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Impact of Pain on Family Members and Caregivers of Geriatric Patients

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SYNOPSIS

This article provides an overview of the literature describing the effects of geriatric patients' pain on family members' relationships, psychological well-being, and physical health. The theoretical mechanisms that underlie the association between patients' pain and family members' outcomes are outlined, and studies describing these mechanisms are summarized. Limitations to the current literature are discussed, and key recommendations for future research and practice are presented.

Keywords

geriatric pain; family members; spouses; interpersonal relationships; relationship closeness; coping; pain perception

The interpersonal consequences of chronic pain have been vigorously examined in adolescent, young adult and middle-aged samples. A wide body of research suggests that persistent pain in the early years of life not only afflicts the individual sufferer, but also close family members involved in his or her care [1–4]. In view of this evidence, consensus statements [5] and clinical guidelines [6] have emphasized the need to address family considerations as part of standard care. However, while the negative effects of pain have been well established among the family members of young persons, a small but growing body of research has begun to examine this phenomenon among the relatives of older persons. Studies in this area are slowly emerging as clinicians, researchers, and policy

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makers acknowledge the increasing prevalence of pain among older people [7–9] and escalating demand for informal caregiving by relatives [10].

The interpersonal effects of chronic pain may differ in later life, given pronounced age differences in individuals' physical disability [11], overall perception of the pain experience [12], and because chronic pain is often one of many burdensome health conditions that older adults and their family members must confront [13]. As such, specific attention to the effects of pain on family members and caregivers of older persons is warranted.

This article provides an overview of the growing, yet limited, literature on the effects of geriatric patients' pain on their family members. Our review focuses on three key consequences for family members: deterioration in relationship functioning, diminished emotional well-being, and compromised physical health. For each consequence, we identify the relevant theoretical frameworks that explain the relationship between geriatric patients' pain and family member's outcomes, highlight the mechanisms that may moderate the effects of patients' pain on family members' well-being and relationships, and present the available empirical evidence of these associations. Given the paucity of research examining the effects of geriatric patients' pain on their relatives, we conclude with several recommendations for future research and clinical practice.

Older Adult's Pain and Relationship Functioning

When considering the interpersonal consequences of pain, researchers point to the reciprocal interactions between the patient with chronic pain and family members. Just as family members play an important role in the patient's adjustment to and recovery from illness, they are also affected by the patient's symptoms and need for assistance. For both middle-aged and older adults, severe pain contributes to increased interpersonal conflict and discord [14–21], as well as decreased emotional closeness and physical intimacy [22–25].

The family systems perspective has been influential in explicating such effects. According to this framework, family functioning is governed by specific social norms and principles [26,27]. When a relative is in pain, family members adjust their social roles to accommodate the sufferer's physical, social and recreational restrictions. Consequently, these adjustments may lead to a paradoxical cycle of accentuated closeness and enmeshment, followed by tension and strain within the relationship, and ultimately withdrawal by the patient [28,29]. For example, qualitative research has shown that worsening pain symptoms may impact the pain sufferer's ability to maintain employment or complete household activities [20], thereby leading him to become dependent upon his relatives. In response, family members who take on these tasks experience resentment and hostility toward the patient, along with feelings of guilt and self-blame as well as a sense of helplessness about how best to provide effective support for their loved one [20,22,23]. Over time, family members may resort to controlling or soliciting behavior, further contributing to patients' distancing from the relationship, and perpetuating the cycle of extreme closeness and withdrawal [20,23].

However, not all families follow this downward trajectory. Research has begun to uncover how specific moderators, including pain perception, coping behavior, and pain

communication distinguish families who suffer from poor relationship quality from those who maintain healthy, satisfied relationships. Insights from these studies offer additional information about the interpersonal nature of chronic pain.

Pain Perception

Both theory and research suggest that family members are often poor judges of patients' pain [28,30]. Studies have shown that spouses may either overestimate [31] or underestimate family members' pain [32], both of which may have consequences for the interpersonal exchanges within the dyad. Whereas overestimation of pain can lead to reinforcement of the patients' sick role and overprotection by spouses [31], underestimation may lead to greater criticism and less support by the family member [33]. Importantly, accurate pain perception may facilitate appropriate care provision and supportive responses by spouses. For example, recent research has shown that spouses of older patients with OA who were more accurate in judges of their partners' pain offered emotional support that was more satisfying to patients, and also reported less caregiving stress [30]. Although studies have yet to examine the direct association between pain perception and relationship quality or satisfaction, this may be an intriguing hypothesis for future investigation.

Coping Behavior

Several theories point to coping as an important component in determining relational outcomes among families with a member in pain [34,35]. Cognitive-behavioral models propose that patients' and family members' behaviors and attitudes about the pain experience will inform their interpersonal exchanges and interactions. For example, the Communal Coping Hypothesis [36,37] posits that some patients with chronic pain use catastrophizing (an intensified emotional reaction to the pain experience) to gain intimacy and closeness with others, and to solicit instrumental support. Although researchers have speculated that patient catastrophizing will be associated with greater interpersonal problems [38], no research has explicitly examined this hypothesis among geriatric pain patients and their relatives. Furthermore, related work conducted on both middle-aged and older adults failed to detect a relationship between patients' somatizing and marital adjustment (i.e. accommodation of a husband and wife to each other) [39]. Therefore, additional research is needed to explore the specific effects of older patients' catastrophizing on their family members.

A separate model of coping, the Transactional Model of Health, integrates concepts from family systems and cognitive behavioral theories [40,41]. Although originally developed for families of patients suffering from general medical conditions, it has since been applied within the pain context. According to this framework, the family develops a relatively stable set of beliefs about illness, pain, disability and coping. These beliefs are proposed to influence the family's appraisal of pain experiences and response to emerging challenges. Interventions drawing upon this framework have developed dyadic coping skills training (CST) for middle-aged and older patients with OA and their spouses. Such programs have reported greater marital satisfaction among patients with chronic pain, but not among spouses [42,43]. A cross-sectional study of middle-aged and older patients with OA suggests that individuals who engage in more passive coping strategies (i.e. escape into fantasy)

experience lower marital satisfaction [44]. Given that prior studies simultaneously assess the outcomes of middle-aged and older adults, it will be important for future work to examine coping strategies specifically among older adults and their relatives, and to examine differences by age (middle aged vs. older adults).

Pain Communication

A third mechanism that is proposed to moderate the association between geriatric pain and relationship functioning is pain communication, including both verbal pain disclosure [45], non-verbal behavior (e.g., displays of physical suffering) [46,47]. According to the Operant Conditioning Model of Chronic Pain, both verbal and non-verbal forms of communication are used to convey patients' desire for support, attention and intimacy [48,49], and to elicit empathic responses from others [32,50]. In turn, affected patients' communication may be maintained by social reinforcement (e.g. the sympathetic response of significant others).

Early research examining the effects of non-verbal behaviors on marital satisfaction among patients with low back pain found that the use of non-verbal behaviors were associated with lower marital satisfaction among female, but not male spouses [27]. The authors hypothesize that this effect may be a result of women's skill at recognizing non-verbal cues of pain and distress [51–53]. However, more recent research focusing on verbal communication failed to detect significant associations between the frequency of middle-aged patients' with chronic pain verbal disclosure and spouses' marital satisfaction [54], though men and women were not considered separately. These somewhat mixed findings point to the need for further examination of both verbal and non-verbal communication, their direct associations with marital satisfaction, and potential differences by gender and pain condition.

Impact of Pain on Family Members' Psychological Well-Being

In addition to poor relationship functioning, relatives of geriatric pain sufferers are also at increased risk of experiencing diminished psychological well-being and elevated stress. The direct effect of individuals' pain severity on spouses' anxiety and depressive symptoms has been documented in both cross-sectional [25;55] and longitudinal research [56], with qualitative research exposing extreme distress and psychological burden among spouses of middle-aged and older patients with rheumatoid arthritis (RA) who suffer from pain [19]. There is also evidence that family members' negative emotions mirror patients' own emotional distress about their symptoms [55]. Studies have shown high levels of congruence in anger and depression among older dyads coping with OA [57].

Efforts have also been made to identify the specific factors that may place family members at greater risk of negative psychological consequences. In particular, research has considered how such effects may be moderated by relationship closeness and pain communication and is summarized below.

Relationship Closeness

Theoretical models posit that family members' psychological reactions to individuals suffering from chronic pain may vary by the closeness of their relationship [58]. It is suggested that family members who report greater levels of closeness may feel more

emotionally connected to their loved one, and therefore share their partner's experience of suffering more intensely. This hypothesis has been supported by longitudinal research with older patients with OA and their spouses. Among dyads reporting greater closeness, increased pain severity in patients was associated with increases in depressive symptoms and decreases in positive affect in spouses over a six-month period [59], a finding that held while controlling for baseline levels of illness severity and well-being among both spouses and patients. Such results suggest that relationship closeness may play a role in predicting which older couples are at greater risk of negative psychological effects of partners' pain suffering. However, additional research is needed to confirm this association, given that this was the single study to examine such effects.

Pain Communication

The effects of patients' pain on family members' emotional well-being may also be influenced by the extent to which a patient engages in verbal or non-verbal communication about his or her symptoms [23]. Longitudinal research, for example, has shown that verbal expressions of pain may exacerbate the association between an older individual's level of pain and their spouses' depressive symptoms. In a recent study, husbands whose wives reported severe OA pain and who engaged in high degrees of pain expression (both verbal disclosure and nonverbal behavior) experienced significant increases in depressive symptoms over a 6-month period; whereas husbands whose wives reported similarly high levels of pain, but disclosed less did not show such increases [56]. Similar results have been demonstrated in cross-sectional research with older patients with OA, where wives' pain behavior (rubbing joints and limping) exacerbated husbands' depressive symptoms and anger [57]. Although these studies point to a potential pathway by which pain communication may impact family member's psychological health, future research should aim to replicate these effects.

Self-efficacy in pain communication—Researchers have hypothesized that self-efficacy in communication may further distinguish patients' and spouses' emotional reactions to the pain experience. For patients, it is thought that low self-efficacy in pain communication may compromise their ability to appropriately discuss pain-related concerns and solicit helpful responses by their loved ones [60]. For spouses, it is suggested that low self-efficacy may elicit negative affective responses, such as worry and frustration [60]. However, only one study has explored these potential associations. Using self-report data from middle-aged and older OA patients and their partners, the study examined whether self-efficacy in pain communication was associated with positive and negative affect in both members of the dyad. The study's findings were generally consistent with the hypothesized pattern of effects: spouses with high levels of self-efficacy had higher positive affect, and spouses of patients with high self-efficacy were less likely to report negative affect [60]. Although this study provides useful insights into the role of self-efficacy of pain communication in affective responses, replication of these findings is needed before strong conclusions can be made.

Impact of Pain on Physical Functioning

Although no studies have explored the effects of geriatric patients' pain on family members physical functioning, emerging evidence points to several negative health consequences for middle-aged spouses, including increased blood pressure, sleep disturbance, and gastrointestinal distress [61]. Research has shown that compared to spouses of healthy adults, middle-aged spouses of patients with chronic pain experience poorer well-being and report experiencing a greater number of chronic conditions (e.g., diabetes, heart disease and high blood pressure) [61; 62]; they are also more likely to report a diagnosis of chronic pain themselves [23].

Relationship Closeness

Recent evidence suggests that patients' pain may affect spouses' abilities to engage in restorative health behaviors (i.e. sleep), and that this association may further depend upon closeness of the relationship. Specifically, research has shown adverse associations between older patients' pain and spouses' sleep quality, with the strongest impact on couples who reported high levels of closeness [63]. Given the dearth of literature on this topic, future work is needed to examine the associations between patients' pain, spouses' health behaviors and physical well-being.

Future Directions

Although the existing literature on geriatric patient pain remains sparse, the available evidence demonstrates important links between chronic pain experienced by older adults and family members' outcomes. The studies reviewed above indicate that persistent pain among geriatric patients contributes to deleterious outcomes among family members, including relationship problems, psychological distress, and physical morbidity. Further, such associations may be moderated by relationship closeness, pain perception, coping, and communication. In general, the available evidence suggests that greater relationship closeness, increased pain communication, and lower communication efficacy are associated with poorer outcomes among family members; whereas accurate perception of pain is associated with positive outcomes. Future research will need to move beyond observational studies toward the development of interventions aimed at addressing the negative consequences of chronic pain on family members. Future research will also need to include greater examination of the potential modifiable risk factors for family members of chronic pain patients. Once those risk factors are identified, subsequent efforts should be made to target dyads who are at highest risk for adverse outcomes.

Although significant advances have been made over the past several decades, productive expansion of the field will require a detailed examination of specific subgroups as well as comparisons by patient age, relationship (spouse versus adult children), and caregiver status. Of utmost importance will be examining how chronic pain impacts older patients and their relatives in the face of multimorbidity. Below, we acknowledge the limitations of the current evidence base and highlight opportunities for future investigation.

Patient Age

One major shortcoming of the existing literature has been the lack of differentiation between middle-aged and older adult samples. As is evident from our review, few studies have explicitly examined the effects of pain experienced by *geriatric* patients on family members. Instead, the studies reviewed simultaneously include middle-aged and older patients, without further comparison between these subgroups and consequences for their relatives. Importantly, middle-aged and older individuals may differ in their perception of the pain experience [12], physical disability [11] and emotion regulation [64,65]. Such differences may have important implications for the interpersonal and emotional effects of pain, including dyadic coping and adjustment. Comparisons by age may therefore expose differences that are relevant for clinical practice and interventions tailored to geriatric patients and their relatives.

Relationship to the Patient

Research examining the effects of later life pain on family members has predominantly focused on spousal samples. Studies have yet to examine whether and how older parents' pain affects their adult offspring, with only one attempt to include adult children to any extent [66]. This gap warrants attention given that adult children often have extensive contact with older parents [67], and are the largest group providing informal assistance to individuals ages 65 or older [68]. Although a recent theoretical model has proposed several pathways by which pain in older relatives may affect adult offspring [69], empirical investigations have yet to surface.

Importantly, the consequences of geriatric patients' pain on adult children may differ from the effects on spouses. Such differences may be examined in light of social structural norms of reciprocity and exchange. According to social exchange theory, adult child caregivers may experience less psychological distress and burden than spouses because providing care to an older parent may be perceived as reciprocation of parents' love and care during childhood [70]. In keeping with this hypothesis, a recent meta-analysis focusing predominantly on caregivers of patients with dementia found that spousal caregivers report more depressive symptoms, greater financial and physical burden, and lower levels of psychological well-being than adult children, but not more emotional burden or social strain [71]. An important contribution to the pain literature would be to make such comparisons among spouses and adult children of geriatric pain sufferers to understand whether and how such differences manifest in this context.

Caregiver Status

Family caregiving is traditionally defined as providing assistance to a loved one with physical or psychological impairment [10]. Recent reviews of the caregiving literature point to the detrimental impact of care provision on family relationships [72] and caregivers' emotional well-being [73,74]. Compared with non-caregivers, caregivers report greater levels of depression and heightened stress [75]. Both theory and research suggest that increased exposure to the suffering of a loved one may place caregivers at heightened risk of adverse outcomes, above and beyond the physical demands of care provision [58]. Although pain studies have not examined this directly, our review suggests that exposure to frequent

pain communication may contribute to poorer marital quality [27] and compromised psychological well-being among relatives [57]. A potential avenue for research would be to examine whether caregivers of geriatric pain patients experience poorer outcomes as compared to non-caregivers, and further, whether these hypothesized differences vary by the quality or frequency of contact between the relative and the pain sufferer.

Chronic Pain and Multimorbidity

Several studies have identified strong associations between the presence of chronic pain and other chronic illnesses [13], mental health issues [76,77], and sleep disorders [78]. Indeed, managing the competing demands of multiple chronic conditions is a significant challenge for many older adults and their family members [79]. However, it remains unclear how older patients and their relatives make treatment choices and manage chronic pain in the face of multiple health conditions. Another important line of research will be to investigate whether and how the presence of multimorbidity differentially affects older patients with chronic pain and their caregivers. Moreover, a thorough understanding of this area is essential for developing tailored interventions that address the complex concerns of patients with chronic pain and other chronic conditions and their family members.

Practice Recommendations

Until clearer evidence becomes available regarding specific approaches to improve outcomes for family members of patients with chronic pain, it is difficult to issue concrete recommendations for practice. Therefore, the recommendations that follow should be viewed within the context of the limited evidence base described above.

Healthcare providers should be aware that chronic pain may have an impact on both older patients and their family members, and should therefore take a dyadic approach to the assessment of possible adverse outcomes on both individuals. Specifically, healthcare providers should consider asking older patients with chronic pain and their loved ones about whether and how the patients' pain impacts their interpersonal relationships. For spousal dyads, one approach is to ask patients and their partners about their marital adjustment by using open-ended questions (e.g., "In what ways has your pain affected your relationship with your spouse?") or validated instruments such as the Dyadic Adjustment Scale (DAS) [80] or Marital Adjustment Test [81]. Whereas open-ended questions may afford an opportunity for patients and their loved ones to discuss a range of issues, standardized tools may help clinicians to quickly identify specific areas of concern.

Providers should also be aware that patients with pain and their family members are susceptible to psychological distress, and should therefore assess for the presence (or absence) of these symptoms in both individuals. Research studies have typically employed the Mood and Anxiety Symptom Questionnaire (MASQ) [82] and the Center for Epidemiological Studies-Depression Scale (CESD) [83] to assess psychological functioning. These instruments show good discriminant validity and reliability and could be readily applied in clinical practice. The 10-item Perceived Stress Scale has also been used with patients suffering from chronic pain and their relatives [84]. This scale asks respondents to report how uncontrollable, overloaded, and unpredictable their lives have been over the past

month. Given that high stress levels are associated with physical morbidities, including elevated blood pressure and susceptibility to infection [85] this scale may provide additional utility in identifying individuals who may also be at risk of diminished physical health.

Although several family-oriented programs have been developed for patients with chronic pain [86], interventions that directly address the effects of chronic pain on family members have yet to emerge. It is therefore not possible to recommend specific programs or therapies to address the negative consequences of pain on relatives. To supplement patients' treatment, clinicians may wish to direct family members to the resources and publications available through the National Institute on Aging [87], American Chronic Pain Association [88] and National Center on Caregiving [89] (see reference list for full details). The National Institute on Aging and American Chronic Pain Association websites provide links to local support groups for patients and family caregivers and offer educational materials describing the common myths and misunderstandings about pain. The National Center on Caregiving offers a variety of resources, including a state-by-state resource locator to help caregivers connect with others, a research registry for individuals who wish to participate in clinical trials, and a series of instructive webinars designed to help caregivers to manage their stress, communicate more effectively with their loved one and with providers, and learn about new legislation and programs that explicitly address their needs.

Conclusion

This review summarizes the existing literature examining the effects of geriatric patients' pain on family members' relationship satisfaction, psychological distress, and physical health. Particular consideration was given to the mechanisms underlying these associations as well as the theoretical explanations for specific outcomes. Despite growing interest in studying the impact of geriatric pain on family members, understanding of this topic is far from complete. Questions remain about whether the associations between geriatric patients' pain and family members' outcomes differ by patient age, relationship to the patient, and caregiver status. Future research is also needed to determine how families cope with chronic pain within the context of multimorbidity, and to identify the modifiable risk factors for family members. As progress is made on each of these issues, family-based interventions designed for geriatric pain patients and their relatives may play an important role in minimizing relationship discord and improving psychological and physical outcomes.

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KEY POINTS

- Persistent pain contributes to relationship problems, psychological distress, and physical morbidity among patients and their family members.
- Theory and research implicate several mechanisms that may moderate the effects of older adults' pain on their family members: relationship closeness, coping behavior, pain perception, and communication.
- Most studies investigating the interpersonal consequences of pain combine middle-aged (< age 64) and older adults (>age 65) into a single sample; limited research has explicitly examined the effects of pain among older persons (>age 65) on family members.
- The majority of research investigating the impact of geriatric pain on family members comes from spousal samples; little is known about the consequences for adult children.
- Future studies should conduct subgroup analyses by age and comparisons of family member outcomes by relationship (spouses versus adult children) and caregiver status.