CHAPTER 2

Suffering and Palliative Care Across the Continuum

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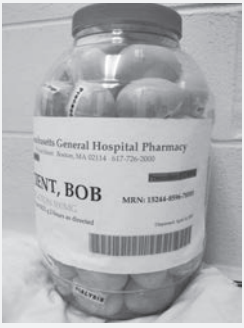
OBJECTIVES

1. Compare and contrast suffering in different cultures and special populations.
2. Describe suffering in relation to a child's developmental needs.
3. Distinguish sources of suffering for patients diagnosed with mental illness and/or substance use and their families/significant others.
4. Consider risks for suffering in the lesbian, gay, bisexual, transgender, queer/questioning (LGBTQ+) population.
5. Examine sources of suffering more common late in life with individuals who have experienced cognitive deficits or impairments.
6. Clarify sources of suffering for student nurses and nurses.

Student Project



Courtesy of Erica Lopes Cabral MSN, FNP-BC, student nurse at the time this was written.

The student described the suffering she witnessed while turning an 84-year-old gentleman in the Intensive Care Unit and looking into his eyes. His eyes conveyed a deep level of suffering that the student had not previously considered when performing other "routine" tasks. It occurred to her that this task was not "routine" to this older patient. In fact, it was yet one more reminder of the suffering, pain, and loss of health and independence that patients have to endure. She used the analogy of a pill bottle to demonstrate how nurses often consider many of their interventions to be therapeutic, while patients may perceive them as a source of suffering.

She labeled "pills" to indicate the suffering she observed in this patient. Some were labeled anasarca (generalized edema), psychosis, pain, amputation, acute respiratory distress syndrome, chest tubes, intra-aortic balloon pump, precautions, postoperative medications, multisystem organ failure, dialysis, psychosis, central line, chest tube, cardiopulmonary resuscitation (CPR), adult respiratory distress syndrome (ARDS), pneumonia, lack of sleep, and sepsis.

Introduction

Suffering is a theme contemplated in various arenas, including health care, politics, law, philosophy, and religion. Despite great strides made to relieve it, much suffering continues, and in some cases, it is seemingly "more outrageous, unjust, and unbearable than ever before" (Gonzalbo, 2006, p. ix). Contestabile (2018, para. 3, p. 1) asserts "the absolute number of extremely suffering people is greater than it was at any point in history until the 20th century. The number of happy people is greater as well; but suffering cannot be compensated by happiness across individuals."

Why is that? Is it because our world seems smaller, more accessible, and more connected, making us more aware of suffering on a worldwide scale—and does this broaden and deepen our awareness and concern? Are we on "suffering overload" because we are confronted daily with humanity's suffering through many forms of media? Is it because we as nurses see new technology and treatments that allow us to alleviate some forms of suffering but perhaps may generate others? Part of the challenge lies in the fact that some suffering cannot be measured readily, such as that related to infants and children, some mentally challenged individuals, some older adult individuals, and so on. Likewise, the measurement of suffering is perplexing because it is so complex, unique, and difficult to get consensus among different individuals (Knutsson, 2016).

Gonzalbo (2006) further asserts that each culture must decide how it will deal with the concept of suffering in its many different forms, as well as determine what meaning to give to the suffering. Furthermore, Gonzalbo suggests that meaning attribution strongly correlates with feelings and causes one to decide if suffering "is related to the will of the gods or fate" or is "a form of punishment or a means of purification" (2006, p. 2). Although pain can be described in neurological terms, cognitive awareness, interpretation, behavioral dispositions, as well as cultural and educational factors have a direct impact on an individual's pain perception (Bueno-Gómez, 2017).

Questions for Journaling

1. Why do you think suffering exists?
2. Does humanity have any control over suffering?

Everyone's suffering is unique and special to that individual and, in most cases, it is interpreted through the individual's cultural perspective, both past and present. Most groups of individuals who experience a common type of suffering or experience the same difficulty together might consider that their group is "special." Any individual or population can be considered "special" in relation to suffering. The purpose of this chapter is not to detract from the significance of suffering

experienced by any individual or group. It is hoped this chapter will help readers learn how to identify and understand the suffering of an individual or group with which they may be unfamiliar and learn ways to alleviate it and/or provide comfort in relation to the suffering—both that witnessed by the nurse and that experienced by the nurse.

Children, those diagnosed with mental illness and substance abuse challenges, and adults between 65 and 90 diagnosed with cognitive deficits are selected as special populations for several reasons. First, it can be challenging to obtain evidence-based data from all three of these populations. Children may or may not be able to express their suffering verbally and/or clearly. Likewise, someone diagnosed with a severe mental illness and substance abuse disorder may face similar difficulties in terms of self-expression of suffering and willingness to share. In addition, adults who have cognitive deficits or impairments may face comparable struggles. All three groups may face similar challenges in expression of their suffering and in obtaining comfort in relation to their suffering. Although the three groups may have some similarities, they will be explored separately because of their unique considerations. Some factors related to each of these groups may be applicable to other individuals or groups experiencing suffering.

Suffering is defined as the "state of undergoing pain, distress, or hardship" ("Suffering" 2021, Oxford University Press). Gonzalbo relates suffering to "pain, sickness, separation, abandonment, death; suffering often impacts an individual physically, emotionally, spiritually, culturally, and psychologically (2006, p. 2). Ferrell and Coyle (2008, p. 243) depict suffering as having three core dimensions: (1) subjection to violence, (2) sensation of being deprived or overwhelmed, and (3) living in apprehension.

The words *patient* and *suffer* come from similar Latin roots, as both mean "to bear"; furthermore, to be a patient means "to suffer" (Råholm, 2008, p. 64; Dempsey & Mylod, 2016). Suffering not only involves bearing some level of distress and pain but also may be worsened through alienation and loneliness. Therefore, the need is paramount for the nurse to connect with patients, as well as bear with them through their suffering. Part of this bearing may involve the nurse's presence and willingness to listen to patients' stories in order to give meaning to their experience of suffering and to assist them through the ordeal (Råholm, 2008).

Bearing witness in nursing practice involves both a moral and a political obligation. We must examine our understandings of power and privilege so that we can authentically bear witness and avoid being complicit in injustice; then, we need to address the associated responsibility to correct injustice after bearing witness to it (Djkowich et al., 2018).

Suffering in Various Cultures

Culture

Suffering occurs within the context of an individual's historical, cultural, sociopolitical, religious/spiritual, and economic perspectives (Barton-Burke et al., 2008). Within those perspectives, individuals will have their own unique experiences that define the suffering experience for them. Everyone suffers differently and uniquely. How people journey through suffering arises from a blend of their traditions and styles (Gonzalbo, 2006, p. 16).

Kirmayer (2001, p. 22) asserts that culture is not merely a trait displayed by patients but rather a transient and transforming concept involving interrelationships that take place between individuals, communities, and larger philosophies and organizational practices. Part of the grieving process or journey for an individual involves redefining and reintegrating the self into life (Shapiro, 2008, p. 41). An individual's cultural background and present cultural environment and experience can impact that redefinition and reintegration greatly. Emotions may be a deeply private experience, yet how we perceive and express feelings may not be as unique or random. Research demonstrates that culture influences the way some Americans and Germans convey their mood, and if this is universally true, it could mean that people within the same culture may express their feelings in similar ways (MacCormick, 2015).

Another important factor related to culture that will influence an individual along the journey is resilience. Resilience is the ability to bounce back and persevere through challenging times (Engel, 2007). When individuals are suffering or experiencing adversity, concentrating upon their strengths may foster resilience. Resilience involves facing stress and dealing with it in a manner that enhances confidence and social competence (Rutter, 1985). Strongly tied to resilience is having a strong internal locus of control, namely, feeling one has more control of one's destiny. This can be achieved by reframing negative perceptions to more positive ones and emotional stimuli to less emotional by better regulating emotions (Konnikova, 2016).

Likewise, hardiness is a trait that can help sustain individuals through suffering. Hardiness is considered to have three main components: (1) commitment (meaning and purpose), (2) control (sense of autonomy over one's life), and (3) challenge (zest for life that perceives change as an exciting opportunity for growth) (Ablett & Jones, 2007, p. 737). Thus, the characteristic of commitment aids individuals in their journey through suffering by affirming meaning and purpose to what they are experiencing. Although individuals who are suffering may not feel in control of the actual circumstances, they can have a sense of control in how they respond to the suffering. Finally, for hardy individuals, change is embraced as a normal attribute of life that presents opportunities rather than problems.

A study done with 32 mothers of children diagnosed with cancer (Stoppelbein et al., 2017) revealed that mothers scoring higher on measures of hardiness experienced less symptoms of posttraumatic stress than those mothers who scored lower. This work suggests hardiness may be a buffer and protective factor, leading the researchers to suggest ways to foster hardiness be examined.

Although certain experiences may be universal, expression of such experiences can vary greatly. Furthermore, care providers and clients often have very different backgrounds and experiences that impact their perspectives on culture (Kirmayer, 2001). In addition, care providers' ethnocultural background, professional education, and work environment will affect how they view clients and culture. Tension exists between what is universal and what is unique. Each patient a nurse encounters is unique; individuality must be acknowledged. At the same time, the nurse must look for aspects common to others' suffering to assist the patient in realizing the universality of suffering.

One's culture provides examples and cues related to resilience or lack thereof. For example, studies with African Americans have indicated that during stressful periods, African American families often have a strong social network to draw upon, tend not to seek help of professionals, and are more likely than other cultural groups

to offer and receive intergenerational help (Laurie & Neimeyer, 2008). Some additional factors to note about African Americans are that they (1) live on average 6 years fewer than Caucasian males and females; (2) often have lost a loved one prematurely and possibly due to homicide; and (3) frequently have endured racism, poverty, and oppression (Laurie & Neimeyer, 2008). Understanding and empathy for a patient whose background may encompass any of the aforementioned are crucial if the nurse is to foster an effective relationship that builds trust and helps the patient.

Another example of cultural diversity nurses may encounter is the way Chinese immigrants face end-of-life issues. Lin (2008) explored how U.S.-resident Chinese immigrants seek meaning when diagnosed with metastatic cancer. Cancer is one of the leading health issues for U.S.-resident Chinese immigrants. It is commonly considered bad luck in Chinese culture to discuss dying and death. Lin found that the 12 participants in this qualitative study felt meaning in their lives helped them journey through their suffering. The specific areas in which nurses can support meaning to life include helping patients who are suffering sense love and compassion, joy and value, hope and faith, readjustment and transcendence, and empowerment and peaceful dying (Lin, 2008, p. 256). Nurses can support these areas by listening to patients' life stories, promoting support and caring from families and religious practices, and ensuring good symptom control (Lin, 2008, pp. 256–257).

People in Western culture tend to avoid suffering and find little value in it. In a grounded theory study by Sacks and Nelson (2007), 18 chronically ill patients participated. The study explored nonphysical suffering and what might be helpful in dealing with it. Although each individual's suffering was different, trust was a common theme and pivotal to the suffering experience. The study supported the importance of nurturing trust in the nurse-patient relationship, especially during a time of vulnerability for the patient. Patients valued talking with nurses about their suffering to get perspective on the suffering situation, provide meaning within the context of the suffering, and reframe the suffering experience. Patients also increased their trust and appreciation for nurses who demonstrated competence in clinical skills, knowledge and trustworthiness, comfort care, and understanding of how a symptom affected the patient (Sacks & Nelson, 2007, p. 688).

Shapiro (2008) contends that families play an important role in helping individuals regain a degree of normalcy and routine when overwhelming circumstances arise. This process is (1) multifaceted; (2) takes place on many levels and dimensions; and (3) involves individual, relational, and cultural expectations. She further asserts that individual as well as family strengths can be stimulated by nursing interventions that support grief and growth (Shapiro, 2008).

CASE STUDY 2–1 Cross Culture

The short-term medical mission team from the United States to Guinea has been working since 7:30 a.m. Overloaded minibuses, trucks, and cars have driven long distances from very remote villages and arrived at the mission compound with many individuals expecting to receive free dental, eyeglass, and medical care. It is 5 p.m. Many are walking up to team members and pointing out what is hurting them or what they need or would like done for them. Some want cosmetic repairs on their teeth rather than health-promoting and life-saving extractions or fillings.

Communication outside the clinic is mostly nonverbal because most of the mission team members do not speak the native languages. There are people from four different language groups who arrived for treatment. Coordination is done by the full-time missionaries who live in the area and can speak one or more of the languages represented. The medical team pressures the team leader to keep the clinics open one extra hour to try to accommodate more people. The team leader is not in agreement with the team but decides to go with their request. The clinics stay open the extra hour. One hour later, many still go unseen, are turned away, and return to their villages without treatment. Team members are saddened and overwhelmed but agree that they are too tired to suggest any further extension today.

At the daily debriefing, expression of feelings is encouraged. The team leader then makes a strong recommendation: all clinics should open and close as previously scheduled for the remainder of the team's time there.

Questions on the Case Study

1. What difference does it make, and for whom, how long the clinics kept open?
2. What factors would impact your decision in such a situation to keep the clinics on schedule or extend the hours?

Healthcare Disparities

Healthcare disparity generally refers to ethnic or racial disparity. However, Healthy People views any different outcome between populations as a disparity (Healthy People.gov., 2019). Healthy People's goals have evolved over the past 20 years, namely, from reduction of health disparities among Americans to elimination of health disparities, to achievement of equity and improved health within all groups (HealthyPeople.gov., 2019). Disparity arises when there is an imbalance in social, economic, and/or environmental advantages. The goal of Healthy People 2020 is to track rates of illness, death, chronic conditions, behaviors, and other types of outcomes as impacted by race and ethnicity, gender, sexual identity and orientation, disability status or special healthcare needs, and geographic location (rural and urban) (HealthyPeople.gov, 2019).

Conditions, such as being diagnosed with cancer, can be an "equalizer" in some respects—that is, cancer affects people of all ages, races, genders, and economic status. It also results in a multicultural experience (Barton-Burke et al., 2008, p. 235). In regard to treatment of cancer, however, it becomes evident that there is an unbalanced aspect in relation to culture. Those who have language barriers or are without sufficient economic resources carry a heavier burden of suffering. In a study with 2,265 cancer survivors, non-White minority cancer survivors self-reported being less likely and frequently to see providers who understood their culture, while those who did have a greater frequency also received more understandable health information (Butler et al., 2019). Therefore, the equalizing effect of a diagnosis such as cancer is negated by disparities related to treatment among those with language or monetary difficulties.

"Race or ethnicity, sex, sexual identity, age, disability, socioeconomic status, and geographic location all contribute to an individual's ability to achieve good health" (Healthy People, 2019, p. 1, para. 1). For example, Native Americans and Alaska Natives have a 60% higher infant mortality rate than their White counterparts (National

Academies of Sciences, Engineering, and Medicine, 2017). Interestingly, Hispanic immigrants have better health outcomes than Whites initially. This is known as the "immigrant paradox," although some of these indicators diminish with time spent in the United States (National Academies of Sciences, Engineering, and Medicine, 2017). With other indicators, it appears the immigrant Hispanic population is doing better, but that is due to a decline in health of the White majority (National Academies of Sciences, Engineering, and Medicine, 2017). White females have experienced increased death rates due to suicide and alcohol-related diseases linked to the drug overdose epidemic; this has resulted in the first national death rate increase in decades and a recent decline in life expectancy for White females (National Academies of Sciences, Engineering, and Medicine, 2017).

Many healthcare inequities still occur, although efforts have been made to address disparity among groups, including Native Americans; individuals in rural communities and urban places; women; lesbian, gay, bisexual, and transgender (LGBT) persons; individuals with disabilities; and veterans. There are numerous reasons for these variations and disparities, such as (1) determination of appropriate means of data collection on race, ethnicity, and language; (2) consideration of the impact of neighborhood-level factors; and (3) exploration of multi-level factors that influence health (National Academies of Sciences, Engineering, and Medicine, 2017). Researchers will need to expand the indicators used to measure health disparity and broaden groups to be surveyed to include Hispanics and their major subgroups, Native Americans, Asians, Pacific Islanders and mixed race, LGBT individuals, people with disabilities, and military veterans (National Academies of Sciences, Engineering, and Medicine, 2017), as well as the homeless population.

Given the increasing diversity of culture within the United States, nurses are challenged to provide culturally sensitive care to clients as well as information and education that are readily understandable to diverse populations. Nursing education programs and healthcare facilities vary greatly in how they provide information to assist nursing students and nurses to become familiar with different cultural groups for whom they provide care. Adequate resources and opportunities must be provided to increase nursing skills and confidence in working with culturally diverse populations (National League for Nursing, 2016; McHenry, 2007).

Suffering in Children and Families

Concerns

What makes the suffering of children unique? Children are considered a vulnerable population based upon their developmental level, immature coping resources, and subjection to adult authority. Being a vulnerable population puts children at risk for suffering. Young children often have not had many life experiences or developed cognitive systems with which to process and handle suffering. They have not lived long enough to "bank" coping experiences that would allow them to respond with maturity and reasoning. Children (infants will be included here as children) most likely will experience some form of suffering for the first time while still young. Numerous factors impact how children face suffering:

- genetics
- birth order
- gender

- environment
- support system
- family mobility
- individual health
- family health
- experience with loss

Although sometimes considered and treated as "mini-adults," children are not small grownups but are impacted on many of the same planes as adults—physical, emotional, sociocultural, spiritual, and/or psychological—in relation to suffering. A person's genetic makeup helps determine what internal resources that individual may have to deal with suffering experiences. A child may have a strong physical, psychological, and emotional disposition inclined toward resilience and hardiness, or the child may be more fragile and susceptible to stressors. Children most frequently learn and reflect the values and spiritual belief systems of their primary caregivers. The social and cultural behaviors of children, whether positive or negative, are greatly influenced by their peers.

Some situations may occur to children that they would experience differently as adults. Examples include separation anxiety, bullying, adverse childhood experiences (ACES), incarceration of a parent, and death of parent (due to illness, accident, suicide, or homicide),

Placement within the family, also referred to as birth order or ordinal position, determines in many ways how a child will be treated by others within and outside the family. Older children often are expected to be courageous and protect younger siblings, whereas younger children may be treated as needing more care and protection. Similarly, gender may affect the way boys suffer, given that some boys are raised to stifle emotions as a sign of being strong and coping with suffering. This is particularly true of more traditional cultures (Dunlap, 2004). Research has demonstrated that later-born sons experience higher rates of delinquency and criminal behavior possibly somewhat due to less time investment of parents (Black, 2017).

Environmental influences include local environmental health concerns related to water, air, and sanitation. Social, economic, and cultural environmental factors have implications for how a child may respond to suffering. In addition, regional and global environmental issues may impact a child's personal environment.

Family mobility and stability shape children's views of their environment. Some children face multiple moves while in their family of origin. Level of involvement of extended family or friends for support may be affected by family mobility and stability also. Such support may be increased or decreased depending upon family circumstances. Children who have caregiver relationships with high levels of responsiveness, warmth, and consistency in discipline may have an enhanced ability to handle uncontrollable and controllable life stressors (Wolchik et al., 2008; Hunter, 2014).

Some children will face acute and/or chronic illnesses. Some acute conditions are more prevalent in children—for example, pediculosis (headlice), varicella (chickenpox), otitis media (middle ear infection), impetigo (skin infection), and Henoch-Scholein Purpura (autoimmune illness). Likewise, some chronic illnesses may occur initially in childhood. Some examples of these conditions are epilepsy, sickle cell disease, asthma, rheumatic heart disease, cystic fibrosis, and autism. Such illnesses, whether acute or chronic, place a strain on the individual and the

individual's family system because of the unpredictability of the illness and the seriousness and/or length of time the family system must cope with the child's illness.

In addition, one or more members in a child's family may experience health challenges, such as conditions that are hereditary or conditions involving substance abuse or dependency. The latter may not only involve interfacing with medical systems but also may involve interactions with legal systems.

Children can suffer many types of losses, including

- pet(s),
- safety and trust,
- familiar environment,
- parents(s),
- sibling(s) or extended family member(s)/significant other(s), and
- health.

For many, especially children, pets are members of the family. Loss of a pet from natural causes, accident, or euthanasia can result in feelings of tremendous loss, guilt, negativity, withdrawal, anger, depression, and illness. Loss of a pet may be the first loss children experience. If pain and/or death of the pet were witnessed or compounded by previous suffering, it can be particularly trying for the child (see Case Study 2–1, Loss of Pet "Rainbow."

CASE STUDY 2–2 Loss of Pet "Rainbow"

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David received Rainbow on his sixth birthday. It was his very first pet, and he was determined to take good care of him. David still was adjusting to the loss of his mother's presence due to divorce. David took great pride in watching over his newfound friend. Rainbow only lived 2 weeks. David was devastated when Rainbow died. David's little body convulsed as he sobbed for about 20 minutes. His father was surprised at his son's strong reaction to this loss.

David asked if he could use his grandmother's Mary Engelbreit garden marker as a gravestone for Rainbow. David and his grandfather buried Rainbow ceremoniously in semifrozen, snow-covered ground near the back steps of their house. The colorful "HOME SWEET HOME" garden marker signifies where Rainbow is buried. On the back of the "gravestone" in black magic marker Rainbow's death is memorialized with these words:

Rainbow February 11, 2008

Questions on the Case Study

1. What differences/similarities do you think may exist among a 3-year-old diagnosed with a terminal illness, an 8-year-old who lost his first pet, a 20-year-old diagnosed with a chronic mental illness, and an 85-year-old diagnosed with dementia?
2. Which individual would be most difficult for you to care for and why?

Safety and trust are foundational hierarchical needs in Maslow's theory (Maslow, 1943). Abuse and violence are not unique to children. However, children are particularly defenseless because of inequities between perpetrator and victim related to size, age, and often dominance in relationship. Children who experience abuse, either physical or sexual, may acquire various maladaptive, antisocial, and self-destructive behaviors and thoughts while struggling with abuse and trying to grasp why it is occurring (see **Table 2-1**, Potential Problems for Children Who Have Been Abused).

Table 2-1 Potential Problems for Children Who Have Been Abused

Academic difficulties
Aggressive behavior
Alcohol and/or other drug abuse
Anxiety
Attention problems
Bad dreams
Bed wetting
Behavior problems
Chronic pain
Compulsive sexual behaviors
Concentration problems
Criminal activity
Dangerous behavior such as speeding
Death
Dehydration
Depression
Dissociative states
Eating disorders
Failure to thrive
Fear or shyness
Fear of certain adults or places
Frequent injuries
Homelessness
Insomnia
Learning problems

Lying
Malnutrition
Oppositional behavior
Panic attacks
Physical symptoms such as headaches and stomachaches
Repeated self-injury
Risky sexual behaviors
Running away
Self-blame, shame, stigmatization
Self-neglect
Separation anxiety
Sexual dysfunction
Sleep disorders
Social withdrawal
Stealing
Stuttering
Substance abuse
Suicide attempts
Teenage pregnancy
Thumb-sucking or any age-inappropriate behavior
Truancy

Data from Hunter, C. (2014). Effects of child abuse and neglect for children and adolescents. *Australian Institute of Family Studies*. https://aifs.gov.au/cfca/publications/effects-child-abuse-and-neglect-children-and-adolescents; Newton, C. J. (2001). Effects of child abuse on children: Abuse in general. *Mental Health Journal in April*. http://www.findcounseling.com/journal/child-abuse/child-abuse-effects.html

Children may be threatened and told to keep the abuse a "secret." Carrying "the secret" can be additionally overwhelming, cause further stress, and impede the child from being able to develop trusting relationships. Multiple exposure to abuse raises a child's risk for experiencing autonomic and endocrine hyperarousal and numerous conditions (see Case Study 2–3, Loss of Health in Child, "Cassandra and Her Mother") (Newton, 2001).

Children can experience suffering from causes unrelated to illness. Bullying and school violence are traumatic for children. Teasing that is constant, hurtful, and unkind constitutes bullying. Children can feel helpless, unprotected, and alone if they experience either bullying or school violence. Bullying is on a continuum of various forms (see **Table 2–2**, Forms of Bullying) (*Helping Kids Deal with Bullies*, 2009).

CASE STUDY 2–3 Loss of Health in Child, "Cassandra and Her Mother"

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Cassandra was diagnosed with an unusual form of the autoimmune disease Henoch-Schonlein Purpura (HSP) at age 7. Most children who are diagnosed with HSP have a resolution of symptoms within about 4 weeks.

She had classic purpura, joint pains, and arthritis, as well as severe abdominal pain and mild kidney involvement. There was no cure—only symptom management. Included in Cassandra's history was a 3-month period of physical abuse by a childcare worker when Cassandra was a toddler. Her family had a strong faith but wondered why a young child had to endure so much pain and why God allowed Cassandra (and them) to suffer so. Cassandra was the youngest of three children. Her siblings responded differently to Cassandra's illness: one cared for her in tangible ways; the other often withdrew or was angry that medical care was not delivered sooner.

With the condition of HSP, Cassandra and her family experienced aspects related to both acute and chronic illness. Cassandra had had 17 hospitalizations. The family developed some "fire drill routines" when Cassandra's HSP pain symptoms returned and exacerbated. For over 2.5 years between purpura outbreaks and worsening episodes, the family held a guarded hope that Cassandra would be healed—and then one day, she was.

Questions on the Case Study

1. Compare two to three differences and similarities that occur in acute and chronic illnesses.
2. Discuss the different aspects of suffering experienced by Cassandra, her parents, and her siblings.
3. How might faith help or hinder a family such as Cassandra's? Support your answer with evidence-based data.

Table 2–2 Forms of Bullying

Hitting, shoving
Name-calling
Threats
Mocking
Extorting money and treasured possessions
Shunning

Spreading rumors
Using e-mail, chat rooms, instant messages, social networking websites, and text messages to taunt or hurt feelings

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Data from Hymel, S., & Swearer, S. (2015). Four decades of research on bullying. *American Psychologist*. https://www.apa.org/pubs/journals/releases/amp-a0038928.pdf; Kids Health. (n.d.). *Helping kids deal with bullies*. http://kidshealth.org/parent/emotions/behavior/bullies.html

Bullying tends to occur towards individuals who have low self-esteem, lack friendships, demonstrate lack of confidence, have learning difficulties, and display physical differences (Black, 2017). Bullying involves intentionality, repetition, and an imbalance of power (Hymel & Swearer, 2015).

School violence, although less frequent than bullying, has major implications for children who witness or are subjected to it. Children who are victims of bullying are at greater risk for involvement in greater and extenuated violence (Dunlap, 2004; Lee, 2018).

Moving, for whatever reason, may be distressing for a child. Leaving the familiar, even if the previous environment was unpleasant or disruptive, represents change and loss of the known. Leaving a familiar environment may occur rapidly, for example, because of disaster or some other event. Children often perceive a change in routine as loss because routine provides a level of comfort, regardless of the circumstances (Dunlap, 2004).

Loss of siblings, parents, and extended family/significant others may occur because of moving; divorce; military service; missionary service; business responsibilities; incarceration; and suicide, homicide, accidents, or other causes of death. Children can begin experiencing separation anxiety any time from ages 4–5 months to the more typical average age of 9 months (Swanson, 2015). By 2 years of age, or the end of the sensorimotor stage in Piaget's theory, a child generally has developed object permanence and realizes and expects that the caregiving figure will return (Piaget, 1932).

Younger siblings in a family in which a child has died may experience more difficulty in coping than older siblings. Older siblings often have more life circumstances, developmental maturity, and additional support systems through relationships, such as marriage (Dyregrov & Dyregrov, 2005). Death of a sibling can result

in survivor guilt, with remaining siblings wondering why they were spared or if they could have prevented the loss of their sibling.

In 2007 (Melhem et al., 2007), a sample of 129 children and adolescents who were 7 to 18 years of age and had experienced the loss of a parent by suicide, accident, or sudden natural death were assessed for complicated grief. Complicated grief was found to be a significant syndrome even after the researchers controlled for current depression, anxiety, and posttraumatic stress disorder. This sample also demonstrated significant functional impairment and correlation with suicidal ideation.

Circumstances that result in separation from a caregiver for an extended period can result in a sense of grave loss for children. Examples of such situations are boarding school for the child; business responsibilities; military commitment of one or more parents; missionary or other service-related responsibilities; parental relocation or prolonged travel due to employment; accidents; marital separation or divorce; or loss of parent(s) to death or other circumstances, such as incarceration. These circumstances also may result in the loss of care by and contact with extended family members/significant others. In the case of divorce, children generally have to deal with the loss repeatedly. Losing parents because of incarceration or suicide carries additional burdens of stigma and negative legacy for a child.

Children whose parents are incarcerated, on death row, or have been executed carry a unique burden (Beck & Jones, 2007; Ford, 2017). These children face stigma; an impeded, if not terminated, parental relationship; and in some cases, the anticipation of a gruesome death for their parent. Specifically, the 2.7 million American children of incarcerated parents are at increased risk for dropping out of school, adopting delinquent behaviors, and becoming incarcerated themselves (Ford, 2017).

Similarities of imprisonment of a parent to the divorce of one's parents *may* include these:

- no resolution or ending
- presence of distorted grief reaction
- intense emotions and higher rates of depression
- high levels of distress, disorganization, and prolonged grieving
- nonfinite loss and disenfranchised grief
- desire to have the absent parent in some form
- limitations of the parent–child relationship and visits (due to barriers of either institutional glass or distance)
- experience of social isolation
- boundaries of the relationship dictated by a legal system
- loss of childhood
- increased role of caretakers in a child's life

Children may be impacted with acute and/or chronic health issues. Impaired health may lead to disability and/or long absences from family or school. Health issues have a bearing upon a child's physical, emotional, sociocultural, spiritual, and psychological health.

Nursing Interventions

Recognizing a child's developmental level is critical when assessing needs, concerns, and requests; children cannot be treated as "little adults." Children are known for resilience—the ability to rise above or bounce back from aversive events and

maintain relative equilibrium in functioning amid the events (Bonanno, 2004; Engel, 2007; Weir, 2017). Capitalizing upon this resilience is helpful when formulating nursing interventions. Following are possible interventions for children dealing with suffering:

- Remember positive and good characteristics about the lost figure or situation; focus upon positive rather than negative is helpful.
- Provide ceremony to help deal with loss.
- Support an individual's faith and culture to enhance healing.
- Recommend bibliotherapy—i.e., select books that relate to the individual's circumstances of suffering.
- Use creative therapies (art, music, play, etc.) according to the child's abilities and desires to help express and process feelings.
- Consider individual and group interventions at school where children spend a good deal of their time and can share with their peers.
- Explore benefits of summer camps that might assist the child in dealing with suffering.

Fortunately, research bears out the finding that children, as well as adults, generally follow a pattern of resilience without professional intervention when grieving; only a small percentage of children experience lasting complications from grief (Currier et al., 2007). Interventions can help ease children's suffering when done in a time-sensitive manner and with specific intervention criteria. Until a child can process the traumatic memories from a loss, not many comfortable or happy memories can exist (Dyregrov & Dyregrov, 2013).

Suffering in Families and Patients Diagnosed with Mental Health Issues and Substance Abuse

CASE STUDY 2–4 Suffering from Mental Illness, "Mariah"

Mariah Porter is a 20-year-old sophomore student attending a large urban university in the northeast. Her college is about 400 miles from home. She recently had a psychotic episode and was admitted to a private psychiatric facility near her parents' home in a small suburban town. She has two older brothers and one younger sister. Growing up, Mariah was known for her intelligence and having her "head in a book." She never had many friends and tended to spend time with her siblings rather than others. She was considered "shy" and "reserved."

Her parents regret that they did not take Mariah for counseling at the school's urging when she was a senior in high school. During the spring of her senior year, Mariah exhibited bizarre behaviors and was convinced that other students were against her. Her primary care provider recommended a psychiatric evaluation. Her parents did not want Mariah "labeled" as mentally ill so did not take her for an evaluation. They struggled with Mariah's strange behaviors for about 1 month and helped her keep up with schoolwork by hiring a tutor. Mariah had been admitted early to college because of her high test scores and consistently high grades

throughout school. This "episode" resolved somewhat, and she was able to graduate. However, she never quite fit back in with her peers after being tutored at home.

Adjusting to city life was very difficult for Mariah. Two of her three roommates were from foreign countries and spoke to one another in their native tongue whenever they were in the college dorm suite. Her third roommate was away from the dorm often with her boyfriend and succeeded in college despite not studying much. Although studying had come easily to Mariah in high school, now she was struggling to maintain her grades and scholarship and lost much sleep trying to do so. She felt isolated and wondered if "others" were trying to make her fail by placing her with these three roommates.

Mariah's parents feel they have "failed" her. They are unsure what the future will hold for Mariah and if she will be able to make it on her own. Mariah has made comments to her parents, such as "You'd be better off if I were dead." She used to be meticulous about her appearance but since her psychotic episode has not paid attention to her hygiene and appearance. The hospital is planning to discharge Mariah within a few weeks. Mariah does not want to go back to college, and her parents do not know how she is going to function anywhere independently.

Questions on the Case Study

1. What kind of "suffering" do you think Mariah may be experiencing?
2. What suffering might her parents be encountering?
3. Are any of them "screaming in pain" and what does it sound like?
4. How does Mariah's "suffering" make you feel?

People who suffer with substance use disorder (SUD) also are subject to stigma and ostracism from their families, communities, and the healthcare system. The opioid crisis in America has brought the attention of this patient population to the forefront. News headlines, case reports in medical journals, and federal agencies (Center for Disease Control and Prevention [CDC], Federal Drug Administration, and the Drug Enforcement Agency) are currently focused on the opioid epidemic. The publicized information typically focuses on a given substance and not the person or the underlying problem of SUD. Statistics typically dominate the headlines and focus on the number of deaths secondary to overdoses in a specified time period, such as a headline from the CDC stating that 130 Americans die daily as result of an opioid overdose (CDC, 2018). Statistics are powerful; however, they do not address the underlying health issue that is the basis for the statistical data. Nurses are on the front line of the current opioid crisis and have a unique opportunity to have a positive impact the lives of this marginalized patient population.

When treating patients with SUD, nurses need to be cognizant of their personal beliefs, biases, and preconceived notions of patients with this condition. No two patients with a given diagnosis are identical and therefore cannot be treated with an algorithmic, one-size-fits-all approach. Each patient's history is unique and the approach to their care needs to be individualized. People who suffer with SUD may be suffering from severe depression, a chronic health issue, pain, and/or a mental illness. The use of a given substance(s) may be a person's attempt to limit the suffering he or she is experiencing with his or her self-medicating behavior.

This is one example of a patient story; it is not representative of all patients diagnosed with SUD. The importance of developing a therapeutic relationship with

CASE STUDY 2-5 Suffering from Substance Abuse, "Chris"

Chris Smith is a married 40-year-old father of two working as a site manager at a local construction company. Ten years ago, Chris suffered a work-related injury that required his need for ongoing treatment of his chronic pain symptoms. Chris was on high-dose opioid therapy for nearly a decade when he was suddenly reduced on his dosing regimen by his primary care provider secondary to her fear that she could get into trouble from her employer and/or federal agencies if she continued prescribing high-dose opioids during an opioid epidemic.

Chris was relatively stable on his opioid medication regimen with no adverse side effects and no history of compliance issues that would indicate a possible SUD. Chris was reduced on his medication by 50% over a period of 1 month and this significantly impacted his pain, functional status, and overall quality of life. Within 6 weeks of his opioid reduction Chris had to stop working due to his functional limitations secondary to uncontrolled pain.

After several months of suffering at home, Chris decided to start supplementing his prescribed opioid regimen with opioids purchased on the street, which helped his pain and functional status. At a scheduled follow-up visit/medication check with his healthcare provider, a random toxicology screen was performed and revealed the other opioid he was purchasing on the street. At this point, his provider decided to taper his opioid regimen due to noncompliance with his opioid agreement, and she diagnosed him with an SUD. Chris subsequently was referred to a suboxone clinic for medication-assisted treatment of his SUD. Chris did not follow through with the suboxone clinic referral; he felt that he did not have an SUD and that he was labeled unfairly. He decided to stop seeing the provider and was lost to follow up.

Questions on the Case Study

1. What kind of "suffering" do you think Chris may be experiencing?
2. What suffering might his family be encountering?
3. How does Chris's "suffering" make you feel?
4. How does Chris's seeking an alternative way to get opiates make you feel?

patients and educating them on their conditions and potential treatment options is necessary to facilitate an optimum plan of care.

The aforementioned case resulted when a provider feared retribution for prescribing high-dose opioids; this fear led to an aggressive opioid reduction strategy for the patient. This reactive approach negatively impacted the patient's health. A slower taper schedule may have allowed him to adjust to the medication regimen over time without compromising his pain control and functional status. The question then becomes how to avoid letting outside influences/perceptions cloud our judgment when we are caring for patients.

Patients with SUD may be suffering from one or more physical and/or psychological problems, and each person needs to have an individualized treatment plan. As nurses we need to recognize that the goal of treatment is to treat the underlying cause of a given disorder/diagnosis, when possible, in order to facilitate a better outcome. The opioid epidemic/SUD crisis likely will be a problem for many years to come and impact thousands of lives. Nurses are positioned to have a positive impact on the lives of those suffering with SUD and create a more supportive healthcare environment.

Concerns

An individual diagnosed with mental illness faces suffering in many forms. Stigma against mental illness goes across diagnoses and cultures (Mannarini & Rossi, 2018). Probably one of the most painful aspects involves stigma. Stigma for the individual diagnosed with mental illness involves "a collection of negative attitudes and beliefs that lead people to fear, reject, avoid, and discriminate against people with mental illness" (Fontaine, 2009, p. 43). At the end of the continuum on stigma is ostracism, a point at which the individual is totally rejected. In addition, individuals suffering from mental illness may perpetuate stigma by internalizing negative stereotypes and becoming immobilized to the point of rejecting help being offered to them (Fontaine, 2009).

Economics impacts treatment options for those diagnosed with mental illness. In many parts of the United States there is a shortage of healthcare providers and healthcare options to treat mental illness. Many people diagnosed with mental illness are uninsured.

Having a family member diagnosed with mental illness may affect the other family members, resulting in lost dreams, relationships, income, and social status, as well as other important aspects of family life. Mental illness often involves cycles of acute and chronic episodes. Such cycling can be very disruptive for both the individual, the family, and/or significant others. Conflicts may ensue over treatment and possible hospitalizations. Involvement with the legal system may result if the individual knowingly or unknowingly breaks laws. Sometimes, those diagnosed with severe mental illness no longer have families who feel able or willing to support them after becoming worn out or angry with dysfunctional behaviors.

Interestingly, 40% to 50% of Americans diagnosed with mental illness return to their families after discharge from acute care (Fontaine, 2009). This places a tremendous caregiving burden on the family.

Fifty percent of Americans experience a diagnosable mental illness in their lifetime (Mehta & Edwards, 2018). Sadly, the prevalence for depression and anxiety within one group, medical students, is estimated between 25% and 56%, higher than estimated prevalence in age-matched cohorts and the general population; reluctance to seek treatment is related to stigma, discrimination, and fear of consequences when filling out licensing applications (Mehta & Edwards, 2018).

Portraying mental disorders as medical conditions that need to be treated with medical treatments and promoting a biogenetic approach are the most hopeful ways to overcome stigma and lower social rejection (Mannarini & Rossi, 2018).

Nursing Interventions

There is no current cure for mental illness, although recovery from mental illness, as well as recovery from addiction, is possible and more likely once the individual recognizes there is a problem and decides to make a change. The best treatment option may be management of symptoms through medication and various therapies. Many diagnosed with mental illness and addiction can lead productive, stabilized lives. Treatment will vary depending on whether the individual is diagnosed with a mental illness or an addiction or both.

Maximizing support systems for both the individual and the family is important. Sharing resources that are a fit for the individual and family promotes a better

outcome. Assisting individuals to function at their highest level possible is an optimal goal. Enlisting the individual's partnership on this journey is crucial for success. Demonstrating genuine care and compassion in relation to patient suffering will enhance the likelihood of initiating a partnership on this challenging journey.

Suffering in Individuals Identifying as Lesbian, Gay, Bisexual, Transgender, or Queer and/or Questioning (LGBTQ+)

Individuals within the LGBT community experience disproportionate rates of physical and mental illness (Schweiger-Whalen et al., 2019). The percentage of American adults identifying as lesbian, gay, bisexual, or transgender is 4.5%; the rise is mostly among millennials (born 1980–1999) and lower among older generations (Newport, 2018). People of color identifying as LGBTQ are twice as likely to report discrimination when applying for work or interacting with police (Allen, 2017).

The National Alliance on Mental Illness (NAMI, 2019) reports:

- LGB adults are more than twice as likely as heterosexual adults to experience a mental health condition.
- LGBTQ people are at a higher risk than the general population for suicidal thoughts and suicide attempts.
- High school students who identify as lesbian, gay, or bisexual are almost five times as likely to attempt suicide compared to their heterosexual peers.
- Forty-eight percent of all transgender adults report that they have considered suicide in the past 12 months, compared to 4% of the overall U.S. population.

Early intervention, comprehensive treatment, and family support are key to helping LGBTQ people function better with a mental health condition. Education is needed to improve cultural competence to address bias and unintended marginalization (Schweiger-Whalen et al., 2019).

Suffering in Individuals with Cognitive Deficits or Impairments

CASE STUDY 2–6 Suffering in the Older Adult, "Mary Salerno"

Mary Salerno, an 88-year-old widow and mother of four adult children, was diagnosed with late onset Alzheimer's disease at 80 years of age. She has lived with her 60-year-old daughter Janine for the last 5 years.

Janine and her husband have become increasingly concerned about Mary. In the past 10 months, Mary wandered from the house on five occasions. All five times, neighbors called to tell Janine that they saw her mother walking down the road. On two of these occasions, the temperature outside was below freezing and Mary was not properly dressed for the weather. Janine has begun to keep the doors locked so that her mother will not wander away.

On the sixth occasion, Mary climbed out of a window onto the porch, went to a neighbor's home, told the neighbor Janine was abusing her, and said she no longer wanted to live with Janine because she is being held as a prisoner. Mary stuck out her arm and said, "See these bruises? That woman is abusing me." The neighbor could not see any marks on Mary's arm and called Janine.

Janine came to the neighbor's house and was devastated when her mother started saying, "I'm not going with her. She abuses me. I have bruises all over my body." The neighbor took Janine aside and told Janine that she did not believe she had done anything to Mary. The neighbor suggested they call the police to get some assistance. A police car with two young police officers arrived at the neighbor's house. Mary would not answer their questions and sat rigidly on the neighbor's lawn chair with her arms folded over her chest.

After numerous attempts to talk with Mary, the police officers called for Sergeant Smith, an older officer who frequently handled domestic issues. Mary seemed to like Sergeant Smith and after some time agreed to get into his police car. When they arrived at Janine's home, Mary said she was not getting out of the police car because she only felt safe if Sergeant Smith were there. Sergeant Smith told Mary he would come back tomorrow to make sure everything was okay if she would go into the house with him now. Mary reluctantly agreed.

Sergeant Smith escorted Mary to Janine's house. He quietly told Janine he would not be back tomorrow but wanted to make sure he could get Mary into the house. He listened to Mary's description of the past few months. He gave Janine names and numbers of potential caregiving facilities. Janine made it clear to him she had no intention of placing her mother in any facility.

Questions on the Case Study

1. What types of suffering are depicted in this case study and who is experiencing it?
2. What do you think about Sergeant Smith's telling Mary he would return the next day when he had no intention of returning?
3. Given that Janine is committed to keeping her mother in her home, what type of interventions might be helpful for this family?

Concerns

Older adults often experience multiple losses. These losses increase in impact and number as one grows older (Lewis & Trzinski, 2006; Lekalakala-Mokgele, 2018). In 10% of cases, grief becomes prolonged or complicated; this is especially true for those in the age range of 75 to 85 years given the multiple losses this age group experiences (Lekalakala-Mokgele, 2018). Some examples of loss include:

- spouses/significant others
- friends
- roles
- economic status
- health
- home
- familiar places
- pets

A qualitative phenomenological study with 10 South African women revealed five themes in relation to death of family members and grief reactions: "Cumulative exposures to family members' deaths; the sorrow of watching them die; death anxiety; putting emotions of family members first; and spiritual and religious issues" (Lekalakala-Mokgele, 2018, para. 18). The researcher asserts that those between 75 and 85 need just as much support as other age groups despite previous and numerous grief experiences.

In the case study about Mary Salerno, she had lost someone or something from each of the areas listed above. Her biggest challenge of late and that of her family had been dealing with her Alzheimer's disease.

Alzheimer's disease is the most common of the dementia disorders. The Framingham Heart Study revealed a lifetime risk for Alzheimer's dementia as being one in five for women and one in 10 for men at age 45 years; risks increase for both women and men after age 65 years (Alzheimer's Association, 2019).

Deficits that occur with dementia include:

- memory
- language function
- motor abilities
- executive function

The areas in which Mary was most affected were her memory and executive function. She enjoyed excellent physical health and had no impairment in her language function or motor abilities. About a year ago, her oldest adult son died. She had difficulty realizing he was gone. Recently, she had become more agitated and depressed, exhibiting behavioral problems such as wandering.

Janine, on the other hand, was physically exhausted keeping up with her mother and was grieving the loss of the close relationship she had once shared with her. She had little time to spend alone with her husband. Janine was depressed and experiencing anticipatory grieving regarding further "loss" of her mother.

Nursing Interventions

Despite difficulty expressing grief, older adults with cognitive impairment appear to undergo some similar types of grieving as those who are cognitively intact. However, loss for them may result in more complicated grief processes. Level of impairment and stage of dementia also will impact how individuals respond (Lewis & Trzinski, 2006). Those who are in the early stages of dementia with short-term memory loss and cognitive issues may have more anxiety if each time they hear about a loved one's death is the "first time" for them. In addition, the early stage of dementia involves profound grief as the individual comes to terms with the extreme loss and separation from one's previous life and anticipated future (Blandin, 2016). Those in advanced stages of dementia may have difficulty grasping the permanence of death and miss the support and understanding from a caregiver who may have died (Lewis & Trzinski, 2006). Being present without judgment can promote adaptation to this new stage of disease; counteract ambiguity; and help caregivers, family, and friends connect emotionally with the person as the individual progressively changes in response to their disease.

Regardless of cognitive impairment or deficit, one of the most difficult experiences a nurse may need to bear with a patient/resident no longer able to be home is hearing the patient/resident repeatedly say, "I want to go home." It is important

Box 2-1 Helping Individuals with Dementia Deal with Death: Spaced Retrieval

Spaced Retrieval

- Used with individuals having mild to moderate dementia
- Involves implicit learning—motor learning and repetition priming—retained longer in individuals with dementia—presented in everyday social context
- Given information targeted for recall
- Asked about information
- Given positive reinforcement for correct answer
- Allowed an interval of time
- Re-tested

Data from Lewis, M. M., & Trzinski, A. L. (2006). Counseling older adults with dementia who are dealing with death: Innovative interventions for practitioners. *Death Studies, 30*(8), 777–787. https://doi.org/10.1080/07481180600853199

Box 2-2 Group Buddies

- Taking spaced retrieval to another level—therapeutic play activity
- Implemented by Trzinski and Higgins (2001) in pilot study with older adults having varied cognitive levels of functioning
- Manipulate play by use of stuffed animals, that is, "group buddies"
- Viewed by group members as confidants, supports, memory tools, and sources of comfort (Higgins & Trzinski, 2001)
- Increases socialization, fosters creativity, and enhances discussion and exploration of feelings

Data from Lewis, M. M., & Trzinski, A. L. (2006). Counseling older adults with dementia who are dealing with death: Innovative interventions for practitioners. *Death Studies, 30*(8), 777–787. https://doi.org/10.1080/07481180600853199

to be supportive to such patients and their family members during these critical times. The nurse needs to calmly, realistically, and reassuringly encourage patients or residents that they need the extra care the facility can provide and that the nurse will do everything possible to provide good nursing care for the patient. Suggesting the family members bring in pictures, music, familiar food (if allowed), or other important connections to the patient's/resident's life can be hope-promoting for both patient/resident and family members.

Support and understanding are key factors in helping those with cognitive impairment. However, two innovative approaches—spaced retrieval and group buddies—help individuals with dementia deal with death and are specifically targeted to assist individuals with dementia who are grieving (see **Box 2-1**, Helping Individuals with Dementia Deal with Death: Spaced Retrieval, and **Box 2-2**, Group Buddies).

Suffering in Student Nurses and Nurses

For entry students, experience with helping patients who are suffering often is limited. Furthermore, they may have had personal suffering experiences they have not

processed. A phenomenological study done with 11 Taiwanese nursing students explored their reactions and responses to the death of peers (Jiang et al., 2006). Themes that emerged from this study indicated that these 11 nursing students experienced

- morbid anxiety
- helplessness after death
- fear of disappearance after death
- thinking of one's own future

In another study in Iran (Naseri-Salahshour & Sajadi, 2019), first-year student nurses demonstrated suffering in response to ethical challenges at the very beginning and then transitioned to indifference after a few months. Types identified were suffering related to self, from others, and from work conditions. The transition to indifference involved diminishing professional commitment, adapting to others' behaviors, and indifference to the conditions. Because the study only involved 11 student nurses and was qualitative, its transferability is limited. An important outcome of this study is that supportive and educational programs for novice nurses are needed to prevent indifference and help novices grow professionally and ethically (Naseri-Salahshour & Sajadi, 2019).

To help patients grieve, student nurses who may not have had much experience with grieving could benefit from support. They also need support to increase their ability to handle the death of patients. A college course titled "Understanding Suffering" was developed by a group of nursing faculty to assist students with their and their patients' suffering. Faculty studied if the course made a difference (Kazanowski et al., 2007). Students demonstrated significantly higher scores on a post-course evaluation of empathy and felt they were better prepared to provide interventions in difficult clinical situations involving suffering.

Nurses meet patients at points of vulnerability. Nurses must confront the many different faces of suffering in patients: physical, emotional, psychological, spiritual, cultural, social, economic, and others. They have the distinct privilege of being positioned to help patients do "the work of suffering," namely, move through pain to healing (Råholm, 2008, p. 64).

Helping patients find a voice in their suffering, even if they cannot speak, is important. Amidst silent suffering, the presence of an attentive nurse may provide the patient a voice, lighten the patient's burden, and begin to bind up the patient's wound (Råholm, 2008).

Interestingly, those working in palliative care with cancer patients do not show higher levels of psychological distress and also demonstrate lower levels of burnout than staff working in other areas of care. With that in mind, it is helpful to try to determine what factors and processes assist nurses in promoting resilience and sustaining a sense of well-being. Ablett and Jones (2007, p. 235) conducted interviews with 10 palliative care nurses and determined that the "job-person fit" was critical, as was the nurses' sense that they

- had chosen to work in this specialty area
- could make a difference in their patients' lives
- were aware of their own mortality and spirituality

Self-Transcending Through Suffering

Self-transcendence, or the sense of going beyond and outside one's self, can come about through suffering; an individual can be "opened, deepened, and spiritually changed" during a suffering experience (Wayman & Gaydos, 2005, p. 264; Van Cappellen, 2017; Ackerman, 2020). In a study by Wayman and Gaydos (2005, pp. 265–269), these themes of self-transcendence through suffering emerged:

- turning point
- pause
- confrontation
- surrender
- extraordinary experience
- touchstones
- change
- valuing life
- unfolding wholeness
- meaningful work
- gratitude
- humility
- an elemental experience—use of metaphors

Self-transcendence can occur without suffering, although it often may occur during suffering. Four key elements in self-transcendence include: shift in focus from self to others; shift in values from extrinsic motivation to intrinsic motivation; increase in moral concern; and uplifting emotions termed self-transcendent positive emotions (STPEs), such as awe, ecstasy, amazement, feeling uplifted, and feeling inspired (Ackerman, 2020). Furthermore, STPEs are intertwined with spirituality and religion (beliefs and practices) and serve important functions when experienced within a religious context (Van Cappellen, 2017; Ackerman, 2020). When nurses explore self-transcendence with patients who are suffering, they can enhance healing when a cure is not possible.

Summary

Everyone's suffering is unique. This chapter examined suffering within a number of special populations, such as the impact of different cultural considerations, different types of suffering experienced by children, unique features related to those diagnosed with mental illness, challenges presented to older adults impaired cognitively, and the importance of student nurses and nurses getting support with their own personal suffering.

Key Points

1. The potential for "suffering overload" exists today as we become more aware than ever before of suffering on a worldwide scale.
2. Children are not "mini-adults" but are impacted in many of the same areas as adults in relation to suffering: physical, emotional, sociocultural, spiritual, and/or psychological.

3. Those diagnosed with mental illness may face unique areas of suffering, such as stigma, financial strain, restricted healthcare access, lack of support systems, and legal concerns.
4. Older adults with cognitive deficits or impairments often face compromised memory, language function, motor abilities, and executive function.
5. It is beneficial if student nurses and nurses can process their own suffering to help themselves and patients journey through a patient's suffering.

Exercise

Answer the following questions.

1. Think about someone you have observed who handled suffering differently from the way you do. What was different? Were there any ways in which the individual demonstrated values and expressions of suffering like you?
2. How would you feel if you were caring for a patient who was screaming in pain? What would you say to the person or do for the person?

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