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Palliative care across the lifespan

Sonya Sabrah
Eastern Michigan University

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Palliative care across the lifespan

Abstract

When a patient or a loved one has a chronic, life-threatening illness, it is critical to guarantee the healthcare provider or family member helping them explore their options in order to make them as comfortable and happy as possible. Palliative care programs aim to relieve the patient or loved one from suffering by managing their symptoms, and working with them to achieve their goals and enhance their quality of life. Many people may confuse hospice with palliative care but it is important to realize hospice has certain requirements that a patient has to meet whereas palliative care programs can be opted into at any stage in their illness. Palliative care has numerous benefits for both the patient and their family members. Some of the benefits include symptom control, improved communication and coordination between healthcare members and family, support for the patient and their caregivers, and assistance with making complex medical decisions and determining treatment choices.

Palliative care services vary based on the patient's age and individualized needs. In the pediatric population, palliative care team members all specialize in pediatrics which is critical since there are countless differences between the pediatric and adult populations. Pediatric palliative care is extremely beneficial because the healthcare team is able to manage the child's illness and at the same time try to attempt curative treatment. There are a few barriers when it comes to pediatric palliative care programs but the solutions are easily accessible. The pediatric palliative care programs have been dramatically increasing over the past few years, proving their effectiveness. With this young population family is a critical role in the patient's treatment which is why parents and even siblings are looked at as members of the medical care team.

The palliative care services for veterans has also proven to be highly beneficial. Palliative care services for the veteran population has improved numerous lives. Mental health issues are more common in this area. There are several sources veterans and their caretakers can utilize in order to find out if palliative care is right for them. Veterans may have their care completely covered through their veterans' benefit package depending on their specific issues and what kind of treatment is required. Palliative care programs are improving the quality of life for chronically ill patients with limited options for treatment for people at any age. Palliative care programs are becoming more and more popular and hopefully soon anyone who qualifies for palliative care can get the help they need to live more comfortable lives.

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Sonya Sabrah

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Palliative care across the lifespan: Pediatric and veteran populations

Sonya Sabrah

Eastern Michigan University

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Abstract

When a patient or a loved one has a chronic, life-threatening illness, it is critical to guarantee the healthcare provider or family member helping them explore their options in order to make them as comfortable and happy as possible. Palliative care programs aim to relieve the patient or loved one from suffering by managing their symptoms, and working with them to achieve their goals and enhance their quality of life. Many people may confuse hospice with palliative care but it is important to realize hospice has certain requirements that a patient has to meet whereas palliative care programs can be opted into at any stage in their illness. Palliative care has numerous benefits for both the patient and their family members. Some of the benefits include symptom control, improved communication and coordination between healthcare members and family, support for the patient and their caregivers, and assistance with making complex medical decisions and determining treatment choices.

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more common in this area. There are several sources veterans and their caretakers can utilize in order to find out if palliative care is right for them. Veterans may have their care completely covered through their veterans' benefit package depending on their specific issues and what kind of treatment is required. Palliative care programs are improving the quality of life for chronically ill patients with limited options for treatment for people at any age. Palliative care programs are becoming more and more popular and hopefully soon anyone who qualifies for palliative care can get the help they need to live more comfortable lives.

Keywords: *Palliative care, pediatrics, veterans, hospice, pediatric palliative care, veteran palliative care, end of life, infants, children, adolescent, role of family, illness, lifespan*

Palliative care across the lifespan: Pediatric and veteran populations

Many people who are diagnosed with chronic or advanced diseases are inadequately cared for (Wagner et al., 2001). The most significant reason for this issue is healthcare members attempting to cure the patient and prolong the patient's lifespan instead of focusing on the predominant goal of improving their quality of life. Palliative care focuses on patients who have serious life limiting illnesses by utilizing a holistic approach in order to decrease suffering and ameliorate their current situation. The focus of this paper is to explain what palliative care is and to compare palliative care services across the lifespan focusing on two populations: pediatrics and veterans. Numerous topics including why palliative care is important in these specific populations, the potential barriers to obtaining palliative care services along with possible solutions, costs, effectiveness, the role of families in their care and true patient stories.

Part 1: Elucidation of palliative care

Palliative care defined

Palliative care is a program for patients with serious or life-threatening illnesses where the main focus is to assist with managing pain and symptoms and providing emotional and spiritual support (Mayo Clinic, 2011). Based on the patient's specific needs and symptoms, the care team will consist of doctors, nurses and other health care providers such as, psychiatric professionals, social workers, pharmacists, nutritionist, chaplains and other health care professionals needed by the individual (Center to Advance Palliative Care, 2012B). When opting into palliative care, a specialist is there to work with the patient, the family members and the other members of the care team to provide an individualized plan of care during and after treatment (Mayo Clinic, 2011).

Initially, major concerns such as pain, delirium, depression, dyspnea, lethargy, insomnia and anxiety will be addressed, along with the prognosis, care goals and possible treatment options (Center to Advance Palliative Care, 2012B). Besides helping to manage symptoms, palliative care will help patients adapt and continue with everyday life as able (Center to Advance Palliative Care, 2012B). Depending on the patient's needs, there are different services available, such as institutional, outpatient and pediatric (Mayo Clinic, 2011). Overall, palliative care programs will assist patients to gain more control over the care they need (Center to Advance Palliative Care, 2012B).

Palliative care vs. hospice care

Many people have a misconstrued idea of palliative care because they associate it with hospice care. Although these two programs are similar with their holistic approach, they are very different in regards to their location, time, payment options and eligibility. Hospice care is an in home service that provides round the clock care, it is also available in certain specialized nursing home facilities (National Caregivers Library, 2015). Palliative care can be institutional such as a nursing home, hospital, or an extended care facility and can also be provided at home (Mayo Clinic, 2011). Timing is another critical difference between palliative and hospice care. In order to be eligible for most hospice programs and for it to be covered by your insurance, you must be terminal or have at most six months to live (National Caregivers Library, 2015). On the other hand, palliative care has absolutely no time restrictions, so you can opt in no matter what stage of illness you are currently in (National Caregivers Library, 2015).

The payment options are also different; hospice care is said to be all inclusive in regards to payments but insurance coverage varies; there are also subsidized options for patients who have limited income, but in most cases insurance is able to cover just about everything (National

Caregivers Library, 2015). Palliative care is administered through the patients' regular medical provider, so it will most likely be covered by Medicaid or their insurance; but the important thing to note is everything will be billed separately (National Caregivers Library, 2015). In regards to prescriptions, if the patient is in the hospital receiving care they are most likely covered for all medications, but if they are receiving outpatient care they will only be covered for the medications that are eligible for reimbursement based on their insurance policy (National Caregivers Library, 2015).

Treatment is another difference between these two programs. While they both provide relief of suffering and help improve everyday life these programs have different end goals. Hospice care puts a large focus on getting whatever they can out of the possible time they have left to live, this allows for a level of comfort to be reached so the patient can concentrate on the emotional and realistic issues of death (National Caregivers Library, 2015). Palliative care has a different focal point; it provides comfort for patients at any stage in their illness, and they do have life-promoting factors (National Caregivers Library, 2015).

When to consider palliative care

The number one indicator that palliative care is right for your patient is if they have a serious illness that is causing pain, stress or other symptoms effecting their quality of life (Center to Advance Palliative Care, 2012A). Some examples of serious illnesses are heart disease, respiratory diseases, kidney failure, AIDS, cancer, and multiple sclerosis; there are numerous others as well (Center to Advance Palliative Care, 2012B). If the patient is still indecisive about palliative care, allow them to consider the following; do they suffer from pain or symptoms due to any chronic/serious illness, have any physical or emotional issues that are not currently under control, or if they need help planning, understanding or controlling their care or current health

state (National Institute of Nursing Research, 2011). The Center to Advance Palliative Care (2011) has an online resource called “Is Palliative Care Right For You?” giving the patient access to this resource will allow them to determine if palliative care will be beneficial to them. Healthcare providers can access this information and give the patient instruction to gain access by using the following link: <http://getpalliativecare.org/rightforyou/> (Get Palliative Care, 2016).

If the patient decides they would benefit from this holistic care approach, advise them to contact their healthcare provider (Get Palliative care, 2015). If the healthcare provider does not bring up palliative care, encourage the patient to not be embarrassed to ask about it. DePasquale (2015) identified that most people feel more comfortable talking to their nurse about their treatment options. It is important to realize that there is absolutely no reason to wait. Serious illnesses can cause life debilitating symptoms, so the sooner the patient seeks out care, the sooner they will be able to receive care that not only improves their life, but gives them control of their treatment. The palliative care health team understands what the patient is going through and provide unconditional physical, emotional, spiritual and psychological support.

Benefits and barriers

Patients can be hesitant to opt into palliative care, but it is important to teach them all of the potential advantages. The first benefit is pain and symptom control. Based on the illness the care team will identify where the pain and discomfort is coming from, and treat those symptoms accordingly. This is the main point of palliative care, treating the symptoms will make their life easier, happier and they will have a greater quality life (Center to Advance Palliative Care, 2012B). For example, a mother who has shortness of breath due to a chronic respiratory disease wants to go to her daughter’s swim meet without having to deal with difficulty breathing. Her palliative care team will find a way to treat this so she can enjoy her daughters swim meet

without any irritation or complications. According to Palliative Care Victoria, (2010) patients who have hospital palliative care consultations experience a reduction of symptoms, greater satisfaction with overall care, and better emotional support when compared with the usual care.

The second benefit is communication and coordination. When people have severe life-threatening illnesses, there are always questions and concerns throughout the entire process, whether it is from the person themselves, or their loved ones (Center to Advance Palliative Care, 2012B). The palliative care team members work with the patient, their family and with other team members to make sure that their needs are being entirely met (Center to Advance Palliative Care, 2012B). The palliative care team stresses the importance of communication between all involved parties to accomplish the goals each individual requires (Center to Advance Palliative Care, 2012B). The third advantage is support. Rather than focusing on just the illness, palliative care encompasses the person as a whole (Center to Advance Palliative Care, 2012B). Support of the whole person allows for comfort and support to be provided whether emotional, physical, psychological or spiritual (Center to Advance Palliative Care, 2012B). This is very critical to help the patient cope and understand their situation, and be able to remain positive about their life (Mayo Clinic, 2011). The fourth benefit is family and caregiver support. It is important to recognize that care givers are also under a lot of stress. The palliative team is also there to provide support to them as well (Center to Advance Palliative Care, 2012B). Comforting and supporting the people who care for the patient will assist to ease their anxiety, stress and ease the decision making process (Center to Advance Palliative Care, 2012B).

When you are the patient's care giver, it may be extremely overwhelming and difficult to make certain decisions regarding their healthcare. Another benefit of palliative care is, to provide guidance with the complex and hard decisions for treatment choices (Center to Advance

Palliative Care, 2012B). Some of these difficult decisions or questions include how to make the right medical decision for the person and end of life care. Questions about aggressiveness of treatment and resuscitation efforts are difficult for care givers to answer alone. These questions are placed on the caregiver if they client is unable to make their own decisions (Lichtenfeld, 2010). There are several other advantages when choosing palliative care over usual treatment options, such as less visits to the emergency room or to the hospital, saves the patient time, stress, and also saves money (Palliative Care Victoria, 2010). Another benefit is improving health resource use. According to Palliative Care Victoria (2010), patients who have cancer and entered into palliative care had a 30% savings cost within the last year of life. Palliative Care Victoria (2010) discussed a study done in the years 2004-2007 and found that patients who opt into palliative care incurred 6,900 dollars less than patients who receive usual care.

The most surprising and miraculous benefit of all is that palliative care can actually prolong life (Lichtenfeld, 2010). Not only are they living longer when receiving this care, but they are living better with an improved quality of life (Lichtenfeld, 2010). Lichtenfeld (2010) reported, "Those patients who received early palliative care had a better quality of life, less depression, and most remarkably lived 2.7 months longer than those who had routine care" (para. 10). There is no exact way to measure why palliative care leads to a longer, improved quality of life than with usual treatment. According to Lichtenfeld (2010), you should never underestimate the healing power of a helping hand, a listening ear, and the willingness and compassion to provide care and support.

Although there are countless benefits to opting into palliative care, there are also several barriers standing in the way. The first barrier is the physician. This is the most critical factor because physicians may think that offering palliative care will cause the patient to lose hope

(Gansler, 2013). Other issues regarding physicians not offering palliative care services include not having enough training in discussion of compassionate care. Physicians may be uneasy about how to approach the subject especially when discussing this topic with family members or loved ones. The physician may also believe that having patients in a palliative care program means that they failed as a physician (Gansler, 2013). There are also patient barriers, which include but are not limited to, the patient misunderstanding the program or believing that this means they have a poor prognosis. They may also be reluctant to discuss the program with their physician because they feel embarrassed. Patients who have a developmental disability have difficulty delegating services and treatment options to their supporting health care and family members (Gansler, 2013). The patient may also confuse palliative care with hospice care and believe they do not qualify or they may mistrust their health care workers, or may not be aware that Medicaid or other health insurances usually cover most of the cost (McAteer & Wellbery, 2013). To fix these issues, it is critical to offer healthcare providers more education in this area so they will be able to better their communication with patients needing this care which will also lead to less patient confusion.

Treatment options

There are several treatment options offered through the palliative care program. The treatment options are divided into categories of concern to make it easier to see what exactly is available based on needs of the patient (MedlinePlus, 2015). The first is physical problems, which consists of but is not limited to, pain, insomnia, difficulty breathing, loss of appetite and nausea (MedlinePlus, 2015). The treatment options for physical issues consists of medications such as opioids, nonsteroidal anti-inflammatories (NSAIDS), radiation therapy, nerve blocks, and spinal infusions (American Academy of Hospice and Palliative Medicine, 2016), nutritional

guidance, physical therapy, and other integrative processes (MedlinePlus, 2015). Palliative care also has treatment options for emotional, social and coping problems such as stress, anxiety, fear, hopelessness, and depression (MedlinePlus, 2015). The treatment options for these issues consists of counseling, support groups, family meetings and mental health providers (MedlinePlus, 2015). Practical problems, such as money issues, job related problems, insurance and legal issues are also addressed with treatment or consultations. Some of these options palliative care offers are explaining complex medical forms, helping understand treatment choices, financial counseling, and transport services (MedlinePlus, 2015). Lastly, they can assist with spiritual issues, some people question their faith when they are challenged by illnesses. The palliative care team help to explore the patient's beliefs and values so the patient can move toward peace and acceptance (MedlinePlus, 2015).

Palliative care rankings

After patients are diagnosed with a serious illness, there are numerous worries, concerns and feelings involved. It is important to recognize that many people do not know what palliative care is, and those who do might think that means they are simply giving up, and they have no hope. Although there is not an exact number for how long it takes patients to opt into a palliative care program after being diagnosed with a life-threatening illness, Gansler, (2013) found that the number of people using this type of service has increased since it was first developed 30 years ago. In fact, since the year 2000, the number of palliative care services in hospitals has increased by 138% (National Palliative Care Research Center, 2011). In national hospitals that have less than 50 beds, 22% have palliative care programs, in the hospitals that have more than 50 beds, 63% have palliative care programs and hospitals with more than 300 beds 85% have these programs (Center to Advance Palliative Care, 2011). The National Palliative Care Research

Center, (2011) used the Dartmouth Atlas of Health Care study to show that, of the 1.5 million Americans who have chronic illness, 70% are admitted into the hospital when they have an estimated 6 months or less to live, if they opted into palliative care earlier they may have been able to avoid an earlier death and years of suffering. The National Palliative Care Research Center (2011) showed that over the last ten years, palliative care services are one of the fastest growing trends in the health care setting.

As previously stated, the number of hospitals that offer palliative care services has significantly increased. Following that trend, the average length of time patients remain in palliative care has also increased. In the year 2011, 69.1 days was the average length of time patients remained in palliative care, whether it was due to death or just opting out of the program. In 2012, the number increased to 71.8 days (National Hospice and Palliative Care Organizations, 2013). Patients who are in palliative care programs may believe they should not remain in this program for more than six months. Why they believe this is not well understood, but the longer the patients remain in palliative care services the better quality of life they experience (National Palliative Care Research Center, 2011). The National Palliative Care Research Center (2011) showed patients who opted into palliative care during the earlier stages of their illness survived 2.7 months longer.

Palliative care is a valuable program to patients dealing with life threatening illnesses. Not only do these programs provide pain and symptom relief, but they are there for emotional, psychological and spiritual support. Palliative care is also beneficial in helping patients gain more control over treatment options and receive help with the hard decisions. Palliative care is an individualized program, so it varies by patient population and their specific needs.

Part two: Pediatric Palliative care

Importance and focus of pediatric palliative care programs

Pediatric palliative care is a family-centered, collaborated approach to healthcare which is used to relieve suffering of infants, children and adolescent patients and to achieve a better quality of life. Pediatric palliative care programs focus on improving the quality of life of their patients as well as providing emotional, psychological, spiritual and educational guidance to all people involved. The pediatric population in particular is in need of these kind of programs because this group varies in the type of care they need and it is extremely different from adult care. They need specialized treatment and medical experts who are familiar in the pediatric setting.

Palliative care is important across the lifespan, but it is of extreme importance to the pediatric population for a number of reasons. Pediatric palliative care programs range from prenatal until the age of 18 and in some special cases even 21 years of age (National Hospice and Palliative Care Organizations, 2015). The first reason why palliative care for the pediatric population is so important is because this patient group is very different from the adult population (Duke Children's Health, 2013). Some highlights of those differences would include factors such as predicting medical outcomes, different responses to drugs and certain therapies, and medical conditions children are born with (Duke Children's Health, 2013). Secondly, children with complex illnesses require medical experts in order to provide the best medical management with the least interference of everyday life (Duke Children's Health, 2013). Lastly, pediatric patients vary by age and throughout each of the growth and developmental stages they require different communication techniques, procedures and educational information. Since palliative care is a health care collaborative program that works with the patient and their

families these healthcare members need to be specialized in caring for this diverse population (Duke Children's Health, 2013).

Palliative care programs for the pediatric population have numerous goals that include both the patient and the family. There are four main goals of palliative care which include, improving the quality of life, managing symptoms and pain, communication and decision making with health care providers and family, and finally caregiver support (Crozier & Hancock, 2012). The primary goal is to relieve suffering and emphasize enhancing quality of life (Escobar and Medellin, 2015). Since palliative care has a patient-family centered approach, it focuses on the family and the patients' quality of life (Crozier & Hancock, 2012). In order to take complete care of the child's body, mind and spirit it is critical to make sure the importance is placed on the quality of the days rather than the quantity (Crozier & Hancock, 2012). The first step is making sure the patient and family members voice their wishes and define what quality of life means to them and what is needed to accomplish it (Crozier & Hancock, 2012). During end of life care, pain is the most reported symptom, and with this pain comes fear and anxiety; patients-especially children need their pain under control if healthcare providers want to help provide them with an improved quality of life (Wilkie & Ezenwa, 2012). According to the American Academy of Pediatrics (2016) this goal can be achieved with expert pain management, other physical symptoms, and through emotional and spiritual support.

As previously stated, in order for patients and their families to have an improved quality of life there must be pain and symptom management along with emotional support and spiritual assistance. Pain management and symptom control is the best way to achieve a greater quality of life, some of these symptoms include shortness of breath, vomiting, nausea, anxiety, fatigue etc. (American Academy of Pediatrics, 2013). A study by Grier Wolfe et al. showed that 89% of

parents who had children with terminal cancer stated their child had at minimum one aggravating physical symptom, with the most common being, fatigue, pain and dyspnea (as cited in, Michelson and Steinhorn, 2007). Achieving the goal of improving the child's quality of life will not occur if they are suffering from these symptoms, which is why pain and symptom control is essential to completing that overall primary goal which is to relieve suffering.

In order to treat the pain and symptoms the World Health Organization (WHO) developed a pain management ladder (World Health Organization, 2011). This ladder is used as a guideline to provide pain relief and it starts off with a mild analgesic such as Acetaminophen or Ibuprofen, then it gradually increases to stronger medications such as Methadone, Morphine etc. (Michelson & Steinhorn, 2007). With the continued use of some of these medications there may be concern about the risk involved such as addiction, and maybe even hastening death. Even though it is known that certain medications such as opioids cause respiratory depression, there are several studies which prove using opiates for symptoms management did not decrease survival chances (Michelson & Steinhorn, 2007). If the medications are given appropriately, and the patients are monitored properly, the patient is not likely to stop breathing and hasten death. It is also critical to make sure the least invasive treatments are provided first; this is important because you do not want to put the child under greater distress (Crozier & Hancock, 2012). Another common concern about medications is tolerance, and gastrointestinal disturbances such as constipation, and decreased appetite (Crozier & Hancock, 2012). Drug tolerance may occur with continued use of medication requiring higher doses of the drug to produce the same effect, but again as long as proper administration is being utilized the risks range from none to minimum (Crozier & Hancock, 2012).

Palliative care programs for the pediatric population also treats psychosocial and spiritual issues. Since pediatrics covers a wide age group, it is essential to tailor care to the educational level and developmental age of the child in your care. For infants and children who are limited in their vocabulary and concept of death, they rely primarily on sensations; so it is critical to soothe them and relax them by holding them (Michelson & Steinhorn, 2007). For example, in the preschool aged child they think death is something reversible, using clear, unambiguous explanations about what is happening to them is the best option (Michelson & Steinhorn, 2007). As for the school aged child, Michelson and Steinhorn (2007) explain that children are now able to have a more mature concept of death and some important interventions in this age group consists of supporting the child's understanding of their situation, letting the child have control when possible and lastly allowing the child to engage in medical decisions. As for adolescents, they have an abstract understanding of death, it is crucial to promote positive self-esteem, respecting their privacy, and allow their participation in important aspects of their care (Michelson & Steinhorn, 2007).

As for the spiritual needs, it must be handled in an individualized technique based on culture, religious needs, and developmental age. Providing an environment that is safe and open are two essential steps in providing spiritual support (Michelson & Steinhorn, 2007). In order to prevent spiritual distress, it is recommended that spiritual needs need to be assessed often, and it can be helpful to contact support from spiritual communities or individuals in the child's life (Foster, Bell, & Gilmer, 2014). The nurse caring for the child who is experiencing spiritual distress needs to make sure they are sensitive to cultural diversity, and that they are able to recognize signs of spiritual distress (Foster, Bell, & Gilmer, 2014). The signs of spiritual distress

consist of emotional symptoms, which include, hostility, loneliness, misery, resentment, and fear just to name a few (Foster, Bell, & Gilmer, 2014).

Communication based on developmental age and allowing the patient to have some control over the decision making process are critical components to improving patient care and they are also critical factors to build trust, and establish open and honest communications. According to Crozier and Hancock (2012), communication is key, especially in pediatric palliative care. Both the child and their family rely on frequent communication, which often includes information that may be sensitive and hard to hear. Establishing an open, trusting relationship with the patient and their family is one of the most important factors to ensure proper decision making options are laid out and the right decisions for the family and the patient are made (Crozier & Hancock, 2012).

Benefits of pediatric palliative care programs

Pediatric palliative care programs have numerous benefits. One of the most important aspects of this kind of care is that the members of your healthcare team work with the patient and the family to manage the illness and possibly receive curative treatment at the same time (Get Palliative Care, 2012A). Another crucial advantage of this program is that the focus is on the child as a whole and will provide the patient and their families with education and support on how this illness will affect the family (Get Palliative Care, 2012A). Not only will the patient get expert treatment but they will also have more information, guidance and support throughout every step (Department of Healthcare Services, 2016). This guidance, information and support is also critical for the patients' family because care giver support is of extreme importance.

Another advantage pediatric palliative care is the respite care. This allows for treatment in and out of the home (Department of Healthcare Services, 2016). There are also numerous

therapy options, some of these include, art, music, play, and massage (Department of Healthcare Services, 2016). When a child at any age is diagnosed with a chronic and life threatening illness there are numerous questions, concerns and feelings involved, the many members of the health care team are there to give the family and the patient options, education and to provide them with support and coping mechanisms to help them in their difficult time (Department of Healthcare Services, 2016). Lastly, the most important benefit of the pediatric palliative care programs is that it will help improve the quality of life of the patient and their families (Get Palliative Care, 2012A).

Barriers of Pediatric Palliative Care Programs and Potential Solutions

Even though palliative care services can be exceptionally helpful in improving the quality of life and providing education and support to both patients and their families, there are several barriers to obtaining this care. One of those barriers is that primary care pediatricians and acute care providers might have a misconception about what palliative care is or they may be uncomfortable with counseling children and their families about palliative care (Komatz & Carter, 2015). The Committee on Bioethics and Committee of Hospital Care (2000) explained that a potential solution to this issue is early consultation with a palliative care specialist. Another barrier identified is delaying the initiation of palliative care programs, and this can be due to lack of availability, and lack of provider and family education regarding palliative care (Hilden, Himmelstein, Freyer, Friebert, & Kane, 2001). This is a serious issue which can lead to a loss of opportunity to encourage palliative care values to patients and their families, being unable to modify the program to the progressing needs of the patient and their families, having to deal with crisis management that exacerbates physical symptoms, which might have been avoidable

with sooner initiation, shortage of education and decision making process and lastly, difficulty with family and patient coping (Hilden, Himmelstein, Freyer, Friebert, & Kane, 2001).

To overcome these barriers there are several aspects that need to be taken into consideration. The first is making sure pediatricians and nurses are able to obtain proper education and training on dealing with end of life care in the pediatric population. This can be done by implanting a mandatory curriculum and educational training for all nurses and pediatricians who wish to work with this population (Hilden, Himmelstein, Freyer, Friebert, & Kane, 2001). Another solution is providing families with educational resources that help them understand what palliative care is and what they can expect from this program (Hilden, Himmelstein, Freyer, Friebert, & Kane, 2001). Adding end of life care to the general and specialized pediatric examinations for nurses and other healthcare providers would also be a good way to ensure proper knowledge on how to deal with patients and families in this setting is accurately understood (Hilden, Himmelstein, Freyer, Friebert, & Kane, 2001). All of these barriers can be minimized. All it would take is more education regarding this sensitive subject, and making these programs are more available which should not be an issue at the rate palliative care programs are growing.

Effectiveness of Palliative Care

There is evidence to support that pediatric palliative care programs are increasing around the United States and that they provide infants, children and adolescents with an overall healthier and happier life (Feudtner et al., 2013). Feudtner et al. (2013) wanted to determine how many hospitals have palliative care programs specifically for the pediatric population. Feudtner et al., (2013) surveyed 162 hospitals in the United States, from the 162 hospitals it was determined that 112 have palliative care programs. In this same study they showed that 50% of all hospitals

across the U.S. have pediatric palliative care programs (Feudtner et al., 2013). There has been a dramatic increase in the availability of pediatric palliative care programs, which started peaking in 2008. It has been shown that this increase is due to the overall effectiveness of the programs (Feudtner et al., 2013).

The fast increase in these programs indicates a new standard of practice. The Children's Hospital of Philadelphia (2011), conducted a study that consisted of 515 patients from six different hospitals with a one year follow up. The results showed that two-thirds survived past the one year follow up (Children's Hospital of Philadelphia, 2011). This was a surprising result because when compared with adults in palliative care programs they usually expect a survival rate of three months (Children's Hospital of Philadelphia, 2011). Pediatric palliative care programs make a difference because they are able to support the patient and their family throughout every stage in the child's illness, thereby reducing fear, anxiety, assisting with the daily care and helping with difficult decisions (Get Palliative Care, 2012B). It can be said that because of the 24-hour support, the increasing growth of the palliative care programs, better and sometimes prolonged quality of life, these palliative care programs are extremely effective for the pediatric population.

Role of Families in Pediatric Palliative Care

Pediatric palliative care identifies that numerous people are affected by a child's sickness, which include parents, siblings and other family members. This also comprises extended family, peers and friends. Palliative care provides support to anyone in the sick child's life (Get Palliative Care, 2012B). The majority of children feel safer, more comfortable and better with family support and care; but the patient caregivers are also in need of support and palliative care programs offer that to them as well (Classen, 2012). This team approach will address the varying

needs of the family and they are able to adapt as the needs of the family changes (Get Palliative Care, 2012B).

According to Classen (2012), family plays a critical role in pediatric palliative care, he claims that separating the child from their parents is trauma itself; manifesting feelings of anxiety, stress and thereby worsening their condition. Children view their parents as the only reliable expert, when the parent is withdrawn or neglecting the child will know this and it affects every element of their well-being (Classen, 2012). Palliative care aims to improve quality of life and reduce suffering to the patients in their care, parents are also suffering through their child's condition (Classen, 2012). It is essential to provide emotional, spiritual, and psychosocial support to the parents and help them cope through this time; they are truly the second patients in your care.

Parents are also part of their child's medical care team; according to Chassen (2012), when you consider the components of palliative care: comforting, psychological support, and of course communication, the medical and parental care cannot be detached from each other. Another important aspect to consider especially because we are dealing with pediatric patients is informed consent and decision making. The parents are the ones who will primarily be making health care decisions for their children and they need to be well informed. Furthermore, Classen (2012) explains that in pediatric palliative care programs, parents are the experts to their children, they are also patients, and part of the medical team. Parents are irreplaceable, and they are a priceless resource, all three of these roles are critical to the child and need to be taken into consideration (Classen, 2012).

Siblings are another important aspect to consider in the role of family. When a child is diagnosed with a life threatening illness the entire family structure is altered. The focus of the

parents is mainly on the child that is ill and it may make the other children feel neglected. The siblings will also be suffering because of the loss or potential loss in a family member (Classen, 2012). A third aspect to consider is the siblings will try to look to their parents for strength and guidance but since the parents are also suffering this will be weakened (Classen, 2012). Sibling support is an essential part of palliative care. Being able to play and communicate with peers or siblings has a strong influence on the patient's mind, body, and spirit (Classen, 2012). When a child is observed after being released back home they have increased appetite, mobility and happiness now that they are able to connect and play with their siblings (Classen, 2012).

Pediatric palliative care teams work with the patient, their family and any member of that patient's life who needs assistance through this time (Get Palliative Care, 2012). Parents are able to get help through numerous forms of counseling, and siblings can also get counseling, and several different therapy options like music, art, and play (Get Palliative Care, 2012). Another factor parents struggle with is doing the "right thing", making medical decisions can be very difficult for the families, which is why communication and getting to know the family is essential in order to provide them with assistance through these choices they have to make (Get Palliative Care, 2012B). Parents, siblings, friends and other people in the ill patient's life are all part of the child's care team, and palliative care programs look to help in every way possible, through every step in their care.

Paying for Pediatric Palliative Care

Paying and reimbursement for pediatric palliative care services is a complex issue, but there is hope for change. According to the National Hospice and Palliative Care Organizations (NHPCO) (2015), the Patient Protection and Affordable Care Act of 2010 states that children who have Medicaid or private health insurance who are qualified for hospice care are also able to

have curative treatments and disease focused therapies. This is a huge step in the right direction for palliative care programs because that means they have more treatment options available to them. Right now the coverage varies on a state by state basis, but the future is looking promising (NHPCO, 2015). In 2012, the UCLA Center for Health Policy showed that patients who were receiving in home services greatly benefited; every month they were able to save 1,677 dollars or 11% per patient (as cited in NHPCO, 2015). The study was also able to show that there was a 32% decrease in the amount of days needed to spend in the hospital, which directly relates to the decrease in stress and sleep disturbances (as cited in NHPCO, 2015). In return these numbers prove that in home services are able to save money but they are also leading to better quality of life, better sleeping patterns, less stress and increased confidence in the providers caring for them (as cited in NHPCO 2015).

True Patient Stories

Levi Shu was born with brain damage; when he was brought into the world he had no heartbeat and he was not breathing (Get Palliative Care, 2015). The Shu family decided to initiate pediatric palliative care almost instantly, and they were immediately amazed at the quality of care this team provided with their son (Get Palliative Care, 2015). Levi's mother Dannielle explained that she was blown away with how the palliative care team was so calm, respectful and how fast they were able to adapt to her sons changing condition (Get Palliative Care, 2015). For families like the Shu's, pediatric palliative care helped control symptoms of the child's illness and be there to help the family understand the treatments and other options in the care. A nurse on Levi's palliative care team explained that it was clear the family wanted to have Levi enjoy his life, and live to the best of his abilities (Get Palliative Care, 2015). Danielle ended with the following statement "He's happy and has a quality of life that is far beyond anything

anybody's ever imagined for him because the palliative care team has been involved with him, with us as a family and with us as parents. (Get Palliative Care, 2015)."

The next patient story is about a boy named Marmaduke who was diagnosed with cancer at the age of 15 months (International Children's Palliative Care Network, 2015). When Marmaduke's condition worsened and became terminal, the family and palliative care team decided to do a home based therapy program (Little Stars, 2015). His father Simone (International Children's Palliative Care Network, 2015) explained "The only way I could get him home was with palliative care... The end of his journey, to have him at home in his bedroom with all his own colors, his own toys, his sounds, have his brothers climbing in and out of his bed – it was as normal an environment as he could possibly have (para. 6)." Marmaduke's pain was taken care of to relieve his suffering and improve his quality of life, and he was able to spend almost five months living happily at home surrounded by his parents, siblings, and peers and in his comfortable environment (Little Stars, 2015).

This is a true story of a patient Ayanda Khumalo* (*name change) who lives in South Africa, he was diagnosed with Rhabdomyosarcoma at 22 months (International Children's Palliative Care Network, 2015). Eventually the cancer had spread to different parts of his body and the family understood that at some point he was going to pass away (International Children's Palliative Care Network, 2015). Dr. Julia Ambler is a pediatric palliative care doctor and she explained that the patient was very symptomatic and his pain was not well controlled. When he was in the palliative care program this completely changed (International Children's Palliative Care Network, 2015). His pain was now controlled and for the first time since his diagnosis his parents were directly involved in his care and decision making process and they decided to have him receive home care and they were even encouraged by healthcare team to administer his pain

medication which they did (International Children's Palliative Care Network, 2015). Dr. Ambler (International Children's Palliative Care Network, 2015) finished with this "So how palliative care made a difference ... is that they firstly got to understand what was going on. Then they got to be involved in the decision making and at the end of the day they had a child that was really comfortable and who died at their own home, which was their choice (para. 16)."

Part three: Veteran palliative care services

Importance and focus of palliative care for veterans

Veterans have sacrificed their time and they have jeopardized their lives, and their sanity in order to protect and serve this country. There are approximately 21.8 million veterans. According to Risen (2014), it is our ethical duty to provide these veterans with proper care if they are fortunate enough to make it home. Many veterans suffer from physical pain, but a large portion also suffer from emotional and spiritual crisis. These crises can be due to numerous causes such as being diagnosed with an illnesses or can be due to the frightening situations they have encountered during the time they have served. Palliative care concentrates on the person as a whole, including their mind, their body and their spirit (US Department of Veteran Affairs, 2016). Since palliative care focuses on the patient rather than just the disease or illness, veterans will be able to get the emotional support that they need (Get Palliative Care, 2012). Because palliative care takes a collaborative approach, veterans greatly benefit. Physicians, nurses, social workers, dieticians, spiritual counselors and numerous other health care members work together to set up a specific treatment plan that fits the patient's specific needs; taking their families, their culture and other influential factors into consideration (Palliative Doctors, 2016). This approach is very beneficial to veterans who appear to need assistance from all of these providers.

Another promising dynamic is the fact that palliative care provides the necessary tools to assist veterans with their daily activities (US Department of Veteran Affairs, 2016). The 24-7 support, and accessible services not only help with managing the responsibilities of everyday life, but it also permits the veterans to be a dynamic part of their treatment and coordinating their treatment plan, so they are in control of their care (Interim Healthcare, 2016). According to Sutton and Grant, (2015), palliative care has been proven to improve health, and satisfy both patients and their family's needs. As many people know, caring for an ill family member can be emotionally, and physically draining, the palliative care support team is there to assist with both patients and their care givers needs (Get Palliative Care, 2012).

Veterans will benefit greatly from palliative care services. By providing symptomatic relief, the veterans will have an improved quality of life (Mayo Clinic, 2013). This improved quality of life will lead to less stress, less emotional and spiritual issues and they will be able to enjoy their life instead of suffering through it every day. Palliative care also promotes patients to take an active role in their care, veterans will be able to help set up their own goals and treatment plan that best suits them; this gives them an active role in their care (Interim Healthcare, 2016). Veterans and their families will get the emotional and spiritual support they need, which will make the family dynamics stronger (Palliative Care Victoria, 2016). Lastly, veterans will be able to complete the tasks of everyday life due to the symptom relief and the palliative care services provided to them.

Veterans choose to join palliative care programs for a wide variety of reasons. If a veteran has cancer, cardiac diseases i.e. congestive heart failure, chronic obstructive pulmonary disease, Alzheimer's or any other life altering illness, palliative care programs will be of great assistance (Get Palliative Care, 2012). An advantageous tool in determining whether palliative

care maybe right for your patient is the veteran shared decision making worksheet (VA Healthcare, 2014). In this worksheet the veteran will consider their needs, explore their options, get others involved, and then take action (VA Healthcare, 2014). Another wonderful tool to utilize is a caregiver's worksheet, since palliative care looks to make the veteran's life as well as their caregiver's life easier to manage and cope with, a family member or person who takes care of the veteran can fill out a worksheet to determine if they need help caring for the veteran, (VA Healthcare, 2014).

An additional reason to seek palliative care is mental illness. It is reported that 30% of veterans develop mental health problems within a few months of returning home and in 2010, twenty-two veterans committed suicide every single day (Dosomething.org, 2016). This is why palliative care programs are so essential, if they have opted into a program who knows how many lives could have been saved. Some mental illnesses that palliative care will assist with consists of, depression, bipolar disorder, and schizophrenia (MacMartin, 2014). If a veteran is seeking a palliative care program due to a serious and persistent mental illness they can expect collaboration between psychiatrists, psychiatric nurses, and their regular health care members (Ellen, Okun, Wogrin, & Corbeil, 2003). According to Ellen, Okun, Wogrin, and Corbeil, (2003), during the palliative care program for patients with serious mental illness, a collaborative team will work together to treat the symptoms, address their spiritual needs and provide support all while trying to assist the patients with living a productive life but also helping them understand and prepare for death in a dignified manner.

Since the veteran population is at risk for numerous mental health disturbances and that mental health issues lead to morbidity, palliative care programs will greatly change the dynamics of their lives. Another critical element to consider when veterans have mental illness is the

support from family. Ellen, Okun, Wogrin, and Corbeil (2003) explain that the word family to patients with mental illness may not be their actual family but it may be their healthcare workers and the word home may not mean their actual house but the place where they feel comfortable; for some this may be an inpatient psychiatric facility. This approach allows veterans to always feel safe and supported.

Whether the veteran is suffering from a disease like cancer or Alzheimer's or a mental illness such as bipolar or depression, palliative care programs will work in a team effort to treat the patient and work with families to assist with living, help prolong life and help the veteran cope with their disease and the process of death in a gracious fashion. The palliative care team members will be there for emotional, spiritual and physical support for the veteran and their family members. Utilizing this program will lead to a reduction of symptoms, more independence and control over their care as well as an ease of mind, body and spirit.

Accessing palliative care programs

If a veteran or caregiver decides that a palliative care program is right for them, retrieving the appropriate resources is very simple. The first and most important step to take is communicating with your doctor about the opportunity and considering the available options in your area (Get Palliative care, 2012). Many people do not consider palliative care because they fear losing the existing relationship with their doctor. This is not factual; because their doctor will be a consistent part of palliative care treatment (Blahd, 2015). In order to get the best results, the patient and doctor will need to discuss critical elements that might influence care. Some of these factors consists of cultural or religious preferences, where to receive care, and what is expectations of these services (Get palliative care, 2012).

It is imperative to tell the patient tells the healthcare provider what quality of life means to them. For example, being able to spend time with family, being able to walk without being short of breath, or having the ability to be independent in making healthcare decisions (Get palliative care, 2012). The next step is having the patient explain to their healthcare provider what they want and what they would not consider, for example, if the patient were unable to breathe would they want a mechanical ventilator etc. (Get palliative care, 2012). As you can tell resources and information about palliative care are easy to obtain. If your patient has made the decision that palliative care is right for them, simply communicate to them about the available options and they will be on their way to obtaining an individualized program that would significantly benefit both the patient and their family.

The effectiveness of palliative care

Many people wonder about the effectiveness of palliative care services, and a large part of this speculation is due to the public's unawareness of what palliative care is. Andrews (2011) found that in a recent study only 24% of people knew what palliative care was. Andrews (2011) explains that while the general public does not have sufficient knowledge regarding this type of care, the demand for palliative care services is growing fast; this need for more palliative care programs indicates its effectiveness. Palliative care has been found extremely beneficial for treating pain along with numerous other distressing symptoms (National Institute of Nursing Research, 2011). The National Institute of Nursing Research (2011) also found that palliative care is more effective in regards to communication among health care members and their patients. Palliative care is also more effective for meeting the patient's true wishes and providing emotional and spiritual support (National Institute of Nursing Research, 2011). Due to the effectiveness of palliative care programs the patients will have an improved quality of life.

Palliative care effects on caregiver's/family members

Before veterans join palliative care services, usually a family member or loved one is caring for them. While being a caregiver is very rewarding, it is emotionally, physically and psychologically challenging (Kristjanson & Aoun, 2004, p. 359). The caregiver may also have their own unmet needs, such as the need for support, communication or additional educational information (Kristjanson & Aoun, 2004, p. 359). Many people do not realize the significant effect being a caregiver has, but it is critical to be aware of this impact, which is why using the handout mentioned above is so important to determine if help is needed. Many times family members are overlooked, and are known as “hidden patients”, because they themselves are going through a lot of trauma due to their loved one being diagnosed with a terminal illness, and having to be the support and care for that person all the time. This leaves no time for their own personal needs which leads to significant amount of stress and other health implications (Kristjanson & Aoun, 2004, p. 360).

Kristjanson and Aoun (2004), found that before veterans get palliative care services, the caregivers and even other family members such as children are more susceptible to illness and accidents. Even though these conditions cause such a significant impact on the family, many caregivers do not want palliative care help because they might feel guilty, like they are just giving up. This is yet another misconception, family members are an integrative part of a palliative care team and they still act as the patients advocate (Kristjanson & Aoun, 2014). Veterans are not the only member of the family that greatly benefit from palliative care services.

After patients opt into a palliative care program the weight on the caregiver is significantly lifted. Once the veteran enters a palliative care program there are family directed goals that need to be achieved. The goals involve, meeting the family needs, reducing caregiver

distress, improving the well-being of caregivers, and empowering the family to help achieve the patients comfort (Wah, 2007). Not only do palliative care services offer family and caregivers ease of mind, and a reduction in stress, but they also offer them what they were lacking before, which is educational information, resources, communication, help and having their own personal needs being met (Wah, 2007). Palliative care is a life changing option for those in need and the great aspect is the family members or caregivers are still there for support and to help the patient through their illness.

Paying for palliative care services

Veterans and their family members may worry about being financially able to cover the costs of palliative care services. Since the care may be long term the veteran might wonder if it is included in their benefits package. According to, VA Healthcare (2014), the palliative care services are covered under the veteran's benefits package if the service is needed. Depending on the patient's condition and the type of insurance, there may be co-payments required (VA Healthcare, 2014). There are numerous factors that influence if co-pays are necessary, such as current financial status, insurance coverage (Medicare, Medicaid), and even service connected status i.e. disabled etc. (VA healthcare, 2014). Veterans should communicate with their doctor, or social worker to see what they are eligible for and to determine if co-payments are required. If palliative care services are required, it will most likely be covered under your benefits package, so there is no need to shy away from a palliative care program due to financial worries.

True Patient stories

Robert, a 77-year-old male with an undying love for baseball was suffering from chronic arthritis, and prostate cancer (Palliative Doctors, 2016). Because of his chronic and debilitating pain, Robert was unable to move around, let alone go to a baseball game (Palliative Doctors,

2016). When he was diagnosed he had never heard of palliative care but decided to give it a try. Robert explained that the care he received was so helpful he felt relief instantaneously (Palliative Doctors, 2016). Silvia, Robert's wife explained that they loved the team of healthcare workers, and they truly made an impact on his life (Palliative Doctors, 2016). Silvia also explained that the quality of care was so great, that when Robert's cancer inevitably advanced, without a second thought they wanted the same palliative care at home (Palliative Doctors, 2016). The palliative care team made Robert's life comfortable and enjoyable and he was finally able to see his favorite baseball team play (Palliative Doctors, 2016).

Jerry Romano, was an air force veteran, he passed away due to advanced heart disease (Stanford School of Medicine 2016). While he was alive, Jerry made a testimonial video about his condition and about the palliative care services he experienced (Stanford School of Medicine 2016). Jerry is a great example of how the patient has control and makes collaborative decisions with healthcare members to best fit what they truly want and need (Stanford School of Medicine 2016). Mr. Romano was very clear, he wants his fellow veterans and all patients suffering from chronic illnesses to know how important it is to work with your doctors and other health care workers, he explains how palliative care services gave him the freedom to make his own decisions with educational information provided (Stanford School of Medicine 2014). Jerry had both a defibrillator and a pacemaker implanted (Stanford School of Medicine 2014). He benefited from both of these devices for a few years before making his decision to take them out (Stanford School of Medicine 2014). Jerry was at peace, and this was due to the palliative care team who were there to meet his emotional, spiritual and physical needs (Stanford School of Medicine 2016).

Conclusion

Palliative care programs are of extreme importance across the lifespan. Whether the patient is a 6-year-old child with cancer, or a 60-year-old veteran suffering from schizophrenia; palliative care programs allow patients who are suffering with a life threatening illness to take control of their care, their treatment all while bringing together a group of specialist who create a holistic environment for the patient to thrive in. Palliative care programs are growing more popular every year and they have been shown to prolong life. Through patient stories you can see how effective they are in providing not only the patient but entire families with unconditional care and support. Through all stages of life, through all the various disease process, palliative care programs improve the quality of life for the patient and their loved ones.

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