ADAPTING COMMUNITY-BASED PSYCHOLOGICAL FIRST AID TO A PALLIATIVE/HOSPICE CARE TEAM: A COMMUNITY-BASED PARTICIPATORY RESEARCH APPROACH

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ABSTRACT

Palliative and hospice care patients face serious or life-limiting illnesses; as a result, patients and their caregivers often have to overcome challenges related to psychological distress. Furthermore, stress related to individuals' medical and psychosocial concerns can lead to crises. While current literature acknowledges patients' and caregivers' experience of depression, anxiety, adjustment disorders, traumatic stress, and other disorders, there remains a gap in addressing these challenges through interventions that are tailored to the unique needs of this complex population. Additionally, professionals that comprise palliative and hospice care teams are often not trained to implement interventions to help prevent and intervene in response to psychosocial distress and crises. This current study proposed the adaptation of Community-Based Psychological First Aid (CBPFA) as a promising framework for providing timely and accessible psychosocial support within these communities. CBPFA is a therapeutic crisis intervention approach often used following disasters; however, it has been adapted for various non-disaster contexts, including with emergency medical service responders, oncology departments, and native communities. Utilizing a Community-Based Participatory Research (CBPR) methodology and a partnership with an interdisciplinary palliative care team at a rural South Dakota hospital, training on CBPFA was provided to 7 palliative team members. Training sessions and focus groups allowed for feedback on the applicability and feasibility of CBPFA for palliative and hospice care settings. The results of this study, using a phenomenological case study approach, exhibit CBPFA to be a beneficial method that builds off the skills of professionals in these settings. This initial adaptation of CBPFA for palliative and hospice care helps to reduce barriers by offering tools to non-mental health-trained professionals to address the complex psychosocial needs and crises of patients and caregivers coping with life-limiting illnesses and end-of-life transitions. CBPFA, adapted for palliative and hospice care, offers practical guidance and support during times of crisis and adjustment and has the potential to enhance resilience, foster coping skills, and improve the overall quality of life for patients, caregivers, and professionals in these settings. Further research and implementation efforts are warranted to evaluate the efficacy and feasibility of CBPFA in other palliative and hospice care contexts.

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Finally, I want to dedicate this dissertation to my mother, who has inspired me throughout this study. Although she is no longer with me to lend a listening ear during challenging times or offer words of support during my achievements, her memory has been a constant presence throughout this journey. Her experience in hospice care has served as a reminder of the importance of this work, and I hope that the adaptation developed in her memory will help others on their journey through palliative or hospice care. Through this project, her generous spirit lives on.

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Adapting Community-Based Psychological First Aid to a Palliative/Hospice Care Team: A Community-Based Participatory Research Approach

Individuals across the lifespan diagnosed with life-limiting or terminal illnesses have a right to patient-centered end-of-life (EOL) care (Arora et al., 2017). This form of care is typically delivered through palliative or hospice care services and depends on the individual's prognosis, treatment options, and preferences (NIH National Institute on Aging, 2021). Emerging in the United States in the 1970s (Finestone & Inderwies, 2008), it is estimated that 20 million individuals benefit from palliative care services worldwide yearly (Cruz-Oliver, 2017). Despite the universal trend of palliative and hospice services, the terms "palliative" and "hospice" hold different meanings across the globe. One country may call this service "hospice care," another may call it "palliative care." Traditionally, a "hospice" was the setting in which "palliative care" was provided (COMECE, 2016). Regardless of the terminology, each patient enrolled in palliative or hospice care services demonstrates the fulfillment of EOL wishes and desire for quality of life.

In the United States, palliative care is a specialized form of symptom management for individuals with severe illnesses. It is traditionally offered with life-saving treatments (NIH National Institute on Aging, 2021). The primary aim of palliative care is to improve the overall quality of life and aid in symptom management for severely ill patients. Cancer, Parkinson's disease, heart failure, and dementia are some examples of severe illnesses for which palliative care patients may be receiving treatment. Palliative care can be offered in various settings, including hospitals, nursing homes, specialty clinics, or private homes.

Conversely, hospice care is an approach that provides symptom management when there is an absence of life-saving treatment (NIH National Institute on Aging, 2021). Hospice care is initiated when the individual is within six months of EOL (Cruz-Oliver, 2017) and is chosen due to non-response to treatment, discontinuation of treatment, or old age (NIH National Institute on Aging, 2021). In the United States, hospice care services can be covered for Medicare-eligible patients if a physician has determined that they have less than six months to live without life-saving treatment. Like palliative care, hospice can be provided to patients in hospitals, nursing homes, hospice centers, or private homes. An interdisciplinary team provides symptom management at EOL and focuses on care, comfort, and quality EOL (National Hospice and Palliative Care Organization, 2021). Approximately 1.55 million Medicare beneficiaries in the United States utilized hospice services in 2018 (National Hospice and Palliative Care Organization, 2021).

Palliative/hospice care services focus on pain and symptom management and are provided to individuals with life-limiting illnesses or who reach EOL (National Hospice and Palliative Care Organization, 2021). Patient symptoms can range from pain and discomfort to restlessness and psychological distress. To ensure that all symptoms are managed appropriately, care teams are made up of several disciplines, including physicians, nurses, hospice aides, social workers, clergy, counselors, and volunteers (Finestone & Inderwies, 2008). Within home hospice care, family members typically serve as the primary caregivers to individuals at EOL (National Hospice and Palliative Care Organization, 2021; Reblin et al., 2015). Often, hospice care teams are available to guide caregivers in their role and may provide respite support to caregivers needing a break. Family caregivers became even more valuable during the COVID-19 pandemic, as medical personnel were in short supply (Kent et al., 2020). Overall, each palliative/hospice team member can support the individual based on their needs, whether spiritual, physical, emotional, intellectual, etc., while also ensuring autonomy and choice in their care (Arora et al., 2017).

As part of the care team, psychologists can play a critical role in ensuring high-quality care in palliative/hospice care settings, promoting a whole health psychosocial perspective related to person-centered care. Psychologists are trained in a range of cultural, developmental and psychosocial concerns that can influence each person's experience of life-limiting illnesses and EOL. They can inspire hope, purpose, and meaning in the face of much suffering for patients, caregivers, and team members. Psychologists are also trained to recognize the difference between typical grief, bereavement, or psychosocial symptoms and distinguish them from more severe pathology that would require more intensive treatment. Unfortunately, palliative/hospice teams do not always have a trained psychologist available, despite this population's demand for psychosocial interventions and assessment (Kasl-Godley et al., 2014).

Several therapeutic interventions have effectively addressed patients' and caregivers' psychological concerns (Kumar et al., 2012). These interventions are carried out by trained mental health professionals, who are not always available to care teams. Additionally, there are limited therapeutic interventions that enable non-mental health professionals to provide psychological support to patients or their caregivers (i.e., family and friends). Therefore, Community-Based Psychological First Aid (CBPFA) would serve as a valuable resource for palliative/hospice teams to provide psychological assistance to their patients and caregivers. CBPFA is an intervention, capable of being implemented by those not trained in mental health, that aims to reduce the occurrence of emotional and behavioral concerns related to stress and can be adapted based on the community it aims to support (Jacobs, 2016).

Purpose of Study

Presently, there is a lack of research focusing on terminally ill populations, their caregivers, and their experience of psychological distress (Crunkilton & Rubins, 2009). However, psychological distress within this population is not novel and persists in palliative/hospice care settings (Akechi et al., 2004; Clayton et al., 2014; Conill et al., 1997; Crunkilton & Rubins, 2009). Additional research is needed to explore the differences in patient and caregiver concerns. Presently, there is no research on the use of community-based participatory research (CBPR) to adapt CBPFA in palliative/hospice care communities. One of the central tenets of CBPFA is its emphasis on building off the community's identified strengths (Jacobs et al., 2016). Regarding palliative/hospice care strengths, team members have immense knowledge related to grief and bereavement. Care teams are also made up of several disciplines, all of whom can contribute uniquely to the adaptation and implementation of CBPFA in their community or care team (National Hospice and Palliative Care Organization, 2021).

This study sought to support palliative/hospice care patients and their caregivers by adapting CBPFA. By utilizing the methodology of CBPR, the researcher aimed to build off the strengths and needs of a palliative care team, with the ultimate goal of promoting CBPFA's efficacy in reducing psychological distress for patients and their caregivers. This study addressed patient and caregiver psychological distress by training a rural South Dakota palliative care team in Community-Based Psychological First Aid (CBPFA), a culturally responsive intervention for individuals in crisis or psychological distress (Jacobs, 2016). Through this approach, the palliative care team can further strengthen their community, defined as the care team, patients, and caregivers, through the development of a palliative-specific CBPFA training for use with interdisciplinary staff and caregivers, with the hopes that an adapted version of CBPFA can help them effectively intervene when patients or caregivers experience psychological distress.

To provide the rural South Dakota palliative care team with the most effective and patient-centered intervention possible, the specific aims of this study were to 1) train the care team on CBPFA to help patients and caregivers cope with crises and psychological distress related to their life-limiting illness or EOL, 2) adapt CBPFA with the support of the care team to ensure that the methods of CBPFA are appropriate for a palliative/hospice care community, and 3) monitor and evaluate the feasibility of, and satisfaction with CBPFA for palliative/hospice care.

Literature Review

Psychosocial Concerns in Palliative and Hospice Care

The goals of palliative and hospice care are to provide symptom management for life-limiting illnesses and ensure quality EOL. This includes managing the physical and psychosocial needs related to patient distress, including acute symptom presentation and crises (National Hospice and Palliative Care Organization, 2021). Broadly, psychosocial needs are described as any combination of cognitive, emotional, spiritual, or behavioral needs of a patient and their caregivers that affect overall well-being. Unfortunately, Baile and colleagues (2011) highlight the frequency with which healthcare teams may fail to detect significant patient psychosocial concerns. There are various reasons why team members may fail to detect such concerns, some being lack of patient disclosure, clinicians' fear of asking, lack of training, and the hectic nature of the environment. Given the occurrence of missed psychosocial concerns, current research emphasizes the importance of healthcare teams being sympathetic to the impact of these concerns, resulting in a more comprehensive understanding of how they can influence patient and caregiver psychological distress (Baile et al., 2011). Psychological distress is one of the many psychosocial concerns that patients and caregivers within palliative/hospice care experience (Clayton et al., 2014; Crunkilton & Rubins, 2009; Grunfield et al., 2004; MacLeod et al., 2012; Washington et al., 2018). Psychological distress can be defined as an unpleasant emotional experience that interferes with one's ability to cope with their diagnosis, symptoms, or treatment (Crunkilton & Rubins, 2009).

Psychological distress can also encompass a variety of mental health conditions that may be relevant for patients and caregivers, including traumatic stress (Ganzel, 2018) and depression and anxiety (Conill et al., 1997; Grunfield et al., 2004; Kasl-Godley et al., 2014; Kozlov et al., 2019). Despite recognition that psychological distress exists in these populations, research suggests that it is often underdiagnosed and under-treated (Kelly et al., 2006). For healthcare teams to manage all patient symptoms and well-being, psychological distress must be assessed and alleviated. Mistry et al. (2015) propose that one way to achieve this is by viewing patient psychological distress on a continuum, allowing healthcare teams, caregivers, and researchers to understand the different presentations of psychological distress better.

Understanding psychological distress on a continuum allows us to understand that when individuals are faced with tremendous stressors, variability in individual reactions is to be expected. For example, two individuals exposed to the same stressor are likely to have varying levels of psychological distress (Spielberger, 1966). Several factors contribute to each individual's reaction, including cognitive appraisal, trait personality, individual thoughts, beliefs, internal state, emotional state, and coping skills. When considering all these factors, the severity and duration of an individual's psychological distress can vary widely. (Spielberger, 1966).

Appreciating individual stress and coping differences can help inform how and when to provide psychological support outside a formal diagnosis.

Patient Psychological Concerns

Traumatic Stress. Ganzel (2018) reports that individuals who have been battling severe illnesses often have an extensive history of invasive procedures, emergency room visits, hospitalizations, health emergencies, and severe side effects, to name a few. These experiences are labeled as “suffering”; however, this term does not properly identify the psychological distress often associated with these experiences, which have the potential to develop into traumatic stress reactions (Ganzel, 2018) or more persistent posttraumatic stress disorders. For individuals diagnosed with a life-limiting illness, the shock of such a diagnosis can be a traumatic stressor, often triggering the development of PTSD (Feldman, 2011; Ford et al., 2015; Volpin, 2018). There are no official estimates of traumatic stress or PTSD in palliative/hospice populations, although PTSD prevalence rates among cancer patients range between 3% and 35% (Feldman, 2011). According to Ford et al. (2015), traumatic stress is the “biological and psychological reactions to psychological trauma or a traumatic stressor, including acute traumatic stress reactions and posttraumatic stress symptoms” (p.7).

Understanding PTSD in patients with life-limiting illnesses or near EOL is complex. Healthcare providers and clinicians are tasked with determining whether the trauma results from the patient’s severe illness or if the severe illness has triggered preexisting PTSD (Feldman & Periyakoil, 2006). For those nearing EOL, PTSD can further complicate the dying process. In patients with a history of trauma, the terminal illness may trigger previous traumatic experiences, resulting in additional psychological distress. Moreover, as an individual reaches EOL, it is not uncommon to review their life. This is traditionally referred to as a life review. Those with PTSD nearing EOL may choose not to engage in a life review, often to avoid triggers. A life review may also negatively affect EOL if the patient lacks adequate coping skills or social support (Feldman, 2011). Patients with a history of unresolved trauma may find this process triggering, anxiety-provoking, and lead to other unpleasant emotions. Third, patients with a life-limiting illness who have PTSD may use avoidance to cope with symptoms related to their illness. This can be detrimental to the individual if it is the medical treatment that they avoid. Avoidance has been linked to a lack of death acceptance, resulting in poorer life satisfaction (Goetzke, 1995). Feelings of distrust may impair the relationship of the patient and their healthcare team, including refusal of care and lack of communication (Feldman, 2011). Individuals with a long history of trauma and PTSD may lack caregiver support due to a long history of avoidance and social isolation (Feldman, 2011; Feldman & Periyakoil, 2006). Lack of social support during the end of life has been shown to lead to increased depression, pain, and reduced quality of life (Feldman, 2011).

Depression, Anxiety, and Related Disorders. Even if exposure to traumatic events does not result in psychological trauma, other psychiatric disorders may develop, such as depression, anxiety disorders, substance use, etc. (Ford et al., 2015). Prevalence rates of depression at EOL range from 11% (Grunfield et al., 2004) to 38.6% (Conill et al., 1997). Anxiety also contributes to psychological distress, with approximately 19% (Grunfield et al., 2004) to 43% (Conill et al., 1997; Kozlov et al., 2019) of hospice patients reporting anxiety-related symptoms. Delirium, a disruption in attention, awareness, and cognition from baseline (American Psychiatric Association, 2013), is also common for patients with life-limiting illnesses. Research estimates that 20-40% of newly admitted hospice patients have symptoms of delirium, with rates increasing as patients near EOL (Gagnon et al., 2000; Kelly et al., 2006; Lawlor et al., 2000).

More importantly, it is essential to understand that psychological symptoms may fluctuate throughout the illness, given contextual factors. For example, factors such as pain, social support, treatment side effects, and disease progression can increase symptom expression (Kelly et al., 2006). Hospice patients with a higher number of these contextual concerns (i.e., pain, loss of independence, diagnosis) have shown increases in their psychological distress (Heaven & Maguire, 1998). However, effective identification of psychological distress and disorders is often difficult in palliative/hospice care populations due to the high number of physical symptoms that may mimic symptoms of depression and anxiety. Like traumatic stress, symptoms of depression and anxiety may be due to the patient's illness or factors unrelated to their disease (Kelly et al., 2006).

Several mechanisms related to patient concerns have been proposed to influence the patient experience of psychological distress in palliative/hospice care, specifically, rumination and increased abstractness (Galfin & Watkins, 2011). Patients diagnosed with life-limiting illnesses may spend more time reviewing their current and future goals, ruminating about how those goals may change or are no longer obtainable. Maladaptive or abstract rumination can lead to symptoms of depression and anxiety due to focusing on "why an event happened" rather than "how an event happened." Recognition of "how" allows individuals to problem solve and explore alternative solutions or "how" to progress their goals. Galfin and Watkins (2011) explain this phenomenon in palliative care patients through Construal Level Theory (CLT). CLT suggests that individuals abstractly examine more psychologically distant events. Patients diagnosed with life-limiting illnesses experience more uncertainty in their day-to-day lives about such things as symptoms, functioning, and family well-being. As a result, their concerns become more psychologically distant, leading to more maladaptive, abstract thinking and rumination, theoretically increasing their risk of depression and anxiety (Galfin & Watkins, 2011).

Patient distress is frequently associated with patient physiological well-being. Increased physical symptoms, such as pain, have also been shown to increase patient psychological distress, including depression and anxiety (Gotze et al., 2014; Vachon et al., 1995). In cancer patients, those in pain are twice as likely to report psychological distress (39%) compared to patients without pain (19%; Schwarz & Singer, 2008). Poorly managed pain has also increased suicide risk for patients diagnosed with cancer (Vachon et al., 1995). When examining patient levels of psychological distress, it is essential to understand how symptoms present over time. Symptoms, such as pain, are often an unavoidable reality when diagnosed with a severe illness (Gilbertson-White et al., 2011); however, distress levels may fluctuate over time. Overall, it appears that patient psychological distress is heavily influenced by disease progression, proximity to death, and increased pain levels (Götze et al., 2014). Understanding patient psychological distress ensures that appropriate intervention promotes patient functioning and well-being.

Caregiver Psychosocial Concerns

Traumatic Stress. Within the palliative care and hospice system, the priority is patient symptom management; however, the needs and concerns of caregivers are also necessary to consider (Clayton et al., 2014; Washington et al., 2018). In traditional hospice care settings, the primary caregiver is a family member or friend, and they receive assistance from a hospice care team (National Hospice and Palliative Care Organization, 2021; Wittenberg-Lyles et al., 2011). Approximately 40% to 60% of family caregivers report high levels of psychological distress (Dumont et al., 2006). Just as patients are at risk of traumatic stress, family caregiver traumatic stress is prevalent in palliative/hospice settings. Despite healthcare teams' efforts to mitigate the psychological distress and burden on caregivers, complicated grief and traumatic stress are still present (Sealy et al., 2015).

For caregivers who have been exposed to many traumatic events while caring for their loved one and who are unable to cope with the passing of the patient, there is the risk of developing complicated grief or posttraumatic stress disorder, particularly in cases where distress increases over time (Ford et al., 2015; Sanderson et al., 2013). According to the United Kingdom public health model of grief in palliative care, approximately 10% of grieving caregivers are at risk of complex grief, requiring additional mental health services (Aoun et al., 2012). Complicated grief has become so prominent in palliative/hospice care that it has been coined "caregrieving" (She & Prigerson, 2018), which acknowledges that grief often begins before the death of a patient. Some known risk factors for complicated grief include pessimism, lack of support, unpreparedness for death, depression, and stressful life events (She & Prigerson, 2018; Sanderson et al., 2013). Insecure attachment styles between caregiver and patient and higher levels of communication, love, and closeness have also been shown to predict complicated grief (Sanderson et al., 2013). Unfortunately, minimal research has been done regarding caregivers' exposure to traumatic stressors, complicated grief, and posttraumatic stress disorder (She & Prigerson, 2018; Sanderson et al., 2013).

Sanderson and colleagues (2013) investigated the role of PTSD and trauma in caregiver grief responses. Using a qualitative methodology, researchers found that all 32 of the caregivers they interviewed used language suggesting trauma. Many of the participants noted that their experiences of trauma persisted several months after the loss of their loved one (Sanderson et al., 2013). Additionally, several participants shared their experiences of witnessing their loved ones die. The researchers suggest that this experience alone could cause significant trauma, even with expected deaths (Sanderson et al., 2013). Of those grieving, the caregivers with the most distress tend to be the least likely to seek treatment (Sealey et al., 2015).

Depression, Anxiety, and Related Disorders. The emotional and physical burden often placed on caregivers can result in psychological distress (Grunfield et al., 2004). Estimates suggest that 39.1% of caregivers experience depression at the start of hospice care, and roughly 30% deal with anxiety (Grunfield et al., 2004). Additional estimates suggest depression could be as high as 59% and anxiety 50% for caregivers (Hudson et al., 2015). Götze and researchers (2014) hypothesize that caregivers experience higher levels of anxiety than patients, while patients experience higher levels of depression. Caregiver depression and anxiety are positively correlated with factors such as caring for a spouse, amount of social support, and financial burden (Dumont et al., 2006; Götze et al., 2014). Dumont and colleagues (2006) found that patient deterioration and decreased mobility led to increased caregiver psychological distress, including depression and anxiety. Patient deterioration is thought to be related to increased caregiver burden. These findings are further supported by a longitudinal study of psychological distress and depression pre- and post-bereavement (Chentsova-Dutton et al., 2002). Researchers found that caregivers' experience of depression peaked just before patient death and remained stable for approximately two months after a patient death. Approximately 13 months post-bereavement, caregiver depression was comparable to that of study control. These findings suggest that symptoms of pre-bereavement levels of depression may be more related to caregiver burden and not the experience of grief (Chentsova-Dutton et al., 2002).

In comparing depression symptoms between caregiving spouses and caregiving children, spouses appeared to have higher rates of depression, as observed by researchers (Chentsova-

Dutton et al., 2000). However, being a young caregiver and caring for a young patient leads to higher rates of psychological distress for caregivers (Dumont et al., 2006). In addition, several studies suggest that female caregivers are at an increased risk of depressive symptoms (Chentsova-Dutton et al., 2000; Dumont et al., 2006; Götze et al., 2014). These findings advise the need for more personalized support as there are several factors to consider when examining caregiver psychological distress.

Furthermore, the impact of caregiver burden and its relation to psychological distress should not be underestimated. Using thematic analysis, Wittenberg and researchers (2011) found that the perception of the “heaviness” of caregiving was frequently a precursor to caregivers’ psychological distress. The burden of their role was often reported to lead to a decrease in emotional and physical self-care. Additional concerns reported by caregivers included conflicting feelings associated with wishing for patient death. Immense amounts of burden coupled with thoughts of guilt increased caregivers’ distress. Fear of the future without the patient and the transition from curative care to hospice care were shown to have similar impacts (Wittenberg-Lyles et al., 2011). The caregiver burden can also be increased by other factors unique to the caregiving experience, such as taking time off from work, decreased work performance, limited social interaction, and separation from social support (Chentsova-Dutton et al., 2000).

The presentation of psychological distress in caregivers may differ from that of the general population. Chentsova-Dutton et al. (2000) found that of 112 hospice caregivers assessed for depression, the most common symptoms reported were low mood (34%), trouble falling asleep (22%), and feelings of loneliness (19%). Surprisingly, they found that 14% of caregivers also reported thoughts of suicide. Of caregivers who endorsed symptoms of anxiety, the most common symptoms included feeling tense or keyed up (31%), fearfulness (16%), and nervousness (15%). Compared to a control group, caregivers had overall higher levels of psychological distress, such as hostility, rumination, and psychoticism. Caregivers who experience higher levels of psychological distress are theorized to ignore their own emotional and physical needs. This often leads to poor health, untreated ailments, and more frequent accidents (Chentsova-Dutton et al., 2000). Ultimately, palliative/hospice care team members are responsible for the psychosocial needs of patients and their caregivers as part of symptom management. This includes understanding the degree of psychological distress they experience (Block, 2006) and recognizing when intervention is necessary.

Crisis in Palliative and Hospice Care

Crises occur in many ways, including trauma, family crises, personal loss, and disaster (James & Gilliland, 2016), all of which can occur during the end of life. Unfortunately, these crises have not been extensively explored in the palliative/hospice care literature (Phongtankuel et al., 2019). A large part of providing palliative/hospice care includes providing crisis intervention. Crises in palliative/hospice care may include pain and symptom management, psychosocial concerns, family crises, communication problems, and caregiver exhaustion (National Hospice and Palliative Care Organization, 2021; Phongtankuel et al., 2019). Being diagnosed with a severe illness and the events leading to an individual entering hospice care can often put people into crisis as well (Feldman, 2011; Finestone & Inderwies, 2008; Volpin, 2018). A survey of palliative social workers indicated that palliative patients' highest point of unmet needs, such as symptoms of depression and family conflict, was immediately following admission (Arnold et al., 2006); thus, monitoring psychological distress from the start is critical.

Much of the literature on palliative/hospice crises focuses on pain and physical crises (Phongtankuel et al., 2019). However, high levels of psychological distress for long periods can lead to various crises not related to the patient's physical health. As previously discussed, depression is a concern in palliative/hospice care (Block, 2006). Patients suffering from depression may endorse thoughts of suicide. As with any disclosure of suicidal ideation, suicide risk is considered a crisis in palliative/hospice care and should be thoroughly assessed. This further supports the need for adequate assessment of depression in the palliative/hospice setting, as suicide can result from undiagnosed or untreated depression (Jaiswal et al., 2014). For patients diagnosed with a terminal illness or nearing EOL, depression and suicidal ideation may look different compared to the general population. Increased pain, depression, feelings of hopelessness, and loss of control are a few of the risk factors for suicide in palliative/hospice care populations.

Additionally, patients' indications of suicidal ideation may appear different. For example, individuals nearing EOL may comment to care teams or caregivers requesting a faster death (Block, 2006). These thoughts may be fleeting and occur in times of significant distress or hold more intent with a concrete plan. Regardless, healthcare teams need to be prepared to assess patients' thoughts and determine risk and also assess whether that thought is related to pain the patient is experiencing or a depressed mood. Understanding the context of patient suicidal ideation can allow for more effective intervention (Block, 2006; Jaiswal et al., 2014).

Crises occur in palliative care and hospice settings. Add in the complications of a global pandemic, COVID-19, and palliative/hospice care teams encountered a new set of crises that have never been faced before (Kent et al., 2020). Three major COVID-19 stressors that could lead to crises were identified by Kent et al. (2020). The first is that social distancing, although necessary to control the spread of infection, can lead to increased isolation and a lack of caregiver support. Social distancing was the term initially used to describe physical distancing. Ultimately, this term was misleading and resulted in psychologically damaging social isolation (Sorenson et al., 2021). Second, the financial difficulties associated with the pandemic, on top of caregivers' preexisting financial strain, can be detrimental to the caregiver and patient. Third, balancing the challenges of going to work and acquiring necessary childcare was complicated for caregivers before the pandemic. Loss of jobs, healthcare, risk of exposure to pandemic disease, and virtual learning have likely intensified these issues. Finally, the authors acknowledge that caregivers face complex patient health and safety decisions. For example, they weigh the risks of missing appointments and healthcare services versus avoiding unnecessary exposure to infection (Kent et al., 2020). These challenges highlight the need for crisis intervention to be flexible and adaptable as new crises developed daily with the pandemic.

Family caregiver crises are also common in palliative/hospice care settings. A study of 183 hospice caregivers found that 42% of those interviewed had experienced some form of crisis (Phongtankuel et al., 2019). These crises ranged from patient pain and symptoms to emotional distress and caregiver burden. Additionally, female caregivers were more likely to report crises than male caregivers. During these crises, most caregivers reported seeking support from hospice staff. Most of these crises were considered inevitable, and some felt the crises could have been prevented. Those who felt these crises could have been prevented noted that education from the hospice care team about the dying process would have been helpful. This need for additional education for caregivers was also found in a study by Reblin and colleagues (2015). Some noted that faster services and organization could have alleviated crises (Phongtankuel et al., 2019).

These studies highlight how healthcare teams can proactively support patients and caregivers in coping with crisis.

In a similar review of what caregivers value, Hughes and colleagues (2019) observed the caregiver theme of hospice aid support at night, specifically during times of crisis. The authors suggest that caregivers recognize the value of crisis intervention across all times, not just exclusively during the day. For example, a time identified as extremely important was immediately following the patient's death. Caregivers noted that this time includes several difficulties, such as bereavement, arrangements, and returning medical supplies (Hughes et al., 2019). Additionally, caregivers noted the importance of proactive support rather than reactive support. For example, staff recognizing increases in psychological distress and the subsequent need for intervention before a crisis or excessive strain (Hughes et al., 2019). Despite best efforts, these studies demonstrate that palliative and hospice's unmet needs should be addressed, especially concerning crises.

Crisis Intervention in Palliative and Hospice Care

The ability of a palliative care and hospice team to provide crisis intervention is an essential factor that allows patients to receive care in their homes (Jack et al., 2013). Unfortunately, crisis intervention techniques for psychosocial concerns in this setting have been explored little in the literature. Chung (1993) emphasized the importance of addressing crisis intervention in EOL care. Professionals providing psychosocial services for patients are often restricted when they have to complete assessments due to time constraints. Chung (1993) highlights that crisis intervention should be a priority even if time is limited. His work stressed the need for patient emotional expression during brief hospice care interventions while remaining person-centered. One of his approaches to crisis intervention focuses on the perceptions of dependence of the patient. This comes down to feelings of worthlessness and the inability to cope with their current situation. He notes that by providing counter messages that promote patient self-worth and coping, providers and caregivers can increase patient self-worth and improve their capacity to cope with crises (Chung, 1993).

To help patients and their families cope with the various crises that can develop in their homes at EOL, the Hospice at Home service was trialed in the United Kingdom (Travers & Grady, 2002). This pilot program was designed to provide specialized interdisciplinary care for patients who usually need to attend a hospital to receive services. The intent was not to replace palliative care provided by hospice teams already in place but to build off of and strengthen them with the hope of reducing the psychosocial distress and reduced quality of life that is typically associated with hospital admissions. A vital component of this specialist team would be to respond to crises at home and provide crisis intervention for up to five days following the start of the crisis (Travers & Grady, 2002).

While piloting the Hospice at Home crisis intervention team, researchers found that the crisis team frequently responded to calls related to psychological distress, particularly that of the caregivers (Grady & Travers, 2003). Additionally, there was an overall positive response to the crisis intervention team, with patients and caregivers reporting satisfaction with the care. The results of this pilot crisis intervention team suggest that having a team equipped to provide crisis services led to a more outstanding quality of life for patients receiving palliative care or hospice at home. It also demonstrates that even if not responding to a direct psychosocial crisis, crisis teams can help alleviate some of the distress experienced by patients and caregivers (Grady & Travers, 2003).

Unfortunately, not all individuals diagnosed with life-limiting illnesses choose to take advantage of palliative care and hospice services. Reasons for this are varied but could be due to patients' and families' unwillingness to accept their prognosis (Morgan & Terry, 2014). As a result, these services may only be utilized once the patient is near EOL, leading to a short-term length of palliative or hospice care service. This leads to several challenges when it comes to hospice program admission. Patients who have not sought services sooner may still be avoiding the reality that their death is near. Anticipated short-term hospice stays may result in increased perceived crisis due to the sometimes-quick nature of the admission, making it essential for hospice providers to implement crisis management strategies at that time.

Additionally, individuals may struggle with a conflict between the desire for resuscitation efforts and the wish to die at home. These two desires are traditionally in conflict with hospice care due to the palliative efforts of hospice rather than curative efforts. Although most hospice providers do not require a Do Not Resuscitate order (DNR), some patients entering hospice may wish to receive cardiopulmonary resuscitation (CPR) if they stop breathing or their heart stops. These hospice patients are often referred to as full-code. Hospice admissions typically navigate these conversations with patients and their families to make decisions in advance. Despite these goals of care conversations and patient wishes, some families may request medical aid during perceived crises or sudden patient decline. A DNR in advance allows emergency responders to assist appropriately should they be called (Collopy, 2010). Given the challenges accompanying hospice admissions, crisis management is almost always necessary; however, short-term admissions make it challenging to provide comprehensive crisis management (Morgan & Terry, 2014).

If a person experiences conflicting emotions or desires at the time of admission, Morgan and Terry (2014) recommend that this is a cue to initiate crisis intervention strategies. They stress the importance of building a therapeutic alliance and using compassionate language and active listening. These recommendations fall in line with suggestions from James and Gilliland (2016) and their discussion of what strategies to use when first initiating intervention with a person in crisis. Similarly, Kent (2020) promotes patient and caregiver empowerment during a crisis, focusing on what can be done versus what cannot. They also suggest that crisis plans should be thoroughly discussed and involve multiple providers to ensure continuity of care (Morgan & Terry, 2014). Finally, these crisis management strategies should be utilized for every individual beginning service, supporting the goal of quality EOL and comfort care.

Short-term hospice stays are not uncommon and can happen under unique circumstances such as natural disasters. Regrettably, there are unclear medical resource access guidelines during humanitarian crises. Thus, those doing crisis intervention during these times must know how to triage those who may need palliative care (Nouvet et al., 2018). Waldman and Glass (2019) developed a field guide to help disaster relief workers assist individuals receiving palliative care during a humanitarian crisis and those needing palliative care due to the crisis. The field guide covers symptoms likely to be experienced, such as pain management and anxiety. It also provides recommendations for pediatric populations (Waldman & Glass, 2019). This is a valuable resource for those interested in disaster response. However, additional training and research are necessary to treat individuals needing palliative care adequately during a disaster (Nouvet et al., 2018).

In a study by Csikai & Raymer (2005) examining the training of social workers in EOL care, social workers indicated an extreme need for self-competence in "assessing the complex needs of patient, family and support systems." This includes facilitating healthy family communications and providing appropriate crisis intervention (Csikai & Raymer, 2005). Additionally, it has been suggested that it is just as crucial for volunteers to be trained in crisis intervention conflict resolution due to the high rates of conflict in their presence. Proper training would help with stress experienced by volunteers and help with volunteer attrition rates (Lafer, 1991).

Current Psychological Support Practices

Much to the disadvantage of patients and their caregivers, several barriers prevent palliative/hospice teams from recognizing the impact of psychological distress. Barriers include patient and caregiver reluctance to disclose, symptom presentation, clinician fear of “opening Pandora’s box,” lack of training, limited interventions, and the chaotic nature of the job (Baile et al., 2011; Crunkilton & Rubins, 2009). These barriers can result in the failure of medical professionals to fully understand the impact of psychosocial concerns on patient and caregiver psychological distress (Baile et al., 2011). Crunkilton and Rubins (2009) hypothesize that psychological distress is expected in these patient populations and perhaps not given the attention it deserves. Patient and caregiver psychological distress may also be indirectly reported, preventing care teams from recognizing their need to intervene (Clayton et al., 2014).

Measuring psychological distress can be difficult for various reasons regarding the end of life. Kelly and colleagues (2006) highlighted the difficulty of assessing psychological symptoms due to measures not being validated for use with palliative/hospice care patients and assessment strategies often being too burdensome on patients. For example, patient interviewing may be difficult or impossible to conduct, and caregiver reports often vary in their patient experience accuracy (Kozlov et al., 2019).

Research highlights several evidence-based interventions for palliative/hospice populations, ranging from short-term to more long-term applications depending on patient needs (Kumar et al., 2012). For example, Dignity Therapy, developed by Harvey Chochinov, M.D., is a short-term therapy designed to treat psychological distress associated with EOL. Dignity Therapy is conducted in one to two sessions, allowing patients to share their history. This history may include life stories, lessons learned, or messages to be passed on to future generations. Sessions are typically recorded, and transcription is created as a written legacy. Dignity Therapy has increased patient reports of quality of life and sense of dignity. However, despite terminally ill patients reporting Dignity Therapy to be helpful, compared to standard palliative care and patient-centered care alone, levels of distress were not shown to change post-intervention (Chochinov et al., 2011).

Similarly, a Short-Term Life Review (STRL), adapted from a structured life review therapeutic technique, is conducted over two sessions and focuses on patients’ identity, memories, and legacy. The first session of STRL is recorded and transcribed. From the first session interview, the therapist creates an album of pictures that represent the patient’s life. The second session reviews the album to emphasize positive emotions and satisfaction (Kumar et al., 2012). STLR has been found to improve patient suffering (i.e., depression and anxiety) and improve happiness (Ando et al., 2008). These outcomes were confirmed in a comparison study of STRL and supportive psychotherapy, with patients receiving STRL reporting better spiritual well-being, hopefulness, and sense of meaning (Ando et al., 2010).

Short-term therapies are traditionally used with hospice patients or those nearing EOL. However, long-term therapies can be utilized with terminally ill patients who are not near EOL in either palliative or hospice care. For example, Cognitive Behavioral Therapy (CBT) for terminally ill populations looks at challenging distorted thinking and beliefs related to their illness or EOL. CBT is an evidence-based intervention for depression or anxiety in healthy adults; despite a lack of research assessing CBT in palliative/hospice populations, expert opinion suggests that patients with anxiety and depression would benefit from sessions (Kumar et al., 2012; Rayner et al., 2011).

Finally, Meaning-Centered Group Therapy (MCGT) was developed by William Breitbart, M.D., to encourage meaning, well-being, and purpose for patients with terminal illnesses to improve despair and distress. MCGT comprises 8 group sessions, where patients discuss identity, meaning, and how their terminal illness impacts them. Compared to supportive group therapy, MCGT improved terminally ill patients’ sense of meaning and spiritual well-being (Breitbart et al., 2010). Unfortunately, MCGT is not as applicable to hospice care patients, as they are often home-bound (Kumar et al., 2012).

In the United Kingdom, emphasis has been placed on using a Four-Tier Model of Psychological Support (National Institute of Health and Clinical Excellence, 2004) for cancer patients and their families. This model supports the education of care teams in identifying and addressing psychological distress in patients. The first tier of the model enlists all medical and social work professionals to recognize the psychological needs of patients. This level of intervention includes psychoeducation, effective communication, and general support. The second tier requires professionals with expertise in psychological distress who can screen for psychological distress and problem-solve as necessary. The third-tier recruits trained and accredited professionals to assess and appropriately diagnose psychological distress. Trained professionals can provide necessary intervention (i.e., symptom management and solution-focused therapy). The final tier utilizes mental health specialists who can diagnose a more comprehensive range of psychopathology and provide more intensive psychological interventions such as Cognitive-Behavioral Therapy (National Institute of Health and Clinical Excellence, 2004). It has been demonstrated that mental health specialists on tiers four and three can provide training to less-specialized team members on tier two and increase their confidence with concerns related to psychological distress, intervention strategies, and practical communication skills. This training model effectively supports the patients receiving care at tiers one and two (Jenkins et al., 2010). Unfortunately, these results have only been found in cancer patient populations and cannot be generalized to patients with other life-limiting illnesses.

Much of the palliative/hospice care literature focuses on addressing the psychosocial needs of patients, leaving little research dedicated to supporting caregiver psychosocial needs. In Great Britain, Walsh et al. (2007) conducted a randomized trial to reduce psychological distress in palliative care caregivers using a caregiver adviser intervention. Trained advisers meet weekly with caregivers and often advise, support, and assess caregivers' needs. Following a 6-week intervention, compared to a usual care control group, caregivers receiving the intervention did not show significant decreases in psychological distress as measured by the General Health Questionnaire (GHQ-28). The researchers concluded that the intervention was too brief, not allowing a change in distress. Likewise, adding additional staff may have been unnecessary due to the sizeable teams that palliative care programs already have (Walsh et al., 2007).

Similar approaches for supporting caregivers have been developed, emphasizing psychoeducation to meet caregiver needs and improve psychological well-being. Hudson et al. (2013) conducted a randomized controlled trial comparing psychoeducational interventions to caregivers in Australia. Although the intervention improved caregivers' competence and preparedness, there were no significant decreases in caregivers' distress. Similar to Walsh et al.

(2007), the short length of the intervention may have led to negative results. However, both studies acknowledge that providing effective interventions for caregiver populations is difficult due to caring for a loved one with declining health (Hudson et al., 2013; Walsh et al., 2007).

As mentioned, palliative/hospice care teams must manage a wide range of symptom presentations, which can be challenging as every patient has different symptoms to varying degrees. Regardless of the patient, the treatment goal is symptom management and comfort (Crunkilton & Rubins, 2009). Effective treatment in palliative/hospice enlists several strategies (i.e., medication management, psychotherapy, existential therapy) and depends on patient needs and preferences. Depending on the training of care team staff, emphasizing medical interventions to manage all symptoms could prevent psychosocial problems from being appropriately addressed (Crunkilton & Rubins, 2009; Kozlov, 2019). CBPFA could significantly impact this population by training palliative/hospice care staff in a psychological approach to managing symptoms. In addition, CBPFA would draw attention to the necessity of psychosocial interventions and increase awareness of psychological distress for both patients and caregivers.

Community-Based Psychological First Aid

Providing therapeutic interventions to palliative/hospice patients and their caregivers does not come without its limitations, and this study aimed to address these challenges by adapting CBPFA to palliative/hospice care. The previously mentioned interventions require formal training in delivering therapeutic services. However, not all palliative/hospice teams have licensed mental health providers on their care teams to provide such interventions (Kas-Godley et al., 2014). Additionally, current interventions fail to teach care team members how to recognize psychological distress and appropriately intervene. This is where CBPFA can bridge the gap. CBPFA is ideal for a palliative/hospice care setting for several reasons. The first is that the whole care team can be trained on the approach, regardless of their role (Jacobs, 2016). Second, it allows individuals to recognize psychological distress both within themselves and those around them. Finally, CBPFA can be adapted to the care team, setting, or community it intends to serve to make it most applicable and practical (Gaster et al., 2018).

Overview of CBPFA

CBPFA is a model of Psychological First Aid (PFA; Brymer et al., 2006) that emphasizes the needs of a specific community (Jacobs, 2016). PFA, on its own, is an early intervention used by mental health professionals working with individuals who have experienced trauma. Traditionally, PFA has most widely been implemented in disaster situations; however, it has successfully been applied in other settings where psychological trauma occurs (Forbes et al., 2011; Vernberg et al., 2008). CBPFA is a form of psychological first aid that gives community members skills to cope with stress and support family, friends, and colleagues who may also be experiencing stress. Training in CBPFA is traditionally focused on non-mental health professionals, making it ideal for populations with limited access to mental health providers.

CBPFA focuses on the strengths within each community while remaining aware of traditions and values. "The CBPFA model of psychological first aid builds on the strengths of the community in which the individual lives and provides a more systematic understanding of how to cope with difficult moments and periods in life" (Jacobs, 2016, p.3). A unique component of CBPFA is that it can be adapted to specific communities to best serve each community's needs. CBPFA is most commonly adapted with a committee representative of the community. The training can be adapted and implemented to serve the community best through collaboration. Trainers in CBPFA will typically explore a list of topics that include "How to be a Helper; Traumatic Stress, Active Listening; Problem-Solving; Instrumental Assistance; When and how to Make a Referral for Professional Assistance; Grief and Bereavement; Self-Care; and Ethics" (Jacobs et al., 2016, p. 1308-1309)

CBPFA Applications

Because CBPFA is intended to build off a community's strengths, it is most effective when adapted to each community it serves (Jacobs, 2016). Through the University of South Dakota Disaster Mental Health Institute, CBPFA has been adapted for various communities and organizations. For example, Tait (2011, 2017) and Bordeaux-Rank (2014, 2017) successfully utilized a Tribal Participatory Research model to train Rosebud Sioux Tribe members in CBPFA. Similarly, emergency medical technicians (EMTs) and paramedics recognized the utility of CBPFA in their work in high-stress situations (Reed, 2013, 2016). Oncology medical staff reported CBPFA to be helpful to patients and colleagues in managing stress (Gray et al., 2019; Larson-Stoa, 2014). Additionally, the effectiveness of CBPFA training was shown in a mixed-method approach in an ungraduated classroom setting (Garigipati, 2020). Using the CBPR methodology, each of these communities and organizations could take components of CBPFA and change them in ways that support their communities' strengths and needs. The goal is to allow the communities to enhance the components of CBPFA they find most necessary and decide how they can be altered to be most applicable (Jacobs, 2016).

CBPFA as Potential Support Method

Adapting CBPFA for palliative/hospice care teams will provide additional psychosocial resources to the community, specifically the palliative team in this study and the patients and caregivers they support. Furthermore, training all staff in CBPFA, not just those with mental health roles, allows all palliative team members to intervene and provide the appropriate support and referral when they encounter a patient or caregiver in distress. Training will also allow staff members to support each other during times of crisis and high stress, as CBPFA acknowledges the necessity of “helpers” taking care of their own physical and psychological health (Jacobs, 2016). The goal of this adaptation and training is to reduce the occurrence of psychological distress or crisis and improve symptom management for those with life-limiting illnesses or nearing EOL. Team members can help moderate patients’ physical symptoms by addressing their psychosocial concerns. CBPFA would allow palliative/hospice team members, regardless of role, to provide timely and accessible psychosocial care and offer patients coping skills when providers are unavailable.

Additionally, service provision looks different for each person receiving palliative or hospice care. CBPFA would allow for flexible support that is adaptable to frequently evolving patient and caregiver needs (Mistry et al., 2014). The various components of CBPFA, such as active listening, problem-solving, grief, and bereavement, are also ideal for palliative/hospice communities. For example, active listening has been demonstrated to increase psychological support essential for patients’ and caregivers’ psychological well-being (Kelly et al., 2006; Jacobs et al., 2016). Lastly, as previously mentioned, CBPFA focuses on the ideals of PFA, including safety, a sense of calm, a sense of self, a sense of connectedness, and the instillation of hope (Brymerr et al., 2006), all of which are principles of palliative/hospice care psychological interventions (Kumar et al., 2012).

Methodology

Community-Based Participatory Research

To support the values of person-centered care and further promote the psychological well-being of patients and caregivers, this study aims to utilize community-based participatory research (CBPR) methodology. There are several defining characteristics of CBPR. These characteristics are what make this approach flexible and adaptable for various communities. CBPR falls under the scope of action research, developed by Kurt Lewin in the 1940s. Action research is a methodological approach used to promote social change (Adelman, 1993). Since its development, action research has evolved into several forms, including participatory research, participatory-action research, and community-based research, to name only a few (Blair & Minkler, 2009). Despite these names being used synonymously in the literature, some believe that action research and participatory research are two different methodologies. Regardless, all value involving community members in the research process (Holkup et al., 2004). For this study, the methodology will be referred to as CBPR and the community members are defined as team members of a rural palliative care team.

Several principles distinguish CBPR from other methodologies. Israel et al. (1998) highlights the first principle as acknowledging that the community itself is its own identity, and its unique qualities define it. Additionally, CBPR incorporates the community's strengths and resources, prioritizes community and researcher collaboration, integrates knowledge from both the community and researcher, and promotes co-learning and empowerment through knowledge exchange. Finally, CBPR allows for flexible change in the research process, explores both positive and ecological models of health, and disseminates findings to all partners in the research process (Israel et al., 1998).

As the name implies, the community, specifically a historically marginalized community, is a central component of CBPR. Participants are considered an essential part of their community, establishing the culture, values, norms, needs, etc. (Burns et al., 2011; Collins et al., 2018). It is then understood that the individuals are the "experts" on the community they live and work in and can provide a valuable perspective. Thus, one of the main principles of CBPR is that the community members and researchers have an equal partnership, with the objective that each contributes to the research process (Collins et al., 2018; Wallerstein et al., 2005). The community members are often designated as co-researchers who may design, collect, analyze, and interpret data. By allowing this equal partnership, community members play an active role in developing research questions, deciding what is relevant to their community, choosing how to answer questions best, and implementing the proposed protocol (Burns et al., 2011).

Additionally, because community members have the power to decide how they want research questions answered, they can decide the procedures used. As a result, the community's participation and control remain flexible. For example, the original agenda of a study may be driven at first by the primary investigator and later shift toward a community-focused or mutual agenda (Wallerstein & Duran, 2006). This feature of CBPR helps facilitate the co-researcher relationship (Burns et al., 2011; Wallerstein et al., 2005).

The researchers will continue working with community members throughout the research process and provide the necessary background in research methodology, ethics, interventions, etc. It is also recommended that researchers engaged in CBPR work to build trusting relationships with the community through community events or volunteer efforts (Wallerstein et al., 2005). A trusting relationship is thought to facilitate further the equal partnership between researcher and community (Burns et al., 2011; Israel et al., 1998). A primary goal of CBPR is that whatever change is made (i.e., intervention, policy), the effects will be long-lasting and serve to benefit and promote the community at large (Collins et al., 2018).

CBPR is a well-established methodology, as is the use of CBPR with palliative/hospice care communities (Macleod et al., 2012; Noh et al., 2016). Palliative/hospice care communities, including care teams, patients and caregivers, are ideal communities for CBPR due to the interdisciplinary foundation they are built on, which promotes the collaborative methodology of CBPR (Noh et al., 2016). By incorporating the palliative/hospice team members in the research process, those participating can have more confidence in the purpose of the research, that it serves to benefit the community and is not exclusively for academic objectives.

Most of the time, the community develops the research questions in CBPR. However, there are some circumstances when it may be appropriate to have a general understanding of community needs before beginning CBPR. In this situation, it is likely that the researcher still needs to establish their role in the community and would use this approach to gain access to it. This is done by offering a service that can benefit the community (Burns et al., 2011). For this study, a service provided to the community while conducting CBPR was adapting community-based psychological first aid (CBPFA; Jacobs, 2016).

Rationale

CBPR utilized in the public health domain allows for a collaborative process when exploring research questions, allowing community members, representatives, and researchers to be involved throughout the research process (Israel et al., 1998). A principle of CBPR is to promote the health and well-being of communities, making the approach ideal for research in health-related areas such as palliative/hospice care. Furthermore, CBPR-based interventions can be reinforced by integrating community knowledge and evidence-based practices. Thus, the community's participation in the research process can improve participants' health (Wallerstein & Duran, 2006).

The principles of CBPR align with the goals of palliative/hospice care efforts in several ways, but more specifically through the promotion of well-being and conservation of dignity (Riffin et al., 2016). CBPR allows for the collaboration of challenging-to-reach palliative/hospice care populations whose needs are unrepresented in research. CBPR in the context of palliative/hospice care allows for the collaborative exploration of patient and caregiver psychological needs, in the case of this study, indirectly through reflection by palliative team members. By drawing on both the community's and researchers' expertise, CBPFA can be adapted best to fit the needs of the palliative/hospice community. Additionally, the collective nature of CBPR allows for increased acceptability and adoption of new programs at the agency level (Riffin et al., 2016).

Despite best efforts to manage symptoms, patients with life-limiting illnesses or nearing EOL are at risk of suffering from psychological distress. Additionally, caregivers are at risk of experiencing psychological distress from the burden of caring for an ill loved one. CBPFA can offer additional psychological skills to palliative/hospice care teams, the first line of support for patients and caregivers. CBPFA allows care team members to recognize psychological distress, appropriately intervene, and provide referrals when necessary. This application of CBPFA to palliative setting can be achieved through a CBPR methodological approach. The primary goals of community-based participatory research in this study were to train a specified care team in CBPFA, adapt the model of CBPFA with consideration and input from the specified care team, and monitor and evaluate the feasibility of and satisfaction with CBPFA. In addition, the researcher built a working relationship with a community of palliative care providers.

Research Questions

Central Question: In the context of palliative/hospice care, what aspects of Community-Based Psychological First Aid Training of Trainers (CBPFA ToT) are appropriate and feasible for an interdisciplinary palliative care team?

Sub-questions:

1. In what ways does CBPFA best apply to the patients and caregivers the participants serve?
2. How do participants find CBPFA ToT to be beneficial?
3. What are potential challenges that participants see in using CBPFA in palliative/hospice populations?
4. What are suggestions for improving CBPFA ToT?
5. Is CBPFA training seem feasible for other staff members?
6. What do participants see as the next steps for this project?
7. How would participants like to see results reported/disseminated?

Through community-based participatory research and phenomenological qualitative analysis, feedback obtained during training sessions and follow-up sessions from participants was used to assess the utility and feasibility of CBPFA ToT.

Method

Participants

Two palliative care teams from rural South Dakota participated in the training and adaptation of CBPFA. The teams comprised of a Doctor of Osteopathic Medicine, a Clinical Nurse Practitioner, Licensed Social Workers, and several nurses. Other nursing staff were allowed to participate in the training and adaptation process outside the care team. Moreover, all team members had varying roles and levels of experience within palliative/hospice care, which allowed for diverse considerations when exploring the adaptation of CBPFA. Although patients and family caregivers were not directly involved in the research process, care team members were encouraged to reflect on the patients they serve and their caregivers. Therefore, the researcher acknowledges that palliative patients and their caregivers are secondary, or indirect, community members. Additionally, this study emphasized the impact of CBPFA on the helpers, or the palliative care team, who ultimately provide CBPFA to patients and caregivers. Although patients and caregivers were the most crucial part of this study, the researcher hoped that training the palliative care team on CBPFA would indirectly impact the patient and caregiver population through the care team.

Participants in the current study were members of interdisciplinary palliative care teams in rural South Dakota, with varying positions and tenure in palliative care (*n* = 7). Due to the nature of palliative medicine and the unpredictability of scheduling and personal leave, not all participants could be present for all days of data collection. However, all participants completed both days of CBPFA training and attended the follow-up focus group as they were able to. All seven participants consented to participating in the CBPFA training and attending the three focus groups.

Measures

Demographics. Demographic variables such as age, gender, specific training experience, hours of direct patient care, and use of psychological interventions were gathered from participants during the first training session (see Appendix A).

Knowledge of CBPFA Questionnaire. The Knowledge of CBPFA Questionnaire (see Appendices D and E), developed by Jacobs (2010) to evaluate American Red Cross PFA training, is a 15-item assessment. As its name implies, the questionnaire includes items that assess participants' knowledge of PFA, including "Assisting with basic needs while providing PFA is necessary because," "When using active listening you should," and "What is NOT a sign of vicarious traumatization?" Participants selected answers from a list of four multiple-choice answers. The measure was administered during the first and last training sessions. Participants' responses were intended to assess the efficacy of CBPFA ToT.

Psychological First Aid Usefulness Questionnaire. The PFA Usefulness questionnaire (see Appendix F) was modeled after the questionnaire utilized by Reed (2013) to assess EMS personnel's perceptions of the usefulness of PFA training. Each item on the 16-item questionnaire is rated using a 6-point Likert scale. Answers range from "I strongly disagree" to "I strongly agree." It includes items such as "I learned a lot about my personal self-care in the PFA training," "I feel more comfortable talking to someone about my problems due to the PFA training," and "I believe I am more likely to recognize when someone is in distress because of what I learned in the PFA training." In addition, the questionnaire has nine open-ended questions to assess participants' opinions of CBPFA.

Procedures

Due to the nature of CBPR, this study's proposed procedure and timeline was flexible and subject to change based on the community's expressed needs during the study (Wallerstein et al., 2005). It was anticipated that the care team might present topics or additional research questions of interest throughout the adaptation process; however, this was not the case. The researcher allowed approximately six months for the study and collaborated with the community to decide its conclusion.

The researcher met with the interdisciplinary palliative care team for two and a half hours over two weeks. This schedule differed from the proposed seven, 30-minute CBPFA ToT sessions to best accommodate the care team's schedules. The two training sessions were conducted on June 21st, 2022 and June 28th, 2022. Prior to the start of the first CBPFA ToT session, participants reviewed the informed consent (Appendix B), completed demographic questionnaires (Appendix A), and a pre-training measure (Appendix C). During both sessions, the care team was actively engaged in CBPFA ToT, offering rich discussion and examples from their experiences in palliative/hospice care. Team members were also prompted to share their perspectives on how CBPFA relates to palliative/hospice care communities to begin facilitating the adaptation process.

At the end of both training sessions, participants were asked to complete a brief feedback questionnaire (Appendix E). Participants completed post-training measures during the second and final CBPFA ToT session (Appendix C & D). After completion of CBPFA ToT, the researcher proposed to follow up with the care team at 30 days, 60 days, and 90 days post-training for focus group discussions. However, due to scheduling conflicts, focus groups occurred approximately 36 days, 77 days, and 139 days following the training. These follow-up focus groups were intended to monitor and evaluate the feasibility and satisfaction with CBPFA for the community and provide support and feedback for the use of CBPFA. Although part of the initial proposal, feedback questionnaires were not given to participants at the end of the focus groups to reduce participant burden. Session content and data collection timeline of the study procedures are summarized in Table 1. All training sessions were audio recorded.

Table 1

CBPFA ToT Content and Schedule

Session	Length & Date	Content	Measures & Questionnaires
ToT Session 1	2.5 hours June 21st, 2022	Introduction to PFA, Being a Helper, Traumatic Stress, Grief & Bereavement	Demographic Knowledge of PFA Feedback
ToT Session 2	2.5 hours June 28th, 2022	Coping & Self-care, Active Listening, Problem Solving, Referral & Ethics, Wrap-up	Knowledge of PFA PFA Usefulness Feedback
30-Day Focus Group	1 hour August 3rd, 2022	Discussion & Feedback	
60-Day Focus Group	1 hour Sept. 13th, 2022	Discussion & Feedback	
90-Day Focus Group	30 minutes Nov. 14th, 2022	Discussion & Feedback	

Note. ToT = Training of Trainers

CBPFA Training of Trainers.

To adapt CBPFA to palliative/hospice care, CBPFA ToT was conducted by the researcher during two, two-and-a-half hour sessions. The researcher has her Master's degree in Clinical Psychology from Minnesota State University-Mankato, completed coursework within the USD Disaster Mental Health Institute (DMHI), and was a third-year clinical psychology trainee in the USD clinical psychology Ph.D. program at the time of training. The researcher conducted CBPFA ToT under the supervision of Dr. Beth Boyd. Dr. Boyd is the Director of Clinical Training for the clinical psychology Ph.D. program at the University of South Dakota. In addition, she has been a faculty member in the USD DMHI since 1993 and has conducted several CBPFA ToT sessions. During her career, she has utilized CBPFA in various national and international disasters and crises. For this study, CBPFA ToT sessions covered relevant CBPFA topics outlined in Jacobs (2016). See Table 1 for an outline of CBPFA ToT sessions and the final training schedule.

CBPFA ToT Curriculum. The CBPFA ToT curriculum used for this study was adapted from the Jacobs (2016) manual in addition to PowerPoints created by current and former instructors of record for an undergraduate CBPFA course at the University of South Dakota. Notably, training materials were reviewed with Dr. Boyd and a current CBPFA instructor of record to ensure the accuracy of the materials, given the nature of having to condense such a significant topic into a five-hour training. The agenda for the first day of CBPFA ToT with the care team included a general introduction, a study review, an *introduction to psychological first aid* (PFA), *being a helper, traumatic stress*, and *grief and bereavement*. To start the training, the researcher reviewed their role as a clinical psychology trainee and personal experience within hospice care. After addressing the researcher's positionality with the team, the purpose of the study and participant expectations were discussed. Emphasis was placed on the collaborative nature of the project, and discussion about each topic was encouraged but not required.

The first module of the ToT focused on familiarizing participants with *PFA* and how CBPFA, a specific model of PFA, builds off communities' strengths and knowledge to help community members utilize skills they already have more effectively. This introduction module also emphasized the importance of understanding ordinary versus pathological reactions when a person is in crisis and how CBPFA is a systematic approach to understanding how to help individuals cope. The module ended with a review of what CBPFA is and is not; for example, CBPFA is not psychotherapy and not for the treatment of psychological disorders; however, it is a means of supporting individuals dealing with stress, crisis episodes, etc.

The second module addressed what *being a helper* means, including a review of Carl Rogers' suggestions for providing psychological support. Characteristics of effective helpers, such as being able to listen, being approachable, and being trustworthy, were discussed. This module, though likely topics most participants were familiar with, supported how community members, including themselves, can effectively provide PFA even without formal training due to their qualities of being helpers. The module concluded with shared concerns about being a helper and how to begin if this is a skill one wishes to cultivate.

The third module brought in the fundamental topic of *traumatic stress*. Traumatic stress was defined, highlighting Jacobs' (2016) explanation that traumatic stress is an "ordinary reaction to an extraordinary event." Much of the module was spent on discussion related to the five common traumatic stress reactions: emotional, physical, behavioral, cognitive, and spiritual. The researcher incorporated examples from Jacobs (2016) and allowed for a discussion among participants about how these reactions are often presented in a palliative care setting. Throughout this module, the normalization of human reactions was also stressed, including how traumatic stress reactions can be dramatically different across individuals and the role other external factors can play in the severity of reactions as well.

The fourth module was on *grief and bereavement*, a topic familiar to the palliative care team. This module reviewed the types of loss an individual can experience, ranging from loss of independence to loss of a loved one. The Kubler-Ross stages of grief were reviewed, and participants provided feedback on how they approached grief-related conversations. The researcher presented emotional reactions that can accompany grief, such as guilt, self-blame, and shame, in addition to how helpers can address or respond to these reactions.

The second training day’s agenda included *coping and self-care*, *active listening*, *problem-solving*, *referrals*, *and ethics*. The fifth module of ToT, *coping and self-care*, began with participant reflection on how they manage stress, their practice of self-care, and self-care within the workplace. Following reflection, the importance of self-care was reviewed, and the role it plays in mediating stress and traumatic stress. The impact of vicarious traumatization on helpers and how it can manifest was discussed with the goal of relating participants’ experiences to that of patients and caregivers they support. The following basic strategies for self-care were considered: sleep, rest, diet, and exercise. The researcher concluded the module by offering strategies for prioritizing self-care and overcoming obstacles that impede self-care.

The sixth module focused on *active listening* and its role in facilitating communication and understanding. The BESTT EARS technique was reviewed in detail, highlighting the non-verbal and verbal ways to engage in active listening (Jacobs, 2016). Challenges to active listening and methods for improving active listening skills were discussed to wrap up the module. The seventh module, *problem-solving*, introduced DECIDE (Guo, 2020), a decision-making model commonly used in medical settings. This acronym differs from the SODAE problem-solving acronym covered in Jacobs (2016); however, it was determined that it was more appropriate given that the ToT was given in a medical setting. Additionally, the DECIDE model includes an evaluation step, which Jacobs (2016) suggests is a critical stage in problem-solving. The researcher covered each step in the DECIDE model and elicited feedback on how it may or may not relate to the palliative care team.

Referrals and ethics were the final modules of the ToT. *Referrals* focused on recognizing when PFA may not be enough and professional support is necessary. This included outlining general indicators that someone may need professional psychological support (i.e., symptoms persisting for more than four to six weeks, impact on functioning, danger to self or others) and possible different referral areas. The discussion on *ethics* reviewed the principles of respect for people's rights and dignity and beneficence and nonmaleficence. Participants were encouraged to reflect on other ethical principles relevant to palliative care and ethical dilemmas they have encountered within palliative medicine. To end the second ToT session, the researcher reviewed the modules covered in both sessions.

Ethical Considerations

CBPR has its roots in social change and doing what is ethically best for an identified community (Hacker, 2013). Therefore, the researcher of this study ensured that all ethical standards were met throughout the research process. This study followed the American Psychological Association's Ethical Guidelines (American Psychological Association, 2017) and guidelines established by the University of South Dakota Institutional Review Board (IRB). IRB human subjects' approval was obtained before CBPFA ToT and data collection. Participants in CBPFA ToT were provided informed consent (see Appendix B), outlining potential risks and benefits and their role as participants in the study. The researcher ensured that the community was respected and that collaboration was maintained for the project's duration. Any findings to be disseminated will be shared with and approved by the community.

Role of Researcher

To reduce interference of researcher bias, values, and personal background impacting the interpretive process of qualitative methodology, Creswell (2016) suggests that researchers address their role through reflexivity. This is done by identifying the researcher's past experiences and addressing how these past experiences may shape study interpretations.

As the researcher, I engaged a palliative care community, established a collaborative research partnership, and commenced the CBPR process. Throughout the planning phase of this study, I worked with the community, a principle of CBPR, to develop and implement a CBPFA training of trainers with an interdisciplinary palliative care team. In addition, I collaborated with the community to guarantee that the community's interests and needs were being served throughout the research process. More specifically, I worked with the identified community liaison of the team during the initial planning phases and subsequent scheduling of the training sessions and focus groups. During the implementation phase, I continued to ensure that community needs were met by regularly obtaining feedback from the community. After the study's conclusion, final themes and sub-themes were provided to the team for their review and comment, to which they provided approval and provided no additional feedback or suggestions.

Several characteristics of myself allowed my partnership with the palliative care community to start. First, I was a third-year clinical psychology student at the University of South Dakota at the start of this study. I had the opportunity to participate in an interdisciplinary palliative care seminar during my second year in the program—participation in the seminar allowed access and collaboration with the palliative care team. Second, at the time, I had four and a half years of formal training in clinical psychology and two and a half years of training in disaster mental health. Third, I had no formal training in palliative or hospice care when training sessions were conducted; however, I am currently receiving formal training as a clinical psychology intern at the Milwaukee VA Medical Center, where I work on inpatient and palliative units and with patients diagnosed with life-limiting illnesses and near EOL.

Additionally, I have personal experience as a family caregiver in hospice care. My personal experience within hospice care inspired and shaped this research proposal. During my time as a caregiver, crises uncovered several areas for me to focus on in this proposed study. Similarly, my role on an interdisciplinary palliative care team exposed me to several crises, which I had the opportunity to observe and play a role in resolving. Fourth, given my training in clinical psychology, I view issues within palliative/hospice care from a psychosocial lens versus a medical lens, allowing me to recognize the clinical utility of CBPFA for this community. Finally, through collaborative efforts, a core principle of CBPR, I could implement a training-of-trainers protocol for the previously mentioned palliative care team.

Additional roles that are critical to review include that of my dissertation chair and advisor, Dr. Beth Boyd, and two coders. As previously mentioned, Dr. Boyd has extensive experience conducting CBPFA trainings and has been a part of several thesis and dissertation committees in which CBPFA was adapted. She also has expertise in qualitative analysis and CBPR methodology. Dr. Boyd has been a participating faculty member in the annual interdisciplinary palliative care seminar, along with her experiences working for Vermillion/Clay County Emergency Medical Services (EMS) and other exposure to palliative/hospice care environments.

Lastly, to reflect on the positionality of the two coders, at the time of coding, one had completed their 3rd year in the Clinical Psychology program, and the second completed their 1st year in the Clinical Psychology program. The 3rd year coder had participated in the interdisciplinary palliative care seminar; therefore, had a general foundation of knowledge in the area of palliative medicine. Both coders were also participating in the Disaster Psychology program at USD. The 3rd year coder had experience teaching an undergraduate course of CBPFA, and the 1st year coder had plans to teach the course in the future. One coder had previous experience coding large qualitative data sets in both an academic lab and their thesis.

The second coder was new to qualitative analysis and was provided training and instruction on the coding process. In summary, the researchers' and coders' experience allowed for well-rounded expertise and understanding of CBPFA, CBPR, and Palliative Medicine.

Data Collection

Access, Sharing, and Provisions for Data Collected. Data collected during the execution of this study was stored in standard and accessible file formats to facilitate sharing and long-term protection in two locations: the researcher's personal computer and a password-protected flash drive. Hard copies of questionnaires and measures were scanned onto the researcher's password-protected personal computer and stored on a flash drive. All raw data collected (i.e., auto recordings) were transcribed and deidentified by the researcher and saved on their password-protected computer and flash drive. Additionally, each CBPFA ToT session and follow-up focus group session was audio-recorded using the researcher's USD-affiliated Zoom account and stored on the researcher's password-protected personal computer. Original audio recordings containing identifiable information were deleted following transcription. The researcher and their academic advisor, Dr. Boyd, had free access to datasets, either from computers used to store data or from password-protected flash drives. The two additional coders were provided access to the deidentified transcripts via a password-protected flash drive. To facilitate collaboration with community collaborators and the palliative care team, collected data and results were provided in electronic form following the data analysis stage of the study. The researcher did not encounter any copyright, ethical, or privacy issues.

Data Analysis

In the current study, qualitative data from CBPFA ToT sessions and focus groups were analyzed using Moustakas (1994) method for phenomenological data analysis in conjunction with a case study approach (Stake, 1995). Phenomenological research is utilized when the researcher wishes to interpret the “lived experiences of individuals about a phenomenon as described by participants” (Creswell & Creswell, 2018, p.61). The data analysis process was comprised of the four standard steps as outlined by Moustakas (1994): 1) horizontalization, 2) clusters of meaning, 3) structural description and 4) essential, invariant structure. Additionally, due to data collection occurring in a group format, a case study approach (Stake, 1995) was used to analyze the data as a whole rather than separating the data by individual team members. The palliative care team shares a unique but similar experience related to their work in palliative medicine; thus, it is appropriate to analyze their experiences as a whole. Combining both a phenomenological and case study approach allows for a greater understanding of the lived experience of the group, in this case, their perceived appropriateness and feasibility of CBPFA within the context of palliative/hospice care.

Results

Quantitative Analysis

Descriptive statistics were used to analyze participant demographic information. Similarly, the outcome measures were analyzed using IBM SPSS. Both descriptive statistics and t-tests were run for this study. More specifically, the researcher compared participants’ knowledge of CBPFA from pre-training to post-training to assess the effectiveness of the CBPFA ToT.

Sample Characteristics & Outcome Measures

Seven palliative care team members were trained in CBPFA, all of whom consented to participate in the study. Of those who consented to participate in the study by completing a demographic questionnaire, six completed the pre-test measure, five completed the post-test, and six completed the PFA Usefulness Questionnaire. The completion rate of all measures was affected by inconsistent participant attendance due to patient emergencies and personal conflicts—all participants (100%) identified as female, Caucasian, and married. The mean age of the sample was 39.43 years (*SD* = 8.62), with ages ranging from 32 to 58 years of age. Participant's education levels included Bachelor's Degree (*n* = 2), Master's Degree (*n* = 3), and Doctoral Degree (*n* = 2); additionally, a total of four participants had specialized training in palliative care. Participants' roles within the palliative care team included registered nurse (*n* = 3), social worker (*n* = 2), nurse practitioner (*n* = 1), and physician (*n* = 1). The mean years of experience working within palliative care was 7.18 years (*SD* = 8.93), with experience ranging from 9 months to 25 years. Weekly hours worked in palliative care were varied from 8 to 16 hours (*n* = 1), 20 hours (*n* = 2), 40 hours (*n* = 3), and 40+ hours (*n* = 1). Number of patients seen weekly ranged from 10 to 100. A summary of demographic data is presented in Table 2.

Table 2

Demographics

Variable	Responses	Frequency (*n*)	Percentage (%)
Gender	Female	7	100
Ethnicity/Race	Caucasian	7	100
Marital Status	Married	7	100
Degree Type	Bachelor's Degree	2	28.6
	Master's Degree	3	42.9
	Doctoral Degree	2	28.6
Specialization	Yes	4	57.1
	No	3	42.9
Role	Registered Nurse	3	42.9
	Social Worker	2	28.6
	Nurse Practitioner	1	14.3
	Physician	1	14.3

PFA Usefulness data were gathered from the PFA Usefulness Questionnaire. Scores on the questionnaire ranged from 70 to 89 (out of a possible 90), with a mean of 81.33 (*SD* = 7.58). The knowledge of PFA scores was calculated by reviewing the pre- and post-training questionnaires and scoring one point for each correct answer. Scores on the knowledge of the PFA pre-training questionnaire ranged from 9 to 12 out of a possible 14 points (*M* = 10.5, *SD* = 1.38). Scores on the post-training questionnaire ranged from 9 to 11 out of a possible 14 points (*M* = 10, *SD* = 1). The results from an independent sample t-test of the pre-training and post-training questionnaires indicate that the CBPFA ToT did not significantly improve PFA knowledge, *t*(4) = -1.12, *p* = .163.

Table 3

Descriptive Statistics

	Pre-Training			Post-Training		
	n	Mean	SD	*n*	Mean	SD
CBPFA Knowledge	5	10.8	1.30	5	10	1.00
CBPFA Usefulness	X	X	X	6	81.33	7.58

Note. SD = Standard Deviation

Qualitative Analysis

In the current study, various methods were used to transcribe, organize, code, and group the data from CBPFA ToT and focus group sessions, as outlined previously. All audio recordings were transcribed using Microsoft Word and then reviewed by the researcher to ensure the accuracy of the transcripts and deidentify the data throughout all transcripts. Final transcriptions were saved on the researcher’s password-protected computer and flash drive. The researcher and two additional coders began the data analysis process by first reading through all transcripts to gain familiarity and a better understanding of the data. In line with the first step of horizontalization (Moustakas, 1994), the researcher and two coders independently reviewed the training session transcripts. They highlighted all expressions that were relevant to the participants' experience. The proposed research questions and sub-questions served as a guide for identifying and extracting these expressions. Following this first phase of horizontalization, the researcher and coders met to discuss the phrases they highlighted to ensure all coders were consistent with parts of the transcript they felt were essential to the experience. This process was repeated for the three focus group transcripts.

Once all relevant statements were identified for all five transcripts, the researcher utilized a qualitative data analysis software called Delve (n.d.) to streamline the next step in the data analysis process: reduction and elimination (Moustakas, 1994). Delve (n.d.) is an online software, available for a monthly fee, that allows researchers to analyze qualitative data in an efficient and organized way. The researcher utilized Delve (n.d.) to code each significant statement from all transcripts, beginning with the first training session. After completing the first training session transcript, the researcher and coders met to compare codes. Each statement was reviewed individually, and codes were checked for consistency across coders. For dissimilar codes, the three coders discussed which code, or codes, fit the statement best based on the meaning and essence of the statements and alignment with the research questions. Additionally, during this stage, any expressions perceived as not fitting the experience or not containing enough information to extract meaning and code were eliminated. Overlapping or repetitive codes were maintained. This process was repeated twice for the second training session and focus group transcripts until all coders agreed.

In the next stage of analysis, clusters of meaning, the researcher began by downloading all codes from Delve (n.d.) and categorized each code into initial themes and subthemes that were representative of the essence of each code. The researcher again met with the coders to review the grouping of codes. Once in agreement on which theme or subtheme each code was best related to, the researcher independently reviewed the codes' categorization, finalizing themes and subthemes. Each theme and subtheme were analyzed while considering the description of the participants' experience with CBPFA within their roles in palliative medicine. The description of each theme serves as the essential, invariant structure of the phenomenon. Finally, the researcher met with the coders to review themes, subthemes and their brief textural descriptions. Once the finalized themes, subthemes and descriptions were agreed upon, they were sent to the researcher's advisor, Dr. Boyd, for review. Dr. Boyd and the researcher met and reviewed each theme and subtheme, discussing how each relates to the proposed research question. Following approval from Dr. Boyd, in alignment with CBPR methodology, codes, themes and subthemes were sent to community liaison for her review and feedback.

Themes

Through the use of a phenomenological case study approach, the discussion from two CBPFA ToT sessions and three focus groups produced four main themes: 1) appropriateness of CBPFA for palliative care, 2) utility of CBPFA modules, 3) context of patient/caregiver goals, and 4) adaptations to CBPFA for a palliative care team; in addition to corresponding subthemes: 1a) unique/difficult situations within a palliative care setting, 1b) feasibility of CBPFA for palliative care, 1c) uniqueness of discipline & care team, 2a) being a helper, 2b) traumatic stress, 2c) coping & self-care, 2d) active listening, 2e) problem solving, 2f) grief and bereavement, and 2g) referral and ethics.

Theme 1 – Appropriateness of CBPFA for Palliative Care. Throughout the ToT and focus groups, the team regularly reflected on the context in which CBPFA is most likely to be utilized by their palliative care team and palliative teams like their own. Participants highlighted the diverse experiences members of palliative teams may have and how CBPFA would benefit their training, including support staff, medical staff, and those not formally trained in palliative medicine. One participant noted the nature of some staff having less experience.

> Especially I think in the long-term care environment, how valuable it would be because. In general, the age group is still very youthful and they're very inexperienced traditionally, and what value that could bring to their satisfaction in providing this kind of care. I see, you know, when you mentioned onboarding, it just was like a light bulb went off because you think in terms of how to prepare someone to be in these situations where … maybe you haven't obviously even had life experience to you've got this family member going off and you're like "Um I'm gonna go get the nurse." That's about all you can do and for them to have just a few more tools in the toolbox to be able to bring some calm while they're getting the nurse who has 30 other patients who is going to be a half an hour before she gets there, some tools to use to help in that situation will benefit everyone.

Another participant noted:

> That's probably the most valuable opportunity within the team as is out there just given the youth of especially we always are very supportive of the CNA group. Because usually it's their first experience. They're either seasoned or they're new and it's their first experience with end-of-life or serious illness that can transition to end-of-life.

Additionally, those entering the field or just beginning to work within a palliative setting would benefit from CBPFA to increase their satisfaction with patient encounters. Participants voiced how other disciplines and support staff within the hospital setting would also benefit from CBPFA. They named several populations, including:

> Patient volunteers. Other disciplines, other practices, Doctors, Nurses, could be any of those specialties, could be … lab or any of those ancillary staff, reception. A team that seeks us out on regular basis is therapy, physical, occupational, and speech.

Similarly, those who are new to the world of palliative care. One participant stated:

> I feel like for people that are … just joining the palliative care community … all these topics are very relevant and really helpful to have a name for.

Even staff who are seasoned providers within palliative care were thought to benefit from CBPFA, simply as a refresher.

> A lot of this stuff is taught when you initially learned like palliative medicine and care. I feel like this was just kind of when you're getting orientated. This stuff was just kind of embedded throughout and so as you kind of introduced these topics again, I felt like it was a nice refresher because we kind of get into our own patterns. But a lot of this … I would say we are familiar with these; [they] are just different terms.

Subtheme 1a – Unique/difficult situations within a Palliative Care Setting. Participants emphasized the unique situations that occur within the context of palliative care, further supporting the appropriateness of CBPFA for this community. Notably, CBPFA was considered beneficial depending on who one might be providing care for, such as children, described as "there are extra layers, I guess to say very simply, very complicated." Working with younger patients or patients with children was said to have "been the hardest" for one participant, possibly leading to overidentification. Several participants identified CBPFA as being useful when palliative patients begin to progress towards goals focused on EOL and comfort, often discontinuing life-sustaining treatment.

> We say it proverbially when the bottom drops out. And then it’s always a crisis and it's always … Friday.

Notably, despite the team’s best effort to prepare patients and caregivers for the worst-case scenario, there can still be challenging situations to navigate when it comes to patients progressing to EOL.

> We try to prepare … think of oncology at the clinic … kind of start preparing that conversation of what's declining and a lot of times it's like that moment when their mobility … They're just very weak, and they're coming to you right away, “you kept saying that they were gonna be declining,” or all of a sudden now like “we can't come to clinic and we can't do treatment any more, what are we gonna do?” That is their panic moment … What they're catastrophizing is real. It's not just all of their “what ifs” anymore … this is the worst of the worst. It's here, now.

Subtheme 1b – Feasibility of CBPFA ToT for Palliative Care. The appropriateness of CBPFA for palliative care was further supported by how the care team could feasibly incorporate the CBPFA into their training and daily workflow. A participant shared that “onboarding would be a good time,” especially given the time constraints many palliative teams face given their commitment to patient care. Several participants acknowledged that time would be their most significant barrier in delivering formal CBPFA training:

> But to sit down with the formal training, I feel like … we've always had really ambitious goals. Even just doing more education for staff on end-of-life care and palliative sort of

> things out at the nursing home and it always comes down to time is our biggest barrier. It's time and resources. I think … this is kind of the same.

However, to combat the relevant issue of time, a participant suggested one-on-one feedback from those trained in CBPFA would be helpful for both staff and possibly caregivers:

> I think to sit down and have … education in a structured time frame is hard. I think one-on-one … when we're interacting with caregivers, I think that that's one thing.

The key to successfully incorporating CBPFA feedback is "finding those opportunities" with staff and "being more aware of opportunity" when feedback can be helpful. This could eliminate concerns related to staff providing the more formal CBPFA due to time constraints and integrate the CBPFA principle of CBPFA-trained individuals providing coaching and feedback.

Subtheme 1c – Uniqueness of Discipline & Care Team. Participant discussion also noted the uniqueness of the palliative discipline and how the mission of palliative medicine merges well with the goals of CBPFA. One participant said they "feel like that is one of the privileges of [their] role. Is that [they] get to walk with people through that journey." The same participant went further in explaining how team members can become emersed in the experience with their patients, through all "the ups, the downs, the stable, the dips" along that journey,

> Finding their acceptance or their reluctance, and supporting their family through that journey. Which can be a very different place from the patient themselves. And finding ways to make that time meaningful for them, whether that's legacy creation or like XXXX said, "what's acceptable to you and what's not acceptable to you?" That journey towards hospice and through hospice for us feels productive, worthwhile, and meaningful.

Palliative teams, their patients, and caregivers can often build strong, trusting relationships due to the journey they walk with them, at times being seen “as a sounding board” or even “having palliative as that safety net.”

> They do become family in a different way, but they have to have some place to vent. We can be a safe place. And anything that we could do to give them empowerment and tools because it is hard when you are the one that's … dealing with that same unmet need day after day, after day. It's many times needs that can't be met in a day … they're not a simple thing like I need a glass of water. It's “my disease is progressing and I am very depressed or very upset.”

Overall, members of the palliative care team found adapting CBPFA to palliative care appropriate, given how well CBPFA and palliative values merge. They emphasized the unusual situations they help manage in the context of palliative care, making CBPFA a feasible supplement to their work with patients and caregivers.

Theme 2 – Utility of CBPFA Modules. Participants were encouraged to reflect on their experiences and discuss how the various components from each CBPFA module applied to their work within palliative care. These rich discussions resulted in subthemes describing the utility of several components of CBPFA.

Subtheme 2a – Being a Helper. Several participants highlighted what it means to be a helper in palliative care. Notably, the journey that palliative care teams are on with their patients and caregivers often results in sharing more than one might consider medically necessary, and palliative helpers may “learn lots of very personal and intimate things about our patients and caregivers.” One participant shared, “I don’t even have to ask … they’re just gonna dump it all.” On the other hand, some individuals “may or may not share anything personal going on.” These personal disclosures are thought to result from the proximity of palliative care teams to their patients. For example, they likely “see them regularly” which can facilitate stronger rapport and feeling “comfortable” with their care teams. A participant shared that part of their role as a helper is “empowering” patients and “giving them the safe space to, you know, feel comfortable and sharing is one of the biggest things.”

Even though team members can connect and listen to patients’ personal stories, participants acknowledged the necessity of adjusting their reactions to patients and caregivers. This was shared as being particularly difficult in the context of palliative care and the quantity of staff interaction with some patients. A participant shared an example of how they managed their reactions and emotions despite trying to be a helper.

> Are you kidding me, I just spent like 8 hours like in your room and on the phone and so then [I ask myself] is it therapeutic to say “what the hell?!” No, it’s not, this is not about [me], my feelings are not hurt.

Participants acknowledged how, at times, it can be challenging to be a helper in the palliative care setting, especially when the help is not received. “When you put your heart and soul into something, and they’ve given massive amounts of times, and then they just like burst everything.” Navigating these challenges of being a helper in palliative care, they voiced at times led to thoughts of “okay, they can go see somebody else.” However, participants ultimately agreed that the best way of coping is remembering to “not take offense,” and “don’t take it personal.” Participants also shared the importance of remembering people’s humanity and the value of compassion that many individuals in the field hold.

Subtheme 2b – Traumatic Stress. Participants appeared to embrace the module on traumatic stress and were able to reflect on common reactions they have noticed in patients and caregivers. In considering emotional reactions, numerous emotions were noted, including worry, guilt, exhaustion, fear, anxiety, sadness, grief, irritation, defensiveness, gratitude, acceptance, denial, calm, peacefulness, offense, distraught, and helplessness. They acknowledged how patient and caregiver emotions can vary, even throughout an appointment or interaction, and how identifying those emotions is beneficial, especially in problem-solving when a person reports they are in crisis.

> One caregiver last week, and it was over the phone, and she was just absolutely distraught because [the patient] was clearly declining at home. It was very superficial and just trying to fix how could we help support her physically. But then, it went back to her being fearful that she hadn't done enough … and that's why [the patient] was declining.

They also spoke about knowing when someone may need additional emotional support and how the degree of the reaction is an indicator to them.

> The disproportionate reaction … of a lot of patients, maybe with like physical pain symptoms, but they're experiencing an emotional or spiritual distress that is very out of proportion. How we would normally treat that particular symptom it's not effective because it's the emotional pain with it that meds or whatever are not going to take care of.

A unique consideration when addressing emotional reactions is the factor of pain, an unfortunate reality for many patients. One participant shared how sometimes physical pain is the most distressing symptom that a patient may express, but emotional distress often complicates their presentation.

> We've had patients, too, where they have those physical symptoms, and they treat it with medications, like pain medication. They actually have like adverse effects from the

> medications because they're actually trying to treat an emotional or spiritual pain or distress.

Similarly, a typical physical reaction participants discussed was pain, often a consequence of their life-limiting illness and possibly maintained by their emotional distress. In differentiating between medical versus psychological, physical reactions, a participant voiced the importance of "knowing the pathophysiology and when something just doesn't make sense, like out of proportion, that's the biggest thing." Another common physical reaction shared was problems with sleep, including fatigue, sleeping all day, or inability to sleep at times.

Additionally, behavioral reactions identified by participants included "putting their foot down…stomping and leaving" or not taking care of themselves. Cognitive reactions that patients and caregivers may experience within palliative care, even without experiencing traumatic stress, were described as being on a spectrum. Common reactions included poor concentration, distraction, hallucinations, vision, and forgetfulness, which were reported to occur with both patients and their caregivers. One participant shared, "a lot of these things we can recognize not only in patients but our caregivers as well." Participants expressed the need to balance normalizing these cognitive responses and being able to recognize when they may be pathological. For example, when reflecting on patients experiencing hallucinations, this can be a normal reaction in the context of palliative care and EOL. However, for the patient and caregivers, it can be uncomfortable.

> Everybody talks about it and like "it's this person they're seeing" and then they'll talk about that experience … just reminiscing with the people that surround them and everybody's like "I don't know what to do with this. I don't know what this is all about."

When reflecting on normalizing reactions, participants highlighted how, in some cultures, visions are often expected and comforting to patients and caregivers—further supporting the importance of understanding cultural and individual differences with the palliative population.

Subtheme 2c – Grief & Bereavement. Fortunately, or perhaps unfortunately, the palliative care team was familiar with grief and bereavement, the final module during the first ToT session. Participants reflected on the complexity of losses that patients, their caregivers, and the team experience in their work within palliative medicine. One participant reflected on patients and caregivers grieving the loss of who the patient was prior to their life-limiting illness.

> She was grieving the loss of what his life has always been and the control that he's always had and how he'd been so active. And now that's changed. It wasn't even him necessarily grieving the losses that he's been experiencing, but her loss of what their life together as a couple used to look like.

The palliative team highlighted the many things that one might grieve, not just the loss of life, including anticipatory grief, loss of independence, relationship changes, and roles changing or ending.

> I think, too, recognizing that somebody didn't just die. It's not just them that they are grieving, but their routine has changed, their roles in the household have changed, just their little things in everyday life changes and it's not necessarily just like the death that is different; it's all the little things that are different.

Participants acknowledged the impact of cumulative grief on their patients and caregivers and how it lends itself to the complexity of coping with grief, such that every individual has to learn to grieve in their way. Their reflections highlight how there does not appear to be a typical way for one person to grieve. This understanding of the complexity of grief helps inform the palliative team and how they offer support during grief. The following are approaches suggested by several participants.

> I oftentimes will say, “What is worrying you the most?” Because oftentimes they have lots of worries, just kind of normalizes that. “I would expect that you have worries…what is heaviest on your mind right now?”

A second participant added:

> We’ve just kind of talked about finding ways to help their loved one live on in their life, and those that they love, and that seems to help provide a lot of comfort and that they can keep their memory and their spirit alive is a little more concrete.

A third offered:

> We’ll do just kind of like legacy creation for the patient.

Some ways of supporting caregivers include comforting statements or reflections about their loved one, such as, “How long were you married…Do you have any children?”

> Just acknowledging what [I’m thinking] and saying, “It must be so hard; I can see that it’s hard for you too that things are different now and that things are changing.”

Another participant added:

> If it’s the caregiver, I always like to say, “you took such good care of them,” and if they had to go to the nursing home, “you did everything you could to take care of them, and you were still there every day. I’m sure they really appreciated that.”

One participant shared how they approach acknowledging the loss of the patient and showing their appreciation and support.

> “I want to offer condolences on the death of your loved one.” or even just like thanking them for allowing us to take care of their loved one. I feel like we find such honor and privilege in caring for patients and families in such a vulnerable time.

The palliative team also described the differing levels of acceptance they noticed due to the proximity of their roles. One participant expressed how different levels of acceptance tend to warrant different levels of personal response, such as some caregivers appearing in crisis and others not based on their perceived acceptance. Acceptance, or reluctance of end of life, can play a precious role when patients have goals of care conversations or make decisions regarding hospice care and facilitate a successful hospice admission.

> Finding their acceptance or their reluctance, and supporting their family through that journey. Which can be a very different place from the patient themselves. And finding ways to make that time meaningful for them. Whether that’s legacy creation, or like XXXX said, “What’s acceptable to you and what’s not acceptable to you?” and that journey towards hospice and through hospice for us feels productive, worthwhile, and meaningful.

Navigating the goals of care conversations with patients and caregivers can be incredibly challenging when there is reluctance; however, one participant remarked on the level of acceptance they notice from patients, even when others may not be in the same place.

> One thing that I’ve noticed is like a piece that people feel when they have accepted. I wonder. I mean more so within the patients; I thought that was just really interesting. Just how some people just are so calm and peaceful and just even when there’s chaos with family or chaos just surrounding them.

Subtheme 2d – Coping & Self-Care. The palliative care team thoughtfully reflected during the Coping and Self-Care module, emphasizing the facilitators and barriers to self-care for patients, caregivers, and themselves. Participants identified the importance for patients and caregivers to engage in self-care to process their emotional and cognitive reactions to cumulative stress, recognizing that "it's a very normal response to the stress that they're under; just providing the support is huge." One participant shared the utility of returning to basic needs when helping patients and caregivers cope, a key component of CBPFA.

> Going back and looking at basic needs. I think we get in these situations that are super complicated, sad and overwhelming and then … really being able to just focus on like their basic needs, and some of those simpler things.

Another effective means of supporting patients when coping was bringing to their attention something they look forward to, a short-term goal to reach.

> Sometimes, it's just asking them, "what are your goals … is there something coming up that you're looking forward to?" Sometimes it's a new baby or wedding or something and those short-term goals are what get them through that little bit… it's just giving them something to look forward to; I think it's important.

Even with the palliative care goal of helping patients and caregivers manage stress and practice self-care, participants expressed the importance of setting boundaries to promote their self-care and manage crisis-like situations. One participant reflected that it is helpful to remind themselves that "their crisis is not your crisis" and that "boundaries are so important" as it can be easy at times to get wrapped up in the panic that a patient or caregiver is experiencing.

Participants described their self-care as a "cycle," which always seems "a work in progress." In reflecting on their self-care practices, several strategies discussed included being honest about their feelings with colleagues, taking a day off, getting lunch, debriefing with the team, and using humor.

> I feel like it's helpful to step back and think about all these things. I feel like the most helpful things are when we are practicing reflection, when we actually are debriefing. That is the most meaningful.

What makes the practice of self-care even more effective for staff is also the support they can receive not only from one another but from their management as well. However, participants acknowledge that even though they receive support for self-care, it is also about making self-care a priority themselves.

> I think it is hard, maybe for management to engage in it or help us engage in it. Because they don't really know exactly what it is that we need… it is all based off of our own initiative to do it for ourselves.

Additionally, participants discussed the importance of knowing when they need to engage in self-care, when cumulative stress or vicarious trauma is building, such as noticing common behaviors or feelings associated with that building. A strategy a participant expressed could be communicated to patients, caregivers, and staff.

> Sort of identifying behaviors…here are some things that you might notice so you know that you're getting burned out or that you're not maybe taking care of yourself as well as you should be, that you're getting stressed out…You can almost feel when like the stress is just kind of building and it's almost like you become kind of like disorganized and it's just like everything is crumbling around you like you don't even know where to start.

To conclude the discussion on coping and self-care, participants reviewed several common barriers to self-care in palliative care. One barrier for caregivers is the possibility of not knowing how to define or engage in self-care and not recognizing the benefits of self-care for coping with distress. One participant shared an impactful story about a caregiver supporting his spouse and the obligation they felt as a caregiver.

> The spouse yesterday when he was like "I don't know, how do you even take care of yourself? What does self-care mean?" And XXXX just explained to him "even if it's just getting your shower done, eating your meals, going to bed at a normal time. Developing a routine in your normal daily activities that itself can be self-care." And I think for him, he kept thinking, "well, do I have to do this, like go out for coffee?" And for him, that would actually be more of a stressor than it would be therapeutic.

The theme of obligation appears not only in caregivers but in palliative staff as well. A participant conveyed, "I think it is harder as the teams are smaller because you don't want to burden your teammates with the extra load when you're gone because you don't have coverage." The participants acknowledged the challenges of working within palliative care and the chaotic nature of the field.

> Like chaos across, like we're seeing patients, outpatient, inpatient, people are getting life flighted in. I just feel like if you're in one place, it's easier to manage your schedule. When you have patients everywhere, I feel like that's maybe hard… I think when we're in those influxes where work is really busy. Maybe we have a lot of high-stress patients, and that's probably the time when we need it the most. But it's hard to break away. I think that's when I have found it's been the most difficult.

Another participant added:

> I agree, I think what we've struggled with too … is that our workload is always in flux and it's one thing when you have a set, controlled environment in a completely different

> situation. When you have patients who have needs around the clock, that makes it tough because if we are not available then someone goes without service.

Subtheme 2e – Active Listening. While reviewing the active listening module, participants emphasized parallels between the BESTT EARS acronym and how they approach patient encounters. Some acknowledged that active listening is part of their training, but even though it seems like "common sense," it can get "overlooked." Non-verbal and verbal aspects of active listening were carefully considered, with several participants noting the importance of cultural awareness and eye contact, therapeutic touch in palliative care, and being cognizant of gender differences. One participant shared how different disciplines may approach therapeutic touch and how beneficial it can be in the context of loss and suffering.

> We had a fetal loss on the OB floor … I'm talking about touch, and they are very like no touch … they don't do hugs. They don't do embraces. They don't touch like shoulders … "in our world, we just don't touch." And with the loss, we kind of talked about supporting the family, and they were Hispanic, so they were very family-oriented and very okay with touch.

The participant discussed the importance of understanding cultural and individual differences regarding therapeutic touch.

> I think therapeutic touch is used a lot with our patients and families, but … you brought up a good point that depending on maybe their cultural norm or just their personality … asking permission … I think of family members who look like they're struggling. Just asking permission, "you look like you're really struggling. Should I give you a hug?" And you can kind of generally, usually read that by just asking permission … that helps to kind of break down that barrier, and it can be very powerful.

Team members also acknowledged the gender differences that can impact a provider's use of therapeutic touch. For example, in reflecting on a conversation with a male colleague, one participant shared, "I feel like … talking about gender is important because a lot of our male colleagues are like 'I cannot touch a patient because it's just like associated incorrectly, regardless of what I'm doing.'"

Participants expressed the value of being intentional in their approach to care to facilitate active listening. "I think just being very intentional before you even go into the room." This intentionality allows staff to be in the moment when providing care and creates a space that helps them focus and slowdown in an environment that can often feel chaotic and rushed.

> I think it's okay to make sure that you have the time to listen intently and completely. Not going in there or not scheduling a patient at a certain time of the day intentionally if you're not going to be able to give them the time that they need.

Another participant shared how being in the moment and intentional when listening can help staff make sense of the patient or caregivers' needs at that time. Leading to a more person-centered approach that is valued within palliative care. "That kind of communication also really shows that I'm here for you."

> Reinforce that slow down and really listen … you can tend to get yourself thinking there's so many things that I need to … as a team, to plug in all of these different resources or things and just getting rushed and missing maybe just the one little thing that they really need, that particular visit or that particular day. It helps to refocus and just turn that listening on again to really just slow things down a little bit.

When considering the verbal aspects of active listening, participants focused on the utility of silence, being able to “read the room … go with the flow” and recognizing that sometimes sitting with the patient or caregiver is what they need. “Silence is okay.”

> We do a lot of active listening and, like honoring the silence, waiting for people to process what they want or don’t want to say … using touch in those moments … we’re acknowledging that we’re here and we’re listening … take your time or say nothing.

Subtheme 2f – Problem Solving. The problem-solving module was particularly applicable to the work the participants engaged in while giving palliative care. One participant said, “We try to be the fixers.” As described previously, the DECIDE Model (Guo, 2020) was used in the CBPFA ToT to best align with the medical nature of palliative care. Of the eight participants, one had used the DECIDE Model (Guo, 2020) with their previous employer. Throughout the module, participants provided feedback on how they might approach each step within the model, beginning with *Defining the Problem.* Notably, from participant discussion, this first step within palliative is not just about defining the problem but also asking, what is the decision to be made? With the evolving nature of chronic illness and palliative medicine, problems often appear out of the blue with limited time for preparation. One participant explained:

> Especially if they have a newer acute problem … it’s one thing to journey along with a chronic progressive illness, but then an acute onset illness, something completely new changes the entire dynamic. And as XXXX said, that assumption that they wouldn’t want to do this or that or, well, all bets are off. This is a new situation.

Discussion uncovered the utility of the DECIDE Model within palliative care, as the steps of the model support the need to slow down and formulate a plan.

> When you think in terms of first aid, there is like this urgency around it, and so many times, it's just a matter of okay, let's slow this down and really focus on what is the need today, what would help them most.

One participant described a recent patient interaction where essential components of the model, explicitly defining the problem, was valuable in supporting a caregiver in distress.

> The staff were just were beside themselves, "we need to, he's freaking out." Well, she's sick, there is something going on, and so if we just like step back and ask, "Why is he freaking out?" It's because we're not addressing what's going on. I think we encounter that more often than not, and it's like, let's just go back to why he is so upset. Well, it's because his wife is extremely ill and we don't have answers for him, so, number one, can we get answers for him? Yes, we can. And then let's figure out, you know, step by step how we approach it. I think it would be helpful for staff in the nursing home and hospital.

On the other hand, another participant highlighted:

> I think almost to the opposite effect; sometimes, it's important to recognize when it's not a problem to solve. I know a lot of the time, we are like, "What do we do? What do we do?" and we don't necessarily need to do anything about it. It's that balance of we don't solve all the problems that everybody has all the time.

The second step of the model, *Establishing the Criteria*, was noted as a beneficial part of communicating with patients and caregivers about their goals and desires when approaching a new decision.

> It would really bring that feeling of helplessness that they have sometimes to a manageable level, and understandably so, when things change so quickly. Sometimes, there's a tendency to kind of forget to ask, "What are your thoughts right now?" in

> reviewing things that sometimes are taken for granted … it comes down to communication and those tools to use.

In *Considering All Alternatives*, the third step of the model, participants expressed the value of multidisciplinary perspectives and the contribution of the palliative perspective.

> The situation right now with all the physicians and the disciplines there. You sort of just recognize that not everyone is very palliative. I mean the whole person that, they're very oriented this way … so you have to like sort of work it in here a little bit and just kind of educate the physicians even just a little bit to make sure that they're recognizing those crises that they're having.

Similarly, communication among palliative teams and other disciplines and with patients and caregivers is invaluable to help them achieve their desired outcomes.

> I think we're very good at communicating, many times, patients will be reluctant. "Well, behavioral health. Does that mean I'm crazy?" They are very good at communicating how important it is to work collaboratively for their well-being … all the way around, mentally, physically, spiritually.

Regarding *Identifying the Best Alternative* through communication with other disciplines, sometimes the simple solution is best. One participant expressed how the best alternative usually allows them to "maximize, within their disease," whatever that solution may be.

> The person that we're working with, coming on their level, so maybe the band-aids are what they actually need at that moment. That is triage.

Unique to palliative care is that the step of developing and implementing a plan of action always occurs as the disease or symptoms change or progress. However, once they have decided to initiate hospice care, the plan from the palliative perspective becomes more concrete.

> It is always in motion. Always those discussions, even after decisions are made … there's side steps and things that need to be re-discussed.

Throughout the training, participants discussed how beneficial evaluation and debriefing are in their work. However, some participants noted how, at times, that may include identifying when the team has done all they can, "recognizing too that we cannot be all, all the time."

> We sometimes get to that point where we're like, okay, we have reached the point where we are officially trying much harder than they are, so it's time to step back and let them own that … We've done what we can here but we can't fix this for them.

A second participant added:

> We're just putting Band-Aids on, what do we do … there's a bigger picture there … we're just not sure how much we can do to help.

Participants also reflected on different facilitators and barriers to problem-solving in palliative care. One of the most significant facilitators was staff adaptability and being flexible within one's role on the team through their shared palliative values.

> Everybody kind of speaks the same language. As the nurse, I don't ever think "I'm gonna stop you right there because that's a social work question." We've had these conversations so many times that you know what XXXX would say, and she probably knows about the healthcare part of it, the nursing part of it too. And she would relay the same information.

However, even with excellent team collaboration and the ability to speak the same language, there were identified variables that were often out of the control of the palliative care team. Some barriers are due to the nature of providing care in a rural area, such as access to resources and travel difficulties. However, they acknowledged that virtual access has helped reduce that barrier. One participant explained:

> Or they don't have access. Resource availability is really difficult, but you've convinced them that they need this thing and then they don't want it because it's not available or not soon enough, and that's really challenging … specifically with psychological services.

Additional barriers highlighted included trust, time, and education.

> I feel like we've always had really ambitious goals. Even just doing more education for staff on end-of-life care and palliative sort of things out at the nursing home, it always comes down to time is our biggest barrier. It's time and resources.

Subtheme 2g – Referral and Ethics. Participants reflected on the benefits of working within an interdisciplinary team and in a hospital setting, where they are fortunate to have access to referrals and resources for their patients. However, they acknowledged potential barriers to making referrals if they do not have access to specific cultural resources or if there is stigma related to mental health. A team member emphasized the importance of normalizing the referral and its purpose.

> Just normalizing that this is part of the team, that we want to help you be more comfortable, mind, body, and spirit … in general, when we refer, we normalize the situation, that this is another way of treating their symptoms.

Due to the frequency of referrals made by the palliative care team, most of the discussion during the final module, referral and ethics, focused on ethical dilemmas that the palliative care team believed to be unique to the setting and how they approach resolving them.

Part of the discussion around referral included asking the palliative team how they differentiate between a patient's wishes for comfort care and hospice versus suicidal ideation

(SI) and wanting to end their life. One participant shared the following way of distinguishing the two.

> Reflecting on how their body is changing, not necessarily like giving up or wanting to die … it's more just having the conversation with them about changes that they're seeing in their body and what their goals are. It has been always helpful to help navigate some of those discussions … it's actually more often us bringing up hospice care as an option; when we see the changes happening in their body, they are maybe making the statements that they're recognizing changes, but they're maybe not able to pinpoint them.

Another participant added:

> I don't know if I ever felt [it was] giving up. I feel like most people are all in different places, but it's a lot more accepting. You have to be to go on hospice, right? You have to sign the papers. [Acceptance] but on various levels, so yes. Rarely have I felt like people are like, "I'm giving up, hospice is the only thing I can do." Because if they feel like they're giving up, then usually, they are not ready for hospice.

In regards to how they assess for suicidal ideation in their patients, one participant mentioned noting, "where are they at in this process" of their disease course, suggesting that thoughts of wanting to die in the earlier stages might raise red flags related to suicidal ideation. Another participant acknowledged that it can be challenging to assess suicidal ideation in traditional ways, given the context of the palliative setting and end of life.

> Even like the question, "Do you want to die?" Well, they are thinking it; they are comfortable with it, but that doesn't mean they are suicidal.

One participant reflected on how assessing for SI "feels" different then a patient wishing to begin hospice care.

> It doesn't have the same feel of desperation or distress … it's a different kind of distress. It feels different, like that conversation feels different.

Participants shared how goals of care conversations and talking about patients' wishes as they approach the end of life can be a powerful way of supporting patient autonomy.

> They're identifying changes and presenting options, hospice being one of them. Gives them some control that once they're able to verbalize "these are my goals," helping them find the care, or the environment even, where their goals can be met and, in turn, gives them the control to make decisions versus "this is my only option, I'm gonna die, hospice is the only thing I have." [Reminding] them that they still have that control, they still have that decision. And then even in hospice care, helping to give them the education that they're gonna remain having options as they go forward … choice is so important, especially when it comes to like health care and chronic illness too, and we're looking towards end-of-life. We just want to maintain that dignity and self-determination.

Participants explained the importance of maintaining patient autonomy and self-determination in palliative or hospice care; however, they also brought up the ethical dilemma of assessing medical decision-making capacity. "Capacity versus poor decision or poor insight, yeah, those are huge struggles every day." One participant shared a question that they often have to ask themselves, "Do they have the right to make their poor choice?…because people are able to make poor choices."

Additionally, when patients are determined not to have decision-making capacity, the boundaries and roles that the palliative care team has to take on can become blurred if there is no power of attorney named or family available to take on that role.

> If a person doesn't have somebody that can make decisions for them … Or folks who come in who are not able to make decisions for themselves and we know that they might have a family here or there, but tracking down that family member, we are like private detectives, we're really good at it.

The palliative care teams' values further complicate patient capacity, or personal bias, to ensure patient safety and patients' decisions to make unsafe choices. "It's also hard for us to say just because that's not our choice. Just because that's not what we would do, it's still not hurting anybody." One participant shared an example of how decision-making can complicate their role in patient care.

> Or alcoholism, they come to the hospital, and they go to the nursing home and sober up and rehab and then decide to go home. And then they're back three weeks later, and we do it all over again. But they still have the capacity to make that choice.

Another ethical dilemma that sometimes relates to decision-making capacity is voluntary stopping eating and drinking (VSED). The following example clearly represents the weight or pressure these decisions can have on team members.

> I feel like scenarios that are complicated would be, they call it VSED, voluntary stop eating, drinking. That one is a very complex thing. And I would share where we're at in America; it's very different. Where I was at previously, VSED is not accepted, not allowed, like a big problem. Whereas, I hate to say in our community that it is more accepted … so, people do it. I would share it's interesting, like seeing how different it is because where I was at previously … it was an ethics consult, and we had to have behavioral health say if they have competency or not, and all these various things. Then here it's just so accepted, and I think walking alongside patients, we're not uncomfortable

> when they're going through it. It's not this terribly traumatic thing, like how people are explaining it.

Feedback from participants unveiled how each component of CBPFA relates to their work with palliative care, highlighting the process of understanding how CBPFA can be applied in this setting. The Utility of CBPFA theme highlights the familiarity that participants had with most of the topics for the CBPFA ToT, further reinforcing the idea that they already possess a similar skill set, making CBPFA easily adaptable and applicable to palliative care.

Theme 3 – Context of Patient/Caregiver Goals. Throughout the ToT sessions and focus groups, participants highlighted how well they get to know their patients and caregivers as they follow them along their journey through palliative care, emphasizing how that journey looks different for each patient. One participant stated, "It's such an individualized experience, and I think everyone is on a different journey…I feel like none of them are the same … dynamics … cultures at play." Notably, what makes adapting CBPFA different for a palliative team is the larger context of how services are delivered, with individual treatment goals in mind. In traditional CBPFA, "helpers" are likely not to understand an individual's background, goals of care, or treatment plan. However, in the context of "helpers" being a part of a palliative team, they can approach crisis intervention with an understanding of the patient and caregiver goals. One team member acknowledged that when they approach a patient in distress, they are "putting it in the frame of what's going on with that patient and what their goals are."

The nature of the palliative discipline and their access to rich information about patient and caregiver preferences and goals can lead to individualized ways of supporting those in their care, especially regarding problem-solving with an individual in crisis. Additionally, this information may allow team members to apply these skills even more effectively, given their more profound understanding of the individual. A participant highlighted how even “giving them permission” to focus on what is most important to a patient can help prioritize their needs in the moment.

> Just asking what is most important to you … what brings you joy today? What would you like to accomplish today? What would bring you happiness today?

Similarly, while the palliative team remains on the journey with the patient, they are equipped to be flexible in their approach to care, allowing them to navigate crises as they arise in a way that is parallel with their goals or even helping to navigate “changing their goals.”

> It's more or less what are their needs. There are times when we may see someone initially to review goals and their symptoms are stable. So maybe right now we see them in three months and I think that's really part of what we are. Our mission is to really cultivate that this is a journey. Hey, we'll see you in three months or six months and we are here if you need something … usually what happens is the bottom drops out … You know things are going well and then all of a sudden something significant changes. So having palliative as that safety net so to speak.

Other times, this deeper understanding becomes relevant to palliative care when patient and caregiver goals are misaligned. “Differences in family versus patient wants and needs, happens very frequently.” Team members spoke to the challenges of traversing these conversations between the two parties when discussing treatment options and how it is part of their journey with the patient.

> Finding their acceptance or their reluctance, and supporting their family through that journey. Which can be a very different place from the patient themselves. And finding ways to make that time meaningful for them, whether that's legacy creation like XXXX

> said, “what's acceptable to you and what's not acceptable to you?” and that journey towards hospice and through hospice for us feels productive, worthwhile, and meaningful.

Understanding the goals of care would likely benefit team members when implementing strategies from CBPFA; some team members acknowledged that just as patient and caregiver roles can differ, palliative discipline values and patient goals can also differ. One participant acknowledged that it can become challenging when there is a misalignment between the team members’ values and what the patient chooses to do, reflecting on thoughts of “Why do you do this to yourself when you don’t necessarily have to?” A participant shared how it can be equally as challenging getting caught between goals from various parties (i.e., patient, caregiver, palliative team, facility):

> I think sometimes it's challenging, particularly when we're working at the nursing home because what the family or caregiver, the resident’s needs are, we're attending to both their needs, but also the facility staff needs and they are not always the same. A lot of times they're not the same … sometimes working with staff to be brought back and re-centered. Because they identify what they feel they need to get taken care of in that moment and to refocus around what you feel in your role may not be as important as what the family is identifying.

Adapting CBPFA for palliative care, given the disciplines’ expertise in prioritizing and identifying patient goals, would likely allow for more effective implementation and training of CBPFA, as they are already skilled in utilizing patient information and goals to provide excellent care.

Theme 4 – Adaptations to CBPFA for a Palliative Care Team. Participants were encouraged to reflect on adapting or adding to CBPFA to make the intervention most meaningful to the discipline of palliative care and the patients and caregivers they serve. Additions to the CBPFA ToT that participants viewed as having utility in palliative care included additional training resources, role-playing, palliative care-specific examples, and modules on rapport building and mindfulness.

A PowerPoint was used to help present CBPFA training topics; however, one participant noted the advantage of supplying additional handouts or readings for participants in the future. "Resources are attractive to a lot of people, some not so much, some others appreciate the material or reading more in detail." Two team members reflected on the helpfulness of role-playing in the context of training, "Role-playing is always fun, it just gets the nerves out so to speak." Similarly, role-playing and using palliative-specific examples to illustrate further skills learned was considered an important addition to the training.

> I would just comment that the palliative care specific case examples, given the recent experience of and during a pandemic, maybe one specific to you know COVID would be really beneficial too.

One team member suggested using "good" and "bad" scenarios to walk future participants through to reinforce further how to apply the skills learned in the CBPFA training in palliative care.

> In this scenario, here's what they were going through. Good and bad examples here. This caregiver made sure he gets respite care in place and took a little bit of time for themselves. And then this scenario where their health started declining … here was the

> intervention that was taken, what could we have done it differently. Here were the results … those kinds of things.

Several participants acknowledged the importance of rapport in their work with palliative care patients and caregivers and how it could strengthen CBPFA in a palliative care setting. One participant shared that rapport building could be as simple as getting to know a patient and showing respect.

> What are their preferences? How do they like to be moved or how do they like their name. Do they like to be called their first name. Do they like the more formal, a nickname? And just kind of open up that way. It brings across like a rapport and just respect.

Given the nature of the relationship between a palliative team and patients, building a respectful and professional relationship is essential. It would help with implementing CBPFA strategies in the future. Something as simple as taking moments to get to know a patient can demonstrate how much a person cares.

> It's just building that relationship … let them know that you're interested in who they are and this is their home now … it shouldn't feel like you're the professional and they’re the patient … professional relations.

The last addition that the team agreed would be helpful was further training, or time spent, on mindfulness. It was described as “definitely applicable” in teaching self-care and a tool to help patients and caregivers problem-solve. In summary, although the CBPFA ToT discussion and focus groups revealed how similar CBPFA principles and skills are to values of palliative care, participants offered additional ways of enhancing the CBPFA ToT to cover areas where palliative care and ancillary staff may have less familiarity. These additions result in a comprehensive CBPFA protocol that embraces the values of CBPFA and palliative care in a way that best supports patients and caregivers.

Discussion

The current study aimed to train a rural palliative care team on CBPFA to facilitate the adaptation of CBPFA for a palliative/hospice care setting. Through a phenomenological case study design, this study intended to understand and describe the aspects of CBPFA that would be most appropriate and feasible to implement with other interdisciplinary palliative/hospice care teams.

Results from the PFA Usefulness Questionnaire suggest that participants found the CBPFA ToT useful and applicable to their unique palliative care setting. They reported that the most helpful topics in the training included traumatic stress, referrals, ethics, and grief. One participant highlighted that the opportunity to discuss and share experiences was most helpful for them. No topics were identified to be unhelpful or that participants recommended removing. Signs of traumatic stress was recognized as a “new” topic, with active listening and self-care being the most familiar topics. Participants expressed that they were likely to use “all” of the components mentioned in the training to help support others. Additionally, although a hypothesis was not proposed for the Knowledge of PFA Questionnaire, results indicated no significant difference in scores from pre- to post-training. This is likely due to most participants’ familiarity with supporting others in crisis and regular practice of problem-solving and active listening, among other skills.

Theme 1 – Appropriateness of CBPFA for Palliative Care

Participants highlighted settings and contexts where the CBPFA ToT would be most appropriate. Several participants mentioned long-term care settings due to the interdisciplinary environment and patient and caregiver proximity. Additionally, long-term care settings may have less seasoned staff or staff who have not received formal training in palliative and EOL care compared to a traditional palliative care team. Staff working in long-term care settings, away from hospital resources, are also unable to rely on palliative care teams to support them 24/7. Their proximity to patients and caregivers also lends itself to the importance of utilizing skills related to problem-solving, active listening, and even referrals.

Staff also shared the utility of other disciplines (i.e., physical therapy, occupational therapy, primary care) receiving CBPFA training, as they often provide care to palliative patients and may be even less equipped to respond to common stress reactions. This would reduce the burden on palliative care teams, who are often asked to support these disciplines when stress reactions arise during encounters with these providers. Other groups mentioned by participants were those new to palliative medicine, volunteers, and support staff. This recommendation aligns with Lafer (1991), who stressed the importance of appropriate volunteer training to support patients further and reduce attrition rates. Lastly, participants recognized the value of the CBPFA training for current providers working in palliative care as a "refresher." Participants demonstrated insight that even those in the field can fall into routines and patterns when supporting patients and caregivers; thus, reminders such as the CBPFA ToT were identified as valuable.

Subtheme 1a – Unique/Difficult Situations Within a Palliative Care Setting. The palliative care team described situations in which their role can be incredibly challenging for them due to the nature of their work with life-limiting illnesses and, at times, EOL. Situations that stood out as traditionally tricky or complex, when the skills from CBPFA would be most relevant, included working with children and young adults, supporting patients as they transition from palliative care to EOL, cases they personally relate to, and when there are frequent changes or disagreements in treatment and comfort care goals.

The participants’ mention of the hospice care transition as a challenging time aligns with research that suggests crises are most likely to occur when an individual enters hospice care (Feldman, 2011; Finestone & Inderwies, 2008; Volpin, 2018). Understanding what situations lead to stress reactions or crises is critical for effectively implementing CBPFA into palliative care and allows for the promotion of patient and caregiver emotional well-being.

Subtheme 1b – Feasibility of CBPFA ToT for Palliative Care. Regarding how feasible it would be for palliative care to implement CBPFA ToT, the team recognized that skills used in CBPFA and one-on-one feedback can be incorporated into their daily work. However, participants expressed challenges in implementing the training, highlighting their most significant barrier as time. Some participants suggested incorporating the CBPFA ToT into the onboarding process for individuals joining the palliative team. However, this would not allow for formal training of other disciplines or staff at partnering facilities. With this in mind, an “outside” trainer would likely need to conduct CBPFA ToT to accommodate the ever-changing schedules across the palliative care team. Another means of disseminating CBPFA across disciplines, or as follow-up for palliative staff, would be through continuing education (CE) trainings. Creating CE courses that would provide professionals credits from their accrediting bodies would likely increase access and incentive for cross-discipline training. CEs also allow for flexible training that can accommodate the busy schedules of medical personnel. Additionally, as CBPFA is often separated into modules, CBPFA could be spaced out into different modules. Care teams could then decide which modules might be most important during initial onboarding versus waiting for new palliative members to have exposure to working in their new roles first.

Subtheme 1c – Uniqueness of Discipline and Care Team. The theme that underscores the appropriateness of CBPFA for palliative care is the uniqueness of the discipline and the role of care teams. Specifically, the values of CBPFA merge well with palliative care values. Often, the context of palliative care focuses on meeting the unmet needs of patients and caregivers, whether physical, emotional, or spiritual. Interdisciplinary palliative care teams can utilize their diverse knowledge and skills to meet the needs and achieve patient goals. CBPFA is another tool for palliative care teams to pull from and empowers them to integrate skills with which they are already familiar.

The palliative care team participating in this study demonstrated their own unique qualities. Throughout the CBPFA ToT and focus groups, discussion among the team revealed how well they truly function as a team. Their participation showed incredible insight into the lives of their patients and caregivers and their role within the team. It was clear through working with them over several months that they are a cohesive group that supports one another and recognizes the value that each team member contributes. The strong team dynamic is likely due to several factors, such as supportive leaders, the nature of their work, the small size, and the rural community they operate within. Their willingness to share feedback speaks to their willingness to share their struggles and joyous moments; this vulnerability with one another ultimately makes them stronger as a team. Similarly, their openness made them a welcoming group who showed a genuine interest in learning new ways to support their patients and caregivers. These characteristics are understandable, given the lasting relationships they build in their palliative work.

The nature of palliative care is that there is often a longstanding relationship between patients and staff. Several participants described this relationship as their "journey" with patients and their caregivers. Their close relationship could make navigating difficult situations or crises more comfortable for patients as they likely view the palliative team as a "safe place." Additionally, it could easily foster a space where palliative team members might be able to provide feedback to caregivers regarding CBPFA principles.

Theme 2 – Utility of CBPFA Modules

Subtheme 2a – Being a Helper. For the participants, they reflected that being a helper means going along on the journey with their patients and caregivers. Being a part of this journey can often mean they learn more intimate details about their lives, at times without needing to ask. They acknowledged that a large part of their role is to build rapport with the individuals they care for so that they are comfortable sharing. The rapport they build and the safe environment they create lends itself to patients and caregivers sharing and being honest with how they are doing physically, emotionally, and spiritually. However, rapport and vulnerability foster a space where patients can express themselves fully, which includes experiences of joy and moments of distress or frustration.

Participants emphasized the importance of learning to manage their emotional reactions, especially around patient or caregiver distress. This may also come with the problematic reality of wanting to offer help and support, but that help not being accepted or received. This truth that participants shared reinforced the need for helpers in palliative care to be compassionate and empathetic, understand where these reactions may be coming from, and remember to "not take offense." Overall, their identity as helpers in the palliative care setting aligns with Jacobs (2016) characteristics of being a helper. There is an emphasis on building trust, approachability, genuineness, and empathy, which further supports the alignment of values between CBPFA and palliative care.

Subtheme 2b – Traumatic Stress. Participants acknowledged the similarities in traumatic stress reactions identified in the CBPFA training and what they noticed with their patients and caregivers. However, they highlighted some unique characteristics within emotional and cognitive reactions that are worthy of further discussion. Discussion and stories shared amongst participants suggested that patients and caregivers experience many different emotional reactions to traumatic stress. Some included worry, guilt, exhaustion, fear, irritation, defensiveness, gratitude, denial, calm, and peacefulness. With the complexity of emotional responses, participants expressed that understanding the emotion and its origin can help them with crisis management. More specifically, it can help guide necessary referrals to mental health or other disciplines. For example, the interaction of pain and emotional distress was described as a frequent occurrence. For the palliative team to best support the patient, they noted the importance of understanding the pathophysiology to distinguish pain from psychological distress and reflecting on whether their reaction is disproportionate to the symptoms described. The palliative team stressed the importance of accurately treating both pain and emotional distress, as ineffectively treating one can exacerbate the other.

In addressing the cognitive reactions of patients, the importance of understanding and normalizing what is typical for patients to experience at EOL or what is typical for someone's culture was stressed. For example, visual hallucinations are a possible cognitive sign that someone is approaching EOL. In some cultures, visiting loved ones who are not with them or who have passed may be a comforting and welcomed experience for EOL patients and their caregivers from various cultures. Participants spoke about joining their patients and caregivers in their experience rather than challenging or pathologizing it. An adapted form of CBPFA for use across disciplines would help promote its normalization.

Subtheme 2c – Grief and Bereavement. Grief and bereavement within palliative care is highly complex and multilayered. There are several types of loss one might experience, and depending on the loss, it may impact some individuals but not others, and how each individual is affected by that loss varies as well. A few types of loss mentioned included loss of independence, strength, life, role, or routines. The palliative care team focused on appreciating that death is not the only route to grief for the patients and caregivers they serve, which is also recognized in CBPFA as well.

With the number of ways patients and caregivers can grieve, the acknowledgment of cumulative grief in the CBPFA ToT was appreciated by participants. They shared about the individuality of grief and the grieving process. One participant highlighted that there is no “typical way to grieve.” This was reflected in how the palliative care team spoke about their approach to grieving and bereavement in their work. The team offered additional insight into how they approach patients and caregivers, such as showing genuine concern, normalizing their reactions, encouraging legacy creation, and just providing ways to keep their loved one’s memory alive.

One of the key ways that the grief and bereavement module seemed to be distinguished from general CBPFA for disaster response was again this discussion of the team being along with their patients during their “journey.” As a result, palliative team members often have a deeper understanding of the things they are grieving, and they are likely to empathize with the losses they are experiencing. Thus, participants shared that they find it essential to show a genuine curiosity about what patients and caregivers are going through. This might include offering encouragement, acknowledging the person's strength and resilience, and showing gratitude for being able to provide care to the patient.

Additionally, the role of acceptance appears to play an influential role in patients' and caregivers' grief and bereavement. Acceptance of the life-limiting illness, treatment options, or patient decisions (i.e., active treatment versus hospice and comfort care) is often a significant factor that helps patients and caregivers cope, and at times, are the difference between psychological stability and perceived crisis. In my recent experience rotating through an inpatient palliative unit, acceptance has played a prominent role in patient and caregiver distress and bereavement outcomes. Overall, this suggests that facilitating feelings of acceptance might help to support patients and caregivers navigating the complexities of loss in palliative care.

Subtheme 2d – Coping and Self-Care. Participants highlighted the significance of processing traumatic stress reactions (i.e., emotional and cognitive reactions) and grief as a means of coping and practicing self-care. However, getting to that higher level of processing can be challenging for the individuals they support. Thus, they agreed with CBPFAs emphasis on helping patients and caregivers meet their basic needs. Meeting basic needs can also be framed as a method of self-care, which can be an effective way to encourage patient and caregiver self-care while promoting health and well-being. Another method suggested to help patients cope was setting short- and long-term goals for themselves. This process can help patients identify events they are looking forward to and instill hope.

The palliative team emphasized the importance of self-care for themselves. Setting boundaries around their relationships with patients and caregivers was one of the noteworthy ways participants practiced self-care, explicitly acknowledging that "their crisis is not my crisis." This understanding likely helps palliative team members with work-life balance and prevents their reaction, or investment in the patient's case, from escalating the crisis further. Moreover, despite the team's recognition of the importance of self-care, they acknowledged that it is an area they are still growing in. Growth within the practice of self-care can be challenging as it is usually up to them to initiate these practices, though they feel supported by their management to devote time to self-care. With the care team's proximity to their patients and caregivers, prioritizing themselves and self-care models healthy coping and lifestyles, an invaluable means of encouraging coping and self-care for patients and caregivers. To model coping and self-care, team members would want to be intentional about their behaviors and recognizing signs of burnout. This not only benefits the palliative team, but they can teach patients and caregivers about signs of burnout while incorporating education on common stress reactions.

While able to acknowledge the importance of self-care, the team also shared some challenges or barriers that patients, caregivers, and themselves face. For patients and caregivers, understanding what self-care truly is can be challenging. Defining self-care coupled with setting realistic expectations for themselves further limits successfully implementing self-care. Participants agreed that self-care can be as simple as eating three meals daily to something bigger, like exploring and utilizing respite services. Based on the participants' discussion, they are well equipped to converse with patients and caregivers on coping and self-care, and the CBPFA ToT was a reminder that encouraging these practices can help support the bigger picture of what they might be going through.

On the other hand, although staff fully appreciate the need for self-care in their work, some barriers reached beyond education and training. Participants shared a common experience about their obligation to the patients they serve and their team. For example, taking a day off means putting the responsibilities on someone else or creating more work for a different day.

With the nature of their small team, to maintain patient care the burden can unintentionally be placed on other team members to provide coverage. With these barriers in mind, palliative team members must be intentional about their self-care outside of and during the workday. The addition of a brief self-care assessment during the CBPFA training may be a valuable way of increasing staff self-reflection on their self-care practices and understanding of the methods that nourish them.

Subtheme 2e – Active Listening. Participants recognized the value of active listening and specifically identified similarities between the BESTT EARS acronym and the approaches they use in palliative medicine. An aspect of active listening that stood out during the discussion was being mindful of cultural and gender differences, specifically regarding therapeutic touch. The palliative team highlighted the importance of cultural awareness regarding active listening, such as eye contact and touch. One story stood out that demonstrated these different areas. The palliative team was supporting a family through a recent fetal loss. They utilized therapeutic touch as a way of being present and supporting the family, a culturally appropriate and helpful behavior. However, during the debrief, the other providers acknowledged that touch was not encouraged in their discipline. Additionally, a male provider shared that even if therapeutic touch were appropriate, they would likely be uncomfortable utilizing it to demonstrate active listening. This conversation suggested that therapeutic touch can be an essential and influential part of palliative medicine while being mindful of cultural appropriateness and ensuring permission is granted.

Additionally, the palliative team stressed the importance of being intentional and fully present during their time with patients and caregivers. Part of being intentional includes creating a space that is calm and slow during a time that often feels chaotic and rushed. The team identified that slowing down facilitates active listening by reducing distraction. This approach allows them to understand their patients' needs better and encourages a genuinely person-centered approach to care. Participants shared how this intentional approach communicates to their patients and caregivers, "I am here for you," and helps team members not get caught up in the fast-paced nature of the job. Lastly, another method of not feeding into the chaos of the environment is honoring the silence, recognizing that silence can be okay and can also demonstrate active listening.

Subtheme 2f – Problem Solving. The problem-solving module was the only CBPFA module adapted for the palliative care team before the CBPFA ToT. Thoughtful consideration went into reviewing the DECIDE Model (Guo, 2020) instead of SODAE typically utilized in the CBPFA ToT. Although SODAE could have been used, using a problem-solving model that incorporated the interdisciplinary nature of the medical field and that would possibly be more familiar to the participants was viewed as the best option. Additionally, using the DECIDE Model (Guo, 2020) allowed participants to weigh in on how the model applies to palliative care.

Feedback from participants related to problem-solving within palliative care largely focused on understanding how to identify the problem that needs to be solved. Even though the palliative team has been on a journey with the patient and likely has an understanding of their goals and treatment plan, when a new problem arises, "all bets are off," and it is essential to approach the problem from a blank slate rather than making assumptions in how the patient may choose to approach the problem. The team emphasized that the best way to solve a problem is by slowing down and taking the time to understand the patient's goals, as they can change from problem to problem, day to day. This approach is reportedly helpful for both patients and caregivers and ensures effective communication between team members and the patient.

One discussion that stood out during the problem-solving model was that palliative team members do not have to solve all problems and likely cannot. Individuals working within palliative care are likely natural helpers, wanting to solve each problem. However, when considering the importance of self-care and coping, members of palliative care teams also benefit from understanding that they cannot be all for everyone. Prompting coping and self-reliance is also a valuable problem-solving approach, which helps foster autonomy and resiliency in situations that can often lead to hopelessness and helplessness.

Notably, when it comes to problem-solving for patients in palliative or hospice care, problem-solving is ongoing. More specifically, one might have the opinion that overall treatment of the life-limiting illness and symptom management are a long fluid problem-solving process or, as one participant said, “maximize within their disease.” The DECIDE Model (Guo, 2020) appears to be most applicable in managing the acute changes, or unanticipated obstacles that occur. Situations like a change in condition, loss of a job, discontinuation of treatment, or family conflict regarding treatment are times when CBPFA skills can be most effective, and they would significantly benefit from more structured approaches to problem-solving.

Lastly, palliative care teams should be able to normalize the facilitators and barriers that may impact their ability to problem-solve. Acknowledging potential barriers allows team members to prepare for the barriers and cope when they are feeling stuck. Palliative care and the challenges that patients, caregivers, and team members face are complex and often life-altering. Thus, palliative teams must recognize when they have trialed every option and that lack of resolution does not necessarily equate to failure as a helper. Allowing space for self-compassion and grace in a physically, emotionally, and spiritually demanding field is vital to coping. It supports the recommendations of Kent et al. (2020) to empower care teams and patients to focus on problems within their control.

Subtheme 2g – Referral and Ethics. The palliative care team expressed the value of referrals within and outside their care team. They acknowledged that being a part of a larger healthcare organization often makes referral easy, as do connections in the rural community. Referrals are an essential part of palliative medicine, especially for the small palliative care team that participated in the CBPFA ToT, because a small team often does not possess the capacity to support every patient and caregiver they see. For example, social workers can benefit from making psychotherapy referrals outside the care team to community mental health or other mental health providers. Overall, participants appeared to have a strong understanding of how and when to make referrals.

The team's discussion on ethics led to compelling insights into several ethical dilemmas that occur in a palliative setting, one of which was the difference between choosing to begin hospice or comfort care versus suicidal ideation. The teams' approach to this possible dilemma focused on the difference between typical death ideation and suicidal ideation. Based on what team members shared, death ideation tends to focus more on physical changes. The idea of hospice may often come from the care team itself, as they recognize those physical changes in the patient. Physical changes are often what might typically be defined as EOL changes. The content of the patients' thoughts also provides insight into whether they are experiencing death ideation. Participants shared that conversations with patients wanting hospice care do not appear like the person is "giving up," in fact, the opposite appears more accurate in that they have exhausted all options and tried everything. Instead, their decision for hospice aligns with appropriate death ideation, given their current physical health or recent medical events.

Assessing for suicidal ideation in this population looks similar to other populations, with an understanding that many patients may be having thoughts about death. However, other factors to consider when assessing for suicide might be to determine where the person is in their disease process. Initial stages of the diagnosis were noted as a time when suicidal ideation may be more prevalent and may warrant referral to a mental health provider. Although more challenging to assess, more seasoned palliative care providers might notice the different “feel” between death ideation and suicidal ideation.

Goals of care conversations from the start of the patient’s diagnosis are likely the most effective means of understanding a patient’s decision should they chose to begin hospice. Defining wishes through an advanced directive or other formal means at the start of a life-limiting illness, or ideally when an individual is healthy, helps to take the guesswork out of hospice decisions. It also gives the patient autonomy over their care, which is extremely important as they often lack a sense of control due to their life-limiting illnesses. Palliative care teams can foster that autonomy through goals of care conversations and ensuring patients are informed about their treatment options.

Another common ethical dilemma in palliative care is the capacity to make medical decisions. Decision-making capacity can complicate the palliative values of autonomy and self-determination. Understanding whether a patient has capacity is essential in the context of palliative care because patients should possess an understanding of their life-limiting illness and treatment options and appreciate the risks and benefits of different medical decisions in order to make a choice that aligns with their goals and preferences. Poor choices do not necessarily mean a patient lacks capacity; however, when deciding between treating or not treating an aggressive cancer or choosing VSED, medical providers want to establish that the patient can understand

and appreciate what their choice means. The degree to which decision-making capacity is assessed can vary depending on organization and state-based regulations. Identifying ethical dilemmas such as capacity reinforces the necessity of referrals and consultation with a palliative care team. Decisions related to ethics should not be made lightly, and the interdisciplinary nature of palliative medicine allows for informed decisions while encouraging patient choice and autonomy.

Theme 3 – Context of Patient/Caregiver Goals

The participants in this study recognized the utility of CBPFA within palliative care. As discussed in Theme 2, the components of CBPFA align well with palliative care values and can easily be incorporated into already-used methods and daily patient encounters. However, there is also an aspect of palliative care that makes CBPFA even more feasible for the palliative setting, and it goes back to the journey that palliative team members are on with their patients. Specifically, palliative team members get to know their patients and caregivers far more profoundly than other disciplines and even more than a traditional helper using CBPFA in other disaster situations. This unique relationship and understanding of the patient, their history, and their goals allows palliative team members to make even more informed decisions when applying CBPFA.

When providing care for a patient in palliative care, context is critical. For example, knowing the patient's physical health history, family history, cultural identity, treatment plans, and goals allows palliative care teams to take a person-centered, holistic approach to the care they provide. Incorporating CBPFA into their palliative training and their complete understanding of the person can allow them to apply CBPFA skills more effectively. Knowledge of patient and caregiver goals also prepares palliative care teams for when "the bottom drops out" because they know what might be at stake for the individuals and can know if and how to intervene.

Components of CBPFA, such as active listening and problem-solving, can equip palliative team members to navigate the problems that arise when patient and caregiver goals misalign—for example, helping a caregiver cope with their loved one's decision to discontinue treatment and initiate hospice care, or helping a patient under distress when their caregiver requests respite. Adapting CBPFA for palliative care allows team members to approach crisis intervention more efficiently while traversing the values of the care team, the patients, and their caregivers.

Theme 4 – Adaptations to CBPFA for a Palliative Care Team

Participants' feedback and discussion throughout the CBPFA ToT sessions and focus groups provided insight into how each module of the CBPFA ToT could be applied to a palliative care setting. Additionally, following the completion of the ToT, participants provided suggestions on what could be added to the training to make it more applicable and helpful for palliative care. Their suggestions included incorporating more written materials, such as copies of slides or the CBPFA manual. Providing additional resources would allow palliative team members to refer back to the materials independently and would likely increase the application of CBPFA.

Furthermore, participants expressed a desire for role-playing and palliative care examples. Role-playing was not included in the CBPFA ToT due to time constraints; however, it would be ideal to allow for role-playing opportunities. Role-playing would solidify how to use the skills discussed (i.e., active listening) and allow the trainer to give feedback. Role-playing can also serve as an ice-breaker and help to break down and make the CBPFA training more interactive. Similarly, palliative-specific examples were recommended for future training. De-identified examples that the palliative team provided during their discussions will be incorporated into the adapted version of CBPFA for palliative care. Discussing unique palliative case examples would be valuable for further understanding traumatic stress, referrals, and ethics. Including palliative examples and case studies would also be advantageous for individuals completing the training who are less familiar with palliative care. They allow for real examples of how CBPFA concepts and skills can be applied to the situations they may encounter.

Lastly, additional modules on rapport building and mindfulness were recommended. Although active listening is a core component of CBPFA, participants reflected that their work within palliative care often goes beyond active listening. Palliative care teams must be able to create a therapeutic relationship with their patients and caregivers, as their time together often spans months to years. Rapport with patients and caregivers helps to build trust and respect. Trust and respect are often the keys that allow palliative care teams to intervene when their patient is in distress or struggling to cope (James & Gilliland, 2016; Morgan & Terry, 2014), allowing for CBPFA to be executed meaningfully and successfully. The team’s recommendation for additional training on mindfulness would be a beneficial supplement to the coping and self-care module. Participants reported less familiarity with mindfulness compared to self-care. Training and practice on mindfulness would benefit staff, patients, and caregivers; thus, including it in training seems reasonable and aligns with CBPFA’s goals of helping themselves and others.

In summary, a common thread across many of the themes of this study is the journey palliative care teams are on with their patients and caregivers. The journey is profoundly personal and multifaceted, marked by compassion, support, and a focus on improving quality of life and symptom management. Rather than separating the journey as its own theme, it felt most appropriate to leave it woven across the themes, just as it is woven through and strengthens the relationship of palliative teams and their patients, and is thus a core thread that brings this study together. Similarly, this study has been a prominent part of my journey through graduate education and grieving the loss of my mother. It has been one of the most rewarding and challenging experiences. The obstacles and accomplishments that have come with tackling such an extensive project, although nothing compared to the obstacles of palliative and hospice care are reminiscent of my journey as a caregiver, an experience I reflected on often throughout this study. As a result, during my journey, I have strived to foster new ideas and ways of supporting patients and their families that promote their sense of dignity, comfort, and peace on their journeys.

Study Strengths

The present study highlights the range of psychological distress that palliative/hospice care teams support patients and caregivers in coping with, as well as challenging situations that are unique to palliative/hospice care. Additionally, the rural interdisciplinary palliative care team recognized the utility of adapting CBPFA for their setting. It provided insight into the alignment of CBPFA goals and palliative care values. The study's design supported collaboration with the palliative care team and a deeper understanding of the applicability and feasibility of adapting CBPFA for palliative/hospice care. Training on CBPFA also provided the palliative care team with new skills that could be implemented in their work—incorporating feedback from faculty and psychology students familiar with CBPFA allowed for the development of the CBPFA ToT that could accommodate the time constraints of training and maintained the integrity of CBPFA. Additionally, using three coders with varying levels of familiarity with CBPFA and palliative medicine allowed for a broad exploration of emerging themes.

The use of the CBPR methodology is a notable strength of the present study, as the process of adapting CBPFA was not based solely on the researcher’s ideas. The actual adaptation was based on the participants' and researcher’s expertise and experience, creating a comprehensive adaptation of CBPFA. In alignment with CBPR principles, this defense is presented on behalf of the palliative team that supported it coming to fruition and the patient and caregiver stories that were reflected on to develop a version of CBPFA that will help future patients and caregivers overcome the challenges of palliative/hospice care. The adapted version of CBPFA is a gift to the palliative care team and those they will go on to care for in the future.

Study Limitations

This study had several limitations, with the first being the small sample size. Due to the small sample size, quantitative data analysis should be interpreted with caution. Although the purpose of the study was to adapt CBPFA to a palliative care community, making the qualitative data the essential part of addressing the research questions outlined. Although the small sample allowed for a case study approach, analyzing the data as a whole prevented the differentiation of data based on discipline. Identifying discipline-specific data would have allowed for a richer understanding of the discipline’s opinions on the CBPFA adaptation.

Second, given the busy schedules of the palliative care team and the difficulty getting all participants together simultaneously, the time constraints were a study limitation. Due to the narrow window to conduct the two CBPFA ToT sessions that accommodated the most palliative care team members, the CBPFA training had to be truncated to include the essential components. These limited aspects, such as more descriptive examples and role-playing, are typical in the more extended version of CBPFA ToT. Additionally, due to the chaotic nature of palliative care, not all participants could attend the entirety of the CBPFA training and focus groups, likely limiting some of the discussion and participant feedback. Lastly, given the difficulties with scheduling, using three focus groups appeared to be more of a burden than beneficial. Given the depth of discussion during the two training sessions, one to two focus groups would have been sufficient.

A third limitation relates to the literature review, specifically the difficulty distinguishing between research on palliative versus hospice populations. There is notable variability in the use of the terms “palliative” and “hospice” dependent on the country in which the study occurred; thus, a review of the literature focused on both settings, whereas data from this study was primarily based on palliative care, with some reference to end of life situations.

Summary and Future Directions

Few studies address prevalent psychological distress among patients and caregivers within palliative/hospice care (Akechi et al., 2004; Clayton et al., 2014; Conill et al., 1997; Crunkilton & Rubins, 2009). CBPFA was proposed to support the psychosocial needs of patients and caregivers and serve as an additional crisis intervention strategy to assist the population. There has been no research to date using CBPR to adapt CBPFA in a palliative/hospice care community. Collaboration with a rural interdisciplinary palliative care team enabled the adaptation of CBPFA and assessment of the appropriateness and feasibility of CBPFA for palliative/hospice care settings.

The specific aims of this study were to 1) train the care team on CBPFA to help patients and caregivers cope with crises and psychological distress related to their life-limiting illnesses or EOL, 2) adapt CBPFA with the support of the care team to ensure that the methods of CBPFA are appropriate for a palliative/hospice care community, and 3) monitor and evaluate the feasibility of, and satisfaction with CBPFA for the community.

In summary, through CBPFA training with the interdisciplinary team, their feedback and discussion suggested that CBPFA is widely applicable to the palliative/hospice setting and would be especially useful for new staff, other disciplines, and as a review for seasoned palliative/hospice care workers. CBPFA, although new to the palliative team, felt familiar to them. Participants repeatedly reflected on the similarities between their training in palliative care and the overall CBPFA framework. Training in an adapted version of CBPFA will empower other palliative/hospice care teams to pull from skillsets they already have to address the psychosocial needs of their patients and caregivers.

Results from this study suggest the relationship between care teams and patients and caregivers is essential to integrating CBPFA into the palliative/hospice setting. CBPFA builds on the relationship and journey they are on, facilitating trust and empathy for the peaks and valleys their patients likely experience as a result of their life-limiting illnesses. The care team's more profound understanding of patient goals and history can catalyze effective CBPFA integration. The palliative team in this study recognized the utility of each CBPFA component and provided insight into how each relates to the care they provide. Lastly, feedback was obtained on further adapting CBPFA for palliative/hospice care through the addition of resources and modules to make CBPFA even more applicable to the palliative/hospice field.

In staying true to CBPR methodology, the adapted form of CBPFA for palliative/hospice care communities will be developed and provided to the participants of this study. Future directions include training other palliative/hospice care communities on the adapted version of CBPFA. Similar feedback on the appropriateness of CBPFA for palliative/hospice care should be acquired in future studies. This feedback would allow for a more comprehensive adaptation that meets the needs of different palliative/hospice care teams. Future studies should also incorporate participation by other populations, such as volunteers, caregivers, support staff, and outside disciplines, to gather feedback on CBPFA from individuals less familiar with palliative/hospice care. Exploration of the effectiveness of the adapted version of CBPFA for palliative/hospice communities should be conducted using outcome measures that assess patient and caregiver psychosocial distress (i.e., depression, anxiety, adjustment disorders) pre- and post-CBPFA training and implementation. Such studies would allow for a deeper understanding of the efficacy of CBPFA for palliative/hospice communities.

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Appendix A

Demographic Questionnaire

1. Which gender do you most identify with?
    - a. Female
    - b. Male
    - c. Transgender Female
    - d. Transgender Male
    - e. Other
    - f. I choose not to answer

2. What is your age? ___________

3. What is your current marital status?
    - a. Single, never married
    - b. Married
    - c. Divorced
    - d. Widowed
    - e. Living with partner
    - f. I choose not to answer

4. What is your race/ethnicity? (Please check all that apply.)
    - a. African American/Black
    - b. American Indian/Alaska Native
    - c. Asian/Pacific Islander
    - d. Caucasian
    - e. Latino/Hispanic
    - f. Biracial or Multiracial
    - g. I choose not to answer
    - h. Other (please specify):

      ____

5. What is the highest level of education you have completed?
    - a. High School Diploma or G.E.D.
    - b. Some College or Associate's Degree

c. Bachelor's Degree/College Degree
d. Master's Degree
e. Doctoral level or J.D. Degree
f. I choose not to answer

6. What field of study is your degree in?

____

7. Did you receive specialized training in palliative medicine?
a. yes
b. no
c. I choose not to answer

8. How many hours per week do you spend working in palliative/hospice care?

____

9. How many hours per week do you spend providing direct care to patients/caregivers?

____

10. What is your role within palliative/hospice care?

____

11. How many years have you worked in palliative/hospice care?

____

12. Approximately how many patients do you provide care for each week?

____

13. Do you utilize specific psychological/crisis intervention strategies in your work?
a. Yes
b. No
c. I choose not to answer

14. What strategies do you use?

____

15. Have you ever been involved in patient care that was especially stressful or difficult for you?
a. Yes
b. No
c. I choose not to answer

16. What types of patient/caregiver experiences do you find especially emotionally or psychologically difficult?

____

____

____

Appendix B

UNIVERSITY OF SOUTH DAKOTA
Institutional Review Board
Informed Consent Statement

Title of Project:	Adapting Community-Based Psychological First Aid to a Palliative/Hospice Care Team: A Community-Based Participatory Research Approach
Principal Investigator:	Elizabeth Boyd, Ph.D., South Dakota Union Building, Vermillion, SD 57069 (605) 658-3710 beth.boyd@usd.edu
Other Investigators:	Kathryn Moore, M.A., South Dakota Union Building, Vermillion, SD 57069 (605) 658-3710 kathryn.ira@coyotes.usd.edu

Invitation to be Part of a Research Study

You are invited to participate in a research study. In order to participate, you must be currently working in palliative or hospice care at Avera Sacred Heart Hospital. Taking part in this research project is voluntary. Please take time to read this entire form and ask questions before deciding whether to take part in this research project.

What is the study about and why are we doing it?

The purpose of this research study is to examine the effectiveness and usefulness of Community-Based Psychological First Aid (CBPFA) in order to develop a community-specific intervention that is not only effective but sustainable for members of the palliative care team at Avera Sacred Heart Hospital. Data will be collected from feedback during CBPFA training and during follow-up feedback sessions following the CBPFA ToT at 30-, 60-, and 90-days. Follow-up sessions will explore participants' training experience, provide an occasion for the researchers to obtain feedback, and be an opportunity for participants to receive technical assistance and consultation for implementing CBPFA in their communities. About seven people will take part in this research.

What will happen if you take part in this study?

If you agree to take part in this study, you will be asked to attend scheduled Training of trainers (ToT) sessions ranging in length from 30 minutes to one hour during seven scheduled team meetings at Avera Sacred Heart Hospital. Training will begin in June of 2022. Attendance at three follow-up sessions 30, 60, and 90-days following the conclusion of training is requested. During scheduled meetings participants will be asked to provide feedback to the researcher regarding the adaptation of Community-Based Psychological First-Aid (CBPFA). You will be asked to complete brief questionnaires on your knowledge of CBPFA, and the feasibility and appropriateness of CBPFA at the first and last training session. Participants will also have the option to fill out feedback forms at the conclusion of each training session. Training sessions and follow-up feedback sessions will be audio recorded for the purposes of facilitating CBPFA adaptation. No identifying information will be obtained from questionnaires or measures.

What risks might result from being in this study?

There are no risks in participating in this research beyond those experienced in everyday life.

How could you benefit from this study?

Although you will not directly benefit from being in this study, others might benefit from the crisis intervention efforts that training participants will be able to offer once the CBPFA ToT is completed. Participants will be equipped to train others in their community, and, thus, build capacity at the local level. Another possible benefit is better psychological support amongst the participants' team, which could be beneficial to participants in a high stress environment.

How will we protect your information?

The records of this study will be kept confidential to the extent permitted by law. Any report published with the results of this study will remain confidential and will be disclosed only with your permission or as required by law. To protect your privacy, we will not include any information that could identify you. We will protect the confidentiality of the research data by not obtaining any identifying information. If we write a report or article about this study is written, we will describe the study results in a summarized manner so that you cannot be identified. Direct quotes from participant feedback may be used in future presentations and publications of study results. However, any participant identifiers will be removed from all direct quotations. If you tell us something that makes us believe that you or others have been or may be physically harmed, we may report that information to the appropriate agencies.

I give consent to be audiotaped during this study.

Please initial: ____ Yes ____ No

I give consent for my quotes to be used in the research; however I <u>will not</u> be identified.

Please initial: ____ Yes ____ No

Access, sharing, and provisions for data collected.

Data collected during the execution of this study will be stored in standard and accessible file formats to facilitate sharing and long-term protection in two different locations: researcher's personal computer and a password protected flash drive. Hard copies of measures will be scanned onto the researcher's password protected person computer, and stored on a password protected flash drive. The researcher and their academic advisor, Dr. Boyd, will have free access to datasets, either from computers used to store data or from flash drives that are password protected. To facilitate collaboration with community collaborators and the palliative care team, collected data will be provided in hard copy and electronic form throughout the different phases of the study (i.e., planning, implementation, and results). The researcher does not foresee any copyright, ethical, or privacy issues. Additionally, each CBPFA ToT session and follow-up feedback session will be audio recorded using the researcher's USD affiliated Zoom account and stored on the researcher's password-protected personal computer.

It is possible that other people may need to see the information we collect about you. These people work for the University of South Dakota, and other agencies as required by law or allowed by federal regulations.

Your Participation in this Study is Voluntary

It is totally up to you to decide to be in this research study. Participating in this study is voluntary. Even if you decide to be part of the study now, you may change your mind and stop at any time. You do not have to answer any questions you do not want to answer. If you decide to withdraw before this study is completed, data collected during your participation will be kept for future use.

Contact Information for the Study Team and Questions about the Research

The researchers conducting this study are Beth Boyd, Ph.D. & Kathryn Moore, M.A. You may ask any questions you have now. If you later have questions, concerns, or complaints about the research please contact Beth Boyd, Ph.D at (605) 658-3710 during the day.

If you have questions regarding your rights as a research subject, you may contact The University of South Dakota- Office of Human Subjects Protection at (605) 658-3743. You may also call this number with problems, complaints, or concerns about the research. Please call this number if you cannot reach research staff, or you wish to talk with someone who is an informed individual who is independent of the research team.

Your Consent

Before agreeing to be part of the research, please be sure that you understand what the study is about. Keep this copy of this document for your records. If you have any questions about the study later, you can contact the study team using the information provided above.

Your signature indicates that this research study has been explained to you, that your questions have been answered, and that you agree to take part in this study. You will receive a copy of this form.

Subject's Name: ____

____

Signature of Subject & Date

Appendix C

Knowledge of PFA: Pre- and Post-training

What do you already know about Psychological First Aid?
Before beginning the Psychological First Aid course, we would like to know how familiar you already are with the material in the course. A number of questions about psychological first aid and resilience are presented below. Please choose the best answer for each question. There is no grading involved, we just want to see what course participants already know coming into the course.

1. Psychological first aid training
    - a. teaches one how to counsel people after stressful events
    - b. helps one to use existing skills more effectively
    - c. gives one the qualifications to be a mental health professional
    - d. teaches one about first aid for psychological disorders
2. Stress reactions after difficult events
    - a. are experienced by everyone exposed to stress
    - b. are ordinary reactions to extraordinary events
    - c. are rarely experienced by most people
    - d. are serious psychological reactions
3. A critical component of coping is
    - a. confronting each crisis head on
    - b. waiting for things to return to normal
    - c. receiving support from loved ones
    - d. numbing emotions with alcohol
4. Assisting with basic needs while providing PFA is necessary because
    - a. it is more comforting than anything else
    - b. people suffer stress reactions due to lack of basic necessities
    - c. basic needs are more important than all other concerns
    - d. one needs to provide physical and psychological first aid
5. When providing psychological first aid you should NOT
    - a. let the person make their own decisions
    - b. keep the information they share private
    - c. maintain strict boundaries
    - d. tell them you are a mental health professional
6. A critical component of self-care is
    - a. taking breaks
    - b. staying awake to help more people
    - c. eating only organic foods
    - d. eating alone to take time to yourself

7. When considering whether to approach people to offer psychological first aid it is important to
a. observe and be aware
b. have a list of questions ready
c. make sure the person is the same gender
d. clear the area of other people

8. If someone is threatening to harm him/herself or someone else
a. it is best for a psychological first aid provider to handle the situation
b. call another psychological first aid provider to back you up
c. it is best to take away all methods of harm (i.e. knives)
d. refer him/her to a mental health professional

9. Active listening skills include:
a. giving advice
b. asking questions
c. problem-solving
d. taking notes

10. The sequence for problem-solving is
a. Stop, Organization, Decide, Ask
b. Stop, Options, Decide, Act
c. Strength, Organization, Determination, Act
d. Strength, Options, Determination, Ask

11. Normal grief reactions typically last
a. year
b. 1 year
c. 2 years
d. 5 years

12. Flashbacks are
a. memories about traumatic events
b. feelings that one is reliving a traumatic event
c. nightmares about a traumatic event
d. a symptom of psychosis

13. When using active listening you should
a. use the phrase “I know how you feel”
b. ask “Why?” questions
c. use short phrases of encouragement
d. tell them everything will be okay

14. What is NOT a sign of vicarious traumatization?
    a. a change in personal beliefs
    b. decreased cynicism
    c. social withdrawal
    d. alcohol abuse
15. When speaking of the death of a loved one
    a. it is best to use words like “loss” so you do not hurt the person’s feelings
    b. it is best to use concrete words like “death”
    c. you will remind the person of his/her pain
    d. assure the person you know how they feel

Appendix D

Psychological First Aid Usefulness Questionnaire

Directions: Please rate your view of the PFA training for the following items. 1 = Strongly Disagree, 2 = Disagree, 3 = Somewhat Disagree, 4 = Somewhat Agree, 5 = Agree, 6 = Strongly Agree

I will use PFA to support patients.	1	2	3	4	5	6
I will use PFA to support caregivers.	1	2	3	4	5	6
I will use PFA to support other palliative/hospice professionals.	1	2	3	4	5	6
I will use PFA to support other people in my life.	1	2	3	4	5	6
I found the PFA training useful for understanding my own reactions after traumatic events.	1	2	3	4	5	6
I plan to use the coping skills discussed in the PFA training.	1	2	3	4	5	6
I learned a lot about talking to people about their problems in the PFA training.	1	2	3	4	5	6
I learned a lot about my personal self-care in the PFA training.	1	2	3	4	5	6
I feel more comfortable talking to patients and caregivers about their difficulties due to the PFA training.	1	2	3	4	5	6
I believe I am more likely to recognize when someone is in distress because of what I learned in the PFA training.	1	2	3	4	5	6
I am more likely to recognize my stress because of what I learned in the PFA training.	1	2	3	4	5	6
I feel I will be able to cope with my stress more effectively because of what I learned in the PFA training.	1	2	3	4	5	6
I learned how to listen to others more effectively during the PFA training.	1	2	3	4	5	6
I learned how to problem-solve more effectively during the PFA training.	1	2	3	4	5	6
I feel that PFA will positively impact my direct care with patients and caregivers.	1	2	3	4	5	6

1. What components/topics of the PFA training did you find most helpful?

2. What components/topics of the PFA training were unhelpful?

3. Do you think anything should be added to the training to make it more applicable to palliative/hospice care communities?

4. Do you think anything should be removed from the training to make it more applicable to palliative/hospice care communities?

5. What components/topics of PFA did you use prior to the training?

6. What components/topics of PFA were new for you as a result of the training?

7. What did you do to support other people before the PFA training?

8. What methods of support are you most likely to use in the future?

9. Any other comments?

Appendix E

Feedback Questionnaire

1. How was today’s training relevant to your role in palliative/hospice care?

2. Do you have any suggestions to make the training more applicable to palliative/hospice care?

3. What parts of today’s training were not applicable to palliative/hospice care?