homeland Security's Coast Guard. Participants were located at multiple duty stations throughout the world at the time of diagnosis, including being deployed on ships. The study was open to all ranks. Spouses provided their service member spouse's rank and branch for simplicity of identifying the branch family they belong to since spouses do not have a branch or rank. Each participant was selected based upon the following criteria: (a) their willingness to participate in the study and complete an interview, (b) their willingness to sign the consent form for participation, and (c) that they had cancer while they or their spouse was on AD. I allowed spouses of the service member or the service member of a spouse to participate in lieu of their decedent spouse. I had two spouses who participated for their decedent AD service member.

Recruitment Process

Recruiting was done solely through Facebook and word-of-mouth. I posted a recruitment flyer on my personal Facebook page and it was shared twenty-one times by friends and family to their personal Facebook pages. Many of these shares were by people who are or were AD service members or spouses. The recruitment flyer was also shared in the following Facebook groups: Military Retirement Information for Spouses and Service Members, Hidden Heroes Caregiver Community, Caregivers of Wounded Warriors, and Military Caregivers and Cancer Warriors. These groups have approximately 26,000 members combined, although some members may be in multiple groups. The study was also shared to a fellow Active Guard Reserve (AGR) Public Affairs Officer (PAO) by a friend who is a retired AGR PAO. Most participants originated from

two of the Facebook groups: Military Retirement Information for Spouses and Service Members and Military Caregivers and Cancer Warriors.

I recruited three times by reposting the recruitment flyer with two weeks between each posting. The first was the initial recruitment to begin the interviews. The second was to recruit additional participants. The third was to try to recruit more participants of color. The first and second recruitment efforts yielded participants. However, the third recruitment effort did not yield any additional participants of color. For the third recruitment, and to try to achieve more diversity, a personal friend who is an African American/Black female and retired from the military posted the recruitment flyer on her own personal page as well as within a group that has members who are military members of color. This effort did not result in any additional participants.

All participants were required to sign their participation consent form prior to the interview session. Before asking any interview questions, I made sure there were no questions or concerns about the consent form. One participant asked for identification prior to beginning, which was provided. No other issues were noted regarding consent for participation.

Demographic Characteristics

A range of demographic characteristics were collected from each participant at the time of the interview: (1) service member or spouse status, (2) military branch of service, (3) education level completed, (4) identified gender, (5) age at diagnosis, (6) age at time of interview, (7) identified race/ethnicity, (8) type of cancer, (9) diagnosis date, (10) military status at diagnosis, (11) duty station assigned at diagnosis, (12) rank of service member at diagnosis, (13) children at diagnosis, (14) marital status at diagnosis, and (15) remission status at time of interview. The demographics are displayed in Table 1.

Participants were about one-half Army service members or spouses and were about one-half male and one-half female. The majority of participants were married and had children at the time of diagnosis. Although the majority of the participants were white, 23 percent of the participants identified as a person of color. Most participants were under the age of 50 at diagnosis and more than half were senior enlisted or an officer.

Table 1

Participant Demographics

Variables	<i>n</i>	%
Branch		
Army	7	53.85
Navy	2	15.38
Marines	2	15.38
Air Force	2	15.38
Education Level		
Bachelors	6	46.15
Some College	4	30.77
Masters	3	23.08
Gender		
Female	7	53.85
Male	6	46.15
Race/Ethnicity		
White	10	76.92
Hispanic	2	15.38
Black/African American	1	7.69
Age at Diagnosis		
20s	3	23.08
30s	4	30.77
40s	3	23.08
50s	3	23.08
Age at Interview		
20s	1	7.69
30s	2	15.38
40s	4	30.77
50s	2	15.38
60s	2	15.38
Deceased	2	15.38
Rank of Service Member		
E1-E4	1	7.69

E5-E9	3	23.08
Warrant Officer	1	7.69
O1-O3	3	23.08
O4-O6+	5	38.46
Children		
Yes	10	76.92
No	2	15.38
Not at home	1	7.69
Marital Status		
Married	11	84.62
Not Married	2	15.38
Remission Status		
In remission	7	53.85
Stable	2	15.38
Deceased	2	15.38
Unsure	1	7.69
Not in Remission	1	7.69

Instrumentation

A semi-structured interview guide, personally created with open-ended questions, was utilized to guide the interviews and collect data. Participants did not know the questions beforehand but could elaborate as much or as little as they felt comfortable for each question asked. Although the questions were similar in nature, there were two separate semi-structured interview guides utilized based upon if the participant was the AD service member or the spouse. If a spouse was being interviewed about their deceased AD service member, the service member guide was utilized. Both guides consisted of three different topic areas. The first focused on the cancer experience and included fourteen open-ended questions. The second focused on the psychosocial needs and included ten open-ended questions. Finally, the third focused on the military life and included six open-ended questions. At the end of the interview, I asked each participant if they had anything they wanted to add that I did not cover. (See Appendix B for interview guides.)

In addition to these topic areas, prior to beginning the interviews, I asked demographics questions to gain a better understanding of the participants in the study. The military service members answered all questions about themselves. The military spouses answered questions about themselves and their AD service members since spouses do not have a branch or rank. Questions of rank were asked of spouses, as well as military service members since higher rank often brings different opportunities and privileges. (See Appendix F for demographic measures.)

Data Analysis

Data Organizing

Interviews were audio recorded using the Zoom video conferencing platform. They were then downloaded into Otter.ai and transcribed into a Microsoft Word document. After completion, I listened to and edited all interviews for transcription errors, spelling, and grammar. I coded all transcripts by hand utilizing Microsoft Word. Saldaña (2021) recommends this method for novice researchers to better understand their data and the coding process. This also allowed me to begin data analysis by being immersed in the data throughout the process.

Data Coding

After transcribing and organizing the data, I conducted initial level coding utilizing the In Vivo method. This method is recommended by Saldaña (2021) for studies that prioritize the participant's voice. It is also recommended for beginning qualitative researchers who are learning how to code, and can be utilized either as a stand-alone method, an initial, or a first cycle method (Saldaña, 2021). I utilized it as an initial cycle method as one of the limitations of using it as a stand-alone method is that it limits the researcher's perspective on the data, but mixed and matched first and second cycle coding as appropriate in the analysis. One way of coding using In Vivo is to arrange the quoted codes into an order of some sort, which I did by

coding each participant's interview into fourteen questions (Saldaña 2021). To do this, I took each of the primary topical questions, made a heading, and coded each participant interview under each heading. There were fourteen headings with codes under each. The first seven headings were related to the cancer diagnosis and treatment of each participant. The next five headings were related to the psychosocial needs. Finally, the last two questions were related to the military life. See Appendix F for more details on the coding descriptions.

After completing the first step utilizing the In Vivo method, I coded the topic questions using subcoding. This type of coding allows for the data to be further coded since the initial In Vivo coding left the data too broad and would be difficult to organize the data and analyze it to gain meaning beyond the participants' line-by-line quotes. Saldaña (2021) suggests that subcoding is appropriate for all qualitative studies and can be applied after an initial coding has been completed.

Second cycle coding was utilized to find patterns and themes among the data once it was subcoded. The main purpose of this research is to identify the psychosocial needs of AD service members and spouses with cancer and to do this, finding patterns and themes helps add meaning to the transcribed and coded data.

Data Analysis Strategy

In creating a data strategy, I utilized the seven attributes for coding that are discussed by Saldaña (2021). These include organization, perseverance, dealing with ambiguity, flexibility, creativity, being rigorously ethical, and having an extensive vocabulary. I examined each of these attributes and created a plan for data coding and organization to ensure scholarly integrity and to make meaning of each participant's experiences. After I did this, I read the transcribed interviews to ensure the preselected coding methods fit the research questions and the interviews

synthesized the data. After completion of the first cycle of coding, I again reviewed the data before moving forward with a specific second cycle coding process to ensure that the predetermined coding method was appropriate. When doing this, I realized that the data needed to be subcoded to condense the In Vivo quotes and make the data more manageable and concise.

To ensure that the data were correctly interpreted, once the subcoding occurred, I performed member checking, with the members who responded to the follow-up, to ensure that the data matched what the participant intended. The second cycle of coding allowed for the creation of categories and patterns or themes emerging from the first cycle coded data into the categories (see appendix E).

The only major coding issue that arose during my coding was that I had not originally anticipated subcoding. However, after completing the initial In Vivo coding to code quotes from the participants' interviews, I realized that the data were still too large and too broad for analysis. Therefore, I added the subcoding prior to moving onto the second cycle coding to analyze the data.

Data Interpretations

The purpose of this study was to gain a better understanding of the psychosocial needs of AD military service members and spouses with cancer. However, additional information was gained through the study, including support systems (or lack thereof) with the military, diagnosis and treatment struggles and support systems, and what it means to the participants to serve as an AD military service member or spouse. This adds more meaning and aids in understanding what it means to be an AD service member or spouse with cancer in the military. Additionally, the psychosocial supports there are in the military environment and which ones are lacking. It also helps gain a better understanding of some of the differences between the psychosocial needs of

AD service members or spouses and civilians. Interpretations and conclusions were made through noting patterns and themes in the second cycle coding.

Quality Assurance and Trustworthiness

Saldaña (2021) discusses the methods in which data quality can be assessed, which include: checking for representativeness, checking for researcher effects, triangulating across data sources and methods, weighting the evidence, checking the meaning of outliers, using extreme cases, following up surprises, looking for negative evidence, making if-then tests, ruling out spurious relations, replicating a finding, checking out rival explanations, and getting feedback from participants. To ensure quality of data analysis and interpretation, I utilized a majority of these tactics. I was unable to utilize triangulation across data sources and methods as it is an unresearched space, and the only methods utilized for this study were those previously outlined. To ensure representativeness, I interviewed participants from various military branches with a mixture of genders, ranks, spouses, or service member status, etc.

Before conducting the first interview, I began memoing to compliment my analytic approach and create field notes of the ongoing research process and create an audit trail. This is a process suggested by Creswell & Poth (2018) to be utilized throughout the analysis process that lends credibility to the qualitative data analysis method. I utilized member checking but did not utilize an outside researcher to create coder reliability as I did not have a colleague familiar enough with both the research and the population. The member checking of the data analysis confirmed that I coded and analyzed the data as the participants intended.

Because of the study's small sample size, the considerable size of the U.S. military, and the unknown number of AD military service members and spouses with cancer, this study does not have the ability to be generalized to the population, as experiences are vastly different based

on many factors. These include cancer type, duty station location, age, status in the life cycle of the service member or spouse, and rank of the service member, etc. However, some transferability may occur as readers discover that many of the findings are similar to their own situation or the situation of someone they know. See Table 2 for further descriptions of credibility, dependability, confirmability, and transferability within the current study.

Table 2

Quality Assurance and Trustworthiness

Credibility	Within this study, descriptions are rich and meaningful by using direct quotes. Conclusion considered accurate by participants utilizing member checking.
Dependability	Research questions are clear and the researcher’s role and status was explicitly described. Quality checks were completed through member checking.
Confirmability	Methods are described in detail for data collection and analysis. Conclusions from data analysis are linked explicitly from the research questions and interviews. Personal assumptions were identified based upon the interviewer’s personal experiences.
Transferability	Recruitment and participant information is described in detail. The findings include thick descriptions to assess potential transferability.

Ethical Considerations

I did not encounter any ethical issues during the research process nor in the presentation of the results, as all participants’ personal information was completely removed so that no participant could be easily identified. This research study was approved by the Institutional Review Board (IRB) at The University of Alabama. The study was approved by the IRB on December 17, 2020, and is included as Appendix D. All participants were required to review and sign an informed consent form, as approved by the IRB, which is included as Appendix C.

To ensure anonymity and confidentiality of all participants, all names were removed from any transcribed interviews, coding, or any other documents used for this study. All participants were assigned a letter as a pseudonym and were assigned as they signed up to participate. No information will be provided in any requests that have identifying information of participants, including requests by funders, fellow researchers, other participants, etc. All Zoom recordings were deleted after transcription and review of the transcriptions were completed.

There were no financial incentives given to participants and all participants were able to withdraw from the study at any time, although no participants did. All participants understand that this research may not benefit them specifically in getting resources in place, as most were either no longer in treatment or were veterans or soon leaving the military. However, they understand that the purpose of this research is to help future AD military service members and spouses who are diagnosed with cancer to help with effectively assessing and providing resources for psychosocial needs.

CHAPTER 4

FINDINGS

The primary purpose of this study was to provide a better understanding of the psychosocial needs of U.S. AD service members and spouses who currently have or had cancer and to recognize their difficulties and gaps in resources with these psychosocial needs. This was done by attempting to (1) understand the psychosocial needs of AD military service members or spouses with cancer and (2) identify psychosocial difficulties that participants experienced while having cancer as an AD military service member or spouse. From February to April 2021, thirteen semi-structured interviews were conducted through purposeful convenience sampling recruited through social media and word-of-mouth. The average length of the interviews was from 60-90 minutes, with one interview at 45 minutes and another at 100 minutes. The criterion for participation was having cancer while serving on active-duty military status as a service member or as the spouse of a service member. Participants were recruited from both within the continental United States (CONUS) and outside the continental United States (OCONUS). There were 13 total participants, with eight participants who were AD military spouses and 5 who were AD service members.

Participants were stationed at the following locations at the time of their diagnosis: Eglin Air Force Base, FL; Point Magoo, CA; Fort Leavenworth, KS; Marine Corps Air Station Beaufort, SC; Travis Air Force Base, CA; Germany; Fort Sam Houston, TX; Quantico, VA; Fort Hood, TX; Fort Belvoir, VA; Fort Irwin, CA; and deployed overseas. All participants who were AD service members were male and all spouses were female. Two interviews were conducted

with the spouse regarding a decedent AD service member. Most participants were under the age of 50 at the time of diagnosis and at the time of the interview. Most participants were married and had children at the time of diagnosis. Most of the participants were white, most were officers or married to an officer, and most had at least a bachelor’s degree. The types of cancer of the participants include the following: thyroid, Ewing’s sarcoma, Non-Hodgkin Lymphoma, Hodgkin Lymphoma, breast cancer, endometroid endometrial adenocarcinoma, cervical, chronic myeloid leukemia, and colon.

Cancer Diagnosis and Treatment

To better understand how most AD service members experience their cancer diagnosis and treatment within the context of being in the military environment, the participants were asked about how they were diagnosed and the experiences they had during treatments. All participants were asked if they completed all treatments prescribed and all stated they had. One participant’s protocol consisted only of palliative care since the cancer was caught at a very late stage. The further descriptive data were coded into categories of diagnosis and treatment with each category having subcategories. See Table 3.

Table 3

Cancer Diagnosis and Treatment

Themes	<i>n</i>	%
Diagnosis		
Being treated for other medical issues	6	46.15
Had to wait for diagnosis and care	5	38.46
Given the wrong diagnosis	3	23.08
No one believe them	2	15.38
“Sucked it up” or told to “suck it up”	2	15.38

Treatments	7	53.85
Used both military & civilian health care		
No communication between oncology & PCM	6	46.15
Fighting	4	30.77
TRICARE/Jumping through hoops		
Only used civilian health care	3	23.08
Only used military health care	2	15.38
PCM constantly changing	2	15.38
NIH study only for oncology	1	7.69

Diagnosis

The most common response regarding diagnosis was that the participants had to wait for their diagnosis and care. Participant M stated,

I went back and forth to the PAs saying ‘hey, what’s going on? This is what I’m feeling.’ And they were like, ‘Well that doesn’t make sense.’ Well, yeah, no I don’t know what it is. So, a lot of run around.

Participant B stated,

So, it was a really bad stigma that he didn’t want to go talk to the doc because it wasn’t going to fly. So, he waited as long as he could and to the point where it was hindering his walking and he wasn’t sleeping.

Several participants were diagnosed while being treated for other medical issues by their PCM or they went through routine cancer screenings such as a mammogram. Participant E stated, “I was just coughing and kind of short of breath and then the Naval hospital diagnosed me with pneumonia and treated it as pneumonia. This happened for two or three cycles until they did a CT scan.” Participant I stated,

I went in, did a mammogram, and then I got a letter saying that they thought they saw something. They would like me to come back in and when I went back in for the second

mammogram, they ended up calling me and saying they saw something, and I needed to do a biopsy.

Another response among the participants about their diagnosis experience was they were just going to “suck it up” themselves and do their duty or that no one believed them and to “suck it up” by their superiors or medical professionals; this was especially evident in the service members’ interviews more so than the spouse interviews. Participant G stated, “I just sucked it up for a while, you know, contributed it to stress; especially with getting ready to retire and all that fun stuff.” Participant M stated,

I didn’t understand what was going on. So, I went to physical therapy. I tried to get x-rays. I tried to do all sorts of things. Unfortunately, people like PAs and the supervisors and such, you have to tell them a story and, somehow, they have to believe you. I’ve run into that my whole career. Like it’s like, ‘Oh, you’re making it up,’ because they see so many people.

One participant had a service member spouse who was deploying overseas, and she told her service member spouse “Well, you are going to have to suck it up, buttercup, and kind of that mentality they take in the military life” when he was worried about leaving her while she was going through cancer treatments.

Finally, participants were given the wrong diagnosis. Some were given the wrong diagnosis and told they did not have cancer, such as Participant A who said,

Immediately after surgery they told me that it was not cancer. They assured me it was not cancer. So, I went in for follow up and he looked at me and said, ‘well, I have to tell you, it came back cancer’.

Or they were told the wrong type of cancer and made to think that their cancer had a much less survivability rate and they would have harsher treatments, such as Participant N who stated,

I was initially told that I was her2 positive. With that, you’re directly going to go to chemotherapy. It turns out that there was a typo. The first doctor should have understood that. It said her2 positive but then it says zero.

Treatment

One of the biggest challenges within the military is having a consistent Primary Care Manager (PCM) because of moves of the service member and spouse and of the physicians. Participant A stated, “My PCM kept changing. I basically started fresh every time. That’s why you don’t really need to keep seeing a different PCM when you’re going through cancer treatment.”

Another issue is communication between the PCM and the oncology team. Although the lack of communication between the primary physician and the treating oncologist is not a military specific issue, I explored the occurrence of communication between the oncology team and the PCM. More than one-half of the participants stated that either there was no communication between their oncology team and their PCM or their PCM was constantly changing, which may also lead to a lack of communication.

Seven participants used a mixture of civilian health care services off the installation and military health care on the installation. Three participants used only civilian health care services off the installation. Two participants used only military health care on the installation. One participant was unique in that his care was provided through a National Institute of Health (NIH) study. Some of these care locations were utilized because of the availability (or lack) of oncology treatment where they were stationed, and some were by choice. When Participant M was asked about his choice of treatment being all civilian off the installation, he stated,

No. I don’t trust the military as far as any sort of medical diagnosis or anything. I think that it is just from experience. Because of what I said earlier about having to tell a story and having hopefully somebody believes them, I guess. But everything has been civilian driven. Thank goodness I was diagnosed off post, because if I was diagnosed here, I don’t know if I would be alive.

An additional challenge for some participants was they felt they were fighting TRICARE (health care program) and had to ‘jump through hoops’ to get care or get a referral to other civilian medical centers, including specialists such as MD Anderson. Often the difficulty identified was because there is more than one region under the TRICARE umbrella and these regions do not necessarily function in the same way. Another assertion was that TRICARE personnel did not listen to the patients. Participant A discussed trying to get a second opinion after having her cancer recurrence:

When he put in the referral, I had told him I will go anywhere. I said MD Anderson was just suggested to me, but I will go anywhere for a second opinion, wherever TRICARE will send me. He put on my referral that I requested to be seen at MD Anderson, so TRICARE sent me there but refused to pay for my travel because they said I requested it specifically and the PCM would not change his statement.

Participant E stated, “MD Anderson worked with me because they couldn’t put in an appointment until TRICARE authorized it and TRICARE kept denying the authorization.”

Others felt they were not given options for different treatments either due to TRICARE options or to the doctors’ abilities or knowledge that would enable proper diagnosis, provide adequate care, or make appropriate referrals. Participant N stated,

I didn’t like the way that he [the physician] said that nothing else could be done. Because I understood. I mean, everyone has Google now. But I also understood there were other options. I said, well, I am not going to talk to you anymore about this because there is something that can be done.

Participant A stated, “TRICARE East did not have the original medication because it was so expensive. But TRICARE West would pay for it. No one could ever give me a reason why. It was just that TRICARE West did things differently.”

Support Systems and Relationships

Support systems and relationships are important throughout an experience with cancer and can often be different for an AD military service member or spouse than for the civilian

population. Often, what is thought of as a traditional support system is unavailable to AD military service members and spouses because they no longer live where their family and longtime friends live because of their military commitment. In exploring the psychosocial needs of AD military service members and spouses with cancer, it is important to understand who makes up their support system, such as personal relationships and relationships with their military community or environment. See Table 4.

Table 4

Support Systems and Relationships

Themes	<i>n</i>	%
Support Systems		
Parents & Extended Family	9	69.23
Spouse	6	46.15
Fellow Military Spouses	6	46.15
Friends/Battle Buddy	4	30.77
Children	3	23.08
Church	3	23.08
Tight knit community	3	23.08
Fellow patients	1	7.69
Personal Relationships		
More difficult on spouse or children	6	46.15
Spouse or children were encouragers	3	23.08
Lack of intimacy	2	15.38
Marriage may not survive	1	7.69
Saved marriage	1	7.69
Military Relationships		
Military spouses were biggest support	5	38.46
No command support	4	30.77
Alone and isolated	3	23.08
Military relationships deteriorated	2	15.38
Maybe COVID affected support	1	7.69

Support Systems

More than two-thirds of these participants reported that their parents and extended family were the primary supports during diagnosis and treatment; followed closely by their spouse.

Teary-eyed, Participant G spoke gratefully about his spouse who he noted as his greatest support saying, “Definitely my wife. I couldn’t do it without her. She is my biggest supporter and a rock to lean on.”

Support for the military spouse participants were primarily their fellow military spouses. Participant I stated, “Those women were angels. They did a ‘food’ thing for me and they were just awesome.” Participant D stated, “So many things were done for me by other military spouses or other people that I met in the community through being a military spouse in that community.” Participant J stated, “But what amazed me were the friends all over the world praying for me. That was the gift the Army gave me. That made me love the Army life even more.”

The other various support systems included a small, tight knit community, children, church, friends or a ‘battle buddy’ and fellow patients. Participant B stated, “Honestly, our flight community is so close. We had his [military] buddies and they were amazing. They checked on him all the time and came over to see him all of the time.”

However, there were several participants who stated they felt alone, isolated, only had support in the beginning, or their command did not support them. Participant E stated, “The command is at the very extreme bottom; they did not support us whatsoever.” Participant A stated,

My husband’s commander, whenever they deployed, knew and told me not to tell anyone. He did not want it to get out that he sent someone downrange while their spouse had cancer. So, I was the key spouse and I got it done. I took care of other spouses and no one knew about me.

Personal Relationships

Personal relationships can have a profound impact on a cancer patient's journey, but cancer can also have an impact on the patient's personal relationships (Quinn, 2020). The military environment can also have an impact on personal relationships. The questions asked of participants explored personal relationships from the time of diagnosis until remission or death. Most participants felt that the cancer and treatments were more difficult on their spouse or their children than on themselves, especially if the spouse was a deployed service member. Participant A said, "Well, I think it hit our oldest daughter the hardest because I was still trying to do everything with her."

Participant P said of her decedent spouse, "We were in this fight together. He had been deployed four times, but this was the hardest battle because he couldn't keep it from affecting his family."

However, many participants also stated that their spouse or children were the ones that encouraged them and as one participant stated, "we were each other's rock." Participant J stated "He has been amazing. He's been so confident and that is just an encourager."

Two participants stated that everything became focused on medical treatments and this led to a lack of intimacy in their marriage. Participant B stated,

It was no longer a relationship between two people. It was, okay, what do we do next? It took a toll. We loved each other very much, but you lose the intimacy and everything like that and it was shitty.

Participant E stated, "This is really impacting our marriage so much."

One participant stated that they felt like their marriage might not be able to survive this, while another participant had the opposite experience. Participant I stated, "We were actually

talking about divorce at the time, and we were talking to a chaplain. Cancer made us closer and that's what got us back on track."

Military Relationships

When asking participants about their relationships from the time of diagnosis to remission, many brought them up in the context of the military. They either talked about themselves and family in the context of the military or their military chain of command. Participants stated that they had either no support from the command, support only in the beginning, or that the level of support provided was command dependent. Participant G stated,

My squadron [unit] was really good in the beginning, but it has been almost a year. When the things kind of slacked off because it is not the new hottest thing. Sometimes I just want them to recognize that I am still here.

Several participants stated that they felt alone and isolated, their spouse was always gone on temporary duty assignments or deployments, or that maybe COVID affected the support they would have received. Participant A stated, "It was extremely isolating because I couldn't go anywhere." Participant E stated, "We don't really have much support, especially due to COVID and basically being shut off from the world."

Many of the military spouses stated that their fellow military spouse friends and neighbors were their biggest support system while they were going through their cancer journey as an active-duty military spouse. Participant D stated,

My parents, even to this day say that they cannot believe how amazing the military community is. I just say that is just how we are. So yeah, it was mostly all military spouses or family members supporting me.

Participant J stated, "And yet, the people who absolutely stepped up and were 100 percent there for me, were my chaplain spouse sisters."

However, a few military service members stated that their relationships with their military friends deteriorated because they simply weren't there for them and that hurt them.

Participant M stated,

We are supposed to be a team and I thought that's what we were and over the years, it has definitely changed, but I've always bent over backwards for people. I have been hurt a lot. Especially with this, nobody was there.

Psychological, Emotional, and Spiritual Needs

In examining psychosocial needs, three main areas emerged throughout the literature.

This research more closely examined these areas both with the AD military service members and spouses with cancer to better understand how they were impacted by cancer. See Table 5.

Table 5

Psychological, Emotional, and Spiritual Needs

Themes	<i>n</i>	%
Psychological		
No previous MH diagnosis	9	69.23
Had previous MH problems	4	30.77
Denial or avoidance	3	23.08
Depression	3	23.08
Wanted a plan	3	23.08
Daily mental battle	2	15.38
Sleep issues	2	15.38
Mental toughness	1	7.69
Emotional		
Anger	4	30.77
Devastation	3	23.08
Fear	3	23.08
Concerned	2	15.38
Did not have time to process	1	7.69
No purpose or confidence	1	7.69
Spiritual		
Are spiritual or religious	9	69.23
Praying and going to church	6	46.15
Not spiritual or religious	4	30.77
Religion/spirituality had no impact	2	15.38
Used music to cope	2	15.38

Psychological

Nine of the thirteen participants did not have any previously diagnosed mental health concerns, while four stated that they did either from personal or military experiences. The most common identified mental health concerns after learning about diagnosis into survivorship were depression, daily ‘mental battle’, sleep issues, or wanting a plan (since as military spouses they are constantly planning due to moves and deployments) and were stressed until it was in place. Participant M stated, “It has affected me a lot. I’m on anxiety medication and I’ve had sleep issues.” Participant L stated, “Once I got the treatment plan, I was good. Because I could control something.”

Another theme among a few of the AD service members was denial or avoidance. This included avoidance of any type of counseling and the denial of mortality when confronted with knowing that the disease is terminal. Participant B stated,

I told him we need to go to counseling because this is serious. He wouldn’t talk about it. He just didn’t want to talk about the fact that he was going to die. His way of handling it was not handling it.

Participant C stated, “Did I get counseling for depression or for anything on here? I actually avoided it.” Participant C went into detail that his mental toughness was what got him through his cancer and that was one of the reasons that he survived.

Emotional

In addition to psychological concerns, there were also emotional experiences that occurred from the time of diagnosis and into survivorship. The most common emotions expressed by participants were anger, fear, and devastation. Participant E stated, “Anger and not being able to process emotions about it.” Participant P stated about her decedent spouse,

My husband was mad. He had given the Army 19 years and two months of his life. They medically retired him, because the WTU wrote that he was not fit for duty. Then 14 days after he medically retired, he was promoted.

Participant D stated, “My first question, I think, was am I going to live? So, devastation, shock, and disbelief, and fear, and anxiety.”

Other participants stated that they were not fearful but were concerned. Participant L stated, “So, was I concerned? Yes. Was I petrified or scared? No, because I knew God wouldn’t take me somewhere, he would not help me.”

There were other notable comments made that were not shared comments with others. One military spouse participant provided a unique answer, but that may represent what many go through due to the military’s operational tempo (pace of the daily work and deployment cycle). She stated that she did not have time to process what was going on due to the many moves and military life in general. Another participant stated that he no longer had a purpose or confidence because of how his unit treated him once he was diagnosed. He stated, “So, I think my heart and desire to do anything for this place, and this unit and this organization, it’s gone. It really is. And I see the looks because I have never been like that.”

Spiritual

During the interviews, some participants discussed their spirituality or religiousness prior to being asked about it. However, every participant was asked if they considered themselves to be spiritual or religious. This was not defined, and all participants answered based on their own definition and how this affected their cancer journey. Most participants stated they were spiritual or religious in some way, though some participants stated they were not religious at all. When asked about this question, participants stated that music helped them to cope. Participant B stated,

I think, for him, what helped him get through is he turned to music. He would just put headphones on and listen to music and that was pretty much the saving grace. He could lose himself in something else.

Those who identified as spiritual or religious were asked how they thought it had an impact on their cancer journey. The most common responses were through praying and going to church or that it had no impact. Participant P stated her decedent spouse used his favorite verse, “I can do all things through Christ which strengthens me” and that God gave him the strength to fight for 29 months after his diagnosis. Participant I stated, “So, it kind of made me fight and see what a beautiful family I did have and be appreciative of stuff. I went to church and it helped a lot.” Participant C stated, “It wasn’t defining. It wasn’t the most important or the least important. It was just a part of my life.”

Military Themes

Since this research focused on AD military service members and spouses with cancer, how participants felt about having cancer within the military environment was explored. Four themes emerged within this data, with subcodes under each main theme. The four main themes included military support, lack of military support, difference in being military with cancer versus being a civilian with cancer, and what it means to serve as an AD service member or spouse. See Table 6.

Table 6

Military Themes

Themes	<i>n</i>	%
Military support		
Good military doctors	4	30.77
Military was our family	3	23.08
EFMP access	2	15.38
Military advocated for me	2	15.38
Lack of military support		
No continuity of care	4	30.77

TRICARE regions operate differently	3	23.08
Had to change MOS	2	15.38
No support	2	15.38
Worry about EFMP affecting career	2	15.38
Differences in being military with cancer		
Had to PCS	7	53.85
No out-of-pocket costs	4	30.77
I don't know anything other than the military	3	23.08
Rank has its privileges	3	23.08
Had to go TDY	2	15.38
Harder being in the military	2	15.38
Provided job security	2	15.38
Spouse deployed during treatments	2	15.38
What it means to be Military		
Proud of service	5	30.77
Loved being a military spouse	3	23.08
Want to be done	3	23.08
Joined to escape small town/poverty	2	15.38
I am just a number to be replaced	2	15.38
Service may have caused cancer	2	15.38
Never knew if my spouse was safe	1	7.69

Military Support

Most of the participants focused on positive aspects of the military and how they were supported during their cancer journey. Two participants thought that the military did a good job advocating for their needs. Participant B stated, “They kept him on active duty, and we were really fortunate that we had a lot of people advocating for us.”

Several participants said that they feel like the military was their family. Further, one participant stated that she felt that way even after her spouse’s death. Participant P stated,

“Since he was in the Army for 19 years and I was in for 10 years, we have a lot of ‘military family members.’ Quite a few of our ‘military family members’ assisted us.”

Several participants talked about support provided through having good doctors in the military health care system or having access to the Exceptional Family Member Program (EFMP). Participant D stated, “If you have a really good EFMP counselor, you learn about all of the things that you can qualify for under the EFMP program that you wouldn’t have known.”

Lack of Military Support

More participants discussed the lack of support from the military during their cancer journey than those who felt they received suitable support. Within this theme was found a lack of continuity of care; TRICARE regions operate differently; service members had to change their Military Occupational Specialty (MOS); there was no support for family even from the Family Readiness Group (FRG); and participants worried about EFMP affecting their career.

Participant I stated, “No FRG leader has called to see if I am okay or need help with anything.” Participant J stated,

I would have worried had we been earlier in the journey. I would have worried that EFMP might have prohibited him from going to a duty station that might have resulted in him losing a promotion or something.

Differences in Being Military vs Civilian with Cancer

Although some participants stated that they did not know anything beyond the military because their whole life had been spent as a military dependent or a combination of dependent and service member, participants discussed the differences between AD military service members and civilians with cancer. Many discussed this based on other health problems they have experienced as a civilian (prior or after AD time) or experiences of their civilian friends or family with cancer.

Most common within this topic were that participants were forced to move or PCS, no out-of-pocket costs for any health care, and rank comes with privileges, even with cancer, such as leave and career progression.

Participant O stated, “I PCS’d three times and I was pregnant. I don’t recommend that for anyone.” Participant B stated, “I can say, we didn’t pay for a single thing. I am grateful for the military for that.” Participant E stated, “What I can say is it is easier in terms of TRICARE covers everything. I haven’t had to worry how we are going to pay for rent or food.”

Participant J stated,

I didn’t have to decide whether to pay the rent or have my next chemo. That burden was completely lifted from me and I feel for the mom who is having to make really hard decisions like that.

Participant E also stated about getting a referral easily to MD Anderson as an officer,

I think I remember just crying over the fact that if he was an E-3, we wouldn’t have had the path smoothed for us. There is some guilt in that. Thinking wow, this wouldn’t happen for every soldier.

Participant M stated,

I’m not the only one that has cancer in the unit. There was a lieutenant colonel who had cancer. He had to have a couple of surgeries and things like that and they [unit members and leadership] checked on him. I just felt like a nuisance.

The other themes were they or their spouse had to go on temporary duty (TDY) during treatments, their spouse was deployed during their treatments, it was simply harder going through cancer in the military, and that being in the military provided job security while receiving cancer treatments.

Participant L stated, “So, really being a military spouse with a deployed husband and having two children actually makes you stronger through everything than you think.” Participant

E stated, “He has job security and I think that has helped because we haven’t had to worry about that.”

What it Means to Serve as an AD Service Member or Spouse

Although understanding what it means to serve as an active-duty service member or spouse may not seem like it has a place in understanding the psychosocial needs of this population with cancer, it certainly helps frame the identity of AD service members and spouses. Understanding identity can help understand the way challenges are approached, the unique needs associated with them, and even how identity can play a role in help seeking behaviors.

Participants reported being proud of their service, that they loved being a military spouse, or they were ready to leave the military. Participant G stated, “I’m proud that I served and did my time, which a lot of people can’t say.” Participant M stated, “I’m proud of the things that I’ve done and the people I’ve served with; we went through tough things together.”

There were several reasons discussed on why participants joined the military, with the most common response being to escape a small town and poverty. One participant felt that being a military spouse meant that she never knew if her spouse was safe, which caused some anxiety. Two participants felt they were nothing more than just a number to be replaced and this was intensified when they got cancer and did not have support from their unit. Finally, two participants stated that it is tough to separate because they believe that being in the military may be what caused the cancer. Participant B stated,

We haven’t been able to connect the dots, but he had his theories and maybe it was his bitterness and anger towards the cancer, but he swears that his service may have caused the cancer. So, it’s a double-edged sword.

CHAPTER 5

DISCUSSION

The purpose of this study was to explore the psychosocial needs of AD military service members and spouses with cancer. Noteworthy findings from the qualitative data are discussed in this chapter. Also included are implications for social work, directions for future research, and study limitations.

This chapter contains discussion of the study's findings that address the research questions: (1) What are the psychosocial needs of U.S. AD military service members or spouses with cancer? and (2) What psychosocial difficulties did those diagnosed with cancer have during the experience with cancer? The primary themes found within the data from the interviews include: (1) cancer diagnosis and treatments, (2) support system and relationships, (3) psychological, emotional, and spiritual needs, and (4) military themes. While there are differences within each participant's experience and psychosocial needs during cancer, there were some commonalities, and these will be discussed in detail in the following sections.

Cancer in the Military

Although previous studies suggest that the existence of prior mental health problems can be more prevalent in AD service members and spouses than in the civilian population, findings in this study suggest that mental health problems are much more likely post-cancer diagnoses for military spouses. However, historically, AD service members underutilize mental health resources and treatment due to the stigma and the possibility of losing their military occupational specialty (MOS) (Michalopoulou et al., 2017). Most of the AD service member participants in

the study stated they felt like they had undiagnosed mental health problems prior to cancer or had not been formally evaluated. Therefore, it may be more important when screening AD service members for psychosocial needs to screen more vigorously for pre-cancer mental health issues that can impact their treatment, help seeking abilities, and their survivorship.

One major obstacle for many cancer patients is financial toxicity that occurs from the long-term negative financial costs of cancer treatments. In studies about the financial toxicity of cancer treatment, 62 percent of participants worried about large bills, 52 percent stated they owed \$10,000 or more from their cancer care, 40 percent stated they had to make financial sacrifices to pay for their care, and 34 percent had to borrow money or go into financial debt to pay for cancer treatments (PDQ Adult Treatment Editorial Board, 2019; Desai & Gyawali, 2020). However, based on the data provided in the study, financial stress is not a concern for AD military service members and spouses. TRICARE covers all health care and treatment costs, and patients have no out-of-pocket costs. Military service members also have financial stability through regular military pay and allowances such as housing and food through basic allowance for housing (BAH) and basic allowance for subsistence (BAS). This is a significant difference since many of the resources, in the civilian community built for cancer patients, focus on financial options and assistance.

More than one-half of the participants discussed having to PCS during their treatments or between the time they got the diagnosis and when they went into survivorship. This is a significant stressor and can create barriers that may not otherwise exist. Most civilians with cancer would attempt to remain in a stable living environment with the same resources and care from diagnosis into survivorship. However, with the operational tempo of the military and the need to take new positions to advance their career, AD military service members and their

families typically move every few years. In 2017, the undersecretary of defense for personnel and readiness, Robert Wilkie, discussed the fact that frequent PCS moves caused unnecessary stress for both service members and families (Harkins, 2017).

The recognition of PCS-related stress is already in the forefront, but not observed as an additional stressor on AD service members and spouses with cancer. This requires not only the normal stress of moving, but also the stress of doing so when undergoing cancer treatments, interrupting continuity of care, displacing the support system, and causing possible added physical and mental health problems. These are important considerations, because a military member often has no say in when they PCS or to which location. The exception is when the family member is enrolled in EFMP and the new duty location does not have the necessary medical resources. However, this does not mean that the service member will not PCS; it simply means that they may have to PCS without their family or get diverted to a different location.

Deployment stress is also a unique aspect of having cancer as an AD service member or spouse. Although the service member would not be deployed if they have cancer, they can still be deployed if their spouse does. Military spouses were seen to have a greater risk for poor health behaviors (such as a lack of exercise, proper nutrition, and preventive care) than service members or their civilian counterparts (Corry et al., 2019). This is compounded for military spouses who feel that they have no support system, or their only source of support is their deployed spouse (Corry et al., 2019). This could be detrimental for the health and mental health outcomes of a military spouse with cancer. The psychosocial needs of a military spouse with a deployed spouse could be greater and different than if the spouse is not deployed. However, because they may have poor health behaviors and issues such as depression and isolation, these spouses may be less likely to identify their psychosocial needs during their cancer treatments.

Another issue unique to the military due to the hierarchy and rank structure is the notion that higher rank has better privileges. Some participants felt this was true, even during their cancer treatments, and could be a barrier to psychosocial supports. This finding is supported by the literature on veterans and health disparities (MacLean & Edwards, 2010). Often enlisted personnel have higher levels of psychological stress and less control over their environment than officers, which can lead to poorer health outcomes (MacLean & Edwards, 2010). Several participants suggested that they may not have the same access to immediate care or additional referrals, time away from work, or different treatment based upon their rank.

One thing that is unique for AD service members is that they cannot simply go to another doctor and ask for a second opinion if they do not feel heard. Many of the participants, both service members and spouses, felt like they were not heard when they told their PCM that something was wrong. The ultimate mission of the military health system is readiness, and this takes priority (Smith et al., 2017). This mission of military readiness can often overshadow other needs, including military physicians missing symptoms of cancer until it is too late for curative therapy (Smith et al., 2017).

It is also worth taking note that the interviews for this research took place during a worldwide pandemic and some participants were experiencing treatments during COVID-19. Although one participant was moved to a Warrior Transition Unit (WTU), which often has better protective factors and unit cohesion, the pandemic limited activities, and the ability to meet people within their new community. This specific participant and his family had a much more difficult time finding a support system. By looking at outliers such as this, it can help us understand how unexpected events can have a profound impact on the psychosocial needs of AD service members and spouses with cancer.

Implications for Social Work

The research does not suggest that AD military service members and spouses with cancer need their own specific resources. However, it does suggest that practitioners should be aware of the unique culture and specific aspects of the military that civilian counterparts may not face and that may in turn influence access to support resources.

Policy and Systems-Level

The Department of Veterans Affairs is the largest employer of master-level social workers in the United States and the DoD employs more than 2,100 clinical social workers (Faulconer, 2019). It was reported that in 2018 there were roughly 1,301,273 behavioral health encounters with social workers through the MHS, including federal employees, contractors, and social workers in uniform (Faulconer, 2019). Changes in policy need to support AD service members and dependents in the case of a serious illness and to support system change overall. Social workers ensure that system level change includes removing stigma surrounding mental health service utilization. Social workers can also advocate for military service members and spouses through involvement in the policymaking surrounding access and barriers to care, health care coordination between military and civilian providers, and the quality of care being received (Wooten, 2015).

The DoD can help create bridges between the military community and the civilian community, including civilian providers, when considering policy change and in monitoring the policies when implemented. One area of common ground may be in creating policy that allows AD service members to move less frequently, maintain service members on active duty if they or their spouse has cancer, so they do not lose benefits such as Servicemembers' Group Life Insurance (SGLI) and TRICARE, and creating a health system that listens to concerns so that

AD service members and spouses are diagnosed in a timely manner. If they remain in their duty locations, there is also continuity withing the civilian community, which is especially important if resources are accessed there as well as within the military system.

The findings suggested that one of the hurdles that most participants faced was not being diagnosed in a timely manner. The lack of communication and a hurried health care system is not unique to the MHS, but improvements can be made within the MHS to assist doctors and social workers in better serving their patients. This is important in a system-wide change, as it could lead to more timely diagnoses and more competent care.

Policy makers, including at the Pentagon, should use this research as a starting point to invest money and resources into additional research and policy changes and resource investment for the AD military connected population with cancer. This research needs to be expanded and conducted at multiple major military installations to understand the greatest needs and the best way to address them. The DoD should fund further research and resources as this problem will continue to grow as more service members and spouses are diagnosed annually and as theatres of operation continue globally.

Providers

Military social workers must use their understanding of the military culture and rank structure to advocate for their patients, including AD service members and spouses with cancer (Wooten, 2015). Advanced training and education about military culture can assist social workers both within the military system and in civilian practices to better understand additional risk factors that may impact the psychosocial needs. Not only does the military have its own culture, but specific groups within the military have subcultures, such as the aviation community, special forces, etc. (Wooten, 2015). Although it is difficult for social workers to be fluent in all

areas of military culture, it could be important for an oncology social worker to understand the closeness of aviation and special forces communities, for example, that may have stronger support systems than other military members.

Since AD service members and spouses often have higher levels of poor physical and mental health, it is important to review the protective factors they have when assessing for psychosocial needs during cancer. Many service members and spouses could have protective factors built into their military life due to their resilience, sense of community, and access to health care and support systems (Sullivan et al., 2020). In reviewing the protective factors that are unique to the military lifestyle, especially resiliency and mission focus, practitioners can use these as strengths to assist patients in having better treatment adherence and improved mental health outcomes from cancer treatments. In addition, since the risk of suicide is higher among military spouses, service members, and veterans than their civilian counterparts, this should be a specific factor that providers assess regularly within the AD military spouse cancer patients (Levine & Sher, 2021). Based on the information learned from this research and previous research on mental and physical health concerns within the military population, it may be beneficial for a screening tool. This tool would be specific for this population and would address gaps in resources as well as protective factors provided by the military when assessing the psychosocial needs.

One area that stood out during this research is that participants wanted answers and wanted a plan. Many felt out-of-control because of the lack of communication and answers from their providers. Shared decision-making provides patient-centered care and could be beneficial in this population, as it has shown beneficial in general oncology care (Coovey et al., 2019). Social workers can help facilitate this shared decision making by ensuring that person-in-environment is

considered, and it is not shared decision-making solely isolated to a specific medical encounter (Clayman et al., 2017).

Community Partners and Resources

Many military service members and their families experience a PCS move every two to three years, often moving to a community that is completely new to them. This equates to approximately 430,000 military families moving somewhere new every year (Razsadin, 2020). Participants in this study experienced these moves even while going through cancer. When moving, one of the challenges is the lack of knowledge of the local community resources. The Military Family Advisory Network created a resource locator map for military families to aid in finding local resources (Razsadin, 2020). However, even though resources like this exist, many military families do not know about them.

The problem is that, even if there are resources in a local community, AD service members and spouses often do not know which resources exist or how to locate them. The social work community, both military and civilian, could create and periodically update resources for spouses and provide to installations so that they can be distributed through both printed and online formats. These resources can include medical specialists, such as local oncologists, support groups, counseling centers and any other resources specific for cancer patients from the time of diagnosis into survivorship or for families of deceased cancer patients.

The Intersection of Military Life and Health

Military life can have a profound impact on the health and well-being of both AD service members and their spouses. As shown in previous research (Wooten, 2015) and within the results of this study, there is multidimensional risk and resilience associated with military life and health. Many military members are less likely to disclose mental and physical health issues

because of the fear that it may impact their military career and ultimately lead to separation from the military after a finding of not being fit-for-duty (Wooten, 2015). The lack of disclosure of symptoms can have an adverse effect on physical and mental health, especially cancer, since the diagnosis may not be timely and could limit treatment options.

Although the literature shows that an increased risk of cancer occurs with the natural aging process, there is an even higher risk for military and veterans exposed to toxicities during their military service (Zhu et al., 2009). Therefore, it is important for AD military service members and spouses to be screened regularly throughout their lifespan and for providers to understand this increased risk occurs not only with the natural aging process but due to toxicities in which they were previously exposed.

Future Research

Future research is needed to gain a better understanding of the experiences that AD service members and spouses have with the cancer experience. These areas include survivorship; transition into life as a veteran/civilian; the long-term impacts that cancer has, such as increased mental and physical health risks; and finally, the protective factors such as resiliency and mission first mentality provided by the military. As cancer is a lifelong issue, these are all factors that can affect this population long-term.

There is a benefit in conducting additional research examining military and veteran identity intersecting with the identity as a cancer patient or the caretaker of a cancer patient. Since military and veterans apply the mission first and mental toughness approach to many areas of their life, this may also reveal itself in their identity as a cancer patient or the caregiver of a cancer patient.

No specific questions about social determinants of health were asked, but the literature suggests that the military has its own social determinants of health based upon the military life. The phenomenon of the “healthy soldier effect” shows that at the time of entrance into the military, the average soldier is healthier than their civilian counterparts but after time health declines more quickly (Washington et al., 2020). Additional research could examine these unique determinants with others already studied to reveal how they affect different illnesses, including cancer. This research should include health promotion behaviors and how the social determinants of health within the military environment may influence them and what can be done to promote healthy preventive care behaviors.

An additional area for future research would be an exploration of how psychosocial needs may differ for persons of color within the AD military setting. There is literature that shows that persons of color are not only at a higher risk for certain cancers, but also under-utilize resources that are often created for white patients. Since this is true and persons of color were under-represented within this study, it may be beneficial to explore further through a mixed method study.

Study Strengths and Limitations

One primary strength of this study is that it begins filling a gap in the current literature. Most current studies either focus on civilians or on veterans, both of whom have a different environment and support systems than most AD service members or spouses. Another strength of the study is that being a member of the population being studied allowed for participants to feel comfortable that I understood the military life and the experience of having cancer within the military. Finally, utilizing Zoom allowed for participants to be located throughout the world and not regionally located.

One limitation of this study is the participant sample diversity. Although multiple ranks are included, there are very few junior enlisted participants. This is a limitation because I think that junior enlisted service members could have different needs due to their inexperience with the military, the possibility of being unmarried or younger with a young family, and lower limited income as compared to senior ranking and officers. There is also little diversity in race. Three participants identified as non-white. The recruiting strategy was broad, rather than targeted, and did not yield many racially diverse participants. One probable reason for this may be based on the recruitment only being done through social media. Future research would benefit from recruitment outside of social media. Due to this, maximum variation was not achieved through this study.

Another limitation is that more than one-half of the population was diagnosed more than three years ago. This was considered a limitation due to the constantly changing policies and culture of the military. The experiences that participants had more than five years ago may not be relevant to the same policies and military behavior that the participants may experience now.

Conclusions

This study brings light to the fact that many AD service members and spouses with cancer have unique environments and are at a higher risk for pre-existing mental and physical health factors that can affect their psychosocial needs after a cancer diagnosis. Based on the findings, it is recommended that further research be completed to ensure that the psychosocial needs of AD service members and spouses with cancer are being addressed at the macro, mezzo, and micro level. This research can have implications for social workers, policymakers, military leadership, communities in which the service members and spouses reside, and other oncology staff.

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APPENDIX A: Participant Recruiting Script/Flyer

Are you a current or former military member or spouse who had cancer while on active duty?

Hi! My name is Kelli and I am a military brat and a former military spouse of a retiree. I am looking for participants for my research study about the psychosocial needs of active-duty military members or spouses with cancer.

This project is IRB approved (protocol 20-12-4166) with the University of Alabama and partially funded by the American Cancer Society.

Participants will complete an interview, via Zoom, that should last no longer than approximately 90-120 minutes, during which we will discuss your experience having cancer while being an active duty military member or spouse. All names, contact information, and clearly identifying information WILL be REMOVED and will NOT be released to anyone, including the American Cancer Society.

Do you qualify?

- Over the age of 18
- Had or have cancer
- Are or was active-duty military or active duty spouse
- Cancer diagnosis/treatment overlaps with active-duty time. Can still be undergoing treatment or be a veteran if diagnosed on active duty.

If interested, please contact me at kkgodfrey@crimson.ua.edu

APPENDIX B: Interview Guides

Psychosocial Needs of Active-Duty Military Personnel Interview Guide

Qualitative Interview Introduction Script:

This interview will be conversational in format. The goal is for me to learn how you see your experiences with cancer while on active duty. The interview may take 90-120 minutes or less.

Consent

You received a consent form prior to this interview via email. You have signed and consented to participate in this study and understand that your participation is voluntary, uncompensated, and that you can withdraw at any time? Do you have any additional questions about the consent form or anything about the study before we begin the interview?

Cancer Experience

I would like to begin with your experience with being diagnosed with cancer while you were serving on active duty.

How did you first learn about your cancer diagnosis? Was it on a military installation or at a civilian provider?

What was your reaction when you were told that you had cancer?

What was one of the first things that you did in response to your diagnosis?

Where were you stationed at the time of diagnosis?

Were you treated on the military installation or off the military installation in the civilian community?

How satisfied were you with the communication between your primary care and your oncology team? Explain your answer.

What were your positive experiences with your oncology team or primary care during your diagnosis and treatment coordination? Please describe. If any, what were your negative experiences?

Did you attend all treatment sessions as suggested by your medical team? Why did you or did you not?

Who did you feel supported you when you were diagnosed

Did you have the same support system going through treatments? Did your family, friends, commander, fellow military comrades? Explain how they supported you.

Do you believe that things were different because you were active-duty military than if you were a civilian being treated for cancer? How? Explain what you mean.

Did you experience any negative side effects from your cancer treatment? Did this affect your role as an active-duty military personnel? How?

What did you struggle with the most during this time of diagnosis and treatment?

Psychosocial Needs

What kind emotions did you experience during your diagnosis? And treatment? After treatment (if complete)? Please explain.

Did you have any previously diagnosed depression, anxiety, substance abuse issues or general emotional distress or other mental health diagnosis such as PTSD?

Did you have any new mental health diagnosis due to your cancer diagnosis? Or treatments? Please describe how you felt.

How were your relationships during diagnosis? During treatment? Please explain.

What was the disclosure of your cancer like to your spouse or other family members and friends? What support did you have from them after your diagnosis and during your treatment?

Were you a caregiver for anyone else while you were undergoing treatments? How did your caregiving responsibilities affect your cancer treatments, or your cancer treatments affect your caregiving responsibilities?

Did you receive any form of counseling (individual or marital) or ever consider counseling?

Do you consider yourself to be spiritual or religious? If so, how did this help you during your treatments?

Military Life

Did you have to move (PCS) between the time of your cancer diagnosis and going into remission (or whatever your current status is)? Describe the effect this had on your cancer treatment.

Did you experience any deployments or temporary duty (away from the installation) between the time of your cancer diagnosis and going into remission (or whatever your current status is)? Describe the effect this had on your cancer treatment

What did it mean to you to be active-duty military personnel? How do you believe being active-duty military personnel impacted your cancer treatment?

Do you believe that having cancer while active-duty military made it easier or harder for you to have support? How so?

Do you believe the military environment supported you during your diagnosis and treatment?
How so?

Closing

What else do you want to tell me about your experience with having cancer as an active-duty military member?

What questions do you have for me?

Interviewer provide resources for counseling (Military One Source, American Cancer Society, and Military Crisis Line)

American Cancer Society (24/7 hotline 888-227-2345); Military One Source (24/7 hotline 888-342-9647; Military Crisis Line (24/7 hotline 888-273-8255)

Thank you for your time and I will contact you for follow-up to check and ensure I understood everything as you meant for me to.

Qualitative Interview Introduction Script:

This interview will be conversational in format. The goal is for me to learn how you see your experiences with cancer while on active duty. The interview may take 90-120 minutes or less.

Consent

You received a consent form prior to this interview via email. You have signed and consented to participate in this study and understand that your participation is voluntary, uncompensated, and that you can withdraw at any time? Do you have any additional questions about the consent form or anything about the study before we begin the interview?

Cancer Experience

I would like to begin with your experience with being diagnosed with cancer while you were serving on active duty.

How did you first learn about your cancer diagnosis? Was it on a military installation or at a civilian provider?

What was your reaction when you were told that you had cancer?

What was one of the first things that you did in response to your diagnosis?

Where were you stationed at the time of diagnosis?

Were you treated on the military installation or off the military installation in the civilian community?

How satisfied were you with the communication between your primary care and your oncology team? Explain your answer.

What were your positive experiences with your oncology team or primary care during your diagnosis and treatment coordination? Please describe. If any, what were your negative experiences?

Did you attend all treatment sessions as suggested by your medical team? Why did you or did you not?

Who did you feel supported you when you were diagnosed?

Did you have the same support system going through treatments? Did your family, friends, military member's commander, fellow military spouses or family readiness group? Explain how they supported you.

Do you believe that things were different because you were an active-duty military spouse than if you were a civilian spouse being treated for cancer? How? Explain what you mean.

Did you experience any negative side effects from your cancer treatment? Did this affect your role as an active-duty military spouse? How?

What did you struggle with the most during this time of diagnosis and treatment?

Psychosocial Needs

What kind emotions did you experience during your diagnosis? And treatment? After treatment (if complete)? Please explain.

Did you have any previously diagnosed depression, anxiety, substance abuse issues or general emotional distress or other mental health diagnosis such as PTSD?

Did you have any new mental health diagnosis due to your cancer diagnosis? Or treatments? Please describe how you felt.

How were your relationships during diagnosis? During treatment? Please explain.

What was the disclosure of your cancer like to your spouse or other family members and friends? What support did you have from them after your diagnosis and during your treatment?

Were you a caregiver for anyone else while you were undergoing treatments? How did your caregiving responsibilities affect your cancer treatments, or your cancer treatments affect your caregiving responsibilities?

Did you receive any form of counseling (individual or marital) or consider counseling since the time of your diagnosis?

Do you consider yourself to be spiritual or religious? If so, how did this help you during your treatments?

Military Life

Did you have to move (PCS) between the time of your cancer diagnosis and going into remission (or whatever your current status is)? Describe the effect this had on your cancer treatment.

Did your military member spouse experience any deployments or temporary duty (away from the installation) between the time of your cancer diagnosis and going into remission (or whatever your current status is)? Describe the effect this had on your cancer treatment

What did it mean to you to be active-duty military spouse? How do you believe being an active-duty military spouse impacted your cancer treatment?

Do you believe that having cancer while being an active-duty military spouse made it easier or harder for you to have support? How so?

Do you believe the military environment supported you during your diagnosis and treatment?
How so?

As the spouse of an active-duty service member, did your spouse receive leave or relief of any military duties to be with you or help you from the time of diagnosis to remission?

Closing

What else do you want to tell me about your experience with having cancer as an active-duty military spouse?

What questions do you have for me?

Interviewer provide resources for counseling (Military One Source, American Cancer Society, and Military Crisis Line)

American Cancer Society (24/7 hotline 888-227-2345); Military One Source (24/7 hotline 888-342-9647; Military Crisis Line (24/7 hotline 888-273-8255)

Thank you for your time and I will contact you for follow-up to check and ensure I understood everything as you meant for me to.

APPENDIX C: Informed Consent

Informed Consent

Please read this informed consent carefully before you decide to participate in the study.

Key Information:

- Participate in a 90-120-minute interview study about having cancer in the military
- No information collected that will connect identity with responses
- Potential for the interview to elicit an emotional response, but resources will be provided for free counseling

Purpose of the research study: The purpose of the study is to explore experiences of AD personnel and spouses who currently have or had cancer to better understand the psychosocial needs.

What you will do in the study: The study will comprise of one semi-structured, informal, and interactive interview with open-ended questions to get an in-depth understanding of the experiences. In this study, the initial interview will focus on your life history with the military, the details of your experience with cancer with being AD military personnel or an AD military spouse, and what you feel your psychosocial needs are. There will be a follow-up session that will strictly be for member checking. Member checking will not be to ensure that I transcribed your words correctly, but that I understood what you were conveying; that my understanding of your experience is correct. The goal will be to complete the session within a 30-60 min timeframe.

Time required: The goal will be to complete the initial interview within a 90-minute format to not be burdensome on you. The follow-up session will be approximately 30 mins.

Risks: There will be no physical risk and minimal risk to mental health or over all well-being.

Resources for counseling include the Cancer Information Services through the American Cancer Society (24/7 Hotline 888-227-2345), Military One Source that provides free and confidential non-medical counseling services to military personnel and dependents (24/7 Hotline 888-3429647), and the Military Crisis Line which provides crisis services to all veterans, service members, and their families (24/7 hotline 888-273-8255).

Benefits: You may benefit from the study if you are still undergoing cancer treatments while on AD or as an AD spouse. These benefits would consist of your voices being heard that you have psychosocial needs, that may be different from the general civilian population, while having cancer and experiencing the active-duty military lifestyle. Even if you do not benefit directly from the research, other AD members and spouses can benefit. This research will also be provided to the American Cancer Society, who has partnered with the Department of Veterans Affairs. Understanding the psychosocial needs of AD military personnel and spouses with cancer may lead to future partnering with the Department of Defense.

Confidentiality: Interviews will be conducted using Zoom and the platform has a secure recording device. An additional recording device will be utilized. All recordings will be saved to the University of Alabama's (UA) Box encrypted web-based storage system. Once confirmed that the recording has been saved to UA's Box, the recording will be deleted off the secondary recording device. The meetings will be saved on Zoom as well. Zoom utilizes the Advanced Encryption Standards (AES) 256 protection and is HIPPA and FERPA compliant. To protect you, identifying information will not be used in any reports, manuscripts, publications, or information provided to ACS resulting from the study. All participants will be assigned a unique pseudonym that will be used throughout the study. To provide any contextual data to quotations within reports and manuscripts, the study participants will be identified using pseudonyms and demographic data (if appropriate).

Voluntary participation: Your participation in the study is completely voluntary.

Right to withdraw from the study: You will be free to withdraw from the study at any time and if they choose to withdraw, their data will be destroyed and not included in the research data or any subsequent publications of the data.

How to withdraw from the study: If at any time you choose to stop the interview or withdraw from the study, you can tell me verbally or through email. If you want to withdraw from the study, there is no penalty for withdrawing.

Compensation/Reimbursement: You will receive no payment for participating in the study.

Using data beyond this study:

The researcher will maintain this data beyond this specific study, and it may be used in future publications, but will not include any identifying names or contact information.

If you have questions about the study or need to report a study related issue please contact, contact:

Name of Principal Investigator: Kelli Godfrey

Title: Doctoral Candidate

Department Name: School of Social Work
Telephone: (256) 283-9175
Email address: kkgodfrey@crimson.ua.edu

Faculty Advisor's Name: Dr. David Albright
Department Name: School of Social Work
Telephone: (205) 348-4416
Email address: dlalbright@ua.edu

If you have questions about your rights as a participant in a research study, would like to make suggestions or file complaints and concerns about the research study, please contact:

Ms. Tanta Myles, the University of Alabama Research Compliance Officer at (205)-348-8461 or toll-free at 1-877-820-3066. You may also ask questions, make suggestions, or file complaints and concerns through the IRB Outreach Website at <http://ovpred.ua.edu/research-compliance/prco/>. You may email the Office for Research Compliance at rscompliance@research.ua.edu. The protocol number for this study is (20-12-4166).

Agreement:

I agree to participate in the research study described above.

I agree to video (audio, photograph) in the research study described above. Neither my audio or video will be shared and all identifying names and contact information will be removed from the transcript.

Signature of Research Participant

Date

Print Name of Research Participant

Signature of Investigator or other Person Obtaining Consent

Date

Print Name of Investigator or other Person Obtaining Consent

APPENDIX D: IRB Approval

e-PROTOCOL

PROTOCOL
IRB Form
University of Alabama

Protocol # 20-12-4166
Godfrey

Protocol Title: The Psychosocial Needs of AD Military Personnel and Spouses with a Cancer Diagnosis
Protocol Status: APPROVED
Date Submitted: 12/09/2020
Approval Period: 12/17/2020-12/16/2021
Important Note: This Print View may not reflect all comments and contingencies for approval. Please check the comments section of the online protocol. Questions that appear to not have been answered may not have been required for this submission. Please see the svstem application for more details.

* * * Attachments * * *

15) Attachments

In this section, please upload additional documents associated with your protocol. Failure to attach files associated with the protocol may result in the protocol being returned to you.

Possible documents for this protocol could include:

Bibliography

Cooperating Institution's IRB Approval

Data Collection Sheet

Debriefing Script

Device Information/Documentation

Grant Proposal/Sub-Contract

Human Participants Training Certificate/Proof of Training

IND Application Letter

Information Sheet/Brochure

Interview/Focus Group Questions

Investigator's Brochure

Letter of Agreement/Cooperation

Package Insert

Patient Diary Form

Phone Script

Questionnaire/Survey

Recruitment Material (e.g., flyers, ads, e-mail text)

Recruitment Statement (if there is no waiver of written consent)

Scientific/PPC Review

Sponsor's Protocol

Sponsor's Protocol Amendment

Study Design Chart/Table

Waiver Request

Other files associated with the protocol (most standard formats accepted: pdf, jpg, tif, mp3, wmv, etc.)

To update or revise any attachments, please delete the existing attachment and upload the revised document to replace it.

APPENDIX E: Coding

Category 1: Cancer Diagnosis and Treatments (Questions 1, 3, 4, 5)

Diagnosis

Wrong diagnosis (3)
Waited for diagnosis and care (5)
Suck it up (2)
Didn't believe me (2)
Other medical issues being treated (4)
Routine screening (2)

Treatments

Alone
No communication between oncology and PCM (6)
Good communication between oncology and PCM (3)
PCM constantly changing
Fighting TRICARE (2)
Don't trust the military for healthcare (I wouldn't be alive because no one believed me in the military)
No options of alternative care

Category 2: Support System & Relationships (Questions 2, 11)

Support Systems

Parents and extended family (9)
Amazing small tight knit community support (3)
Fellow patients
Military Spouses (5)
Spouse (6)
No command support or only in beginning
Children (3)
Church (3)
Friends (3)
Battle Buddy

Military Relationships

Alone & Isolating
Support depends on the command
No help
COVID affected support
My spouse was always gone
Relationships degraded with fellow military SMs

Hurt that military, friends, and extended family weren't there for me or my family

Personal Relationships

Difficult on kids and spouse

Focused on medical treatments

Lost intimacy

Possible pending divorce

Previously considering divorce but cancer saved marriage

We were each other's rock

Cancer was harder than 4 previous deployments

Category 3: Research Questions Psychological, Emotional, and Spiritual Needs (Questions 8, 9, 10, 12)

Psychological

Need a Plan (3)

Previous MH diagnosis (4)

No previous MH diagnosis (9)

Depression (3)

Avoided counseling

Denial of mortality

Mental toughness

Daily mental battle

Sleep issues

Emotional

Devastated (3)

Fear (3)

Anger (4)

Disbelief

I didn't have time to process it due to moves and military life

Concern

Confidence is gone due to unit

No purpose

Trust issues

Spiritual

Music to cope (2)

Not religious (4)

Religious (9)

Praying and going to church to cope

Category 4: Military Facets (Questions 6, 7, 13, 14)

Military Support

Military advocated for us

Military is like family before and after death

EFMP supported us
Good Military healthcare system

Lack of Military Support

TRICARE regions operate differently (3)
Lack of continuity of care (4)
Difficult to navigate the military and TRICARE
Had to change MOS (2)
Military didn't care about cancer because they didn't treat me
Sometimes ranks/gender treated differently
People worry about EFMP affecting career (2)
Still required to report for duty
No support for family, even FRG (2)
No mental health support for SM or family
Command does not care/Abandoned
Suck it up and push through
Made me feel useless
Military needs to improve in accuracy of diagnosis and apologize when wrong
Wrong diagnosis adds extra stress
Military doctors need to learn from their mistakes
Military doctors need to give patients treatment options

Difference in being military with cancer

Had to PCS (7)
Had to do TDY (2)
Spouse deployed during treatments (2)
Better benefits
No out-of-pocket costs (4)
Military may have caused cancer
I don't know anything other than military (3)
Harder being in military (2)
Job security (2)
Military spouses are a good support
Wonder if I would have the same support if spouse was a lower rank
Relied on military spouses that were strangers
Was harder on my deployed spouse

What it means to serve as a SM or SP

Military was everything
Military gave me more than a small-town life
Great career and retired even after cancer
Love being a military spouse (3)
Volunteerism
Meeting new people
Proud of service (3)
Made me proud to be an American

Military families give up a lot
Being a military spouse made me strong
Being a military spouse, I never knew if my spouse was safe
I want to be done with the Army
Learned to embrace the suck through deployments
Change needs to occur in the military environment, especially at Fort Hood
I am just a number to be replaced
Fort Hood says they care but they do nothing to show it
The military is a family and I can still have a career and be a military spouse
Joined to escape poverty

APPENDIX F: Demographic Measures
Participant Background Data Sheet

Demographic Information

Branch of Service:

Education Completed:

Marital Status:

Gender:

Age:

Race/Ethnicity:

Cancer Type and Diagnosis Date:

Military Status at Diagnosis:

Military Installation at Diagnosis:

Rank at Diagnosis:

Type of TRICARE (Only for Spouses):

Children: