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ORIGINAL ARTICLES

# The extra burdens patients in denial impose on their family caregivers

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## ABSTRACT

*Objective:* The purpose of this study was to explore the impact of advanced cancer patients' denial on their family caregivers and how they cope, in order to enable clinicians to better support them and their caregiving.

*Method:* As the objective was to obtain clinically useful findings, an interpretive descriptive design was used. Data consisted of prospective semi-structured interviews with 16 family caregivers of advanced cancer patients in denial, field notes, reflexive journals, and memos during the analysis.

*Results:* Caregivers experienced extra burdens with the patient's denial. Feeling bound to preserve the denial, which they perceived as immutable, they were prevented from seeking information to manage the patient's care. Additionally, those caring for noncompliant patients felt disenfranchised from their role, resulting in feelings of powerlessness and guilt, and felt burdened by managing medical situations that arose from noncompliance. Caregivers described the ambivalence of feeling frustrated and burdened by the denial while recognizing it as a long-standing coping pattern for the patient. The denial prevented them from acknowledging their own needs to the patients or seeking informal support. They therefore developed solitary coping strategies, sought professional psychosocial support, and/or employed denial themselves.

*Significance of results:* Caregivers of patients in denial experience added burdens, which they must bear without most of the usual sources of support. The burden is accentuated when patients are noncompliant with care, placing themselves in dangerous situations. Healthcare providers should identify patients in denial and support their caregivers in meeting both their caregiving and their own needs. Evidence-based strategies to accomplish this should be developed and implemented.

**KEYWORDS:** Denial, Caregiver burden, Disenfranchisement, Noncompliance, Cancer

## INTRODUCTION

Patients are living longer with cancer (Golant & Haskins, 2008), while the trend toward shorter hospital stays is leaving their families to provide complex

care at home for longer. Caregivers provide physical care, symptom control, and emotional, practical, and social support for the patient, as well as assuming the roles of care coordinator, spokesperson, advocate, and proxy decision maker (Stajduhar et al., 2008). This burden often results in caregiver distress and burnout (Glajchen, 2004; Stenberg et al., 2010). Research firmly links caregiving to increased risks of morbidity and mortality, citing such adverse consequences as sleep

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deprivation, depression, anxiety, and economic hardship for caregivers (Funk et al., 2010; Schulz & Beach, 1999; Stajduhar et al., 2010).

One source of caregiver distress may be patient denial. Patients in denial do not accept, or appear oblivious to, their diagnosis, minimize the implications of their disease, delay seeking treatment for recognized symptoms, have little or no adherence to medical recommendations, or appear unconcerned or detached about their illness (Goldbeck, 1997). The effects on family caregivers of providing care and support for these patients is little understood. A review of the current literature in August, 2011, using MEDLINE<sup>®</sup>, Cumulative Index to Nursing and Allied Health Literature (CINAHL), PubMed, PsycINFO<sup>®</sup> and combinations of the key words: *advanced cancer*, *patient denial*, *caregiver*, *spouse*, and *communication* revealed two retrospective studies that focused on the thoughts and experiences of the caregivers of patients who employed denial (Beach, 1995; Saldinger and Cain, 2005). These studies reported that patient denial closed communication channels between the patient and caregiver and compromised spousal intimacy. A caregiver's expression of awareness was seen as an act of disloyalty by the patient, thus preventing the sharing of emotions related to the cancer and its implications. The impact of this communication barrier on the caregiver was not explored. Because of the retrospective nature of both studies (conducted after the patient's death), the caregiver accounts may have been subject to a recall bias (Fossey et al., 2002). The caregivers in one study (Saldinger & Cain, 2005) were exclusively spouses, which precluded learning about the experience of other family caregivers. Studies that focused on caregivers revealed that the caregiving role is much easier when the patient is "aware of and accepting of their illness" (Stajduhar, 2003) and that caregivers describe "falling to bits inside" when they must engage in the pretense that the patient is not dying (Riley & Fenton, 2007). These studies hint at the possible hardship experienced by the caregivers of patients in denial but do not elaborate further about the exact nature of the hardships.

Strategies employed by family caregivers to manage patient denial were not found in our literature search. Rabinowitz and Pierson (2006) compiled a list of non-evidence-based strategies for healthcare professionals to manage patient denial; it is unclear how pertinent they are to family caregivers.

We chose to focus on caregivers of patients with advanced cancer, as most of the patient's last year of life is spent at home (Health, 2008) during which the caregivers are typically responsible for providing most of the physical and emotional care of the patient (Stajduhar et al., 2008). The purpose of this study was to re-

veal the impact of advanced cancer patients' denial on caregivers from the unique perspective of the caregivers, and to suggest ways in which clinicians could help the family caregivers of these patients. It explores the consequences of patient denial for the caregiver during visits to the clinic and in the home environment. Finally, it uncovers strategies that caregivers have employed to work with these patients and to reduce their own stress and distress.

## METHOD

### Design

A prospective interpretive descriptive methodology was chosen to create ways of understanding patterns and themes in a clinical phenomenon that yield applications by allowing those experiencing it (caregivers) to reflect on, interpret, and explain their experience as it is unfolding. This design highlights implications for improved clinical practice, and avoids the recall biases of previous studies.

### Sample

We purposively sampled primary family caregivers of advanced (stage 3 or 4) cancer patients in denial for whom the primary goal of treatment was palliation. The caregivers in our sample were the primary unpaid providers of support to the patients (Canadian Hospice Palliative Care Association, 2011). They were at least 18 years old and able to speak English or French. We later used theoretical sampling to gain the male perspective, as our initial participants were mostly female.

Patients in denial were identified and approached by their primary professional healthcare providers from the inpatient oncology/hematology and palliative care departments and from the outpatient oncology/hematology clinic and clinical research unit of a large urban teaching hospital in Canada between 2007 and 2008. These healthcare providers ascertained the patient's willingness to be approached by a researcher about a study about communication (as opposed to "denial" so that patients did not feel judged or confronted about their coping mechanism). Researchers obtained consent from interested patients to collect demographic and other relevant information from their charts and to approach their primary family caregiver about participation in the study. Researchers then approached the primary family caregiver identified by the patient to give a more detailed account of the study and to obtain informed consent. The hospital's Research Ethics Board approved the study protocol.

Although we had 19 participants, the researchers excluded data from 3 participants during analysis

when it became apparent that the caregiver did not perceive that the patient was in denial (see Identifying Patient Denial section below). The 16 participants whose data were used had a mean age of 56.0 years (range: 37–80). The majority of the caregivers were female (81%) in keeping with estimates that 68–77% percent of caregivers are female (Stajduhar et al., 2008). Spouses comprised the majority of caregivers (10/16); the others were former spouses (2/16), a parent (1/10), a friend (1/10), a sister-in-law (1/10) and a sister (1/10).

### Data Collection

Four sources of data were used. In-depth semistructured interviews were conducted once with each family caregiver (81% in English, 19% in French), in a private location by NK (a senior social worker) or, in one case, by SRC (a senior psychologist). The interviews lasted 1 hour. Each caregiver was asked to describe the patient's denial and how it affects the caregiver's daily life, caregiving role, and relationship to the patient. Caregivers were also asked about the meaning that they ascribed to the denial, the benefits and challenges associated with it, and how they managed the care of a patient in denial. Eighteen interviews were audiotaped and transcribed verbatim with the caregiver's consent. One interview was not audiotaped as per the caregiver's preference; notes were taken throughout the interview instead. As data were being concurrently analyzed, participants were recruited until a redundancy of information was apparent, suggesting saturation.

Detailed field notes were written following each interview to allow for a greater recollection of the interview context and to capture nonverbal impressions. MD and NK also kept memos throughout the project in order to keep track of discussion points and links between emerging data and relevant journal articles. They also kept a reflexive journal where their biases, assumptions, and beliefs were written down before data collection and analysis. Theoretical links were discussed between these and the research question. This process of bracketing (Drew, 2001) was undertaken to minimize interference of the researchers' preconceived ideas about the topic during data analysis.

### Data Analysis

Data analysis was done in accordance with the principles of qualitative research as described by Morrow (2005). NK and MD read the interview transcripts independently multiple times to obtain an in-depth understanding of their content. SRC read the transcripts to familiarize herself with the content. Transcripts were then examined line by line independently by NK and MD to manually code key phrases

that described the caregivers' perceptions of patient denial; how the denial affected their lives, roles, and relationships with the patients; and which strategies they used to care for the patients in denial. For each transcript, codes that illustrated a particular concept were grouped into categories. The researchers then independently grouped categories into themes: broad statements describing the relationship between the category and the research question. Together, all three researchers examined the phrases, categories, and themes for each transcript and discussed any divergent data interpretation until consensus was reached. They then compared codes, categories, and themes across transcripts.

### Rigor

To ensure that the results were accurate and thorough, NK checked all of the data transcripts against the original audiotapes. Data were organized into codes, categories, and themes independently by MD and NK to ensure that all points of interest were identified and interpreted. The researchers then compared codes, categories and themes and challenged each other's interpretation when they differed. Throughout the process, an audit trail was maintained to ensure consistency in decision making and to facilitate an accurate recollection of the process for report writing.

### Transferability

Findings from purposive samples in qualitative studies are not intended to be generalized, but are transferable to the extent that there is congruence between the environmental or circumstantial contexts in which the study took place and those of the contexts to which they are being transferred (Lincoln & Guba, 1985). Thoughtful extrapolation allows the results to be transferred to settings that are similar but not identical.

### Identifying Patient Denial in the Transcripts

It is reported that 4–47% of cancer patients experience denial. This large span can be attributed to the difficulty in recognizing or defining denial, because of its complex and multiform nature (Vos & de Haes, 2007). Patients are seldom in denial about all aspects of their experience, rather they may deny a particular aspect of their situation such as their diagnosis, the impact of their disease, or their related affect (Vos & de Haes, 2007). Furthermore, they may fluctuate between awareness and denial or give people differing impressions of their denial by choosing to reveal awareness to certain people

and not to others (Hinton, 1981). As such, it is important to establish criteria for patient denial to give the study focus and transferability (Vos & de Haes, 2007). In order to be considered for this study, each caregiver's account of patient denial must have included evidence of denial related to diagnosis, prognosis, symptoms, or affect.

We did not directly assess denial in the patients for two reasons. First, asking patients about their denial may have upset an important coping mechanism at an important time in their lives. Second, the important issue in this study is the caregivers' perception of experiencing patient denial and not the extent to which the patient is actually in denial.

## RESULTS

### The Caregiver Experience of Patient Denial

Denial created a pervasive communication barrier between the patient and caregiver regarding the illness experience, which impacted on major spheres of caregiving. All of the caregivers accepted to maintain the patient's denial, which most of the caregivers perceived to be immutable. The patients were reluctant to express their needs, as if acknowledging them would confirm the gravity of their situation. Their caregivers were placed in an ongoing dilemma; on the one hand they wished to support the patient's denial in order to preserve the patient's sense of "normalcy," whereas on the other hand they were trying to attend to complex care needs, which the denial precluded them from effectively managing. These conflicting demands resulted in caregivers feeling psychologically burdened by maintaining denial. The burden was especially great when denial led patients to be noncompliant with their care (9/16). These patients blocked caregivers from obtaining medical information and monitoring symptom control. The patients' nonadherence to medical regimes exacerbated their condition, thus increasing their demands for physical care from their caregivers. These caregivers were disenfranchised from participating effectively in the illness experience, thus compounding their emotional burden.

Predominant burdens imposed by denial on all caregivers will be presented, followed by the burdens experienced by a more particular subset of caregivers who felt disenfranchised. The strategies used by caregivers to cope with the denial will then be described.

### The Burden of Maintaining Denial

"He wishes to continue as if nothing is happening. . . It's *impossible* with the pain. . . and everything."

The psychological burden associated with maintaining denial was expressed by caregivers in various ways. Having to maintain patient denial resulted in caregivers feeling increased anxiety; "I could strangle myself. Because I really am a pack of nerves," depressed moods, or "feeling enraged." Despite the feelings it created, 13 of the 16 caregivers were able to identify ways in which the denial was beneficial to the patient. Benefits included providing patients with hope and/or quality of life and enabling them "to keep fighting." The simultaneous burden of maintaining denial while recognizing its benefits for the patient generated strong ambivalence for the majority of caregivers. One caregiver stated: "It makes me impatient. . . It makes me angry. . .but I keep that anger to myself. . . I was having difficulty because one part of me was in anger but I had to be empathetic, gentle. . .it's a wall, . . .it puts me in conflict with myself."

Whereas some caregivers embraced the role of being solely in charge of patients' treatment plans, others felt emotionally weighted by this demand. One caregiver described her inability to engage the patient in problem solving, leaving her without a mandate to deal with the responsibilities of daily life: "We couldn't even begin to work on issues as he could not accept there was any problems. . .for me it was difficult to take charge of the situation. . .it was like a dead end with no exit. . .denial is difficult on many levels." Four of the 16 caregivers reported that denial prevented them from addressing end-of-life planning, not knowing where documents were kept, unable to prepare wills or make funeral arrangements. One caregiver said: "I would like to know how she'd like to be remembered. But that's, that's putting things in a past tense like: I'm gone . . .that's an example of. . . those festering things. . ."

To preserve the patients' sense of normalcy, several caregivers were unable to claim the legitimacy of their own physical and psychological needs, or avail themselves of additional support for patient care within the home, a feature held in common with other caregivers of palliative care patients (Funk et al., 2010).

We now turn to the subset of 9 of the 16 patients, whose noncompliance with care prevented disenfranchised caregivers from fulfilling their caregiving roles.

### The Plight of the Disenfranchised Caregivers

#### *In the Clinical Setting*

During medical appointments, 4 of the 16 caregivers were blocked by patients from accessing medical information on the status of the disease, its

implications, treatment decisions, and associated risks “I just couldn’t quite get a handle on it.” Either the patient demanded that the caregiver “stop asking questions” or, in recognizing the patient’s discomfort, caregivers withdrew. One caregiver stated: “I hesitate asking very pointed questions when she’s there because she’s very uncomfortable with those questions.” These caregivers were left with the responsibility of providing patient care while lacking basic information to accomplish this mandate. Unable to participate in treatment decisions, one caregiver stated “That’s kind of the verboten subject, . . . I’d want to know the upsides of this chemo version compared to the downsides. . . She resents those questions . . . I get frustrated as hell.” Another caregiver was unable to plan or prepare her young children: “What are the risks? What can happen? . . . I’m worried. . . I have a family to take care of, knowing that it’s serious. . . My kids don’t know. . . Yes. I’m scared of course. Nights? Pffff, I don’t sleep.”

Three caregivers were prevented by patients from reporting to the oncologist acute symptoms such as severe pain, profound diarrhea, and weight loss, which resulted in two patients being prescribed contraindicated chemotherapies. One patient then developed life-threatening symptoms. The caregivers felt guilt and devastation.

#### *At Home: “He Almost Died by His Own Hand”*

The cluster of patients (9/16) who did not acknowledge their severe medical symptoms or adhere to medical advice placed an additional strain on their caregivers, arising from the patient’s fragile status. Symptom management in particular was challenging for caregivers, as the noncompliant patients either underreported their symptoms or refused their caregivers’ efforts to respond to their medical needs in a timely manner. In refusing to cooperate with their caregivers to arrange timely medical interventions, four of these patients placed themselves in potentially life-threatening situations (e.g., a patient with febrile neutropenia refused to go to hospital). This led to the caregivers pleading and cajoling the patients into seeking medical help, or covertly trying to reach the doctor. These incidents left the caregivers guilt-ridden by the sense of failure in their inability to respond to the patient’s urgent medical needs. One caregiver stated: “There was a significant delay. . . It dragged. . . he wasn’t feeling well for several days. . . I said to him: ‘Now, you have to go to the hospital’. He said ‘no’ . . . And it was no. . . The next morning, he couldn’t stand up. He was completely incoherent. . . Nothing. . . was functioning. If we had not taken [him] to hospital, he would have died. . . It’s difficult because you feel almost guilty. . .

to have to push him to go to the hospital. . . and you get there so late that you feel guilty. . . as if you could have forced him to get there before.”

Three of 16 patients’ reluctance to acknowledge the severity of their pain led to noncompliance with pain medication. One caregiver reported sleep disruptions for both the patient and herself because of the patient’s pain crisis, which resulted from the patient’s insistence on being undermedicated. These caregivers, prevented from intervening, helplessly witnessed their loved ones in pain for extended periods. “He’s been crying for the past three days. He’s got pain in the neck, pain in the back, and he doesn’t want me to talk about it. He’s having a hard time walking . . . he doesn’t tell the, the nurse. . . So that’s, it’s a bit tough, tough to manage. . . it’s demanding.”

## **Coping Strategies**

### *Familiarity with Patient’s Coping Style*

All 16 caregivers acknowledged the patient’s denial as an immutable extension of the person they had always known. Ten caregivers described the patients as having challenging personalities, using descriptions such as “rigid,” “a man who created his own truth,” and “secretive.” All caregivers referred to patients as having a closed style of communication (Saldinger & Cain, 2005). For example: “Everything was fine, [in the past] except we could never address emotional issues” or “I’m used to him not saying how he feels.” Their familiarity with this coping strategy enabled the caregivers to contend with the communication barrier caused by denial.

### *Feeling Rewarded in Their Role*

An important factor modulating the caregivers’ sense of satisfaction with the caregiving role seemed to be whether patients were compliant or noncompliant with their care. Most of the caregivers of the compliant patients felt rewarded in their role. For example, caregivers described having their roles affirmed by a patient’s trust in their medical decision making or a patient’s acknowledgement of their efforts. For the caregivers of the noncompliant patients, there was a dearth of positive feedback from the patients, leaving caregivers feeling dissatisfied with their efforts. They coped by accepting that their efforts to maintain the denial provided benefit for their patients.

### *Solitary Stress-Reduction Strategies*

Many (7/16) caregivers demonstrated significant reliance on their inner resources, identifying solitary distractions such as reading, taking walks, computer games, smoking, or going to work as stress-reduction strategies. These likely arose as coping mechanisms

because of the isolation that denial imposes on caregivers, and their inability to garner support from others. Six caregivers received professional psychological support informally through their healthcare team or through formal private counseling. Two caregivers noted that pharmacotherapy helped them to cope.

### *Caregiver Use of Denial*

Unexpectedly, six caregivers effectively used denial as an emotion-focused coping strategy (Lazarus & Folkman, 1984) to provide themselves periods of relief from their own suffering. As explained by one caregiver:

There are times when denial permits us to take care of ourselves. When I left on vacation to rest, the suffering was no longer ever present; it was like it no longer existed. For one week, unconsciously I thought to myself: "Everything is well," otherwise I could not have been able to have pleasure in eating. I would have felt guilty sleeping. . . And for moments it allowed me to be a bit self-centred, and take a breath of air, before diving back in. But the denial is only temporary. Because reality overtakes. The pain, we return to the pain, which continues to increase. . . It's not simple. But I think that on the whole, the [my] denial has passed. Sometimes I try to believe that things will work out. It permits me to survive. . . to continue living. . . One part denial, and one part reality. . . it's a mix of all sorts of things. . . it's weird.

Most of the caregivers were less aware of their use of denial as a coping strategy than this one, but nonetheless deployed it when their sense of hope was threatened in the face of the patient's deteriorating condition.

## **DISCUSSION**

Our study is the first prospective study that goes beyond identifying the communication problems associated with denial and extends our understanding of the nature of the burdens that patient denial imposes from the family caregivers' perspective and of how they coped with these burdens.

Our results showed that all of the caregivers accommodated the patient's use of denial as a coping strategy, which most of the caregivers perceived as immutable, even though it created a pervasive barrier in communication between the patients and themselves. This hindered illness-related dialogue, impeding the caregivers' ability to clarify directly the patients' shifting medical needs and concerns. The result was that caregivers were precluded from effectively responding to patient needs or sharing their own feelings and

concerns with patients. Unmet patient needs predict the more onerous aspects of caregiver burden (Sharpe et al., 2005). These caregivers identified patient compliance or noncompliance with patient care as a feature that modulated the degree of caregiver satisfaction in caring for patients in denial.

We found two sources of caregiver burden that have not been previously reported: 1) the burden of maintaining denial, shared by all of the caregivers, and 2) the added burden from being disenfranchised from the caregiving role by a noncompliant patient.

### **The Burdens of Maintaining Patient Denial**

The review by Stenberg and colleagues (2010) on the effects of caring for cancer patients identified >200 problems and burdens related to caregiving in areas such as looking after the physical, social, and emotional needs of the patient. In the review, denial is listed as an emotional problem for caregivers with no reference to its impact on caregiver burden. Our study identifies the burden on caregivers to maintain patient denial as having two main components. First, the act of maintaining patient denial caused psychological strain because they had to contain their illness-related thoughts and emotions, leaving many of them feeling "alone in this relationship," negating the mutual support mechanisms patients and caregivers can provide for one another (Rose, 1999). Funk's review of home-based family caregiving at the end of life concluded that the cost of caring for patients at the end of life involves intense, often negative and at times conflicting emotions (Funk et al., 2010). Our study suggests that the emotional cost for these caregivers was greatly increased in order to protect the patient's denial, as many of the caregivers felt that they could not share their own fears and anxieties with friends or family, which could have mitigated their emotional strain (Stajduhar et al., 2008).

Second, maintaining denial significantly increased the caregiver burdens in relation to their sense of efficacy in accomplishing the practical responsibilities of daily life (Stenberg et al., 2010). Most of the patients in denial could not acknowledge the implications of their illness, and they were unable to participate in illness-related dialogue with their caregivers.

### **The Extra Burden of Being the Disenfranchised Caregiver of a Noncompliant Patient**

#### *In Clinic*

Although obtaining information from the treating team is important for family caregivers (Proot

et al., 2003; Stajduhar et al., 2008), the caregivers of the noncompliant patients were unable to obtain this support from the patient's healthcare team. This caused uncertainty about treatment and patient care, a known source of stress for caregivers (Rose, 1999; Grbich et al., 2001). Caregivers' unmet informational needs (Steele & Fitch, 1996; Osse et al., 2006) can have a negative impact on caregiving (Aoun et al., 2005), including an increased risk of fatigue and burnout (Proot et al., 2003). Caregivers also need to provide relevant clinical information to the healthcare team (Stajduhar et al., 2008). The disenfranchised caregivers were unable to report this information and correct the misleading information provided by the patient to the healthcare team, sometimes with disastrous consequences for the patient.

We confirmed findings that caregivers who are caught in a moral dilemma between their sense of obligation to support the patient's style of coping, and their own values about how they should advocate for the patient's needs, can experience stress-related guilt and a greater psychological burden (Milberg et al., 2004).

### *At Home*

The caregivers of noncompliant patients in denial exhibited several sources of stress noted by Funk and colleagues (2010) in their review of end-of-life caregiving at home: uncertainty about treatment and lack of knowledge about patient care (Aoun et al., 2005); inadequate skills to manage patient's symptoms (Hudson, 2004), in particular pain (Armes & Addington-Hall, 2003); and insufficient guidance from the healthcare team (Broback & Bertero, 2003). The caregivers felt that their stress related to these factors was aggravated by their patients' closed communication style (Saldinger & Cain, 2005) and need to minimize the implications of their illness (Vos & de Haes, 2007). They felt disenfranchised from addressing patients' acute care needs, which created a hazardous relational context in which to provide effective care.

One of the most difficult aspects of care is helplessly watching a loved one deteriorate (Grbich et al., 2001). The perception of a patient's suffering may evoke a caregiver's feelings of insufficiency. Caregivers may feel lacking in the competence, power, or resources to relieve the patient's suffering, stop the patient's deterioration, or elicit help from the healthcare team (Milberg et al., 2004). For the disenfranchised caregivers in this study, the sense of helplessness and insufficiency were grossly exacerbated by their patients' noncompliance in all spheres of care. Although the caregivers understood that their efforts to relieve suffering were limited by the

patient, they still experienced profound psychological distress, described as anger, frustration, guilt, and devastation.

The noncompliant patients did not positively acknowledge the efforts of their caregivers. Affirmation of one's ability to provide care is a source of satisfaction for caregivers that is known to decrease vulnerability (Funk et al., 2010). A lack of affirmation may increase the caregivers' uncertainty about their own capacity to provide adequate care, leading to a sense of insecurity (Funk et al., 2010).

### *Coping Strategies*

Paucity in communication' between members of a couple is often a continuing pattern of behavior established for many years, in which couples have directly or indirectly not shared significant affective content (Hinton, 1981). All of the caregivers in our study described the patients as historically closed communicators (Saldinger & Cain, 2005), supporting Hinton's (1981) findings that this communication style is closely identified with patient denial. Their familiarity with this ongoing pattern of communication was identified by caregivers as a key factor that enabled them to tolerate the constraints that patient denial imposed on their efforts to manage patient care.

Northhouse (1987) suggests that a couple's functioning is dependent upon the reciprocal nature of their coping strategies and their ability to provide each other mutual support, which directly affects the stability and well-being of their relationship during stressful experiences. Reciprocity and mutual support, which are normally integral to the role of the caregiver, were not available to the caregivers of patients in denial. Not only were these caregivers deprived of mutual support within their caregiving relationship, but many of the family caregivers, in order to protect their patient's denial, could not access their informal supportive social networks, which might have helped them alleviate their emotional suffering (Northhouse, 1987).

### **Study Limitations**

The results of our study are only transferable to the extent that the environmental or circumstantial contexts in which our study took place are congruent with the contexts to which they are being transferred.

Our study did not consider the effects of the ethnicity of the patients or their caregivers. Ethnicity may play a role in the way in which people communicate about illness and may also influence the nature of the caregiver role. Future studies could be done to investigate the role of ethnicity on the experience of caregivers working with patients in denial.

## Implications

Research on the physical and emotional toll on family caregivers providing end-of-life care has focused increasingly on risks for caregiver morbidity including depression, anxiety, fatigue, and burnout (Glajchen, 2004; Golant & Haskins, 2008; Stajduhar et al., 2008; Kim et al., 2010; Ostlund et al., 2010). Unmet psychosocial needs, a hallmark for the caregivers of patients in denial, is a consistent and strong predictor of poor mental health across all phases of survivorship for caregivers (Kim et al., 2010). Dumont et al. (2008) identified predictors of complicated mourning for family caregivers that included: difficult relational context; patient denial; communication problems between the patient and the family caregiver; and the presence of psychological and emotional burden. All of these factors applied to all of the caregivers in our study. Lack of formal supports (healthcare professionals) (Grande et al., 2004; Dumont et al., 2008) and informal supports (family and friends), common to most of the caregivers in this study, have also been associated with negative bereavement outcomes (Dumont et al., 2008). These findings strongly suggest that the family caregivers in this study are at a significantly elevated risk for psychological and physical morbidity while caring for the patients and in bereavement.

Our findings indicate that family caregivers of patients in denial, especially those of noncompliant patients, may be at elevated risk for morbidity. It is important for healthcare professionals to identify patients in denial, which may simply involve asking the patient to describe their understanding of the illness and their expectations of treatment. Further research will be necessary to determine whether this does identify this population. When time permits, denial assessment tools may be used to assist the identification process; however, they are prone to limitations. The Hackett–Cassem Denial Rating Scale only shows a modest correlation with common markers of denial (Riley & Fenton, 2007) and the Denial in Cancer Interview (DCI), which covers patients' account of their illness and the expert's impression of the level of denial, has only been tested with lung cancer patients (Vos et al., 2007). When patient denial is identified, the healthcare team can approach family caregivers with a view toward providing them with timely support. Patients' approval to speak directly with their caregivers about their condition can be sought, which would allow the caregivers to alert the team to the patient's noncompliance, which may or may not be possible to influence, but may possibly reduce caregivers' own feelings of guilt and helplessness.

Future topics for research should consider interventions relating to the needs of the caregivers of

patients in denial, with particular attention to the disenfranchised caregivers of noncompliant patients in denial, and reducing the risks to these patients. The support needs of family caregivers who use denial as a coping strategy may differ from those of caregivers who do not use denial, and may benefit from further study.

Caregivers of patients in denial experience added burdens that they must bear without the usual sources of support. The burden is accentuated when patients are noncompliant with care, placing themselves in dangerous situations. Healthcare providers should identify patients in denial and support their caregivers in their role while assisting them to meet their own needs. Evidence-based strategies to accomplish need to be developed and implemented.

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