The Psychological Health of Patients and their Caregivers

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Committee

13.1 Why Is Psychological Status Important in the Management of Hip Fracture?

Hip fractures are associated with reduced health-related quality of life (QoL). Buckling and colleagues [1] have found a pre-existing need for care, limited function, cognitive impairment and depression to be independent factors associated with lower QoL during a patient's post-surgical period. To assign a realistic value to osteoporosis and osteoporotic fracture treatment, it is important to understand the full impact that osteoporotic fractures have on QoL. In fact, QoL can predict mortality, as well as physical and psychological functioning [2].

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For an explanation of the grouping of chapters in this book, please see Chapter 1: 'The multidisciplinary approach to fragility fractures around the world—an overview'.

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13.1.1 Why Is Psychological Status Important in the Outcome of Hip Fracture?

Depression, delirium, and cognitive-impairment rates, at the time of hip fracture, have been estimated at between 9% and 47% (mean 29%), between 43% and 61% (mean 49%), and between 31% and 88% (mean 47%), respectively [3]. Mental health status at the time of surgery has been reported as being an important determinant of the outcome, with mental disorders associated with poorer functional recovery and higher mortality rates [4]. For example, a functional decline can lead to disability and may lead to prolonged hospital stays, institutionalisation and even death [5].

It has also been suggested that pre-fracture dependence in ADL is a stronger predictor of further functional decline—resulting in institutionalisation or death—than pre-fracture dementia [6]. Furthermore, delirium is associated with lower functional outcome in both short and long term and recovery increased length of stay, high risk of dementia and persistent cognitive deficits [7]. Delirium is also associated with other hospital-acquired complications that translate into higher rates of institutionalisation, greater need for rehabilitation and home healthcare services after discharge, increased mortality and healthcare costs, as well as an additional burden on the patient, hospital staff and family caregivers [8].

13.1.2 Why Is Psychological Status Important in Rehabilitation from Hip Fracture?

A study [9] showed that delirium was independently associated with poor functional outcome 1 month after fracture even after adjusting for pre-fracture frailty. Also at the 6-month follow-up, it constitutes an independent risk factor for institutionalisation among hip-fracture patients who live at home before the fracture. In the case of patients who are able to return to their homes, delirium is a strong predictor of functional decline at the 6-month follow-up [10]. Regarding depression, the literature showed that approximately one in five people who are not depressed at the time of their fracture become so after 8 weeks [11]. In a long-term study [12], functional healing was evaluated after 2 years in elderly cases with hip fractures, and depression was reported to have affected healing. A negative effect of depression on daily living activities emerged also at the end of a 6-month period. A patient's active participation in the rehabilitation process has a positive effect on healing. However, the presence of depression disrupts this process because of reluctance, negative cognition and symptoms similar to psychomotor retardation. Depression in elderly hip-fracture cases was found to have affected daily living activity negatively.

The psychological state of the individual who suffers from a hip fracture is highly relevant when determining how well that person may recover [13]. The affective responses to a hip fracture predict both psychological and physical functioning over time, providing a potential target for the enhancement of recovery from this

debilitating injury [14]. It is also suggested that the effect of rehabilitation after hip fracture can be less effective if functions are restricted due to fear of falling (FOF) [15]. For all the aspects mentioned earlier, it seems important to take care of the HF patient's psychological status.

13.1.3 Why Is Caregivers' Psychological Status also Important?

Hip-fracture (HF) patients are among the most vulnerable of hospitalised patients. The associated caregiving rehabilitation task often falls to a member of the family. Most caregivers (86%) are family members (predominantly women) also known as 'informal caregivers' [16]. They fulfil their role for between 7 and 11 h per day on average and anything up to 10–15 h when clinical conditions worsen: the more serious the fracture, the more support is needed [17, 18]. Usually, they have no professional assistance-procedure skills. Informal caregivers must cope with physical, psychological and social stressors that affect their health status and quality of life negatively.

The primary stressors experienced by informal caregivers are related to the severity of the patient's disease and the amount of time devoted to assisting him/her. Informal caregivers are an important resource for elderly patients suffering from hip fractures because they play a key role during their recovery. One important task is that of motivating the patients to adhere to their therapy programme. Elderly patients with a hip fracture may present with a complexity of other problems, which may be challenging to both them and their carers.

13.1.4 Consequences of Caregiving

The level of family caregivers' mental health has been shown to be an important predictor of care recipients' institutionalisation [19], and a risk factor for care-recipient mortality. Objective primary stressors can affect various dimensions of burden differently: functional health has been found to be associated with time-dependent, physical and developmental burdens; cognitive status has been found to be associated with a time-dependent burden. Patterns of change in family caregivers' mental health over time have also been explored, as have the relationships between family caregivers' mental health and recovery outcomes of elderly hip-fractured patients. The findings suggest that, during the first year following patient discharge, family caregivers' mental health is associated with patients' post-fracture recovery, including the recovery of physical functionality, reduced pain and better health-related outcomes.

These results also suggest that, when estimating recovery times and health-related outcomes of patients who have suffered from hip fractures, healthcare providers should also consider the mental well-being of family caregivers. An understanding of the relationships between caregiver-related predictors and the recovery of elderly persons after hip-fracture surgery might provide a more holistic view of that recovery [20]. The perspective that tends to dominate much of the

literature is that care by family members is provided solely to older adults living at home. When caregivers are monitored over considerably long periods of time, it becomes evident that family caregiving responsibilities do not end with institutionalisation of the disabled relative. Instead, this key transition appears to affect the type and intensity of help provided.

Unlike earlier studies that treated institutionalisation as an ‘endpoint’ in family caregiving, recent research has emphasised the continued involvement of relatives in care and the effects of nursing-home admission upon the stress and mental health of family members. There is a lack of literature addressing family caregiving for frail elderly people and its consequence on the life quality of family caregivers. The subjective responses of individuals to the environments in which they live play an important role in maintaining the status of their care recipients. High levels of depressive symptoms and low levels of life satisfaction in caregivers may also be associated with the low quality of the care provided to their frail care recipients and even with maltreatment of the elderly [21].

Caregiver burden and its associated stress impact negatively upon the caregivers’ perceived general physical and mental health [22] and have been negatively correlated with the functional status of elderly family members 1 month after discharge following hip-fracture surgery [23, 24].

13.1.5 The Relationship Between Caregivers’ and Patients’ Psychological Status

In a recent study, we found a correlation between the patient’s psychological well-being and the caregiver’s burden. At the 2-month follow-up, the outcome of ADL scores was negatively associated with caregiver burden ($p < 0.01$). Follow-up functional ability was higher in patients whose caregivers reported lower burden during their hospitalisation ($p = 0.03$). Interesting results regard the correlation existing between a patient’s psychological well-being and his/her mood; greater psychological well-being corresponds, in fact, to lower likelihood of depression.

A mutual relationship seems, therefore, to exist between the patient’s psychological well-being and the caregiver’s burden, so that improvements in the state of health of the one boost that of the other, and vice versa. This datum confirms the importance of using a bio-psycho-social approach when dealing with both patients and caregivers and evaluating the HF patient’s and caregiver’s psychological status [25, 26].

13.2 How Should the Psychological Status of Patients and Caregivers Be Assessed?

In Table 13.1, we illustrate the different areas we believe it is important to evaluate to obtain a complete assessment of HF patients and relative caregivers during the different stages of the illness and recovery.

Table 13.1 Areas to be evaluated in an integrative assessment in HF patients and caregivers, at different staging (1 = admission; 2 = discharge; 3 = 90 days follow-up; 4 = 1 year follow-up; 5 = 2 years follow-up)

Areas	Staging				
	1	2	3	4	5
<i>Patient</i>					
Quality of life	X		X	X	
Fear of falling			X		
Pain			X	X	
Activities of daily living	X		X	X	
Delirium	X	X			
Depression	X		X	X	X
Cognitive status	X				
Stress		X	X		
Anxiety		X	X		
<i>Caregiver</i>					
Psychological well-being	X		X	X	
Caregiver's burden	X		X	X	

13.2.1 The Psychological Evaluation of the Patient

The recovery process that follows surgery varies based on the patients' comorbidities, cognitive and functional status and their psychosocial state. Well-being in this sense means more than health as such. It is important to evaluate different negative and positive dimensions to assess patients' psychological status when following a bio-psycho-social approach.

13.2.1.1 Quality of Life

Health-related Quality of Life (QoL) is recognised as an important measure of health status that may be used for evaluating disease and health care services [27]. It is a broad, multidimensional construct that includes domains such as physical, psychological and social functionality [28], which permits identification of specific aspects of QoL and targeting of interventions needed.

Some patients suffer from QoL [29] and well-being loss [30] while others move to nursing home facilities [31]. According to Rasmussen and colleagues [32], well-being and self-efficacy are resources for both health and illness to be considered when exploring ways of promoting possibilities of recovery. The importance of patients' perception of the care they receive has been highlighted in the literature over the past few years [33]. Without QoL data, the burden of osteoporotic fractures is likely to be underestimated [34]. The EQ-5D has been recommended for the assessment of QoL in elderly patients [35]. Although this instrument shows good psychometric properties in elderly patients, assessing the QoL of cognitively impaired patients is difficult. In people with mild and moderate dementia, these tests yield good validity and good-to-average test-retest reliability for the descriptive system, but not for the Visual Analogue Scale (VAS), which is a part of this questionnaire.

Proxy assessment is, in some cases, the only way to gather information regarding QoL, when patients are unable to respond. Family caregivers tend to overestimate health limitations concerning less visible items (pain and anxiety/depression). Very frequently, healthcare professionals rate patients at the same level for all five domains (some problems with everything). No consensus has been reached as to the most appropriate proxy to apply, but a proxy assessment of EQ-5D seems, in our opinion, to be the best option when assessing QoL in patients with severe dementia. QoL should be assessed using the EQ-5D method upon admission to determine pre-fracture QoL and in post-admission 90-day and 1-year follow-ups. In patients affected by severe dementia, EQ-5D should be completed by a proxy, if one is available [36].

13.2.1.2 Fear of Falling

Fear of falling is linked to self-efficacy—the belief people have about their capability to perform certain tasks [37].

After a hip fracture, older people have reported that their lives have changed physically, personally and socially [38]. McMillan and colleagues [39] conducted interviews 3 months after discharge from the hospital and found that during hip fracture rehabilitation, older people struggled to take control of their future lives by trying to balance risk-taking and help-seeking. The interviewees were aware that, on the one hand, it might prove risky to move around and that they were afraid of falling but, on the other, they wanted to be active and were trying to do things. They were determined to regain independence. To make progress, some of the interviewees stressed the importance of giving information to patients and to include them in talks regarding their progress. In the patient follow-up, FOF should be assessed 90 days after admission.

13.2.1.3 Pain

In the HF patients, pain should be assessed, initially, during the EQ-5D test; however, as we said before, the VAS used by EQ-5D is not reliable in cognitively impaired patients [35]. Therefore, VAS within EQ-5D rates overall body pain, while we are also interested in the pain at the site of the fracture. The Verbal Rating Scale (VRS) performs well in cases of patients with dementia, and it is more informative regarding fracture-site pain [40]. Liem and colleagues [36] agree that this test should be used on the second day after surgery—or, in cases of conservative treatment, the second day after admission—and at 90 days and 1 year after admission.

13.2.1.4 Activities of Daily Living

Activities of daily living (ADLs) are an important health outcome in the orthogeriatric population. Recovery of pre-fracture health and functional levels is one of the main goals in hip fracture management. Therefore, it is important to assess deterioration in functional level over time. The literature provides a vast selection of ADL measurement tools, but the Katz Activities of Daily Living Scale [41], is the most widely used. In many cases, it may prove difficult to assess pre-injury ADLs accurately at the time of admission. In such cases, we suggest consulting a proxy, who

will typically be a family member, friend or caregiver. ADLs should be assessed upon admission to evaluate pre-fracture status. During patient follow-up, ADLs should be assessed after 90 days and 1 year after admission.

13.2.1.5 Delirium

Delirium in hip-fracture patients usually occurs during the 2–5 days following surgery. It is common in elderly hip fracture patients, occurring in 10–61% of cases [42]. It can represent a difficult clinical condition to assess, as a fluctuation of symptoms can lead to failure to recognise its onset [43]. Dementia and cognitive decline, measured by MMSE, were found to be independent risk factors for delirium [44]. The Confusion Assessment Method (CAM) [45] is a reliable and valid measure of delirium in the general medical and surgical population. The CAM focuses on four features: (1) acute change in mental status with a fluctuating course, (2) inattention, (3) disorganised thinking and (4) altered level of consciousness and is a valuable instrument with which to assess delirium. Delirium should be assessed upon admission to evaluate the pre-fracture status and on discharge after acute hospitalisation.

13.2.1.6 Depression

Depression is the most common hip-fracture-related psychological disorder, although it is frequently difficult to assess it [46]. An independent relationship was found to exist between low functional capacity and depression symptoms in the elderly [47]. In elderly people who cannot walk well enough to perform daily living activities, social isolation often occurs, and social isolation is in itself a risk factor for depression [48]. Therefore, we can say that a vicious circle of low ADL is created between pre-existing depression and an increase in depression that feelings of inadequacy when performing daily activities can produce. The Geriatric Depression Scale (GDS) may be a valuable instrument by which to assess depression [49]. Depression was observed more often in females and those who had lost their spouses [11]. Depression should be assessed upon admission to evaluate its pre-fracture status. During patient follow-up, it should be assessed after 90 days, 1 and 2 years from the date of admission.

13.2.1.7 Cognitive Impairment

Some studies suggest that cognitive impairment, found in 31–88% of elderly patients experiencing hip fractures, was a predictor of poor functional recovery after hip-fracture surgery [13]. Furthermore, pre-fracture cognitive impairment is also associated [4] with higher mortality rates. The Mini-Mental State Examination (MMSE) [50] may prove to be a valuable instrument for the assessment of cognitive impairment. Cognitive impairment should be assessed upon admission to evaluate the pre-fracture status.

13.2.1.8 Stress

The importance of the overlapping mechanisms of osteoporosis and psychological stress were documented recently.

These factors can be extended to fragility fractures [51]. The Perceived Stress Scale [52] can prove useful when assessing stress. Stress should be appraised at discharge and 90 days after admission.

13.2.1.9 Anxiety

This emerged as one of the most important aspects regarding patients, especially their evaluation upon admission [26]. The Short Anxiety Screening Test [53] has been shown to be an easy and valuable one for the assessment of anxiety in this type of patient. Anxiety should also be assessed upon discharge and 90 days after admission.

13.2.2 The Psychological Evaluation of Caregivers

The increased risk of burnout identified among informal caregivers is closely related to their perceived level of burden, defined as a multidimensional response to negative appraisals and perceived stress [54]. Joint assessment of the dimensions of burden and well-being, that coexist in caregivers' experience, allows for the identification of personal and relational resources that may be usefully included in interventions addressed to caregivers [16, 17, 54].

13.2.2.1 Psychological Well-Being

The concept of subjective well-being (SWB) is multi-component by nature. It is affected by positive (e.g. happiness), negative (e.g. depressive symptoms) and cognitive components (e.g. life satisfaction). Its multiple components are affected by different sets of social determinants and develop differently at successive life stages [55]. High care-demand levels may affect multiple aspects of caregivers' lives, including free time, social life, emotional and physical health as well as personal development. These subjectively defined stressors are also called caregiver burden. Perceived caregiver burden may adversely affect their self-esteem and their sense of competency as a caregiver [21]. These might cause caregivers to suffer from higher levels of depressive symptoms and become less satisfied with their lives.

In other words, multidimensional caregiver burdens may play a mediatory role in the association between objective primary stressors and caregivers' SWB. The Psychological General Well-Being Index (PGWBI) [56] can prove to be a valuable test for the investigation of patients' and caregivers' psychological well-being. Psychological well-being should be assessed after admission and at 90 days and 1 year after admission.

13.2.2.2 The Caregiver Burden

Informal caregivers have to cope with physical, psychological and social stressors that affect their health conditions and quality of life negatively [57]. Over the last 30 years, researchers have paid special attention to the investigation and assessment of burden [58]. The Caregiver Burden Inventory (CBI) [59] provides information

regarding both the Objective Burden (OB)—the time and commitment caregivers devote to caring activities daily—and the Subjective Burden (SB)—perceived lack of everyday opportunities, fatigue, physical problems, issues related to socialisation and participation, and how they feel towards the care-recipient. Caregiver burden is an all-encompassing term used to describe the physical, emotional and financial responses of a caregiver to the changes and demands caused by providing help to another person with a physical or mental disability.

Increasing numbers of studies have examined the caregiver-burden phenomenon, the lack of support given to caregivers and interventions focused on relieving caregiver burden; this increase is probably due in part to greater evidence of caregiver burden being a determining factor in the quality of life (QoL) of caregivers. Several studies have revealed an association between the characteristics of patients and caregivers and caregivers' QoL, with caregiver burden serving as an important predictor of QoL. Caregiver burden has also been used as an outcome variable rather than a predictor [60], suggesting that caregiver burden and QoL are closely related. Thus, caregiver burden seems to be a potential moderator of the associations between patients' and caregivers' characteristics and caregivers' QoL. Some studies have shown that caregivers of elderly people suffering from hip fractures experienced a multidimensional burden, including tiredness, emotional distress and role conflicts [22, 23].

Many caregivers assume the caregiver role with little or no preparation and have to learn to deal with several aspects of care in a very short time. Often caregivers do not know what to expect during hip fracture recovery. They face situations where they have to address various care-related tasks, such as the arrangement of rehabilitation services and assistive devices. These situations become more stressful when caregivers must juggle their work and family lives. The care burden related to hip fracture, an acute injury, may decrease over time; however, it is often prolonged over 12 months or more [61]. Caregivers tend to experience the greatest stress during the first 2 months after fracture, the stress being associated with increased care demands and costs. Family caregivers of hip-fractured patients were reported as experiencing moderate burden [23]. Furthermore, the caregiver's burden was negatively related to the physical function of older patients with hip fracture. On the other hand, social support has been associated with a diminution of the caregiver burden [24]. The caregiver's burden should be assessed after admission as well as at 90 days and 1 year after admission.

13.3 How Can Psychological Status Be Influenced Positively by the Orthogeriatric Team?

We have found that a mutual relationship seems to exist between the patient's psychological well-being and the caregiver's burden, so that improvement in the state of health of the one boost that of the other, and vice versa. The correlation emerging between patients' psychological well-being and their caregivers' burden confirms the importance of using a bio-psycho-social approach towards patients and

caregivers [25, 26]. Unfortunately, no specific researches have nowadays studied how the psychological status of the patient and the caregiver can be positively influenced by the orthogeriatric team. Further studies are therefore needed to better understand what can be done to improve psychological health.

In the previous paragraphs, we showed the different negative and positive dimensions that are important to evaluate, the staging we suggest and instruments we believe to be the most appropriate. The orthogeriatric team should address these aspects following a bio-psycho-social approach. The inclusion of a psychologist in the team can help in the assessment of the patients' and the caregivers' psychological well-being, using the tools we have detailed earlier, but also enables psychological counselling. In the course of counselling, the psychologist can also obtain more qualitative data, to tailor the intervention based on the resources and needs emerging and give feedback to the patients and their caregivers on the problems and the strengths that emerged in the assessment. A pilot study suggested, for example, the positive influence that twice-a-week counselling, for about 45 min, had a positive influence on HF patients' depressive and anxious symptoms. Although long-term follow-up studies are necessary to evaluate whether good early results are sustained over a longer period, these data suggest that counselling can be useful in these patients [61].

The literature shows that these patients risk much longer, and more frequent hospital stays than other adults. Comprehensive discharge-planning programmes, including early identification of those at risk, can alter these statistics. Upon admission to care facilities, early multidimensional assessment can provide significant indications of how to address the entire course of patient treatment more efficiently. In our experience, the organisation of formative courses for caregivers and the implementation of a 'caregiver help desk', with the collaboration of case manager nurses, can be additional tools that the orthogeriatric team can use to promote a comprehensive discharge-planning programme enhancing, in this way, the psychological health of HF patients and their caregivers.

Greater psycho-educational support can be provided to patients and caregivers during rehabilitation, given the longer length of stay, compared to admission in other post-surgical settings.

13.4 Cultural Influence and the Anthropology of Care

To support patients and caregivers better, it is important to include cultural and anthropological influence in the dynamics of care.

All over the world women are the predominant providers of informal care to family members with chronic medical conditions or disabilities, including the elderly and adults with mental illnesses. It has been suggested that several societal and cultural demands are made on women obliging them to assume the role of family caregiver.

Stress-coping theories propose that women are more likely to be exposed to caregiving stressors, and are likely to perceive, report and cope with these stressors differently from men [62, 63].

Many studies, which have examined gender differences among family caregivers looking after people with mental illnesses, have concluded that women spend more time in providing care and carrying out personal care tasks than men. These studies have also found that women experience greater mental and physical strain, greater caregiving-burden, and higher levels of psychological distress while providing care [64, 65].

However, an almost equal number of studies have not found any differences between men and women as far as these aspects are concerned. This has led to the view that though there may be certain differences between male and female caregivers, most of these are small and of doubtful clinical significance. Accordingly, caregiver–gender is thought to explain only a negligible proportion of the variance in negative caregiving outcomes [66, 67].

A similar inconsistency characterises the explanations provided for gender differences in caregiving such as role expectations, differences in stress, coping and social support, and response biases involved in reporting distress. Apart from the equivocal and inconsistent evidence provided, there are other problems in the literature on gender differences regarding the issue of caregiving. Most of the evidence has been derived from studies on caregivers dealing with elderly people suffering either from dementia or a variety of physical conditions [68, 69].

With changing demographics and social norms men are increasingly assuming the role of caregiver. However, the experience of care-providing men has not been adequately explored. The impact of gender on the outcome of caregiving may be mediated by several other variables including patient-related factors, socio-demographic variables, and the effects of kinship, culture and ethnicity, but these have seldom been considered in research into gender differences [70, 71].

Beyond the gender aspect, each culture and nation have its own way of establishing the care relationship between the patient and the caregiver. A study conducted in different European countries, for example, found that in countries where cross-generational support is more strongly established (Italy, Spain), the impact of fragility fractures on caregivers is generally higher than in the other countries (i.e. France) [72]. Contemporary literature reveals that global economic shifts, migration, and chronic disease are enlarging the demand for care of the elderly while, at the same time, altering intergenerational expectations; the critical roles older persons play in familial care systems as global care chains are becoming increasingly clear [73]. Migrant care workers frequently look after elderly people with significantly different bodily and historical experiences, drawing creatively upon their models of care to define cultural and gender-based identities and make claims concerning their contribution to the nation [74].

These aspects need to be considered, for example, during training courses for caregivers.

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