Experiences of pain and suffering are often seen as part of old age (Kirsch & Smith, 2000; Helme & Gibson, 2001; Gagliese & Melzack, 1997). This raises the question: do elders themselves view pain and suffering as a ‘normative’ part of old age? To explore this question, the chapter first considers the concept of pain, a word that at times has been used interchangeably with suffering; the differences and similarities between the two in the context of old age; and why such differences are crucial to an adequate understanding of the experience of suffering in old age. Finally, research findings on the meanings that older adults give to the suffering experience will provide a context through which to consider whether gerontological research has acquired adequate ways to grasp and interpret elders’ experiences of pain and suffering.

Pain

Pain is primarily conceptualized as an experience of the body, though most people will also experience emotional pain (Cassell, 1982). For example, Chapman and Gavrin (1999) describe pain as ‘a threat or damage to one’s biological integrity’ (p. 2233). The International Association for the Study of Pain, as cited by Flor (2001), defines pain as ‘unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage’ (p. 1099). Stated simply, pain is the sensation associated with adverse events (Fordsyce, 1988).

As Hide, Bourke and Mangion (2012), whose work focused on perspectives on pain in the eighteenth century and their influence on modern views, have argued, ‘pain has been understood to be a universal yet intensely personal experience [. . .] it differs from person to person, social group to social group, and it changes over time and space’ (p. 1). Pain, according to them, is deeply rooted in the historical and cultural context. It is not a sensation devoid of a greater social framework.

In gerontology, pain, which is often used in conjunction with the term suffering, has been largely explored from a health stance rather than through the lens of personal meaning. For example, Gagliese and Melzack (1997) looked at chronic pain in older people, and found that although the majority of older people experienced pain intense enough to interfere with normal function, many did not receive appropriate pain management. The focus of the study was on why pain is unsuccessfully treated, however, not on what pain means or how it is experienced.
In a similar vein, Helme and Gibson (2001) conducted a review of studies of pain in older people to estimate its prevalence. Although most studies included in their review rely on self-report of severity and duration of pain, the authors note that the context of painful symptoms and the meanings attributed to them shape the experience of pain. Overall, they found that although reports of pain increase with age, they do so only until around age 80, when reports of pain decline or hold steady for reasons not clearly understood. They speculate that stoicism, unwillingness to label something as painful, or assumptions that pain is a normative part of ageing may partially explain the decline. As with Gagliese and Melzack’s (1997) findings, these authors found that pain was assumed to be a part of ageing, and that pain exists outside of a cultural or social context.

It should be noted that there are numerous other studies that examine pain and ageing, the overwhelming majority of which focus on pain in relation to a particular disease or disorder (e.g., pain and prostate cancer, pain and hip fracture). Few studies have looked at pain as a concept and even fewer at how older people themselves view the experience or meaning of pain and whether they consider it to be a normal part of ageing.

**Suffering**

Suffering has been defined in medical, psychological, and religious idioms as ‘the state of severe distress associated with events that threaten the intactness of the person’ (Cassell, 1982: 240); ‘a threat to our composure, our integrity, and the fulfillment of our intentions’ (Reich, 1987); and ‘being aware of the many ways humans can be or are broken’ (Black, 2006a). These definitions share the perception of the all-encompassing nature of suffering as a threat to an integrated existence or to the ‘wholeness’ of a human being. The threat that suffering portends is made to the entire self. For this reason Cassell (1982) described suffering as a consequence of personhood. He commented that ‘bodies do not suffer; persons do.’ Frank (1992) suggested that when talking about suffering it is important to allow for its ‘bigness’—it may result from a life-changing illness, a psychological break, or a crisis of the soul. In addition to the ‘bigness’ of suffering, Black (2006a) argued that there was a ‘littleness’ of suffering in old age that must also be considered. This littleness of suffering includes daily frustrations, humiliations, no second chances to right a mistake, and loneliness. Because a human being cannot be separated into parts, it is the entire person—the body, mind, and spirit—that is assaulted in the major events of life or the moment-by-moment experiences of everyday life that can be defined as suffering (Black, 2006a).

When considering what comprises ‘suffering,’ it is important to consider two different ways in which the term is used. One is in an everyday sense of having a condition, as in, ‘I suffer from arthritis.’ The second is as a state of being, such as, ‘I suffer because I have lost hope.’ Distinguishing the two uses of suffering—first, as a verb describing discomfort associated with the presence of a chronic illness and, second, as an existential state of being that seems impossible to resolve—is helpful when considering the place of suffering in ageing (Strang et al., 2004). For example, since many older people have multiple comorbid conditions, it could be said that in the first use of the word, many older people suffer from multiple health situations. However, saying that many older people suffer in the second use, to denote that they are experiencing a deep threat to self because of something, suggests a very different level of experience.

An example might be useful. An older woman, when asked to define suffering during an interview on the meaning of suffering in older age, said, ‘A broken arm.’ When asked, ‘Do you mean the pain of a broken arm?’, the woman replied, ‘Not the pain so much but the fear.’
then explained: ‘I went to my granddaughter’s wedding. I wore a long dress, high heels. I felt beautiful. At the reception I walked across the dance floor and slipped and fell [crying]. That was three years ago. I could not handle it. I could not get over it. I still can’t’ (Black, 2006b).

This example reveals the second meaning of suffering—as an existential negative state of being that implicates the entire person (Becker, 1999; Cassell, 1982, 1991; Charmaz, 1999; Strang et al., 2004). It includes a sense of self, whereby the self is both actor and acted upon, watcher and watched, and subject and object of life experiences (Black & Rubinstein, 2004). It also includes a real and embodied fear of what would happen if she fell. The sense this woman had of her ‘self’ as a beautiful woman was ruptured by a fall visible to all the guests at the wedding. To say ‘I suffer because of my fear of falling’ is substantially different from saying ‘I suffered from a fall.’ Her broken arm symbolizes suffering not because of the physical pain but because it represents a break with her former sense of self. It is her awareness that this former sense of self can become at any moment disrupted, incomplete, and broken (Kahn & Steeves, 1986) that causes suffering.

Unlike pain, which features in the clinical care literature, suffering has more often been explored in religious and philosophical studies. Few research studies focus directly on suffering in the general population (Rodgers & Cowles, 1997). In the ageing literature, suffering has been limited to: how old people themselves define suffering (Black & Rubinstein, 2004; Black, 2006a); causes of suffering in older age (Black & Rubinstein, 2004); and generativity (investing oneself in future generations) and suffering (de Medeiros, 2009).

In an ethnographic pilot study, Black and Rubinstein (2004) asked 40 older men and women about their definitions, descriptions, and theories about suffering. There were as many different notions of suffering as respondents in this study. Overall, suffering was a construct under which the respondents placed a variety of extreme and negative experiences (Black & Rubinstein, 2004; Black, 2006a). In disclosing incidents, events, or time periods of suffering, elders revealed suffering’s contextual nature; personal biography and cohort history informed their experiences and definitions of suffering. In this study, Black (2006a) and Black and Rubinstein (2004) identified three overarching themes of suffering: lack of control over self, suffering as loss, and suffering as having value.

The first, suffering as lack of control over self, described older adults’ feeling of betrayal by their body or life circumstances. For example, a 79-year-old man, when asked what he could not control in his life, replied, ‘The big things: ageing, illness, life, death.’ For this man, perhaps ageing and illness portend death, which is the ultimate lack of control of the self. This speaks clearly to the experience of suffering (Black & Santanello, 2012).

The second theme, suffering as loss, speaks to old age as a time of mourning. Older adults frequently experience the loss of significant others or those who shared a cohort history, the loss of health, and the rupture of a relationship with themselves through dementia. Suffering as loss may also refer to a depletion from within. Closely linked with the first theme, the lack of control, suffering as loss speaks to older adults’ fears or experiences of changing skills or strengths related to their ability to make choices about the major and minor events and incidents in their lives. Choice is important here. In fact, many elders named ‘having a choice’ as significant in whether an experience was named suffering. De Medeiros (2009), in her case study of suffering and generativity, describes an 85-year-old man who was staving off a form of loss—loss of self—through creative expression (e.g. poetry, woodworking). To address this loss, he would bring a small wooden dog he had carved, along with poetry he was writing, to various social settings, including the interview. Both the poems and the wooden dog therefore functioned as a conduit for connecting to others and reliving key moments from his life associated with each creation. In this way, he created a sense of permanence that combatted the sense of fading away.
that he associated with suffering. Fading away, for him, described how something (e.g. a piece of steel that rusted) or someone continued to become less over time, eventually disappearing. For him, the thought of fading away caused an extreme threat to self that he addressed by creating more permanent extensions of himself (e.g. poems, art).

The third theme, the value of suffering, speaks to elders’ beliefs in benefits that emerge in the wake of suffering, especially suffering as interpreted through cultural or religious belief systems. These are explored more fully in the next section. Here the value of suffering is related to its meaning. Black (2006a) found that, for some elders, searching for and finding meaning in suffering was a significant activity. A crucial aspect of finding meaning was interpreting the suffering according to one’s worldview, belief system, and place in time. Because suffering is not a discrete experience with one cause, a linear course and a consistent expression, memories of past suffering may influence the present, present suffering may color the past, and an anticipated suffering may shadow both present and past. Likewise, suffering is laden with cultural connotations; it is constructed, represented, and paraphrased by symbols that are shared within a culture (Martin, 1987).

The language of suffering

Perhaps one of the reasons for the dearth of articles on suffering in particular in old age involves challenges in the language of suffering. Sociologist Iain Wilkinson (2001) cites Max Weber (1946) when pointing out the difficulty of articulating suffering by writing, ‘In almost every instance where writers venture to comment upon “the brute fact that suffering exists,” they struggle to find a language which is adequate to express and think through what happens when we are beset by this experience’ (p. 423). We are unsure not only of how we should define suffering, but also how we should talk about it.

If we look and listen carefully, we may note that suffering itself is a unique form of communication (Black, 2006a) that uses several languages. Certainly suffering is spoken through the body. As the first means of self-revelation, the body is the medium through which one experiences oneself and the world (Murphy, 1987). When the boundaries of the body break down through suffering, the body becomes stigmatized through lack of mobility, distorted configuration, obvious pain, or conspicuous silence. In other words, facial expressions and bodies communicate suffering, and individuals make sounds, such as cries or groans, that are part of the experience.

Changes that occur in elders’ identities and roles also speak of suffering. Aged sufferers may assume a new or restructured role, such as a ‘sick person,’ ‘housebound elder,’ or ‘patient,’ which is framed by their current circumstances of illness, pain, or loss. Altered roles may be a form of suffering itself. Likewise, to recreate an identity based on illness or loss requires the difficult work of acknowledging the altered facts of one’s life and measuring losses against what remains. Or, older persons may rework roles and identities in order to maintain a self concept that accommodates who they were, are, and want to remain with the new facts of old age and suffering.

Most writers on suffering agree that another language of suffering is narrative. Just as the body reveals pain, suffering can be revealed by new identities more in keeping with a diminished lifestyle. Telling a story also communicates suffering. A narrative embeds the story of suffering within the elder’s life story; within the aspects of his or her identity, such as age, class, ethnicity, and gender; and in the multi-layered vantage of older age. Stories of suffering may re-integrate a self fragmented by suffering (Scarry, 1985). Narrative ‘repair’ may be accomplished by explaining a cause, effect, and probable outcome of personal suffering.

Yet, we cannot discuss the languages of suffering without mentioning silence. In her book Suffering, Dorothee Söelle (1975) reports that language is integral to the ‘progress’ of suffering,
and that a primary feature is muteness. For some experiences of suffering, whether they occurred in the distant past or currently persist, there may be no words, or no desire for words, to describe them.

**Suffering, culture, and belief systems**

Culture as native starting point to understanding how pain and suffering are experienced and made known is defined as the shared blueprint of both the local and larger worlds into which people are born and take part in shaping. Thus, as a lived experience, suffering is informed by a personal culture’s (smaller, local, familial) and shared culture’s (larger, public, societal) systems of meaning, such as the way a family or a society makes sense of a negative incident or event. An experience of suffering also takes personal biography and cohort history into account. An experience that in one culture (either smaller or larger) might be defined as suffering, might not be in others. For example, a 78-year-old woman who lived alone described ‘not hearing another human voice throughout the day except on TV’ as suffering. An older man who lived in a community shelter described suffering as the ‘constant talk—chatter, arguments, laughing’ he could not escape. Suffering, like culture, speaks itself through a particular actor with a particular story (Reissman, 1997). For the woman and man described above, suffering was described in relation to personal experience and interpretation. What can be considered suffering in one person’s story is not necessarily suffering in another’s.

Suffering also speaks through social institutions and religious belief systems, both of which are related closely to culture. Veena Das (1997) argues that social institutions themselves produce suffering, while also producing the ways through which suffering may be understood. Initiation rituals, for example, provide a context whereby enduring pain has a transformative meaning, something that although unspoken is understood by other members of a given culture.

Belief systems are important in the sense of finding meaning as a source of comfort for suffering or fending it off. Individuals, families and cultures may look to their belief systems to make sense of suffering in general, and specifically of a loved one’s suffering or one’s own. A belief system may offer answers to questions such as the ageless ‘Why?’ A crucial aspect is its ability to support a continuous worldview that may be threatened with rupture through suffering. A belief system operates within several dimensions. Each might offer meaning for those world or life events that are mysterious, frightening, or pain-producing, such as suffering, but also some sense of control over such events.

Religious institutions represent places where ideas of suffering and its meaning and value are communicated and modeled. For example, Kimble (2000) describes the Christian tradition as accepting the reality of suffering as something that everyone will encounter at some point in their lives, that suffering and dying are filled with meaning, and that suffering is redemptive in that it can lead to positive, inward contemplation. The stories of Job and Jesus, for example, provide examples of tolerance, acceptance, and virtue in suffering. In the Buddhist tradition, Tarling (2012) describes suffering as ‘a fundamental constituent of being, a punishment for sins committed in a previous incarnation’ (p. 114). The fact of suffering’s existence forms the first of the four noble truths, that life is full of suffering, people suffer because of wants, suffering is not inevitable, and one can follow a path that will lead to an end of suffering.

In addition, models and religious teachings provide a way for people to not only understand their suffering (e.g. it is a necessary part of life) but to also understand how to bear their suffering. In a study on views of suffering and redemption in patients coping with cancer, Käppeli
(2000) interviewed 29 Jewish and 71 Christian cancer patients ranging in age from 20 to 96, to understand the role that religion played in mediating their suffering. The author reported that most of the participants related their illnesses to ‘something transcending its worldly nature and context’ (p. 85). In short, their religious views enabled them to frame their experience as something meaningful.

Davies (2011), however, suggests that our consciousness of suffering has shifted away from a religious view to a medical one, and that there is a tendency to pathologize suffering. Suffering, then, becomes not only ineffable, but defective or deviant. In his essay about suffering from a historian’s standpoint, Kimble (2000) argued that, in contrast to the past, ‘a rather odd and oppressive judgment has also fallen upon the person who is suffering. His or her suffering is viewed as avoidable, the result of a defective personality structure, a lack of enlightenment, or even irresponsibility’ (p. 149). In looking at how suffering had been viewed across several historical time periods, Kimble asserts that suffering, which was once a virtue, has now become a source of weakness. The growing emphasis on personal responsibility, according to Kimble, has resulted in transforming the sufferer into someone who is somehow implicated in his or her own suffering rather than a victim.

Conclusion

In this chapter we have highlighted some key aspects of pain and suffering that are linked to identity and ageing (Black & Rubinstein, 2004). In doing so, we noted the role of institutions and culture in shaping how pain and suffering are experienced, and how suffering in particular is communicated, and understood. Although in gerontology pain is often addressed from a medical aspect, it is not often dealt with conceptually, and its links with, and differences from, suffering are rarely addressed. The fact that suffering is so rarely mentioned in gerontology except in the context of pain raises some curious questions. What risks does the acknowledgment of suffering pose, and for whom? Why is the language of suffering so elusive? What would happen if we initiated open dialogue about suffering, much in the same way that there are growing dialogues about death and dying? We suggest that suffering exists as the silent enemy of ageing, that, like many other aspects of older age, suffering has become a problem that needs fixing through better health, diet, and exercise.

Although several studies have explored the experiential problems of old age, such as decline, fear, illness, loneliness, and grief, the infusion of the experience of suffering into daily chores or thoughts has rarely been addressed as a central focus of study. Research has neglected the intimacy and banality of elders’ suffering, and the way in which suffering corrodes or strengthens worldviews, values, and spiritual beliefs. If a theory of suffering is notably absent from research on suffering, perhaps it is because a general theory of suffering cannot hold the depth and breadth of personal suffering.

What is needed is greater attention to the constructions and paradoxes of suffering in old age and the role of belief systems and institutions, including gerontology, to shape how suffering is conceptualized and made known. Also needed is an understanding of how suffering is conceptualized and experienced in a variety of settings, such as long-term care. Does context provide a different way through which to interpret experience and meaning and ultimately to either challenge or support self and identity? Gaining further insight into how suffering can be meaningful or meaningless is also worthwhile. For example, silent, stoic suffering can be a virtue, while voiced suffering can be a detriment. By embracing suffering as a concept important to the human condition and one worthy of study, we may help others lay claim and give voice to their suffering.
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References


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