faculty members and led to a number of studies unquestionably validating the concept for a wide variety of conditions that seriously and permanently affect functioning. In the course of research, the nursing profession has developed research instruments (e.g., Burke, 1989; Eakes, 1995; Kendall, 2005). In nursing today, the concept is considered to be a middle-range theory. Middle-range theories are considered to be aimed at specific phenomena which, though limited in scope, are capable of generating research. Two antecedents have been posited by the nursing profession: the initial event of a living loss and the "unresolved disparity" resulting from the loss.

The role of fantasy is central to the existence of chronic sorrow. The pesky question arises: If we could not dream or fantasize, would chronic sorrow exist? The fantasy of what should and could have been and what was often unquestionably expected is predictably and unpredictably activated during the course of chronic sorrow, and the disparity between fantasy and reality can be cruel and wounding. Jacob Arlow, a psychoanalyst and contributor in a variety of ways to the analytic field (Arlow, 1964), explored the role of fantasy, especially unconscious fantasy, and understood its power in the construction of the self. He posited that when we experience outer reality, we simultaneously experience inner reality. The fantasy of what should or might have been and was expected can be activated numerous times during the course of chronic sorrow. It is the disparity between fantasy and reality that is at stake when sorrow is intensified or when there are triggers that activate intensity. The fantasy of what might have been (often a major factor and component in identity development) does not easily extinguish, if it ever does. After all, a self is made; it does not just magically appear. In his classic work on disability, Goffman (1963), in attempting to speak for the person who is disabled, referred to the loss as a social stigma and referred to the self-perception as a "spoiled identity."

As a form of disenfranchised grief, chronic sorrow is frequently launched by trauma. With very few exceptions, trauma occurs at the time of diagnosis, whether at birth (when there are obvious visible anomalies), when a devastating injury occurs, or when a condition that is not remediable is confirmed (e.g., Huntington's, ALS, etc.). For Bauby (1997), trauma occurred when he "graduated" from being a stroke patient with an uncertain prognosis to being profoundly quadriplegic (i.e., "locked in"). From that point forward, he would think of life as being "before" or "after" that "graduation." It is not at all unusual for a professional who engages in therapy with someone coping with chronic sorrow (or perhaps chronic depression when chronic sorrow has transitioned into this disorder) to encounter PTSD symptoms or other effects of trauma that require amelioration in order to address other major issues.

Professional Involvement

Professionals involved in working with those contending with chronic sorrow require certain expertise in areas such as trauma amelioration, existential therapy (including narrative and meaning co-construction), anger management, family therapy, identity clarification, strengthening, community resources (including advocating for these when none exist), and referral for psychotropic medication if or when necessary. There are several approaches to the problem of flashbacks, and professionals can usually readily avail themselves of training in techniques that ameliorate them. Foci of professional help also include, among other things, early onslaught, disorganization, disenfranchisement, triggers, stress management (both acute and chronic), symbiotic enmeshment, anger, depression, loss spirals, etc. In work with families, Rolland's (1989) psychosocial typology of illness can be helpful to clinicians by linking chronic illness to the family life cycle and to individual and family dynamics. Rolland's four broad distinctions (e.g., onset, course, outcome, and degree of incapacitation--each a part of a continuum), are all applicable to conditions related to disability.

It is critically important, perhaps vital, that professionals assume and communicate their understanding that chronic sorrow is a normal and understandable response, as helping clients to view themselves as non-pathological can alleviate negative assumptions and initiate a new sense of self as positive, capable, and resilient, while coping with issues that are sometimes fundamentally overwhelming but not insurmountable. Persons beset with chronic sorrow frequently report that simply knowing that chronic sorrow is recognized (is "real") and that it is non-pathological can be the source of immediate relief and comfort. As with all human distress, a feeling of being understood, accepted, and validated can go a long way.

Wolfelt's (1998) "companioning" model for the bereavement counseling relationship is proposed. The model is one of parity. Imagery inherent in "companioning" is very different from that involved in "treatment." The model implies collaboration and replaces the medical model and others with one that is growth-oriented and based on relationship. The basics of "companioning" include: (a) honoring the spirit (not focusing on intellect); (b) curiosity (not expertise); (c) learning (not teaching); (d) walking alongside (not leading); (e) stillness (not prodding forward); (f) discovering the gifts of sacred silence (not filling all vacancies with words); (g) listening with the heart (not analyzing with the head); (h) witnessing (not directing); (i) being present (not taking the pain away); (j) respecting disorder and confusion (not imposing logic and order); and (k) going with another into the soul's wilderness (not taking responsibility for mapping a way out).

Family Identity

Chronic sorrow conditions unquestionably represent a disruption of the family life cycle; however, the cycle is understood. When they learn that a family member is damaged to the extent of lifelong dependency, family members are normally extremely upset. Disorganization and chaos in the family may persist for a year and even for as long as two years following onset. Although family functioning may be erratic, disorganization during this time can be considered normal. New role demands are common even in constant-course conditions as family life cycle transitions are more complicated and often precluded. There can be a loss of privacy and frequent adverse effects on siblings as well as on the marital relationship, a disaffiliation with customary support resources, and many re-shapings of family functioning. Role flexibility is crucial for coping. Addressing problems as they arise, while no longer making adjustments on an assignment-of-priority basis, can become the new norm. Family members usually make every effort to "look good," and their efforts in this regard often mask how difficult life is and can be.

An especially stressful family transition occurs when caregivers can no longer carry the load due to aging factors or to their own disabilities, and when decisions and follow-through must occur in order to survive the vicissitudes of this kind of drastic change. Frequently, family members have assumed many things that do not stand up to disclosure. It has also been found that frequently the oldest daughter (or oldest sibling of the person with impairments) has been assumed to be the person who will take over the responsibility that the parents have carried. Active planning and open family discussion are critical, even when they reactivate old resentments, grief, and anger. Parent caregivers who are attempting to provide a secure future for their child with impairments may experience additional stress through complaints, accusations, and bitterness from other family members who may be verbalizing their feelings for the first time. Obtaining legal assistance in appointing guardianship, constructing trusts, and other arrangements is often an imperative; doing so is recommended.

Financial strain can be a significant factor in families. Finances are commonly further depleted by costly equipment and modification of the living quarters, as well as when parents must resign or withdraw from the workplace to be with the family member who is disabled. Studies are needed to increase early identification of families most at risk of permanent decompensation so that needs are met, and future stressors are planned for. Family functioning, the severity of the affected person's condition, and the person's "pre-injury" functioning are generally predictive of both family and individual functioning one year following onset. Early professional intervention may prevent family system collapse.

There is a paucity of research on the effects of chronic sorrow conditions on siblings. There are some indications that in adolescence and early adulthood, siblings benefit from parental mandates, permissions, and encouragement to disengage from family responsibilities and, when age-appropriate, to make lives for themselves separate from the family. Although siblings may suffer from an onslaught of stressors, there appear to be potential sibling benefits, especially in the context of character development. These include: (a) increased maturity demonstrated by empathic accuracy, insightfulness, and intuitiveness; (b) appreciation of wide human diversity; (c) appreciation for the good things in life; (d) keen awareness of prejudice and its damage; (e) patience, including serving and loving without expectations; (f) precocious independence and self-confidence; (g) incisive humor; (h) clear priorities and a sense of proportion; (i) vocational direction and clarity; (j) philosophical depth; and (k) creativity in meaning and life construction (Roos, 2002b). However, siblings are at risk of harboring guilt that can interfere with making satisfying lives of their own. On the one hand, parents may look to them for reassurance that they are managing the family and are parenting in a satisfactory way, as demonstrated by siblings' accomplishments. On the other hand,

and simultaneously, siblings may be prone to suffer from guilt when they accomplish things their disabled brother or sister can never accomplish. They are at risk of sabotaging themselves and falling appreciably short of what they are capable of.

When loss and grief are disenfranchised, such as in chronic sorrow, there are often no customary supports or expectations. There are no rituals, no expectations or assurances of recognition of the loss (as the person who is the source of the loss continues), and adaptations are usually drastic and disorienting. In some cases, the person who is the source of the loss may be essentially socially unrecognized so that s/he appears not even to exist. An enigma can ensue in which one might assume that if there is no existence, there is no loss. Therefore, grief is unacknowledged (and unaddressed) by those in the social context.

Disability and Social Justice

From time immemorial, people with disabilities and their families have had a very difficult existence. When babies have been born with obvious disabilities, infanticide has been an acceptable practice off and on from earliest days throughout history. Plato favored abandonment of an impaired infant in a mysterious, unknown place—i.e., passive euthanasia. Popular opinions, referring to a "lack of contribution" to society by impaired individuals, led to assumptions that they were not deserving of life or belonging with those who somehow "contributed." Contributions have been thought of in concrete and measurable terms (often economic). Reasoning that has led to conclusions or meaning of "contributions" has typically not included "immeasurables" or abstract thought of any kind. "Ugly laws" were enacted throughout the United States banning individuals with impairments that rendered them "unsightly" when in public places. People with disabilities, especially epilepsy, cerebral palsy, craniofacial defects, and other neurological and/or psychiatric disorders, were the focus of witch hunts, public floggings, and burning at the stake during early American history. These individuals were often seen as "devil-possessed" witches. Based on an unfortunate and inaccurate connection being made between low intelligence and criminality, a eugenics movement took place in many parts of the world, including the United States, Canada, England, and Europe, that resulted in the involuntary sterilization of many thousands of individuals who were determined to be of "poor stock." Those with disabilities were the ones who were subjected to the perfecting of the extermination practices used in the Holocaust. In Germany during this time, parents were praised and referred to as heroes when they killed their newborn infants who had obvious defects. Many infants and young children with impairments were taken from their families and sent to specialized clinics where they were put to death. Sem-Sandberg (2014) has written eloquently about the lives of these children.

A social contractarian philosophy has undergirded the great majority of social/political systems to date (Rawls, 1996, 2001). Social contracts have typically been based on the idea that there is a mutual advantage when people live together that does not exist when people live on their own. Classical theorists have assumed that social contracting individuals are men who are roughly equal in capacity and equally capable of productive economic activity. Although their interests may be represented, there have typically been no seats at the bargaining table for women, children, non-human animals, persons with disabilities, and (frequently) the elderly. Some omissions have been rectified in contemporary contract situations. However, according to Nussbaum (2006), no existing social contract doctrine includes people with severe and atypical physical and mental impairments in the group of those by whom basic political principles are chosen. People with disabilities have been stigmatized and excluded. Historically, people with severe mental impairments have not even been educated and have been excluded from the public realm.

From the viewpoint of justice, people with disabilities have not been treated as full equals, and their needs have frequently not been considered when basic principles are chosen. The social contract tradition presents basic questions such as, "By whom and for whom are basic social principles designed?" (Nussbaum, 2006). Those admitted to the bargaining table have typically included parties who design principles for citizens who are without serious mental or physical impairments. However, human (and even non-human) beings are primary subjects of social justice, although they may not be capable of participation in procedures that result in political principles. Perhaps it is time at last to consider that human (and even non-human) beings have dignity and worth, even when impaired, and deserve to be treated with respect and on the basis of equality with others. Primary subjects of social justice, even when incapable of participating in procedures through which political principles are chosen, deserve to be treated with respect on the basis of equality with others. Classical political theories emerge from the general idea that social and political beings find fulfillment in relations with others. These theories may result in more equal political justice; however, it may at last be time to consider outcome-oriented theory rather than procedural theory.

Existential Issues

It appears to be the nature of human beings to search for meaning in existence and to need stabilizing beliefs about living. To be affected by chronic sorrow is to be existentially molested. Professional helpers are better off in their delivery of services when they are comfortable dealing with existential issues. It can be a good thing to be endowed with a center of "existential knowing." That some of us endure catastrophic loss while others blunder along relatively unscathed is a quandary that can gnaw at us and cause us to question many aspects of our lives indefinitely. When we are beset with chronic sorrow, we struggle to find meaning and coherence in a world that no longer makes sense. Questions without sensible answers can include: How can a God who loves me allow such devastation to occur? Is this unbearable and profound loss a punishment? What crime has been perpetrated that can deserve such punishment? Is the universe so uncaring and so random that it metes out these tragedies? I am no longer the person I used to be; who am I now? Existential issues can become intrusively foreground. For some who are confronting chronic sorrow, the work of making sense of such a loss and of somehow integrating it can often be a lifelong endeavor—if it ever happens.

Self-Loss and Other-Loss

The terms self- and other-loss can be used to identify the primary locus of the loss. The subjective meaning of a self-loss may be different from what is experienced when the loss refers to vital aspects of someone we care for deeply (other-loss). From the viewpoint of other-loss, Doka and Aber (1989) used as a metaphor the horror movie *The Invasion of the Body-Snatchers*, in which the loss of the original personality is portrayed that includes its replacement by a "parasitic consciousness." This particular kind of loss can be extremely difficult to sort out. Taken on a case-by-case basis, this kind of loss is one of dimensionality, and the continuum of loss can range from comatose states to severe mental illness. Severe changes in personality can also result from some types of seizures and from other neurological disorders. For some, the person who is in an intractable coma can be perceived as the same as dead (a situation often referred to as "psychological death," or the concept of social death discussed in Chapter 3). This same person may be treated quite differently by others; i.e., as fully alive. In either case, there is a cessation of the individual personality that once existed. Ethical issues can loom large in cases of other-loss when the loss is of the mind or consciousness. Ethical decisions can be fraught with great difficulty.

Clark Elliott (2016), a professor of artificial intelligence in the Chicago area, has written about the aftermath of his concussion that was sustained in a car accident. Now recovered, he has written about his fears, his painful awareness, and his grief for the loss of his former competent self. He functioned measurably poorer as a brain-damaged person. His book, titled *Ghost in My Brain*, refers to his awareness of the presence of his former self as he was struggling to do simple, basic things. He has written about his reunification with his former self in the course of his recovery. It is easy to wonder what would have happened if Elliott had sought therapy and had he been pushed to let go of or say "goodbye" to his former self?

Beethoven can be a poignant example of self-loss experienced when the loss has been of the one attribute that is most treasured (i.e., Beethoven's hearing). He wrote, often in his letters, about his anguish and perpetual frustrations as well as about his search for treatment and restoration. Although he continued to produce music, he was never again the person he had been, nor could he enjoy activities that he once enjoyed and took for granted. He repeatedly experienced disappointment and could not stop wanting and seeking restoration and/or the miracle of recovery.

For caregivers coping with other-loss, there is usually no choice but to continue to care for the one who has sustained serious and permanent disabilities. The "no choice" rule predominantly applies to suicidal thoughts and feelings. There is reason to believe, however, that in cases of equivocal death of persons with severe disabilities, coroners and medical examiners should be exceptionally cautious and very thorough when evaluating the cause of death of someone who is fragile and unable to defend him- or herself. Common assumptions should be carefully ruled in or out. Killing the person with severe disabilities and then completing suicide are not unknown happenings. Situations such as these can surprisingly occur when it has been thought in social settings that the caregiver is managing well and that the one who is cared for appears to be happy and well taken care of. A community can be plummeted into confusion and disbelief.

When other-loss involves a person who has been idealized, the loss is of elements that have been real and those that have been fantasized. The dreamed-for future is no more. In chronic sorrow conditions, one is sometimes forced to take an untenable position. Letting go of unrealistic dreams and images of how things should be now and in the future is experienced as disowning a cherished part of identity. Since what has been cherished is often a unifying element, releasing it takes an effort of will. The effort is painful and feels very wrong, and it is like partaking in some sort of atrocity. Our children are often the repositories and conveyors of our idealizations. They can be our hopes for completeness and our dreams and aspirations for the future. When the child arrives and is seen as severely impaired, most of us will love that child with all our hearts. What is unacceptable is the serious impairment and how it will ruin our fantasies and how it can ruin the life of our child—the child we have.

Polarization

Some groups currently associated with those who have disabilities have recently begun to assume an opinion that those who perceive themselves as coping with chronic sorrow conditions are resigned to their circumstances and that these groups may be a barrier to efforts aimed at research (or more trials) in the direction of remedies or even cures. Many such groups are focused on efforts to identify causes (frequently thought to be genetic) of various conditions and to find ways in which conditions can be prevented or remedied. For some, identifying with chronic sorrow appears the same as being opposed to remedies, prevention, and cures. The thinking involved in these matters is bifurcated. The assumption is that chronic sorrow, or grieving in any manner, is equated with defeat and resignation—in general, a very wrong assumption. Those with chronic sorrow conditions in their lives are most likely to go to extreme lengths in order to help the person who is disabled, suffering, or prevented from having what is considered to be a normal life in some way. It is not at all clear that advantages always accrue to those whose goal is "finding cures." It is, however, frequently very difficult for people to think in a wholistic, integrated manner (i.e., "both/and"). It would be difficult, if not entirely impossible, to find someone who is struggling with chronic sorrow conditions who would opt out of finding and making use of most measures available to improve the condition of someone who is loved and the recipient of devoted care who is thought to be prime for benefiting from a newly developed intervention or cure. Becoming aware of chronic sorrow and its process and effects can be a benevolent process that is ultimately a clear benefit to entire social and family systems. Chronic sorrow and/or the awareness of its effects does not mean that cures, research, and benefits are not wanted or that there is opposition to cures and remedies.

Trends

Today people are living longer than ever in history and are subject to disabilities and disease processes typical of aging adults, including Alzheimer's and other dementias. Family members and others who are themselves aging and worn out are now becoming "early" caregivers for their parents or other family members. Those in their 70s are taking the reins to care for parents in their 90s while sometimes having adult children living in their homes. While helpful, government pension plans rarely adequately cover living expenses. This growing situation is fertile ground for increased chronic sorrow. As more and more "perfect" babies are introduced to the world, the intensity of chronic sorrow may increase for those who do not or cannot avail themselves of relevant technology. The numbers of people expecting "perfect" babies, including such specific details as eye color, certain facial characteristics, etc., appear to be increasing. The possibility exists that increasing numbers of abortions may occur when parents insist on choosing the sex, the appearance, and the attributes of a prospective baby, including whether there is a possibility that certain genetically based health conditions are potentially "programmed" into a fetus.

The increased availability of advanced imaging techniques allowing for definitive diagnoses of significantly increased numbers of conditions will also influence both the frequency and extent of chronic sorrow. Wartime conditions, appearing to worsen as they continue, are impacting the frequency and extent of traumatic (and permanent) injuries that are affecting ever-growing numbers of adults of military age. Increasing numbers of active military personnel are surviving horrendous injuries, including loss of limbs, craniofacial and permanent brain injuries, and other physical traumas that were once the causes of certain death. It is possible that our increasing technological advancements are serving to "de-humanize" us and render us less attuned and caring for those contending with permanent and severe disability. The extent and nature of chronic sorrow may be shifting, changing, and impacting the future.

A variety of viewpoints may influence the prevalence of chronic sorrow. For example, belief in eventual remedies may contribute to the fantasy that life can be perfect, that what was expected can occur, and what has been lost can be restored. Patterns of hope alternating with despair can increase both the intensity and frequency of distress that emerges from chronic sorrow conditions. Competence in dealing with chronic sorrow, as well as its recognition and understanding, will be needed far into the future.

In the future, helping professionals will face rapid shifts and expansions of technological innovations and concomitant positive and negative spinoffs. New professions will likely proliferate as a result of increased reliance on technology. Fears already exist that the United States will become more fragmented rather than multicultural. A patchwork of subgroups may appear in which the primary focus is on self-interests rather than on support and inclusion of those who are "different." As a result, grief may become a unifying force, globally and professionally. The ever-increasing numbers of support groups may serve to contain and inhibit conflicts while influencing a growing concern for others.

A sad speculation is that as the numbers of elderly grow, especially those with severe disabilities, so too will the likelihood of abuse. Professionals may need the skills of an investigator, and they will need to become more conversant in the law as it applies to diminished capacity and to abuse and violation of civil rights. Administrative competence may increase in importance in professional training as professionals take on more oversight and supervision of direct caregivers. Aspects of chronic sorrow conditions appear to be increasing. Now is the time for professionals to be tuned in and aware of all aspects of this type of grief.

Key Terms

Chronic Sorrow: An ongoing response to losses that are continual and unending in nature; the chronicity of the feelings and the ongoing nature of the loss differentiate chronic sorrow from other forms of grief.

Other-Loss: Refers to loss experiences in which vital aspects of someone we care for deeply are lost. Examples may include a loved one becoming comatose, experiencing drastic personality change, or losing oneself to severe mental illness.

Self-Loss: Losses that are focused on the change of one's identity and concept of self, such as the loss of an attribute with which one subjectively identified.

Questions for Reflection

1. Define chronic sorrow and explore what differentiates chronic sorrow from other variations of loss experiences. Additionally, why do you think awareness of chronic sorrow is important?
2. The author raises a philosophical question: "If we could not dream or fantasize, would chronic sorrow exist?" Explore your thoughts regarding this question and identify how you would answer it. Are dreams and fantasies of a different life a positive or negative experience (or both) for an individual's grieving process?
3. Provide an analysis that explores the role of self-loss or other-loss in one of the following aspects of chronic sorrow: the family identity, disability, social justice, or individual existential concerns. Furthermore, do you think there are any positive aspects that could co-occur with the experience of such devastating loss for a grieving individual?

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CHAPTER 15

Parenting a Child With a Serious Disability

Annie Cantwell-Bartl

The grief that parents experience in supporting a child with a serious disability has many unique features. It also shares some characteristics with the grief experienced by individuals who have experienced other losses. Caring for a child with a serious disability is demanding and extends over a lifetime. It is also a privilege. The nature of the child–parent relationship in this situation is complex and does not follow the usual developmental trajectory. There is also greater-than-usual dependency and intensity within the relationship.

A range of factors influences the grief of any individual. These include a person's developmental history, relationships, styles of grieving, religious and cultural background, ethnicity, and experience of other losses. Grieving individuals also embody unique vulnerabilities and strength, all of which have an impact on their grief experiences. Grief is not only an intrapsychic response, because individuals exist within a social context (Harris, 2011; Harris & Winokuer, 2016). Within any social group, there is a dominant narrative. This dominant narrative influences how experiences are validated and also how they are interpreted (Harris, 2011).

To aid in understanding of the nature of the grief of parents of children with disabilities, I have incorporated a case study of Jennifer and Tom, a couple in their 30s. They already had a six-year-old child, Alice, when Jennifer became pregnant with baby Michael, who was born with a disability. This case study illustrates their experience, as told by Jennifer.

> We had longed for another baby. I found it hard to get pregnant again and I had four miscarriages. I came from a family where there was not much support and I hoped married life would be better. And then I lost all those babies. I felt so sad, and very few people recognized our sorrow. Our families were pretty disengaged and friends just suggested that we have another try. We felt alone. Tom did not talk much about how the losses affected him. In contrast, I talked a great deal, but I felt very few people wanted to listen. We wondered whether we would ever have another baby. Finally, I was pregnant again, and we were delighted. Our obstetrician told us that I was carrying a healthy child.
>
> When Michael was born, he was beautiful and looked strong. We celebrated and got ready to go home from the hospital. Suddenly, Michael