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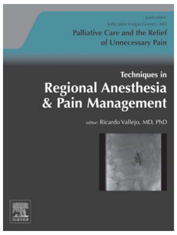

Psychological and family-related facts of suffering in patients with chronic diseases

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ABSTRACT

Illnesses that limit life or functioning have the potential to cause significant distress and lead to suffering. Suffering is a subjective and multidimensional experience that results from the person's appraisal of threat and exhaustion of coping resources. Detection and management of suffering in patients who are chronically ill have become of great interest in the last few years as relief from suffering was established as one of palliative care main goals. Psychological, sociocultural, and family issues that contribute to suffering are discussed. Also, assessment strategies and instruments, as well as interventions toward relief from suffering, are described. Therapeutic approaches should be individualized and include issues in the physical, psychological, sociocultural, and spiritual domains to plan for comprehensive interventions suited to the patient's needs and to attain better symptom control. Regarding family suffering, interventions that reinforce the perceived social support, facilitate communication and emotional disclosure, effect on the family's level of cohesion and flexibility, and enable role distribution, resilience, and meaning of the illness as a learning experience will reinforce adaptation and alleviate suffering.

Introduction

Suffering is a common human experience.[1] Illnesses that limit life or functioning and that may be perceived as a threat to the person's integrity or a menace to the fulfillment of personal purposes, have the potential to cause significant distress and lead to suffering.[2] In particular, conditions where persistent or severe pain or both are common symptoms, frequently co-exist with suffering.[3] However, suffering and pain are considered to be distinct phenomena, although they may share common features and neurobiological pathways.[4,5]

In the last decades, the interest on the detection and relief of suffering in health care settings has expanded as a shift toward a biopsychosocial and spiritual model of health has gained weight, and as suffering alleviation, along with the prevention and cure of diseases, is recognized as one of the main objectives of health care.[6,7]

Definition and conceptualization of suffering in health care

Efforts toward the definition of suffering in the health care context begun in the 1980s. Sounders and Baines[8] used the term “total pain” to describe a single, integrated, and multidimensional experience comprising physical, psychological, social, and spiritual aspects. Cassell[2,7] defined it as a specific

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state of severe distress associated with events that threaten the intactness of the person and explained how this experience is subjective and goes beyond the body itself, requiring a social context, consciousness, a sense of personal identity, a sense of the future and the past, and a desire to preserve personal identity. Meanwhile, pain scholars made an effort to differentiate suffering from pain. Loeser and Melzack[9] determined levels of pain and defined suffering as a negative emotional response that could be triggered by pain and other events. Chapman and Gavrin[4,10] further developed the concept and offered a model to understand the relationship between suffering and pain. According to them, suffering entails "a complex negative affective and cognitive state, characterized by a perceived threat to the integrity of self, the perceived helplessness in the face of that threat and exhaustion of psychosocial and personal resources for coping."[10] More recently, Krikorian and Limonero[1] offered an integrated view of suffering and defined it as the result of an imbalance between perceived threats and regulatory processes (which include coping resources and physical or biological, psychological, social, and spiritual responses).

All definitions of suffering emphasize on its subjective nature and on being the result of the person's appraisal of threat. There is consensus regarding its multidimensionality and, thus, the physical, psychological, sociocultural, and spiritual dimensions should be considered altogether. In the next sections, factors particularly related to the psychological, sociocultural, and familial aspects are discussed.

Psychological issues

Facing a chronic or life-threatening illness entails a series of challenges and efforts toward ongoing adjustment. Emotional distress is a common experience throughout the illness trajectory and may range from normal emotional reactions to mental disorders, such as depressive and anxiety disorders. It has been found that gravely ill patients with a mental disorder experience more severe suffering.[11] Also, patients with more severe suffering experience anxiety, feelings of sadness, hopelessness, helplessness, loss of dignity, and a desire to die, among others.[3] Fear and anxiety may occur during particular stages of the illness trajectory and manifest in avoidant behaviors, catastrophizing, or in death anxiety.[3] Loss of control is a common problem when facing chronic and disabling conditions and may lead to helplessness and hopelessness, and eventually to demoralization.[3,12] Spiritual aspects, such as hope, dignity, and meaning in life, have been found to protect from suffering and foster well-being; meanwhile, hopelessness is linked to significant suffering and the desire to die.[13]

According to Charmaz,[14] suffering in patients who are chronically ill is related to the loss of the self, which manifests in leading restricted lives, social isolation, loss of dignity, and a sense of being a burden to others. Wittmann et al[15] found that suffering was linked to constraints of the self and the impossibility to achieve important purposes. Similarly, Black and Rubinstein[16] found that suffering was related to loss of control, loss of the self, identity, or life itself; while attaining meaning in the experience was important for suffering relief.

In summation, events that are perceived as threatening for the patient have the potential to cause suffering, particularly when the resources to cope with them are exhausted and the person's integrity is menaced.[1] Consequently, sources of suffering are individual, dynamic, and context-related.

Sociocultural and family issues

Chronic, progressive, or advanced illness when perceived as distressing may entail a personal, familial, or social suffering experience. Suffering may be mediated by sociocultural issues, such as ethnic and religious backgrounds, work-related aspects, gender, and socioeconomic factors, among many others.[17] Different studies have shown how factors, such as the family life cycle, its socioeconomic status and illness-related beliefs, may influence the effect the illness has on the family.[18-20]

Thus, an adaptation process that comprises continuous adjustment efforts for the family as a unit occurs along the course of the illness.[18] Adaptation is a dynamic process that depends on the illness stages, beginning from diagnosis and treatment and continuing even after the patient's death, in the case of life-limiting conditions. Families use different strategies for coping, which entail a series of efforts, reactions, and responses toward adjustment to the illness experience; aspects such as family cohesion, structural flexibility, communication, perceived social support, resilience, and the ability to learn from the illness experience may enable or block the adjustment process.[21]

When facing the illness of a member, the family manages to comply both with the life cycle tasks of and with those of caregiving. Changes of the member's roles and functions may occur, which frequently lead to the identification of a primary caregiver in whom most caregiving efforts are concentrated, with the occasional support of other members (relatives, friends, or others). The primary caregiver plays an essential role and the relationship between him or her and the patient is of particular relevance when assessing family suffering.[22,23] Kurtz et al[24] found that physical symptoms and immobility in patients with cancer caused by the illness were predictors of depression in both the patient and the caregiver. Similarly, the cognitive, behavioral, and physical disability of patients with dementia, as well as some sociodemographic variables, influences the emotional and existential suffering of their caregivers.[25] In another study conducted in patients with rheumatoid arthritis, the spouses of patients who were also depressed manifested more stress in the illness experience.[26] According to the results of a qualitative study conducted in caregivers of patients with cancer and noncancer pain,[27] caregivers manifested high levels of suffering that were linked to witnessing physical symptoms and pain in the patient they cared for and having little control over these symptoms, having difficulties to comply with caregiving tasks, and perceiving that the caregiving role limited their own lives. However, most considered to have learned from the caregiving task and being satisfied with the role they assumed.