

UNDERSTANDING JOINT DECISION MAKING AND INTERPERSONAL PROCESSES  
AMONG OLDER ADULTS WITH CHRONIC PAIN

A Dissertation

Presented to the Faculty of the Graduate School  
of Cornell University

In Partial Fulfillment of the Requirements for the Degree of  
Doctor of Philosophy

by

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May 2015

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# UNDERSTANDING JOINT DECISION MAKING AND INTERPERSONAL PROCESSES AMONG OLDER ADULTS WITH CHRONIC PAIN

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Cornell University 2015

This dissertation compiles three papers that focus on the social context of chronic pain. Chapter 1 presents a conceptual framework of hypothesized risk factors for adult children of parents with chronic pain. The proposed framework is based on prior literature and theoretical models that highlight the interpersonal effects of chronic illness and pain on family relationships.

The following two chapters explore older adults' social networks beyond the family context, and focus explicitly on decision making about pain treatment. The study presented in Chapter 2 employed in-depth interviews to investigate the social and decisional preferences of ethnically diverse (Hispanic and non-Hispanic White) individuals with chronic pain conditions. Qualitative content analysis was used to identify key themes in participants' responses. Results revealed that, when making treatment decisions, older adults prefer to involve emotionally reassuring social partners and peers with similar pain conditions or treatment experiences. Overall, participants' perceptions of their treatment decision making processes were more positive when the support they received matched the support they desired.

The study presented in Chapter 3 employed survey methods to investigate the types (informational, emotional, instrumental) and sources (e.g. physician, relative) of decision support that individuals desire and receive when considering total joint replacement (TJR). Guided by theoretical frameworks from psychology and social gerontology, I examined the social structural (relationship to the patient) and experiential characteristics (having had TJR) that influence

decision support preferences among TJR candidates. In parallel, I hypothesized that there would be an age-graded preference for emotional rather than informational support. Finally, I investigated whether higher congruence in desired and received support is linked with respondents' decisional conflict and certainty.

Multilevel models showed that healthcare providers, family members, and individuals who had undergone prior TJR were key sources of decision support. There were no age differences regarding the types of support individuals desired and received. Overall, greater congruence in emotional support desired and received was associated with reduced decisional conflict, whereas greater congruence in practical support desired and received was associated with greater willingness to undergo surgery.

The final chapter draws connections between the three papers and proposes directions for future research.

## BIOGRAPHICAL SKETCH

Catherine Riffin studies the individual and contextual factors that influence decision making and health outcomes in later life. She has an MA in Human Development from Cornell University and a BA in Psychology with concentrations in Philosophy and Spanish from Mount Holyoke College.

To loving my parents, Max, and of course, Patrick.

## ACKNOWLEDGMENTS

I have been fortunate to receive outstanding mentorship from an exceptional dissertation committee. My sincerest gratitude goes to my Committee Chair, Dr. Corinna Löckenhoff, who encouraged and challenged me to improve the precision of my academic work, and served as an extraordinary role model for achieving a well-proportioned work-life balance. I am extremely grateful to Dr. Karl Pillemer for his guidance and support of my scholarly and professional development over the past five years, and especially as I prepare for my post-graduate transition. I have deeply appreciated the opportunity to receive mentorship from Dr. Cary Reid, who not only provided a valuable link to the practice of geriatrics and pain medicine, but also helped clarify my research interests and career goals over the course of my graduate studies.

In addition to my dissertation committee, I am truly indebted to Françoise Vermeulen who not only offered exceptional statistical consulting for the analyses in Chapter 3, but also “life” consulting throughout my graduate experience at Cornell. I would also like to extend my heartfelt thanks to Emily Chen and Marie Cope, as well as Cara Kenien, Allison Lasky, Lauren Meador, and Marcus Warmington who have served as peer mentors over the past several years. Finally, a special thanks goes to the hard-working and enthusiastic members of the Healthy Aging Lab, especially Sara Hachey and Stephanie Martinez whose unwavering dedication and commitment to this project brought it to fruition.

This work was supported by the Lawrence and Rebecca Stern Family Foundation, an Edward R. Roybal Center grant from the National Institute on Aging (P30AG022845), and a President’s Council of Cornell Women Affinito Stewart Grant (to Corinna Löckenhoff).

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## PREFACE

Over the past decade, increased research attention has been paid to the problem of chronic pain. This growing interest has been punctuated by the recent blueprint for action by the Institute of Medicine (IOM, 2011) citing the urgent need for more and better empirical data on chronic pain to help shape health care and policy efforts. The IOM's message is timely given that over 52 million U.S. adults suffer from chronic musculoskeletal conditions (Barbour et al., 2013), a number which is expected to exceed 67 million by the year 2030 (Hootman & Helmick, 2006). Importantly, chronic pain sufferers rarely manage their symptoms and make treatment decision alone; rather, they draw upon the advice, practical assistance and emotional support from their health care providers, family members, and friends (Laidsaar-Powell et al., 2013). Given the highly dynamic and interpersonal nature of chronic pain (Snelling, 1990), an interdisciplinary and comprehensive research strategy is needed.

In this dissertation, I present three papers that draw upon social science theory and methods to address research questions related to interpersonal communication, treatment planning, and decision making among chronic pain sufferers and their social networks. The first chapter presents a conceptual framework of hypothesized risk factors for adult children of parents with chronic pain. Whereas prior theoretical models have focused on the problem of pain in young families (Turk, Flor, & Rudy, 1987) and spousal dyads (Leonard, Cano, & Johansen, 2006) our framework explicitly focuses on adult child–parent relations. Given the extensive interaction aging parents have with their adult children (Fingerman, Pillemer, Silverstein, & Sutor, 2011) and the pervasive problem of chronic pain among older people (AGS Panel of Persistent Pain in Older Persons, 2002), we contend that our model offers a timely contribution to the present literature; one that holds the potential to set the stage for future research initiatives.

The conceptual framework described in Chapter 1 offers one lens with which to examine social networks and pain, specifically focusing on the adult child-parent dyad. Chapters 2 and 3 offer a complementary perspective by examining middle-aged and older adults' broader social networks in the context of decision making about pain treatments. To date, little research has examined the role of social networks in relation to pain treatment decisions. On the one hand, the clinical literature has focused predominantly on patient-provider shared decision making within medical encounters (Moumjid, Gafni, Bremond, & Carrere, 2007). Meanwhile, social science research has focused on informal support networks, primarily in caregiving contexts (Smith & Christakis, 2008). On the whole, these research streams have remained largely separate over the past decade.

Chapters 2 and 3 seek to integrate these literatures by investigating both formal and informal sources of decision support involved in pain patients' treatment decisions. To gain first-hand understanding of middle-aged and older adults' preferences regarding decision support and pain treatment, these two chapters gather information directly from the patient. Drawing from the patient population at Weill Medical College/New York Presbyterian Hospital, senior centers in New York City and online arthritis web boards and community forums, I used a sequential mixed methods design to capture older adults' preferences for involving others in their pain treatment decisions.

Chapter 2 focuses on qualitative data in the form of in-depth interviews which were conducted with a purposive sample of older adults with chronic pain conditions. This exploration offered preliminary insights into the preferences for decision support among culturally diverse (Hispanic and non-Hispanic White) individuals who were considering a variety of pain treatments. Given the qualitative nature of this study, I was able to capture nuances of

individuals' experiences that might have been lost in a forced-choice paradigm or focus group format. Moreover, the rich narrative database that was generated by this approach enabled me to closely examine age-specific patterns of decision support-seeking as well as ethnic differences in the desire for formal (i.e. healthcare provider) versus informal (i.e. family member, friend) decision support. Equally important, this method afforded the discovery of unanticipated themes and information about pain patients' social networks; specifically, I noted the important role that experientially similar others (i.e. individuals with similar pain conditions) play in influencing older adults' perspectives of their own treatment decisions.

This initial inquiry set the stage for a follow-up study (Chapter 3) which employed survey methods to investigate the types of decision support (i.e. informational, emotional, instrumental) pain patients desire and receive when making the decision to pursue joint replacement surgery. Importantly, joint replacement represents a prime example to explore clinical decision making. The choice to undergo this procedure requires the involvement of multiple stakeholders, including formal (i.e. health care providers) and informal (i.e. family members) network ties who offer a vast spectrum of support functions (informational, emotional, instrumental), each of which is integral to the decision making process. Not only do TJR candidates require informational guidance about whether and when to undergo the procedure, but also emotional reassurance throughout the decision making process and practical assistance both before and after the surgery is complete.

The background information gleaned in Chapter 2 helped inform the primary predictor and outcome variables for this quantitative investigation, and allowed me to make specific predictions regarding total joint replacement (TJR) candidates' social and decisional preferences in this treatment context. In Chapter 3, I also employed theoretical frameworks from psychology

and social gerontology to guide my hypotheses. Specifically, I integrated traditional sociological perspectives suggesting that individuals' support selection is contingent upon social structural norms with insights from homophily theory (Merton, 1968) proposing that effective decision support may also stem from others who have experienced a similar stressor. I hypothesized that both social structural (e.g. relationship to the patient) and experiential (e.g. prior joint replacement) characteristics will contribute to TJR candidates' selection of decision support networks. Further guided by socioemotional selectivity theory (Carstensen, 2006), which proposes an age-related shift in priorities from information acquisition in early life to emotional meaning in later life, I conjectured that older TJR candidates would desire and receive less informational and more emotional support than would younger patients. Overall, I proposed that the alignment between the support patients desired and received would be associated with reduced decisional conflict and greater certainty in the choice to pursue surgery.

The findings offered partial support for my hypotheses. Within the sample, joint replacement candidates desired and received informational guidance, instrumental support and emotional reassurance from their healthcare providers, family members, and similar others who had undergone a successful joint replacement. Contrary to expectations, there were no age differences in the support patients desired or received. Overall, respondents experienced reduced decisional conflict when they reported higher congruence in the emotional (but not informational or instrumental) support they desired and received, and greater willingness to undergo surgery when they reported higher congruence in the instrumental (but not informational or emotional) support they desired and received.

Overall, the research described in this dissertation is situated at the intersection of social science and medicine. It is thus poised to make theoretical and empirical contributions to both

literatures as well as offer specific insights into the development of patient-centered care. Specifically, the latter two chapters underscore the value of examining patients' broader social network in relation to pain treatment decisions. As noted, the social science and clinical literatures regarding patient decision making have largely remained distinct entities over the past decade. This dissertation speaks to the need to integrate these two literatures and develop a more complete perspective of patients' decision support networks, including both formal and informal channels.

A second contribution of this work is its attention to the communication processes and reciprocal exchanges between chronic pain sufferers and their social networks. Although prior literature has described the interpersonal effects of suffering in caregiving contexts (Monin & Schultz, 2009; 2010), research explicitly examining adult child-parent relations in the domain of pain management remains underdeveloped. A better understanding of this unique dyadic system will strengthen future research and targeted interventions. As such, the theoretical framework described in Chapter 1 offers an important first step in developing a strong evidence base for interventions that address the specific needs of adult children caring for an older parent in pain.

A third and final contribution of these chapters is the emphasis on positive interpersonal exchanges and joint decision making between pain sufferers, their family members and health care providers. Importantly, older adults possess a unique set of decisional and social preferences, especially when making difficult health decisions (Löckenhoff, Hsiao, Kim, & Swarts, in press). By applying social science theory to clinical contexts, this dissertation informs health care practice by offering theoretically-driven accounts of how older and middle-aged adults form their social and decisional preferences when making important pain treatment decisions.

In general, a major strength of this research is its interdisciplinary approach to investigating pain communication, treatment planning, and decision making among chronic pain sufferers and their social networks. It is my intention that the integrative and multi-modal method of employing social science theory to clinically-relevant issues will help pave the way for future research and interventions. The final chapter of this dissertation speaks to that aim. In Chapter 4, I draw connections between findings of each paper and delineate implications and suggestions for future research.

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## CHAPTER 1

### CHRONIC PAIN AND PARENT-CHILD RELATIONS IN LATER LIFE: AN IMPORTANT, BUT UNDERSTUDIED ISSUE

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## Abstract

Chronic pain is a debilitating and pervasive health problem, particularly among older adults. Researchers and clinicians acknowledge that pain conditions do not occur in isolation, but rather exact a toll on the individual sufferer and the family system at large. No research, however, has explicitly explored the impact of older parents' chronic pain symptoms on their adult children. In this article, we present relevant predictions from theoretical models that identify the interpersonal effects of chronic illness and pain on family relationships. Guided by theory and empirical research on these topics, we present a conceptual framework of hypothesized risk factors for poorer relationship quality between adult children and parents with chronic pain. We conclude by offering an agenda for future research.

## **Introduction**

Over the past decade, researchers and health policy makers have focused increased attention on the problem of chronic pain and its management. This heightened interest is evidenced by a recently-issued report from United States Institute of Medicine, which calls for urgent attention to the disabling effects of chronic pain (Institute of Medicine, 2011). While arthritis and arthritis-related diseases (e.g., back pain) remain the most common causes of chronic pain in older adults (AGS Panel on the Pharmacological Management of Persistent Pain in Older Persons, 2009; Lawrence et al., 1998) other pain producing conditions also occur commonly in this age group, including neuropathies (e.g., diabetes, herpes zoster), vertebral compression fractures from osteoporosis, as well as cancer and cancer treatments (AGS Panel on the Pharmacological Management of Persistent Pain in Older Persons, 2009; Lawrence et al., 1998; Rao & Cohen, 2004; Schmader, 2004). A growing body of evidence also indicates that diverse chronic illnesses such as advanced heart, lung and/or kidney disease are also common causes of later life pain (Potter, Hami, Bryan, & Quigley, 2003; Walke et al., 2007; Solano, Gomes, & Higginson, 2006). Chronic pain contributes to functional disability via several mechanisms including activity restriction, mobility impairment, social isolation, and depression (AGS Panel on the Pharmacological Management of Persistent Pain in Older Persons, 2009). Chronic physical pain is a common, costly, and often disabling condition and one that poses challenges for both health care providers and caregivers (AGS Panel of Persistent Pain in Older Persons, 2002), particularly among older adults.

Although estimates of prevalence vary from study to study, they suggest that up to 50% of all community-dwelling older people live with chronic pain (Helme & Gibson, 2001). The negative consequences of chronic pain include diminished quality of life, problems sleeping,

cognitive and physical disability, immune dysfunction, depression, and social withdrawal (Jakobsson, Klevsgard, Westergren, & Hallberg, 2003; Karp, Reynolds, Butters, & al, 2006; Reid, Williams, & Gill, 2005; Tan, Jensen, Thornby, & Sloan, 2008; Zhu, Devine, Dick, & Prince, 2007). Indeed, the most frequently cited cause of impairment in activities of daily living in later life is pain (Leveille, Fried, & Guralnik, 2002).

Given the extent of chronic pain among older people, a surprising gap exists in the literature on the topic. Specifically, the impact of an older parent's chronic pain on his or her adult children has not been explored. Adult children typically have extensive contact with older parents and many are engaged in the provision of support to parents in need of care (Fingerman, Pillemer, Silverstein, & Sutor, 2011; Sutor, Gilligan, & Pillemer, 2011). In addition, a growing literature has established the impact of a family members' pain on spouses and on parents of young children and adolescents. Although this literature has not focused on later life, it suggests that the impact of chronic pain on family relations may extend to older parent – adult child relations.

To date, no studies have been conducted to address the effects of older parents' chronic pain experience on relationships with adult children. Providing a systematic and comprehensive review of existing research is therefore not possible. The goal of this article is to shed light on this under-researched issue by setting forth a conceptual framework to guide future studies. We begin by reviewing literature relevant to this topic, asking: 1) Should we expect chronic pain in older parents to affect parent-child relationship quality? and 2) What factors may moderate the association between chronic pain and parent-child relations? We conclude with suggestions for a research agenda on this topic.

### **Chronic Pain: Should It Matter in the Older Parent – Adult Child Relationship?**

Accumulating evidence has documented the association between the experience of chronic illness and family relationships (Martire, 2005). Both empirical research (Gallant, Spitze, & Grove, 2010; Turk, Flor, & Rudy, 1987) and clinical practice (see Martire, Lustig, Schulz, Miller, & Helgeson, 2004 for a review) have shown that the family plays an important role in an individual's adjustment to and recovery from chronic illness. The attitudes and responses of family members to their ailing relative may contribute to the patient's psychological adjustment, maintenance of health behaviors and overall symptomatology (Snelling, 1990).

However, the association between chronic illness and family relations also operates in the reverse direction, in that the patient's symptoms, emotional distress, and need for physical and emotional assistance exacts a toll on the family system, leading to increased discord and diminished relationship quality (Leonard, Cano, & Johansen, 2006). In particular, there is consensus in both the empirical and the clinical literature that the experience of chronic pain has "spill-over" effects into individuals' family relationships. Clinical evidence of the impact of chronic pain on family relationships (Kerns & Turk, 1984; Lewandowski, Palermo, Stinson, Handley, & Chambers, 2010) has since been supported by empirical documentation of the specific adverse effects on family functioning and interactions. A considerable body of research substantiates the link between chronic pain and family discord, revealing that chronic pain conditions may contribute to conflictual family environments and to negative relationship quality (see Leonard et al., 2006; Palermo & Chambers, 2005; Palermo & Eccleston, 2009 for a review).

Due to problems in communication and coping brought on by the patient's pain condition, the family often experiences social, emotional and relational disruption. In particular, Palermo and colleagues (Palermo, 2000; Palermo & Eccleston, 2009) have reported that chronic pain in children affects not only parental well-being, but also family functioning more generally.

Further, a recent systematic review of studies on the effect of adolescents' pain on family function found that chronic pain among children was associated with lower family cohesion and higher levels of conflict (Lewandowski et al., 2010).

Such findings are echoed in studies of marital dyads. Compared with control groups, chronic pain sufferers and their spouses experience significantly lower family cohesion (Romano, Turner, & Jensen, 1997), and as with parents of young children in chronic pain, spouses also report problems in communication (Flor, Turk, & Scholz, 1987). In turn, poor communication may contribute to compromised marital quality. Indeed, some estimates indicate that over half of both persons with pain and spouses exhibit high levels of marital dissatisfaction in the presence of chronic pain, with approximately one third reporting severe levels of dissatisfaction (Kerns & Turk, 1984).

Although, as noted, no studies have specifically addressed the effects of parental pain on intergenerational relations, recent work by Monin, Schulz, and colleagues (Monin & Schulz, 2010; Schulz & Sherwood, 2008) points toward a possible impact. They propose a potential source of adult children's distress, beyond frequently cited stress of care provision or challenging behaviors by the care recipient: exposure to the suffering that results from chronic disease. In a series of studies, these researchers examined the impact of three forms of suffering on spousal caregivers: physical, emotional, and existential. Although not focused specifically on chronic pain, this program of research suggests that suffering makes a significant contribution to caregiver distress, beyond such previously established predictors as the relative's disability, behavior problems, and the amount of care provided (Schulz et al., 2009; Schulz et al., 2008).

In summary, the literature on the effects of chronic pain on other family relationships (married couples and parents of young children and adolescents) indicates that the presence of

chronic pain in the family negatively affects relationship quality among role partners. Further, research on the impact of suffering on a caregiver's well-being supports this view. Based on this combined evidence, a major priority for researchers should be to systematically examine the impact of pain on relationships with adult children in the family.

### **Moderators of the Link between Chronic Pain and Parent–Adult Child Relationship Quality**

We have focused up to this point on the direct relationship between older parents' pain and relationships with children. However, there are grounds to hypothesize that the effects on the parent-child relationship may vary considerably by characteristics of the parent and the adult child (e.g., gender), characteristics of the dyadic relationship (prior closeness and tension), and contextual factors (co-residence, frequency of interaction). As depicted in Figure 1, we propose that these variables will contribute to differences in an adult child's relationship with his or her afflicted parent. Although there are other potential moderators, we have focused on these factors because evidence from both the literatures on intergenerational relations and on chronic pain in younger families suggest they may be related both to the impact of pain on family relationships.

#### *Co-residence, frequency and quality of contact*

The research we have reviewed on pain and the family has focused on the consequences of chronic pain on spouses and parents of young children. However, these two contexts share a structural characteristic that is different from older parents and their adult children: the person experiencing chronic pain and the role partner reside with one another, thus exposing the role partner to the relative's pain on a frequent, if not continual, basis. However, fewer than 10% of older parents live with their adult children, so such intensive direct exposure to the pain suffering of parents is much more limited. Although data are lacking on the impact of contact on chronic pain, it seems likely that adult children who have more frequent interaction would be more

affected by the parent's pain.

The chronic pain literature does not address this issue directly, but researchers advocate for examining the frequency of pain communication as a means of uncovering the relational aspects of the pain experience (Cano & Williams, 2010). Specifically, communication patterns between patients and their relatives may contribute to overall relationship quality and satisfaction. The patient, for example, may engage in overt pain expression, such as pain disclosure (i.e., verbal "social sharing" of the experience) or pain behavior (i.e., nonverbal actions conveying physical distress) (Stephens, Martire, Cremeans-Smith, Druley, & Wojno, 2006). In addition, patients may display catastrophizing (i.e., an intensified emotional reaction to the pain experience). Adult children who are in more frequent contact with parents may therefore be exposed to pain disclosure and behavior, which is often upsetting and stressful (Newton-John & Williams, 2006). Moreover, exploring not only the duration and frequency of interaction, but also the quality of contact within the pain context will help understand whether communication about pain leads to deleterious family outcomes.

### *Gender*

Gender of the child is likely to be related to the impact of pain on parent-child relations. Research has demonstrated stronger affectional ties and greater confiding between older parents and daughters than with their sons. Mothers generally have closer relationships with their children than fathers, and children report feeling more closely attached to their mothers than to their fathers (Bengtson, 2001; Fingerman, 2001; Rossi & Rossi, 1990; Spitze, Logan, Deane, & Zerger, 1994; Sutor & Pillemer, 2006; Ward, 2008). Both sons and daughters interact more with their mothers than their fathers and report a higher quality of affect toward them than with fathers (Buist, Dekovic, Meeus, & van Aken, 2002). Further, daughters give disproportional

support to the older generation (Chelsey & Poppie, 2009; Horowitz, 1985; Spitze & Logan, 1990; Sutor, Pillemer, & Sechrist, 2006). Indeed, not only do daughters provide more support than do sons, but daughters are typically both mothers' and fathers' preferred source of emotional support and help during illness (Sutor & Pillemer, 2006). Thus, the pattern of greater contact and closeness with daughters may make them more vulnerable to the effects of a parent's pain.

Further, both the chronic pain and suffering literatures suggest that compassion and empathy are key factors in shaping relational outcomes for care recipients and their relatives (Goubert et al., 2005; Monin & Schulz, 2010). Notably, empathic responses to patient suffering may vary by caregiver gender. For example, compared with male caregivers, female caregivers not only tend to be more sensitive to their loved one's emotions (Monin & Schulz, 2009), but also report a greater desire to meet others' needs (Williamson & Schulz, 1990). In addition, men and women differ in their views of and reactions to the caregiving relationship. Whereas men report less emotional gratification when they perceive the relationship as less close, women display more resentment toward the care recipient (Williamson & Schulz, 1990).

Empirical evidence from the pain literature also documents gender differences in the caregiving relationship. Research indicates greater marital dissatisfaction among wives with a husband in chronic pain than vice versa (Bermas, Tucker, Winkelman, & Katz, 2000; Hafstrom & Schram, 1984). Also particular to the pain context, research suggests that satisfaction with pain-related communication may be lower among wives (Newton-John & Williams, 2006). Although some studies have failed to find gender differences (Geisser, Cano, & Leonard, 2005), in general, the literature portrays a consistent picture of lower relationship satisfaction among female caregivers. We therefore expect that adult daughters will experience greater disruptions in

relationship quality than sons.

### *Caregiver status*

Among adult children of older parents, it is possible that the effect of chronic pain on relationship quality depends in part on whether the offspring are providing care to his or her parent. Recent reviews of the caregiving literature suggest the detrimental impact of care provision on family relationships (Quinn, Clare, & Woods, 2009). Characterized by deterioration in overall communication (de Vugt et al., 2003) and relationship quality (Lyons, Zarit, Sayer, & Whitlatch, 2002), entrance into caregiving may lead to tension and strain in family life. Compared with non-caregivers, caregivers report less reciprocity in the relationship (Gallagher-Thompson, Dal Canto, Jacob, & Thompson, 2001) and greater levels of dependency in the patient (Jordan, Eccleston, & Osborn, 2007).

Among parents of young children in pain, research has found both feelings of strain and accentuated closeness within the dyad (Eccleston, Crombez, Scotford, Clinch, & Connell, 2004). Qualitative studies present a similar pattern of results, in which parents note that they “bonded more” with their child, creating an extremely close, but ever dependent relationship (Snelling, 1994). As proposed within the suffering literature, compassion and empathy are essential components in conditioning emotional reactions among caregiving relatives (Monin & Schulz, 2009). As such, increased emotional closeness may imply greater empathy between the members of the dyad (Olson, Portner & Lavee, 1985), and thus, allow both parent and child to share the burden of the pain. Given the stressful nature of the pain experience, heightened levels of strain also emerge as both partners contend with emotional anguish. It is therefore possible that providing care to an older parent with chronic pain may generate ambivalence rather than unambiguously positive or negative assessments of the relationship (Pillemer, Sutor, Pardo, &

Henderson, 2010).

### *Summary*

Despite the absence of studies testing whether parental pain affects intergenerational relationship quality, taken together these related literatures provide consistent suggestive evidence that chronic pain can make a strong, independent contribution to the quality of parent-adult child relations. The literature also provides supporting evidence that the effects of a parent's chronic pain on relationship quality are likely to be moderated by: a) proximity and contact; b) child's gender; and c) whether the child has provided care to his or her parent during a recent illness or injury.

### **Promising Directions for Future Research**

In previous sections of this paper, we raised a number of issues that merit further study regarding the impact of parent's chronic pain on adult children, arguing that the experience of pain by the older parent is likely to affect both closeness and tension within the dyad. In support of that argument, we integrated literatures on family caregiving and suffering among older people with research on younger families with a member who is a pain sufferer.

We believe that this topic provides a very fertile area for future research. We propose several avenues for exploration, highlighting the need for rigorous methodological approaches to investigate the role of older parent pain in later life families. In guiding our suggestions for future work in this area, we again turn to literature on the effects of family members' pain on spouses and parents of young children, but we also indicate how this literature may be adapted for the study of adult children of aging parents.

### *Pain perception*

Accurate perception of the patient's pain by family members is critical to a family

member's ability to provide appropriate care and assistance to the relative in pain (Goubert et al., 2005). Thus, one potential area for research may be the simultaneous exploration of pain perception by both patient and relative. Within the context of spousal relationships, the partner's perception of the patient's symptom severity may contribute to marital satisfaction and adjustment (Romano et al., 1991) as well as higher quality emotional support by the spouse (Manne & Zautra, 1989; Martire et al., 2006; Martire, Stephens, Druley, & Wojno, 2002). Similar associations have been documented among parents of children with chronic pain, such that worried parents tend to engage in more pain-promoting behaviors (e.g., encouraging excessive rest, providing physical assistance/taking over a task) (Guite, Logan, McCue, Sherry, & Rose, 2009).

Levels of agreement between the patient and relative about the pain experience have implications for the dyad. In general, when concordance rates are high, the overall relationship tends to fare better (Martire et al., 2006). Unfortunately, family members often are inaccurate judges, frequently overestimating the patient's pain and disability (Beaupre et al., 1997; Cremeans-Smith et al., 2003; Redinbaugh, Baum, DeMoss, Fello, & Arnold, 2002; Riemsma, Taal, & Rasker, 2000), which in turn may have ramifications for the dyad (Goubert et al., 2005). Overestimation may contribute to greater depression (Cremeans-Smith et al., 2003) and disability among patients (Goubert, Eccleston, Vervoort, Jordan, & Crombez, 2006; Guite et al., 2009), as well as increased soliciting behavior among relatives (Guite et al., 2009).

Future studies of older parents and adult children can therefore shed light on concurrent and divergent assessments of the pain experience by the patient and family member. Within the context of later life families, we may expect to see similar outcomes for adult children with a parent in pain, where greater pain disclosure leads to greater relationship strain. Inquiry in this

area may provide greater insight into the dynamics of the overall adult – child parent relationship.

### *Pain communication*

Another topic for future study is investigation of overt pain communication among older parents and its effects on adult children. Although few studies have explicitly examined the effects of patient pain communication on family members (Newton-John, 2002), emerging evidence suggests that spouses' frequent communication about severe pain may be associated with decreased emotional support from their partners (Stephens et al., 2006). Other research, however, provides a more favorable view, indicating that somatization among patients actually may not compromise marital adjustment in spouses (Feinauer & Steele, 1992; Newton-John & Williams, 2006). Gathering information from both members of the dyad may be essential in understanding the interwoven nature of the relationship. For instance, within parent-adolescent relationships, catastrophizing among parents may contribute to their own feelings of parenting stress, beyond the child's pain intensity (Goubert et al., 2006). Future endeavors may benefit from exploring how simultaneous catastrophizing in both adult children and their parents may have ramifications for the overall quality of the relationship.

Thus, the growing body of empirical work argues for additional exploration of dyadic communication within the context of chronic pain. As such, theoretical models have begun to consider how emotional disclosure and validation may also predict relational outcomes. Moreover, it has been hypothesized that verbal and nonverbal communication fosters exaggerated concern for the afflicted individual (Leonard & Cano, 2006; Stephens et al., 2006), perhaps contributing to strained relationships. This body of research can provide a fruitful direction for research in later life families given that advanced age is linked with greater abilities

in emotion regulation (Charles, 2010; Urry & Gross, 2010). Due to age-related changes in the ability to regulate one's emotions, older adults may catastrophize less than individuals in earlier life stages, especially as they are more likely to employ selective strategies such as "thinking positively" to combat worries (Hunt, Wisocki, & Yanko, 2003). Studies exploring pain communication can be useful in understanding how families at different life stages cope with the pain experience.

### *Coping*

Extending from research on pain communication, future inquiry into coping strategies may contribute additional insight into management of the pain experience. Although many studies portray a bleak picture for families with a member in chronic pain, other research reveals a more favorable view. In fact, there is some evidence to suggest that family members actually remain quite satisfied with their relationships, even when a relative experiences high levels of pain (Bermas et al., 2000).

One hypothesized element in distinguishing families in distress from those that are well-adjusted is coping behavior. Recent empirical work provides direct support for this association, revealing less marital satisfaction among spouses who engaged in more passive, rather than active, coping strategies (Bermas et al., 2000). Findings such as these extend earlier theoretical accounts, which propose the way in which a family approaches the pain experience may dictate relational outcomes. For instance, early frameworks posit that chronic pain may be "either a threat or a challenge" (Turk et al., 1987) and further, that familial adaptation to chronic illness will have repercussions for relationships and interactions among individual members. Building on this line of research, Berg and Upchurch (2007) recently proposed a developmental-contextual framework which highlights dyadic coping as an integral component of spousal

adjustment to chronic illness. Empirical tests of this theory, however, have primarily focused on the patient's experience rather than on outcomes for the relative.

Particular to later life families, coping behavior among parents in chronic pain may have implications for their adult children. As noted, because older adults tend to regulate their emotions more efficiently than younger adults (Charles, 2010) and worry less overall (Hunt et al., 2003), a divergent pattern of results from those in young families may emerge. Some studies suggest that coping styles among older adults in chronic pain mirror those of younger individuals in pain (Keefe & Williams, 1990), and but it remains to be seen whether these styles will have a distinct impact on offspring rather than on spouses.

#### *Impact of pain and family relationships on family members' well-being*

The preceding discussion suggests that having a parent who suffers from chronic pain may have a negative impact on the parent – child relationship. It is also possible that older parents' chronic pain and the disruption caused for families will negatively affect the psychological well-being of offspring. More specifically, the patient's own symptoms, emotional distress, and need for physical and emotional assistance may elicit emotional reactions by family members (Kerns & Turk, 1984). Prior work has investigated this association in young families and spousal samples, providing a potential foundation for future research on the psychological health of adult children of parents in chronic pain.

The relationship between mood disturbance and chronic pain is well-documented; estimates suggest that 30-50% of all chronic pain patients suffer from depression (Banks & Kerns, 1996). Accruing research suggests that rates may be equally high for spouses and parents of young children with chronic pain. In fact, reports of significant spousal depressive symptomatology range from 20-50% (Ahern, Adams, & Follick, 1985; Kerns & Turk, 1984),

with estimates for parents at approximately 40% (Eccleston, Crombez, Stcotford, Clinch, & Connell, 2004). Notably, prevalence surveys also reveal that both spouses (Comstock & Helsing, 1976) and parents (Cadman, Rosenbaum, Boyle, & Offord, 1991) of chronic illness patients exhibit higher levels of depressive symptoms and negative affect than community samples.

Evidence from earlier studies of spousal chronic pain and partner depression consistently documents the presence of psychological distress in both members of the dyad. For example, in an exploratory study of 30 male chronic pain patients and their wives, over one-half of both patients and spouses reported significant levels of depressed mood (Kerns & Turk, 1984). Later work (Flor, et al., 1987; Schwartz, Slater, Birchler, & Atkinson, 1991), however, provides more conservative estimates of spousal depression, with averages around one quarter of the spousal sample. Even these modest appraisals of psychological distress among spouses pose concern for scholars and practitioners, catalyzing a wave of psychosocial intervention plans incorporating close family members in the therapeutic approach to treatment (Martire, 2005).

Therapeutic interventions targeting adolescents and young children in chronic pain also advocate for family involvement. These initiatives echo the adult literature in suggesting that family participation in behavioral treatment may be a promising avenue in managing not only the sufferers' symptoms, but also family members' psychological distress (Eccleston, Malleson, Clinch, Connell, & Sourbut, 2003). Of note, parents may benefit in both the short- and long-term from such interventions: recent reports indicate significant improvements in parental depression and stress at immediate and three-month follow-up assessments (Eccleston, et al., 2003).

Even with the assistance of therapeutic interventions, individual differences in psychological well-being among family members exist. Systematic reviews reveal considerable variability in the experiences and outcomes of caregivers (Pinquart & Sörensen, 2003). Whereas

some caregiving relatives manage the stress and strain of assisting a loved one, others languish in the face of such trying circumstances. Individuals' coping abilities and perception of caregiving demands may influence their health, well-being and response to the overall experience.

Importantly, personality characteristics may play a role in shaping such reactions. For example, those high on the trait of neuroticism not only appraise the caregiving experience more negatively (Bookwala & Schulz, 1998), but also exhibit heightened reactivity to care-related stressors (Koerner, Kenyon, & Shirai, 2009). Moreover, these individuals suffer from depressive symptomatology (Bookwala & Schulz, 1998) as well as compromises in subjective physical health (Hooker, Monahan, Shifren, & Hutchinson (1992), This may be particularly salient within the chronic pain context where the relative must confront issues related to both emotional and physical anguish of the ailing family member.

In addition, relatives' respective outcomes may hinge upon the patients' own beliefs and behaviors toward intervention efforts and treatment planning. It is plausible that a compliant and amenable attitude toward treatment by the patient may lead to increased well-being among family members. On the other hand, oppositional or aversive behaviors could contribute not only to discord within the dyad, but also to heightened levels of anguish and strain by family members. The additional stressor of dealing with a noncompliant and combative patient may further contribute to deterioration in relatives' health outcomes. Although speculation of this relationship has been documented in clinical reports (Groves, 1978), this prediction has yet to be tested in empirical research.

Although studies have not investigated this issue directly, some studies have explored the association between patients' emotional distress and family members' own psychological health (e.g., Cohen, Vowles, & Eccleston, 2010). A considerable body of research has demonstrated

that exposure to other individuals in chronic pain elicits affective distress in the observer (Goubert, Craig, et al., 2005). In an integrative review, Craig (2009) highlights the social and interactive nature of pain, and the degree to which pain suffering and pain expression affect significant others. Both verbal and nonverbal expressions of pain lead can lead to concern and anxiety on the part of relatives.

Notably, personality may shape the way in which chronic pain patients disclose and communicate about their symptoms. The trait of neuroticism, for example, has been associated with more somatic complaints (Affleck, Tennen, Urrows, & Higgins, 1992), greater pain catastrophizing (Affleck, et al., 1992) and overall heightened levels of distress among chronic pain patients (BenDebba, Torgerson, & Long, 1997). In turn, these conditions have been implicated as risk factors for poorer psychological health among family members. Given this potential pathway by which patient communication may contribute to decrements in family members' emotional well-being, assessments of both patient and relative personality should be a priority for future exploration.

Lumley and colleagues (2011) note that those in close relationships with affected individuals not only experience stress from seeing their loved ones in pain, but that they have difficulty determining what actions to take to best support the relative and can feel powerless to ameliorate the situation. Feelings of powerlessness, in turn, lead to "torture...worse than frustration" for the relative, especially as the patient's condition persists over time (Jordan, et al., 2007). Such qualitative reports underscore how parental distress is accentuated when parents feel helpless in assuaging their child's pain. Furthermore, the cyclical and antagonistic relationship between powerlessness and distress may be difficult to sever, leaving family members in a depressed and helpless state as the patient's symptoms worsen. Conversely, self-efficacy beliefs

may buffer such deleterious outcomes, and have been linked with positive health and well-being among caregivers (Rabinowitz, Mausbach, Thompson, & Gallagher-Thompson, 2007).

Taken together, the findings presented above reveal potential pathways by which chronic pain may elicit compromised emotional well-being in both the afflicted individual and close relatives. Future research may thus provide practical benefits by including psychological distress as a clinical indicator of the negative impact chronic pain in older parents has on relationships with their offspring.

### *Methodological concerns*

We have proposed several rich areas for future study; however, research on the dynamic nature of pain within families is not without methodological challenges. Lack of prospective data and a primary focus on cross-sectional studies limit our understanding of directionality of family functioning and pain (Eccleston et al., 2004). Causal directions for the impact of chronic pain on family members, even in early life, have yet to be established, and longitudinal assessments are necessary to illuminate outcomes over time. In addition to longitudinal research endeavors, smaller focus group studies may help clarify how older parents' pain may impact their adult children's emotional health. Further, qualitative data may unearth features unique to the adult child-parent relationship when a parent experiences chronic pain.

### **Conclusion**

In summary, the existing literature suggests several hypotheses regarding the potential impact of older parents' chronic pain on their adult children. First, the large body of research on family caregiving has established that parental chronic disease and related problems matter for adult children in terms of perceived relationship quality. Second, the literature on the effects of chronic pain on other family relationships (married couples and parents of young children and

adolescents) indicates that the chronic pain experience is likely to affect both closeness and tension within the dyad. Guided by these two sets of findings, we propose a conceptual model of hypothesized factors that may moderate the association between chronic pain and adult child-parent relations. Specifically, we conjecture that the adult child-parent relationship quality may vary by: a) proximity and contact; b) child's gender; and c) whether the child is the primary caregiver.

The proposed model suggests a variety of avenues for future research, testing the hypothesized pathways between a parents' pain experience and the quality of intergenerational relationships. After testing for direct effects of pain on relationship quality, we suggest that moderators be considered, and in particular co-residence and contact; gender, and whether or not the child is a caregiver. Another fruitful area for exploration is the degree to which a parent's pain negatively affects the child's psychological well-being, which in turn may affect relationship quality.

In this paper, we have highlighted three specific areas for future study that may moderate the association between pain and relationship quality: pain perception, pain communication, and coping within the dyad. We then suggest that the familial disruption caused by an older parents' chronic pain may also contribute to compromises in adult children's psychological health. Overall, we conclude that based on the evidence provided in this article, further exploration of the impact of chronic pain on older parent – adult child relations appears to be justified.

Finally, it is important to note the potential importance for practice and policy of establishing this topic as a priority for research. Family caregivers provide the majority of assistance impaired older persons receive, and the economic value of these services is very great (Houser & Gibson, 2008). Therefore, it is critically important to understand the factors that

facilitate or inhibit caregiving activities on the part of adult children. It is possible that difficulty coping with a parent's pain may discourage some potential caregivers, given the disruption in family relationships sometimes caused by pain suffering. Further, caring for a parent in pain may potentiate caregiver stress and burden, leading to exhaustion and termination of care. Improving caregivers' ability to understand parents' pain and to help them manage it may therefore ultimately promote care at home and discourage use of institutional settings.

To this end, we suggest a focus both on acquiring additional basic knowledge about chronic pain and older parent – adult child relations and in developing interventions to improve coping with pain as a family. Within young families and spousal dyads, gains in treatment outcomes for both partners are most pronounced with family support and involvement (Martire et al., 2004). Pain-coping skills training (CST) interventions, for example, are most effective with spousal assistance. Compared to control groups, spouse-assisted CST not only attenuates patient pain symptoms, but also increases feelings of self-efficacy and marital adjustment among spouses (Keefe et al., 1996). In addition, interdisciplinary cognitive behavioral (ICBT) pain management programs involving family members simultaneously improves patient functioning while reducing parental distress and anxiety. Such therapies are easily transferrable to later life families and are likely to provide benefits to both older persons in need of assistance and their caregivers.

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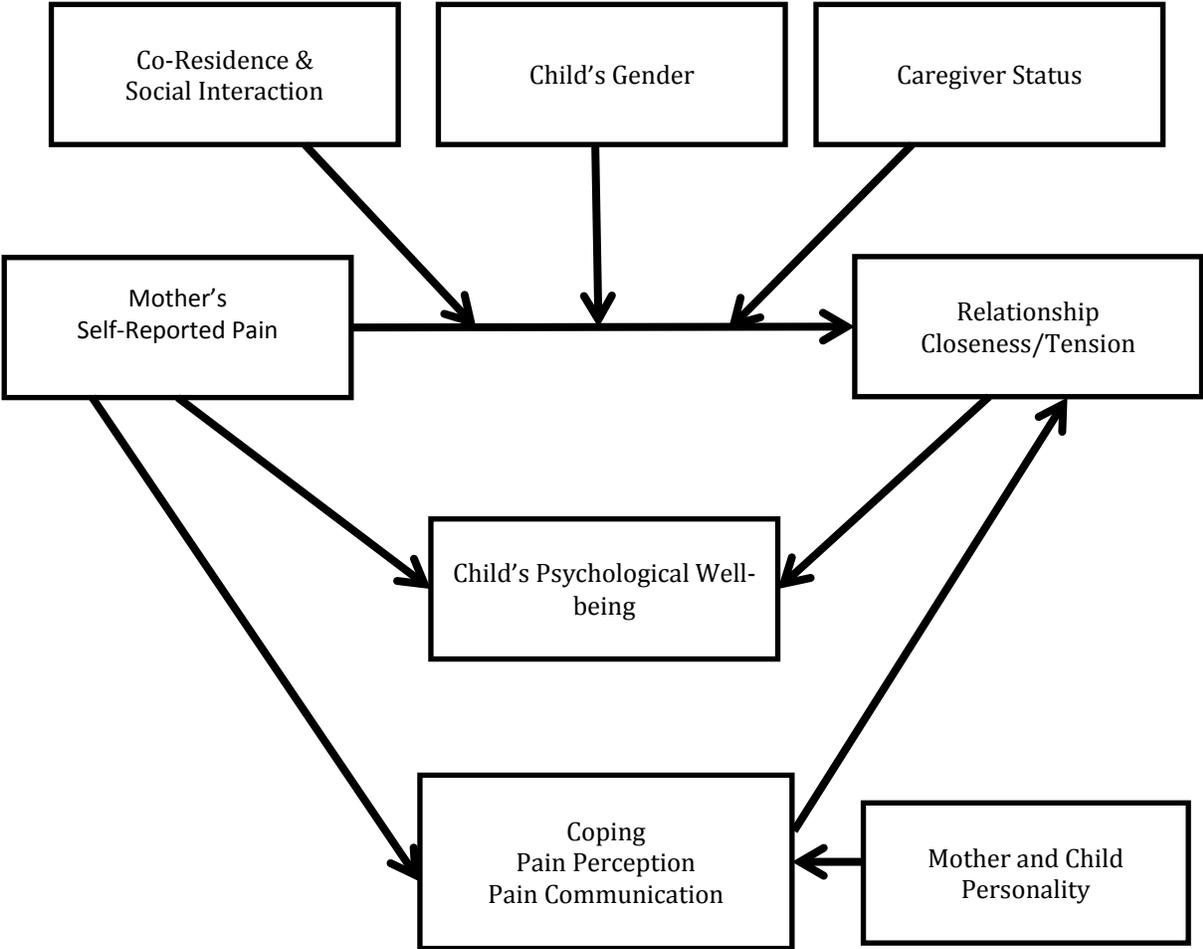
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Figure 1. Proposed Conceptual Model



## CHAPTER 2

### DECISION SUPPORT PREFERENCES AMONG HISPANIC AND NON-HISPANIC WHITE OLDER ADULTS WITH CHRONIC MUSCULOSKELETAL PAIN

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## Abstract

**Objectives:** Despite broad recognition that social networks play a key role in the management of chronic musculoskeletal pain (CMP), little is known about when and why older adults with CMP choose to involve others in treatment decisions. This study investigates the *types* (i.e., informational, emotional, instrumental) and *sources* (i.e., formal, informal) of support Hispanic and non-Hispanic White CMP patients desire when making decisions about their pain care.

**Methods:** Semi-structured interviews were conducted with Hispanic and non-Hispanic White older adults with CMP ( $N=63$ ) recruited from one medical center and one senior center in NYC. Interviews were transcribed, then analyzed using content analysis.

**Results:** CMP patients sought network members who supported their emotional well-being throughout the decision-making process. When considering high-stakes treatment decisions, participants selectively involved individuals who had similar pain conditions or first-hand experience with the procedure. Participants' perceptions of the decision-making process were contingent upon the congruence between the support they desired and received. For Spanish-speaking participants, positive perceptions were linked with adequate language competence by their providers.

**Discussion:** Results reveal the importance of empathic and culturally sensitive patient-provider exchanges across diverse patient populations. Findings suggest that social networks beyond the patient-provider dyad influence patients' decision-making satisfaction.

## **Introduction**

Chronic musculoskeletal pain (CMP) is a widespread and debilitating illness affecting half of community-dwelling older adults (aged 65+) and 80% of those living in care homes (Helme & Gibson 2001). Effective symptom management and treatment of CMP requires sustained therapeutic regimens and ongoing support from health care professionals, informal caregivers, and family members (Clark, 2003). Both formal and informal social networks are critical not only to the day-to-day care of older CMP patients, but also to treatment planning and clinical decision making across the illness trajectory (Hooten et al., 2013). Despite the growing awareness of CMP as a public health issue (Institute of Medicine, 2011) and recent calls for increased scientific attention to decision making and chronic illness (US Department of Health and Human Services, 2011), research regarding affected patients' preferences for involving others in their treatment decisions remains limited. Given the paucity of research on this topic, the present study offers initial insight into this area by employing a qualitative content analysis to investigate older CMP patients' desires for formal and informal decision support.

The persistent nature of CMP requires complex treatment decisions throughout the course of illness, often involving multiple stakeholders, including interdisciplinary health care professionals, family members, and friends (Sperry, 2009). Moreover, such decisions hold high emotional salience for both the sufferer and close others, particularly when considering the vast spectrum of possible treatment options varying in terms of relative risk and invasiveness. Therapeutic options include pharmacologic, nonpharmacologic, and for many CMP conditions (e.g., osteoarthritis of the hip or knee, spinal stenosis) surgical interventions. Patients must routinely weigh the potential benefits versus risks, as well cost of undergoing a given

intervention. For older CMP patients, another consideration is the extent to which a given treatment may negatively impact on other chronic conditions (e.g., taking an analgesic agent that lowers pain levels but leads to worse kidney function). Particularly important, a poor treatment outcome has the potential to exact a dramatic physical toll not only on the affected individual, but also on close others involved in daily care provision and assistance (Monin & Schultz, 2009).

Despite long-standing recognition that social networks play a key role in the management of CMP (Turk, Flor, & Rudy, 1987), little is known about how such networks function within CMP patients' treatment decisions. To date, the majority of studies on treatment decision making in CMP have explored informational exchanges between physicians and patients, specifically with regard to patients' desire for shared decision making (SDM) (e.g., Kroll, Richardson, Sharf, & Suarez-Almazor, 2007; Sherwood, McNeil, Palos, & Starck, 2003). They consider the factors that promote or dissuade individuals from engaging in collaborative discussions with their physicians as well as patients' perceptions of their medical interactions. The current research emphasis on shared decision making (SDM) is not unique to CMP, however. Across medical contexts, SDM has been acknowledged as the "pinnacle of patient-centered care" (Barry & Edgman-Levitan, 2012), with supporting literature citing patient-provider communication as a critical element in promoting high-quality decision making (Street, Makoul, Arora, & Epstein, 2009).

In contrast with the expanding literature on patient-provider SDM, there has been comparatively less empirical investigation of joint decision making and communication involving older patients and their informal networks (Cicirelli, 2006; Fingerman, 2001; Fingerman, Nussbaum, & Birditt, 2004). Indeed, most research investigating close others'

involvement in older adults' medical decisions has focused on the singular perspective of an appointed surrogate (Cicirelli, 2008), especially in the context of acute illness (Hilton, Crawford, & Tarko, 2000; Maliski, Heilemann, & McCorkle, 2002) or end-of-life (Carr & Khodyakov, 2007). Although some studies on CMP decision making have considered the involvement of close others (Katz et al., 2011; Ross, Carswell, Hing, Hollingworth, & Dalziel, 2001), they maintain a restricted focus on advice-seeking rather than exploring the full spectrum of decision support functions to include informational, emotional, and instrumental support (Malecki & Demaray, 2003).

The present study seeks to fill a critical gap in this literature by exploring older adults' preferences regarding the *sources* (i.e. formal and informal) and *types* (i.e. informational, emotional, instrumental) of support older CMP patients desire when making decisions about their pain care. To guide this qualitative content analysis, we draw upon lifespan theories of motivation and emotion (Carstensen, 2006), proposing that age-related changes in information processing and social network formation may have implications for older CMP patients' decision support preferences. We further consider the role of experiential similarity in the context of CMP decision making, with a specific focus on when and why CMP patients seek decision support from others with similar pain conditions. In addition to examining general trends in patients' decisional networks, we undertake a cross-cultural comparison of Hispanics and non-Hispanic Whites to explore alternative mechanisms underlying CMP patients' preferences for informal decision support.

### **Age-Related Changes in Information Processing and Social Networks**

Lifespan theories of motivation and emotion provide an integrative framework for

predicting age-associated changes in social and decisional preferences. According to socioemotional selectivity theory (SST) (Carstensen, 2006), time horizons influence goal selection across the lifespan. Specifically, SST posits that expansive time horizons in young adulthood lead to a prioritization of goals that benefit the future (i.e. information-seeking and knowledge acquisition). With advanced age, time horizons constrict and priorities shift toward present-focused goals. As perceived time grows shorter, meaningful relationships and emotionally gratifying information are prioritized over establishing new contacts and gathering novel information.

With regard to empirical research, the majority of studies considering age-differences in medical decision making have been conducted with cancer patients. Such studies indicate that older cancer patients not only seek less health-related information from their providers (Bennett et al., 2007), but also prefer more a passive and deferent role in treatment decisions (Elkin, Kim, Casper, Kissane, & Schrag, 2007; Pinquart & Duberstein, 2004). Also consistent with this age-graded pattern, empirical evidence from the gerontological literature suggests that older adults prefer to be surrounded by their loved ones in old age, and view professional carers as intrusive strangers in their final moments (Gott, Seymour, Bellamy, Clark, & Ahmedzai, 2004). A similar trend might be expected among older CMP patients, who may seek validation and reassurance from close social partners, and delegate emotionally-aversive or difficult decisions.

### **Experiential Similarity and Network Formation**

In addition to motivational changes across the lifespan, *social homophily*, or the tendency to develop and maintain supportive relationships with similar others (Thoits, 2011), may also play a role in shaping CMP patients' decision networks. Both theory and research suggest that

when individuals find themselves in stressful situations, they seek out similar others for emotional sustenance and informational guidance (Suitor, Pillemer, & Keeton, 1995). Research considering older adults with chronic illness suggests that both empathic responses and information exchange between similar others influences individuals' own perceptions and decisions regarding treatment (Gallant, Spitze, & Prohaska, 2007). Our study extends this notion to the context of CMP: We propose that CMP patients will seek out experientially similar others not only as sympathetic confidants, but also as informal advisors regarding treatment options.

Although older adults are generally adept at selecting positive and supportive social relationships (Luong, Charles, & Fingerman, 2011), involvement by others may hold deleterious consequences if support is not desired from a specific network source, or if the type of support offered does not match the recipient's needs (Boutin-Foster, 2005). It is therefore critical to acknowledge CMP patients' decisional preferences and ensure an optimal fit between the support they desire and receive.

We also consider the role of culture in social network formation. In the following section we delineate how cultural differences may further distinguish CMP patients' decision support preferences, especially with regard to the involvement of informal networks.

### **Ethnic Differences in Decision Support Preferences**

Within Hispanic cultures, individuals routinely draw upon informal rather than formal networks for their medical care (Carbone et al., 2007; Ransford, Carillo, & Rivera, 2010). However, within the context of CMP, it remains unclear whether this reliance on informal networks is an active *choice* (resulting from cultural beliefs and preferences for alternative healing practices), or simply due to a lack of *access* to adequate formal support (resulting from

structural obstacles including language barriers). Given these competing rationales for why Hispanic CMP patients may seek informal rather than formal support, a goal of the present research is to uncover when and why Hispanics involve certain others in their pain treatment decisions.

On the one hand, literature suggests that the involvement of informal networks in Hispanics' healthcare stems from the provision of *alternative medicine*, such as herbal treatments and home remedies (Delgado & Humm-Delgado, 1982; Ransford, Carillo, & Rivera, 2010). Alternative treatments typically reflect cultural beliefs and healing practices that are not generally considered part of conventional medicine (American Institutes for Research, 2002) and are routinely employed by Hispanic elders (Najm, Reinsch, Hoehler, & Tobis, 2002). Evidence from this research stream seems to indicate that Hispanic CMP patients may draw upon informal networks due to normative cultural practices and preferences for alternative medical treatments.

Meanwhile, other research suggests that Hispanics' reliance on informal networks may stem from a lack of access to culturally competent healthcare, which according to the US Office of Minority Health includes both cultural (beliefs, values and customs) and linguistic support for diverse patient populations. Particular to CMP treatment, lack of interpreter services and cultural understanding by providers have been identified as major obstacles to collaborative decision making between Spanish-speaking patients and their physicians (Ransford, Carillo, & Rivera, 2010; Sherwood et al., 2003). Indeed, one in five Spanish-speaking US residents delay or refuse necessary medical care because of language barriers with an English-speaking doctor (Robert Wood Johnson Foundation, 2001).

For both structural and cultural reasons, Hispanics may avoid formal medical support and

instead turn to informal networks when considering pain treatment options. However, because prior research tends to focus either on patient-provider relationships or on familial interactions, it remains unclear whether this reliance on informal networks may stem from cultural preferences for alternative medicine or from language barriers to formal care.

### *The Present Study*

The present study elucidates decision support preferences among older adults with CMP by exploring the relative function of formal and informal social networks in pain treatment decisions. Although theoretical models suggest that age differences in information processing and social relationships may be relevant to CMP decision making, such predictions have yet to be examined. Also unclear is the extent to which experiential similarity or culture play a role in CMP patients' decision support preferences, and whether the match between patients' desired and perceived support has implications for patients' satisfaction with the decision making process as a whole.

Given the lack of published research in this area, we employed semi-structured interviews to obtain qualitative data on whether and why culturally diverse CMP patients turn to relatives, friends, and healthcare providers when making decisions about their pain care. In particular, we explored patients' a) preferences regarding the types (i.e., emotional, instrumental, informational) of support they desired from formal (i.e. healthcare provider) and informal (i.e., family member, friend) network ties, and b) perceptions of and satisfaction with the support they received. Ethnic differences and decision characteristics (i.e., type of treatment) were considered throughout.

## **Methods**

### *Sampling and Recruitment*

Following standard qualitative research methodology, purposive sampling (i.e. selective sampling of participants based on their ability to contribute sufficiently rich and relevant data to the research topic) was used to identify patients with musculoskeletal pain ( $N = 63$ ) from an outpatient practice serving older adults and a senior center located in New York City. Patients were notified of the study in the waiting room of the outpatient practice or common area of the center. If the individual agreed, a research assistant explained the study and administered an oral screening to assess eligibility. Individuals were eligible if they were aged 60 and above, cognitively intact (Callahan, Unverzagt, Hui, Perkins, & Hendrie, 2002), and self-reported a diagnosis of chronic non-cancer pain, including arthritis or other chronic musculoskeletal conditions (e.g., back pain) for 3 or more months. Individuals who had a lifetime history of cancer were not excluded from participation. All individuals within the target communities were fluent in English and/or Spanish. Oral consent and contact information were obtained from all patients willing to participate. The study protocol and interview materials were approved by the Cornell University Institutional Review Board.

*Cultural considerations in recruitment and interviewing.* Credible and trusting relationships with potential participants were established through weekly visits by a bilingual Hispanic research assistant to the senior center. In addition, all participants were called by a bilingual Hispanic research assistant and offered a choice regarding the language (English or Spanish) in which the interview was conducted.

*Participant eligibility and sample characteristics.* Of the 201 individuals recruited at both sites, 118 (59%) agreed to complete the screener when first approached. Of those completing the

screeners, 70 (59%) met eligibility criteria, and of these, 63 (90%) completed the full interview. The most commonly cited reason for declining participation was lack of time. The final sample consisted of 29 non-Hispanic Whites and 34 Hispanics. See Table 1 for sample characteristics.

### *Interview*

The interview guide (see Appendix) was designed to elicit CMP patients' preferences for formal versus informal decision support, level and type of support they desired and received, as well as their perceptions of and satisfaction with the joint decision-making process. Feedback on initial drafts of the interview was obtained from an advisory panel of key informants including a geriatrician, a gerontologist, and developmental psychologist. Because the authors of this manuscript come from non-Hispanic backgrounds, Hispanic research assistants with cultural backgrounds similar to those of the study participants reviewed the interview guide to ensure its relevance to the Hispanic sample. Pilot interviews were then conducted with three older adults suffering from CMP (not included in the final analysis). Based on informant feedback, revisions were made to clarify content and wording, and to expand upon specific topics of inquiry (see Appendix for the final version).

The interview guide consisted of both closed and open-ended questions. Background questions asked participants to report their pain diagnosis, indicate how long they had the pain problem, and rate their current pain severity on an 11-point scale (McCaffery & Pasero, 1999). Open-ended questions targeted the context of patients' treatment decisions (i.e., pain condition and treatment modality), their preferences for consulting others in their social network (e.g., physician, friend, spouse), the types of support they received when making treatment decisions, as well as their overall satisfaction with the decision process. Interviews continued until no new

themes emerged, signaling that thematic saturation had been reached (Hsieh & Shannon, 2005).

Interviews were conducted from July 2013 to May 2014 at the convenience of the participant either in a private room located in the physician's office / senior center or by telephone depending upon participant preference. With the permission of the participant, the interview was audio recorded. Non-recorded interviews ( $n = 3$ ) were not included in qualitative analysis. Interviews lasted between 15 to 45 minutes and were conducted by trained research assistants. At the completion of the interview, participants were financially compensated for their time.

To enhance consistency of delivery by the interviewers, a standardized protocol was developed by the investigators. Research assistants were trained in the protocol using a multi-phase process of 1) listening to two or more pre-recorded interviews conducted by the primary investigator (CR), 2) conducting three mock interviews, 3) shadowing the primary investigator in conducting patient interviews, and 4) conducting three or more supervised interviews. To further ensure consistency and adherence to the interview guide, audio recordings of all interviews were reviewed immediately by the primary investigator. Feedback was provided on an ongoing basis.

Each interview was transcribed verbatim by two individuals. The transcripts were then compared by a third reviewer (as well as the primary investigator) to ensure accuracy. Spanish interviews were first transcribed, then translated into English by two bilingual research assistants. All transcripts were imported into Dedoose Version 5.0 (SocioCultural Research Consultants, 2013), a qualitative analysis software program, which was used for data management and analysis.

### *Analysis*

Direct content analysis occurred in a three-step process of coding, data reduction and identification of themes (Hsieh & Shannon, 2005). First, coding of the raw data involved line-by-line extraction of key phrases, termed meaning units. Meaning units were then compared both within and across interviews, and grouped based on underlying similarity. This process continued until no new categories emerged. Finally, meaning units were synthesized and collapsed into central themes. To systematize data analysis, a standardized coding guide was developed by the primary investigator, and revised based on feedback from all co-authors. The primary investigator then trained two research assistants in the procedure. A randomly selected group of 25 transcripts were used to calculate interrater reliability and consistency (per cent agreement between raters). Average consistency was 94% for all codes (range: 0.64 – 1.00).

Throughout data analysis, several techniques were employed to ensure rigor, which is established through the principles of credibility, auditability, and fittingness (Lincoln & Guba, 1985). In this study, *credibility* was maintained through systematic content analysis by the research team. To establish *auditability*, documentation of analytic decisions and interpretations was maintained by the primary investigator and reviewed by the research team throughout data collection and analysis. Deviant case analysis was also implemented to examine alternative interpretations and reduce biases. Detailed discussions with healthcare providers demonstrated *fittingness* (i.e. transferability) of the study findings to other contexts.

## **Results**

In the following sections, we first delineate the types of support solicited and received from each network tie, focusing separately on formal and informal sources. We then examine individuals' perceptions of the decision-making process and explore how differences in *desired*

versus *perceived* support may have implications for patients' satisfaction with the process as a whole. Within each sub-section, we first report common trends in the full sample, then focus on ethnic differences at the end of each section. Quotations are labeled with the participant's age, gender (M = male and F = Female), and race (H = Hispanic and W = non-Hispanic White).

### **Formal Network Ties and Support Provision**

With regard to formal support, participants described the informational guidance and emotional reassurance they received from health care professionals. These types of support are discussed in turn, with a focus on the contexts in which each type of support was received.

#### *Informational Support*

Participants described the central role physicians played in their pain treatment decisions. In general, patients held the belief that "doctors are the experts" with specialized training to guide the decision process (81/F/W). Consistent with predictions from SST regarding an age-related tendency towards greater passivity in decision making, participants' responses suggested a strong reliance on and deference to their doctors, particularly when pursuing high-stakes or specialized treatment regimens. Patients who were taking strong prescription medications to treat their pain (e.g., oxycodone, steroids) also relied heavily on their doctor to make a decision. As one participant stated, "I certainly wouldn't take or get off a medication without consulting the doctor" (79/M/W). Regarding his change in medication, another individual reported: "If I don't talk to the doctor, I don't know what's happening to me and what type of medicine I should take" (67/M/H).

For Spanish-speaking participants, language barriers impeded in-depth treatment discussions during medical visits. Specifically, respondents described the need for improved

language competence by their American physicians: “[When] an American [physician] treats me that doesn’t know Spanish I get jumbled ... I have to say ‘here,’ ‘there’; I can’t specify more because they don’t understand” (64/F/H). Others lamented the lack of high-quality interpreter services: “[My doctor] never tells me anything, and since we use an interpreter we can’t talk much” (61/M/H). Such descriptions point to the importance of matching patient-provider language and providing adequate interpreter services when bilingual providers are not available.

### *Emotional support*

Emotional reassurance by providers was an integral component of CMP patients’ decision making as well. Consistent with predictions from SST suggesting that older adults draw upon social partners who support their desire for emotional stability, participants emphasized the importance of compassion and empathy by their providers when engaging in treatment discussions. One participant explained “I went to [the doctor] because he was empathetic, gentle and listened” (68/F/W). In another vivid narrative, one individual described her doctor as “the kind who would put her arms around you” (70/F/W). In general, patients highly valued doctors who took the time to discuss, listen and weigh the various treatment options.

Although participants described the value of compassionate interactions in broad terms, they underscored the significance of emotional support when considering a new treatment regimen or when experiencing treatment side effects. In such cases, patients appreciated doctors who “listen to me and to what I’m saying” (70/F/W). Another patient who experienced side effects after switching arthritis medications pronounced: “Dr. [X] is an amazing doctor ... She would talk to me about everything. She was so nice and interested” (77/F/H).

Within the Hispanic sample, participants also articulated the importance of having a

culturally competent provider. For example, one individual defined his medical experience as “incredible! When I get there [my doctor] receives me with a blessing and he’s not my family!” (61/M/H). Reports such as this reveal Hispanics’ desire for care by providers who offer emotionally decision support conveyed through culturally sensitive interactions.

### **Informal Network Ties and Support Provision**

Informal networks served multiple functions as informational, emotional and instrumental resources throughout the decision process. Specifically, our analyses revealed two distinct sources of informational support: Individuals either provided information based on their own experience or based on their expertise (medical knowledge and knowledge about home remedies). Below, we examine each support type in greater detail.

#### *Informational Support*

*Provided by others with expertise.* In addition to soliciting medical advice from physicians, patients often reported reaching out to friends who had formal medical training. “I have some friends who are physicians and who are specialists. I might send an email asking about a certain drug or a certain treatment to get advice that way” (68/F/W). Although some participants turned to friends explicitly to acquire medical information, others found themselves developing contacts based on proximity. As one participant reported “Some friends of mine in the house I talked to, one that’s a retired nurse ... We always talk about pain” (86/M/W).

Whereas non-Hispanic White participants typically turned to friends with formal medical training, Hispanic participants seemed to seek close others who had expertise in alternative treatments or home remedies. When describing their interactions with informal network members, Hispanic participants often spoke of individuals from their home country and

emphasized their preference for informational guidance from individuals outside traditional medical systems: “My daughter-in-law who is Dominican knows a lot of home remedies” (64/F/H). Another participant, recounted her experience learning *sobo*, a massage treatment: “*Sobo* ... alleviates my pain. Someone gave me the idea and I followed it ... He was a baseball coach there in Puerto Rico” (61/M/H).

*Provided by others with experience.* Consistent with predictions from homophily theory, participants selectively accepted guidance from others experiencing similar pain conditions or treatments. Similar others were deemed excellent informational sources with the ability to provide empathic and tailored advice. For example, one participant asserted she would not trust the advice of friends “unless someone has the same thing, then I certainly would listen to them” (67/F/W). Drawing upon the advice from others with similar pain conditions was most often reported among participants considering surgical procedures. One participant reached out to an acquaintance “who had a lot of experience not only with broken bones, but knee replacement and joint issues” (74/F/W). In gathering information from similar others, participants’ responses revealed a focus on the positive: “two of my friends who had knee replacements ... I relied on [them] to make sure they had a positive experience” (75/F/W). In general, participants selectively sought positive information from others who had pursued a similar treatment.

Information-seeking from similar others was also common among Hispanic participants: “My friends that have pain, we talk. Some tell me what they take and I tell them what I take” (73/M/H). Another remarked of her friends, “the ones that have pain ... tell me that they exercise ... then others tell me about medications” (64/F/H). Across both Hispanic and non-Hispanic White subsamples, descriptions by participants provided specific evidence for the important role

similar others play in guiding their treatment choices.

### *Emotional support*

Consistent with predictions from homophily theory, participants also frequently turned to others with similar experiences for emotional support “because they’ve been through it” (71/F/W). In particular, participants found the social sharing of the pain experience helped to normalize the experience and “helps me feel calm” (77/F/H). Also consistent with predictions from SST regarding an age-related focus on emotional gratification, participants turned to emotionally supportive relatives for reassurance when contemplating high-stakes treatment decisions, particularly surgical procedures. “I talked to my wife about ... building up my courage for the next knee replacement” (86/M/W). Another participant noted: “[My wife] was with me when I had the knee replacements ... and gave me all kinds of emotional support. She’s great” (66/M/W).

Hispanic participants in our sample described emotional support from relatives throughout the course of care. They frequently mentioned their family members, explicitly referring to the compassionate qualities of their relatives: “My son has a way of understanding me. He knows where I’m coming from and how I feel” (69/F/H). Another put it simply: “My brother understands” (61/M/H). Similar to non-Hispanic Whites, Hispanic participants emphasized the importance of emotional reassurance by family others when considering surgery: “I could not bear [the pain] any more... but [my daughters] helped me move forward.” (83/F/H). For both ethnic groups, compassionate interactions with close others were critical to fostering positive treatment discussions as well as assuaging concerns about invasive procedures.

### *Instrumental support*

Instrumental support from informal contacts was deemed an essential factor in decisions to pursue invasive treatments, particularly procedures with the potential to compromise the individual's functional ability. For example, one participant with two knee replacements explained the decision to undergo joint replacement was heavily based on "the fact that [my husband] was still active and had a car and could drive me" (75/F/W). Further clarifying that practical support was specific to having a surgical procedure, one participant stated: "My friend will be there to take me home because that's required ... Usually I go on my own" (70/F/W).

Hispanics participants also described the involvement of their relatives in routine medical visits and treatment decisions. For example, one participant noted that her sister attends all medical appointments: "Anything that happens she is there. If they give me medicine that might hurt me, she'll be there just in case" (67/M/H). Another noted, "[My son] will go with me to different doctors... wherever I have to go" (69/F/H).

In summary, our analyses indicated that both formal and informal networks were integral to participants' treatment decisions. Both Hispanics and non-Hispanic Whites deferred to formal network channels, especially regarding high-stakes treatments (i.e., strong pain medications, joint replacement) and physical interventions. For Spanish-speaking participants, adequate language competence by providers enhanced informational exchanges. With regard to informal networks, participants sought close others who bolstered their emotional stability. Across both ethnic groups, participants selectively involved others with similar pain conditions when pursuing highly invasive treatments, and emotionally close family members for procedures that compromised functional status. With regard to advice-seeking from informal networks, non-Hispanic Whites typically turned to close others who had formal medical training, whereas

Hispanics participants appeared to solicit advice from close others who had knowledge about home remedies and alternative healing practices.

### **Patients' Perceptions of the Decision-Making Process**

Participants' perceptions of the decision-making process were contingent upon the congruence between the support they *desired* and *received*. In keeping with SST, harmonious interpersonal interactions served to improve individuals' perception of the decision-making process through validation and encouragement. As one individual noted "[My husband] was very supportive. He knew it was a decision I needed to make and he didn't force me into it. He let me come into it in my own time" (71/F/W). Another put it similarly: "My daughters ... accepted what I decided and it was a good decision" (83/F/H). Participants further underscored the value of empathic interactions when gathering information regarding a treatment choice: "When you're given information you feel like you're part of an intelligent community of people who are out for your betterment. I've had a wonderful experience" (70/F/W). Such responses illustrate participants' focus on the interpersonal and emotional aspects of clinical decision making, even when describing informational exchanges.

For Spanish speakers, linguistic compatibility with their providers was essential to promoting positive perceptions of their medical encounters: "He's a great doctor... He's professional and friendly and tries to speak my language. He's always done everything well. Even though he is American he can speak Spanish" (63/F/H).

On the other hand, dissatisfaction with the treatment decision-making process was associated with pressure by others. One participant described her daughter's involvement: "As soon as something is wrong she wants to gear into action. Do this, do that, go here, go there. It

drives me mad ... She's very aggressive and wants me to do exactly what she says" (70/F/W). Another reported, "I was scared. I felt obligated to get the surgery by the doctor and others [friends] who scared me" (63/F/H). In general, conflictual interactions conferred deleterious effects for respondents wishing to feel supported in their decisions.

Within the Hispanic sample, it was common for participants to consult close others regarding their pain care and accept ongoing guidance from loved ones. Dissatisfaction with the decision-making process emerged when the participant selected a treatment that did not align with the recommendations by family members.

"If I had listened to [my son] I wouldn't have had [the surgery], but I was in pain and the doctor wanted me to have it. The day of the surgery [my son] begged me not to do it ... From that day until now I'm in a wheelchair. I cannot walk. [My son] was right. All those surgeries were not necessary" (69/F/H).

Overall, these results suggest that CMP patients' satisfaction with the decision-making process stems from emotionally-supportive interactions and adequate language competence by providers. These findings further extend predictions from SST to acknowledge the importance of emotionally meaningful interactions for older adults' treatment decisions. They also highlight the need for appropriate language services for Spanish-speaking patients.

## **Discussion**

Our findings offer an initial step toward understanding the relative function of *formal* and *informal* social networks in the decision-making process of chronic pain treatment. In general, our results support existing theoretical frameworks suggesting that older adults maintain a preference for social network members who offer emotional reassurance and stability, especially

in high-stakes treatment contexts (e.g., joint replacement). In addition, our findings underscore the salience of providers' language competencies in Spanish-speakers' perceptions of their treatment discussions.

A unique contribution of this study to the literature on CMP decision making was the investigation of CMP patients' perceptions of the decisional process, where congruence in patients' desired and received support was linked with increased satisfaction. Specific to our sample of older adults, empathic interactions were essential to individuals' feelings of validation in their treatment decisions, as were emotionally-nourishing behaviors and actions by close others. This finding may be viewed in light of theoretical predictions from SST regarding the importance of emotional gratification in later life as well as literature emphasizing the need for empathic communication and mutual understanding in provider education (Berkhof, van Rijssen, Schellart, Anema, & van der Beek, 2011).

Our results extend recent literature citing the importance of building a therapeutic relationship through patient-provider communication, especially as it facilitates patient understanding, trust, and patient-provider agreement on treatment (Street, Makoul, Arora, & Epstein, 2009). To promote a better understanding of treatment options among older patients, informational guidance by trained professionals should be conveyed in an emotionally palatable fashion, especially when describing invasive or high-stakes treatment options. Extending our qualitative findings, observational studies of patient-provider interactions should systematically examine dyadic exchanges in treatment visits to further evaluate successful communication processes (Figure 2).

When considering the spectrum of treatment options, participants selectively expanded

their informal support networks as they considered more invasive or risky procedures. Another novel finding was participants' preference for empathic understanding and tailored informational guidance from individuals who had first-hand experience with the procedure. Participants viewed experientially similar others as uniquely qualified to offer effective decision support, both as sympathetic confidants and as informal advisors regarding treatment options. Indeed, responses revealed feelings of validation and encouragement by others who had gone through a similar treatment choice. Future quantitative investigations should systematically examine this finding, especially among patients considering invasive treatments (e.g., joint arthroplasty).

Participants also sought family members for a range of decision support functions, a finding which aligns with literature citing the pivotal role that family members play in older adults' medical care (Gallant, Spitze, & Prohaska, 2007; Seeman, 2000) and treatment decisions (Washington, Burke, Joseph, Guerra, & Pasick, 2009). Participants' reliance on informal decision supports highlights the need for family-based healthcare. Specifically, family members should be engaged in the process of collaborative treatment planning and goal-setting with the patient. To expand upon the findings from this and prior studies, future research should investigate ways to promote "buy-in" from the family unit with the ultimate goal of helping patients feel comfortable and confident in their medical encounters (Figure 1).

Also unique to this study was a comparison of decision support preferences among Hispanic and non-Hispanic White CMP patients. Whereas prior quantitative research has pointed to Hispanics' dissatisfaction with their medical encounters (Morales, Reise, & Hays, 2000), our interviews yielded vivid descriptions of patients' experiences with their healthcare providers. Especially poignant was Spanish-speakers' inability to engage in in-depth treatment discussions

with providers who could not speak their language.

Our finding corroborates empirical research (Ransford, Carillo, & Rivera, 2010) and clinical perspectives (Coleman-Miller, 2000) indicating that language competence among providers is essential to enhancing patient-provider trust and communication, as well as evidence from a recent meta-analysis outlining the benefits of cultural and linguistic competency training on patient outcomes (Lie, Lee-Ray, Gomez, Berekyei, & Braddock, 2011). Access to high-quality interpreter services has been shown to promote positive communication and improve perceived healthcare quality among non-English speakers (Flores, 2005). These findings, along with the results from the present study, reflect the need for system and practice change, including the engagement of bilingual providers and interpreters in treatment discussion. To maintain a patient-centered focus, it is paramount that future studies assess the impact of incorporating patient-identified features of cultural and linguistic competency into pain treatment delivery on clinically-relevant outcomes, including patients' treatment satisfaction and adherence.

### *Limitations*

The qualitative study design was selected to capture an in-depth understanding of CMP patients' social preferences; however, there are several limitations to this method. As is common in qualitative research, our analysis was based on a small sample of individuals. Moreover, participant selection was restricted to one medical center and senior center, both in New York City. Although we are confident that thematic saturation was reached, our findings do not generalize beyond our study population. To ensure generalizability and transferability of findings, a larger sample representing both individuals undergoing medical care *and* non-medically treated community-dwelling individuals is necessary. Moreover, the limited sample

size of this initial inquiry does not allow us to systematically examine relevant covariates or compare patients' preferences across treatment contexts. Therefore, future quantitative assessments should examine patients' preferences within specific diagnoses (e.g., osteoarthritis, low back pain) and treatments (i.e., joint arthroplasty, injections) and control for relevant covariates, such as patients' sociodemographic characteristics, intensity of pain, time since diagnosis, age stereotypes, and self-efficacy in pain management. Finally, it was outside the scope of this study to consider the vast heterogeneity within the ethnically defined "Hispanic" sample as well as the potential site differences between the outpatient clinic and senior center. Future research should aim to understand differences within Hispanic subcultures and across modes of treatment.

### *Conclusion*

In summary, this study provides an initial understanding of the social network structures underlying older adults' CMP treatment decision making. In particular, our findings indicate that emotionally-supportive guidance and validation by both formal and informal networks is critical to CMP patients confronting treatment decisions. From a practical perspective, a better understanding of patients' preferences could help to enhance patient-provider communication and mutual understanding. To this end, future research should aim to systematically investigate such preferences in diverse treatment contexts (e.g., joint replacement, physical therapy) and delineate decision typologies based on individuals' preferences. Overall, extending this line of research will pave the way for interventions to improve decision support for culturally diverse individuals with CMP.

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*Table 1. Sample Characteristics*

Variable	Non-Hispanic Whites	Hispanics	Difference Test
<i>N</i>	29	34	
% recruited from medical practice	100%	6%	<.001
Mean age ( <i>SD</i> )	76 (11.0)	70 (7.6)	<.05
% with college degree	93%	26%	<.001
% married	45%	29%	<i>n.s.</i>
% living alone	52%	71%	<i>n.s.</i>
% interviewed in English	100%	6%	<.001
% interviewed by telephone	86%	97%	<i>n.s.</i>
% Female	66%	56%	<i>n.s.</i>
Pain duration (years)	6.0 (5.7)	8.1 (10.5)	<i>n.s.</i>
Pain intensity level ( <i>SD</i> )	5.3 (2.6)	6.7 (3.4)	<i>n.s.</i>
% arthritis/joint pain	48%	56%	<i>n.s.</i>
% spinal/back pain	17%	12%	<i>n.s.</i>

*Note.* Pain diagnosis was coded from open-ended question (multiple responses possible). Pain level was assessed on an 11-point Likert scale. The percentages for arthritis/joint pain and spinal/back pain do not add to 100% because some participants reported the presence of multiple musculoskeletal disorders (e.g., fibromyalgia).

*Figure 1. Recommendation for Practitioners*

**Practitioners should consider:**

- Inquiring whether the patient has concerns regarding current pain treatments, and asking whether s/he has engaged in discussions with relatives or friends regarding his/her pain care that s/he feels would be important to share
- Offering to include key family members within office visits, especially when considering major treatment decisions, and emphasizing collaborative goal-setting and treatment planning across the course of care
- For patients considering surgical procedures, offering the names of patients who experienced good, neutral and poor outcomes (and who are willing to describe their experience with the procedure)

*Figure 2. Recommendations for Researchers*

**Researchers should consider:**

- Conducting observational studies of patient-provider interactions to evaluate successful communication processes
- Assessing the benefits of incorporating patient-identified features of cultural and language competency into pain treatment visits on clinically-relevant outcomes, including patient treatment satisfaction and adherence
- Investigating strategies to promote “buy-in” from family members and friends, with the ultimate goal of helping patients feel comfortable and confident in their medical encounters

APPENDIX

Cover Sheet #: \_\_\_\_\_

Interviewer: \_\_\_\_\_

Date of Interview: \_\_\_\_\_

PATIENT INTERVIEW

Confidential: No information shall be presented or published in any way that would permit identification of any individual.

READ

Before we begin, there are a few points I need to cover:

1. I want to assure you that none of the information you give will be released in any way that would permit identification of you or your family.
2. Your participation in this study is, of course, voluntary.
3. If there is any question you would prefer not to answer, just tell me and we will go on to the next question.

First, I'd to get a general sense of the pain you're experiencing.

1. How long have you had the pain problem?

Months

Years

2. During the past month, how many days did you cut down on your usual activities because of your pain? Would you say...

(Read Responses)

0 days - 1

1-7 days - 2

8-14 days - 3

≥ 15 days - 4

REF - 7

DK - 8

NA - 9

3. Thinking about your pain, please rate the pain/discomfort you are experiencing **right now** on a scale of 0 –10. A "0" means you are experiencing no pain/discomfort whatsoever at this time and a "10" means you are currently experiencing the worst pain/discomfort you can imagine.

1. How about **in the past week?** Please rate the pain/discomfort you have experienced

this past week on a scale of 0 – 10. Same as before, a "0" means you are experiencing no pain/discomfort whatsoever at this time and a "10" means you are currently experiencing the worst pain/discomfort you can imagine.

## COMMUNICATION AND DECISION-MAKING

We're interested in learning about whether you talk with or seek advice from others when making decisions about pain treatments, like joint replacement or taking a strong pain medication. Some people consult their doctors, spouses, adult children or friends while others don't. We're interested in hearing about whether you prefer to make decisions alone or whether there's a particular person you turn to for advice.

- I. *Has there been a situation where you've talked with someone (your doctor, a family member or friend) about getting a particular treatment or procedure? (Clarify: can you give an example of a decision you've had to make in the past year when you've reached out to someone for advice?)*

Probes:

- a. What was the decision about? (What type of treatment?)
- b. When was this? Was this the most recent time you made a treatment decision?
- c. Who did you turn to first for advice?
- d. Were there other people involved in this decision other than that person?
  - i. How much influence did each of those people have in your decision?
  - ii. Did you find their feedback/advice helpful? How has it been helpful/harmful?
  - iii. Did you change your mind about the decision after talking it over?
  - iv. Did you tell other people about your decision without soliciting their feedback?/advice  
e.g., was there anyone you wanted to inform, but not necessarily consult?  
e.g., why did you decide to tell them instead of asking for their opinion or advice?  
e.g., did that person/people support you in other ways (practical or emotional)?
  - v. If participant did *not* consult with others, why not?

e.g., no one to turn to

e.g., prefer to make the decision by self

e.g., didn't need help

vi. Have you turned on other kinds of media to inform your decision?  
(websites, TV ads?)

e. What about other external influences? For example, have financial constraints have gotten in the way of getting certain treatment?

II. *What kinds of treatment decisions do you usually talk over with your physician (or other health care providers, e.g., physical therapists, alternative medicine) or seek their opinion?*

III. *Do you turn to relatives or friends for advice?*

IF YES, probes:

- a. Do any of your close friends or family have the same (or similar) pain condition to you? (Follow-up: What does s/he do to cope with the pain?)
- b. When or why do you turn to your physician instead of your relative/friend (or vice versa)?
- c. Does anyone accompany you to your doctor appointments (e.g., adult child, spouse)? What is his/her role at the visit? Do you find his/her presence helpful?
- d. Have you ever been in a situation where you received contradictory feedback from your physician and a relative/friend?
- e. Did you (have you ever) change(d) your mind about the decision after talking it over?
- f. How important is discussing treatment decisions with your physician, or a close relative or friend?

IV. *In general,*

- a. How did your decision ultimately play out? In other words, can you walk me through an important conversation you had that shaped the outcome of your decision?
- b. Have you been pleased with the outcomes of your treatment decisions? Are

you generally satisfied with the treatment you've received?

- i. Can you give an example of a good decision? An example of a bad decision?
  - ii. Do you think your (dis)satisfaction with your treatment was a result of the decision-making process or the way the decision was made?
- c. Have you ever felt forced or pressured into a decision? By whom? Under what circumstances?

## APPENDIX

### **Decision-Making and Pain Management**

#### **Coding Guide**

1. Situations in which an older person in pain seeks counsel or discusses treatment choices regarding their pain
2. Characteristics of the decision, such as the use of formal (e.g., Western healthcare systems, physician consultation) versus informal (e.g., alternative medicine, friends and family) modes of treatment
3. Patients' perceptions of the joint decision-making process (e.g., decisional conflict and satisfaction)

## *Background/Contextual Information*

- **Interview-level codes and "descriptor fields"**
  - **Age**
  - **Gender**
  - **Education**
  - **Marital Status**
  - **Living arrangement**
  - **Race/ethnicity**
  - **Medical condition**
    - Spinal stenosis
    - Back pain
    - Arthritis (osteoarthritis or rheumatoid arthritis)
    - Neuropathic pain
  - **Pain duration**
  - **Pain rating - current**
  - **Pain rating - week**
  - **Comorbid conditions**
  - **Presence of another during the interview**

## ***Context of the Treatment Decision***

\*\*\* Please remember to code only when the excerpt explicitly states information (i.e. do not infer meaning from a statement).

\*\*\*ALSO remember to include any and all codes that can be applied to an excerpt.

- **Type of treatment**

- **Medication**

- *Clarification:* this code pertains to prescription and OTC drugs
- *Examples:* OTC medications (e.g., Aspirin, Tylenol), RX medications (e.g., oral pain relievers, steroids, topical cream), injections (e.g., cortisone shots, infusions) and patches

- **Surgery**

- *Examples:* hip or knee replacement, surgery for arthritis in fingers / wrists

- **Physical Interventions**

- Includes self-directed exercise (e.g., dance/stretching, yoga, self-initiated exercise classes or movement) and formalized exercise: physical therapy

- **Alternative treatments**

- *Clarification:* alternative treatments cover only non-pharmacological and non-nutritional aspects of treatment
- *Examples:* acupuncture, meditation, massage, seeing chiropractor, church/faith based healing

- **Nutrition**

- *Clarification:* this code is distinct from “medication” because it pertains to herbal treatment, supplements and changes in nutrition habits as opposed to prescription and OTC medications found in a drugstore
- *Examples:* calcium supplements, tea, nightshade vegetables

## ***Involvement in Treatment Decisions***

- **Individuals involved in treatment decisions**

- *Clarification:* use this code even if participant wasn't necessarily seeking advice, but still involved someone in his/her decision making process
- *Example:* participant told doctor that she wanted to get surgery, but didn't necessarily solicit advice
  - **Health care professionals**
    - Includes generalist practitioners and specialists (e.g. primary

care/geriatrician, surgeon, orthopedist, GI doctor, podiatrist, rheumatologist, gynecologist), mental health specialists (e.g. psychiatrist, psychologist, social worker), physical health specialists (e.g. physical therapist) and other formal health care providers (e.g. nurse, home health aide)

- **Alternative health care providers**
  - *Examples:* acupuncturist, spiritual healers, chiropractor
  
- **Relatives**
  - *Clarification:* use this code when a participant mentions anyone in his/her family who is involved in the treatment decision, even if the participant wasn't necessarily seeking advice from that person.
  - *Examples:* adult child, spouse, sibling
  - **Relative with formal medical knowledge**
    - *Clarification:* use this code when the family member specified also has formal medical education or background. Could be someone the patient would not necessarily turn to first under other circumstances, but the individual's medical expertise drew the patient to him/her.
    - *Examples:* sister-in-law is a physician; adult child is a OT
  - **Relative with alternative/home remedy knowledge**
    - *Clarification:* use this code when the family member has knowledge about home remedies or alternative treatments. This code is distinct from "relative with formal medical knowledge." It pertains to individuals with knowledge of non-Western healing practices, such as yoga, herbal supplements or natural elixirs.
    - *Examples:* adult child creates natural elixir to soothe pain
  
- **Immediate (non-family) social network**
  - *Clarification:* this code may either refer to someone the respondent specifically solicited advice from or someone the respondent happened to speak with at random.
  - *Examples:* colleague, neighbor, friend; random person in the doctor's office, a neighbor who was walking by, etc.
  - **Acquaintance/friend with formal medical knowledge**
    - *Clarification:* use this code when the acquaintance/friend specified also has a formal medical education or background. Could be someone the patient would not necessarily turn to first under other circumstances, but the individual's medical expertise drew the patient to him/her.
    - *Examples:* sister-in-law is a physician; family friend is a physical therapist
  - **Acquaintance/friend with alternative/home remedy knowledge**

- *Clarification:* use this code when the family member has knowledge about home remedies or alternative treatments. This code is distinct from “acquaintance/relative with medical knowledge.” Instead, this code pertains to individuals with knowledge of non-Western healing practices, such as yoga, herbal supplements or natural elixirs.
  - *Examples:* acquaintance creates a topical ointment from plants, friend makes elixir from natural ingredients and/or home goods
  
- **Support provided by other**
  - **Emotional support provided by other**
    - *Clarification:* use this code when the respondent mentions empathic or compassionate qualities of the social network member. (For example, a respondent might mention that her spouse is a good listener or that her adult child is someone she can trust.) This code can also be used to describe an interaction with a close other, such as when a patient receives a hug so she feels more emotionally close to him. A participant might also refer to the cultural sensitivity of the doctor (e.g., the doctor also speaks Spanish, understands cultural background (gives blessing at visit)
    - *Examples of empathic qualities:* individual is caring/ understanding, is a good listener, someone who can be trusted, someone who PT feels emotionally close with, can relate to, someone who can be trusted, is open-minded, someone who is easy to communicate with.
  
  - **Instrumental support provided by other**
    - *Clarification:* use this code when a respondent describes a situation in which someone provides practical help, such as assisting with daily tasks, or referring the patient to a provider. This code also is distinct from “informational support.” It is used to capture when a network member provides ACCESS to information (NOT information itself).
    - *Examples:* husband drives patient to appointments, friend offers referral to a specialist, adult child helps participant access information (i.e. research medications on the computer, find providers by phone)
  
  - **Informational support provided by other**
    - *Clarification:* use this code when the respondent specifies receiving information about a certain treatment (e.g., advice, guidance, suggestions for treatment options, etc.), regardless of whether the advice was solicited/unsolicited or desired/undesired. This code is divided into information by *expertise* (given by someone who is an expert on a topic) vs. information by *experience* (given by someone who also suffers from pain or who has gone through a similar treatment).

- **Information by expertise**
  - *Clarification:* use this code when the individual offering the information/advice has expertise about a certain treatment or remedy. This code is further categorized into two sub-codes pertaining to a) mainstream medicine; b) alternative medicine/home remedies
  - **Medical expertise/knowledge**
    - *Clarification:* this code pertains to information offered about mainstream Western medicine. Use this code when the participant explicitly mentions a *doctor's* expertise or medical knowledge OR a *friend/relative/acquaintance's* medical knowledge.
    - *Examples when referring to doctors:* the doctor should know what course of treatment is best because s/he is a medical expert; the doctor has the necessary medical training to inform the decision; physician offers information about side effects of a prescription drug; respondent went to doctor because he/she is well respected in the field/well-known.
    - *Examples when referring to friends/relatives:* family friend is a physical therapist, acquaintance is a physician, sister-in-law is a physician
  - **Alternative/home remedy knowledge**
    - *Clarification:* this code pertains to information offered about alternative medicine/home remedies, such as yoga, herbal supplements or natural elixirs.
    - *Examples:* acquaintance creates a topical ointment from plants, friend makes elixir from natural ingredients and/or home goods, family friend offers advice on acupuncture, patient seeks advice about specific herbal supplement
- **Information by experience**
  - *Clarification:* use this code when a participant mentions speaking with a close other who has gone through a similar treatment or has a similar pain condition. This code may also be used when a participant draws inferences about another person's pain and uses those inferences to formulate his/her own treatment expectations or to inform his/her treatment decisions (e.g., saw what a sibling went through when dealing with arthritis).
  - *Examples:* a participant might ask a friend about what to expect from surgery; a respondent might say she talked with her friends about her arthritis because her friends also have pain; a respondent might reflect back on a parent's experience with pain to inform her own decisions about treatment (e.g., mother had good experience with surgery so patient decides to pursue surgery too); a participant might

see a close friend use physical therapy successfully to alleviate pain.

- **Reason for not turning to others**

- **To protect others**

- Clarification: use this code when a respondent says he does not want to bother others by discussing pain symptoms.
- *Examples:* doesn't want to burden others by discussing pain

- **Self-Reliance**

- Clarification: use this code when a respondent describes self-efficacy in pain management. The respondent might mention personal qualities (e.g., independent, self-motivated) or behaviors (e.g., using previous experience or media) to show self-reliance. A respondent who is self-reliant will view himself as the primary decision-maker or someone who does not need input from others.
- *Examples:* views self as independent, can manage alone, everyone is different: what works for others might not work for individual, others can't tell you how you feel, patient already has a plan and doesn't need advice, relies on media instead of people (studies in medical/science journals, browses the internet), draws on previous experience or observes experience of another to inform self-management

### *Perceptions of the Decision-Making Process*

- **Negative view of medical doctor**

- *Examples:* distrust/skeptical of doctors and/or Western medicine, physicians are closed-minded, doctors do not listen, doctors are overworked and tired, doctors are busy, or feeling belittled by doctors

- **Pressure by others**

- *Clarification:* use this code when the patient mentions feeling forced into a decision or to pursue a treatment by a close other (family, friends, or providers).
- *Examples:* patient is ordered by the doctor to take medication; adult children force the patient to see a doctor or to pursue surgery

- **Conflicting or divergent views**

- *Clarification:* use this code when there is discord among social network members regarding the patient's course of care (e.g., the patient may disagree with his doctor's opinion or with the views of his family members or friends). This code should also be applied to excerpts describing a disagreement between close others (e.g., spouse and adult child disagree about

- treatment decision), between health care professionals (e.g., specialist and GP have different perspectives) or health care professionals and close others (e.g., spouse does not agree with doctor's opinion).
- *Examples:* doctor suggests a treatment and patient refuses; patient requests surgery and doctor thinks it is not a good idea; friend tells patient to see a doctor and patient does not want to; adult children do not agree with patient's treatment decision

### ***Decision/Treatment Satisfaction***

- **Dissatisfied/regrets treatment**

- *Clarification:* the code "dissatisfied/regrets treatment" should be used when a patient's expectations are met by ineffective or sub-par treatment (signaling a mismatch between expectations and outcomes).
- *Examples:* treatment is time consuming and onerous (e.g., exercise is too time-intensive), treatment is painful, treatment has side effects (e.g., soreness from injections), treatment was not effective (e.g., required another knee replacement after first one), short term effectiveness (e.g., built up a tolerance after many years of usage; treatment was only short-term), treatment didn't work/no good solution; treatment caused negative experiences

- **Satisfied with treatment**

- *Clarification:* participant explicitly states that the procedure/treatment improved previous pain levels or functioning. Typically, the interviewer explicitly asks the participant if she/he was satisfied and why, and the participant subsequently offers a reason. Use this code even if treatment was effective only in the short-term, then use "dissatisfied with treatment" if the patient mentions the treatment stopped working. Both satisfaction and dissatisfaction can be used to code the same excerpt if the patient first mentions effectiveness, then relapse; treatment caused positive experiences
- *Examples:* a participant is pleased that the surgery improved her mobility; a respondent expresses that physical therapy helped with morning stiffness.

## CHAPTER 3

### JOINT REPLACEMENT CANDIDATES' DESIRE FOR AND RECEIPT OF DECISION SUPPORT WHEN CONSIDERING SURGERY: IMPLICATIONS FOR DECISIONAL CONFLICT AND WILLINGNESS TO UNDERGO SURGERY

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## Abstract

**Objectives:** Appropriate decision support for total joint replacement (TJR) is an under-investigated, but highly critical aspect in promoting optimal decision making for patients considering this procedure. The present study investigates the types of decision support that TJR candidates desire and receive when making the decision to pursue surgery. Specifically, we consider the social structural (relationship to the patient) and experiential factors (having had TJR) that influence individuals' decision support preferences as well as the role of age in support provision and receipt. We then examine whether higher congruence in desired and received support is linked with reduced decisional conflict and greater willingness to undergo surgery.

**Methods:** A telephone survey was conducted with 50 individuals (aged 40+) who were contemplating knee or hip replacement. Interview questions assessed sociodemographic and personal characteristics, social network composition and structure, desired and received decision support, pain symptoms and location, decision conflict, and willingness to undergo surgery.

**Results:** Analyses indicated that TJR candidates desired and received decision support from both formal and informal network sources, including health care providers, family members, and individuals who had previously undergone TJR. With regard to type of support, respondents more often desired and received informational and emotional support than instrumental support. There were no age differences in individuals' desire for or receipt of informational, emotional, or instrumental support. Overall, respondents experienced lower decisional conflict when they reported higher congruence in the emotional support they desired and received and greater willingness to undergo surgery when they reported higher congruence in the instrumental support they desired and received.

**Discussion:** This research provides an initial understanding of TJR candidates' social support preferences during decision-making, and underscores the importance of empathic interactions and practical assistance in reducing decisional conflict and uncertainty among individuals considering joint replacement.

## Introduction

Arthritis is a leading cause of pain and disability among individuals aged 60 and above (CDC, 2010). Total joint replacement (TJR) has been shown to be a cost-effective (Daigle, Weinstein, Katz, & Losina, 2012) and efficacious treatment for this condition, both in terms of improving health-related quality of life (Ethgen, Bruyere, Richy, Dardennes, & Reginster, 2004) and physical outcomes (Vissers, Bussmann, de Groot, Verhaar, & Reijman, 2013). Yet only 10% of individuals who are appropriate candidates for TRJ are willing to undergo surgery (Hawker, Wright, Coyte, Williams, Harvey, Glazier, & Badley, 2000). Given this discrepancy, accumulating research has attempted to identify the individual and contextual factors contributing to variation in patients' decision to pursue TJR.

At present, the majority of quantitative research on TJR has considered the individual-level characteristics associated with the choice to pursue surgery, including patients' pain symptoms (Woolhead, Donovan, Chard, & Dieppe, 2002) and sociodemographic characteristics (i.e. age, income, gender, living arrangement, rurality, ethnicity; Hawker et al., 2000; Karlson, Daltroy, Liang, Eaton, Katz, 1997; Modi, Veillette, Gandhi, Perruccio, & Rampersaud, 2013). Less research, however, has examined the broader social context or psychological processes involved in patients' decisions or willingness to pursue TJR. Instead, studies incorporating psychosocial dimensions of TJR decision making typically focus on the link between social support and health-related quality of life *after* the surgery is complete (Ayers, 2004; Badura-Brozo et al., 2009; Escobar, Quintana, Bilbao, et al., 2007; Ethgen, Vanparijs, Delhalle et al., 2004; Fitzgerald, 2004; Sepucha et al., 2013). Importantly, a better understanding of the psychosocial factors underlying patients' decisions to pursue TJR may help promote patient-

centered decision assistance for individuals considering this invasive procedure.

In this paper, we contribute to the present literature on patients' pursuit of TJR by examining the types of decision support individuals desire and receive when considering surgery. In particular, we examine whether certain social structural (i.e. network member's relationship to patient) and experiential characteristics (i.e. network member's prior *successful* or *unsuccessful* experience with TJR) influence the sources (e.g. physician, relative) and types of decision support (i.e. informational, emotional, instrumental) that individuals desire and receive when contemplating surgery. We approach our investigation from a lifespan perspective by considering how patients' age may be associated with support seeking and receipt.

In the following sections, we present relevant theoretical frameworks derived from psychology and social gerontology as well as a review of the literature on patients' decisions to pursue TJR. Guided by these theoretical perspectives and empirical studies, we outline several hypotheses regarding the types and sources of support that patients desire and receive when considering TJR, and whether congruence in desired and received support is linked with (i) decisional conflict and (ii) willingness to pursue surgery.

*Definitions.* Following prior literature, our study defines subjective *decisional conflict* as the "state of uncertainty about the course of action to take" (p. 25; O'Connor, 1995). We also examine *willingness to undergo surgery*, or the self-reported likelihood that the TJR candidate will pursue surgery (e.g. certainly will, undecided, certainly will not). With regard to social support, this paper differentiates three commonly described dimensions (Cohen & Willis, 1985; House, 1981; Thoits, 1982): *informational* (provision of knowledge or advice), *emotional* (reassurance and empathetic listening), and *instrumental* support (tangible assistance with a

practical problem). Also following prior definitions of social support systems (Caplan, 1974), we examine both informal (i.e. family members, friends who have been through surgery) and formal sources (healthcare providers) in patients' decisions to pursue surgery.

## **Decision Support for Joint Replacement**

### *Theoretical Frameworks*

Perspectives from psychology and social gerontology offer guidance as to the potential mechanisms linking social networks and support provision with the choice to undergo joint replacement. On the one hand, theoretical frameworks propose that social structural norms and expectations may influence support provision and receipt from one's formal and informal networks. In particular, sociological perspectives propose that individuals' social support selection is contingent upon the salience of the relationship between the caregiver and care recipient, where kinship is a key dimension predicting support selection (Cantor, 1979). Following social norms, family members are traditionally expected to offer practical aid (Messerli, Silverstein, & Litwak, 1993) and emotional comfort during times of stress (Cohen & Willis, 1985; Thoits, 2011). In addition, norms of filial responsibility propose that adult children, in particular, should be the major sources of material aid and practical assistance to aging parents (Gans & Silverstein, 2006).

Such models have been extended to include formal networks, proposing that the "dual specialization" of informal and formal systems will promote optimal support for the impaired individual (Litwak, 1985; Noelker & Bass, 1989). Healthcare providers, for example, may be chosen over family during times of illness (Messerli, Silverstein, & Litwak, 1993) and are expected to serve as expert advisors regarding health-specific resources and information

(Brashers, Goldsmith, & Hsieh, 2002). Given these considerations, it appears logical that structural norms will predict patterns of decision support seeking and receipt among TJR candidates, especially regarding their preference for practical and emotional support from family members and informational support from providers.

On the other hand, homophily theory (Thoits, 2011) argues that effective support provision is likely to stem from others who have experienced similar stressors or situations. It is proposed that because experientially similar others have first-hand knowledge of coping with a particular illness or life event, they may possess the unique ability to validate others' emotions and concerns and offer detailed advice by providing specific health-related information and knowledge (Gage, 2013; Thoits, 2011). In the present study, experiential similarity explicitly refers to individuals who have previously undergone TJR.

Insights from behavior economics also offer support for the role of experientially similar others in TJR decision making. According to predictions derived from prospect theory, optimal decision making may largely depend on an individual's ability to accurately predict how s/he will feel in the future (Loewenstein, 2000). As such, experientially similar others may provide a valuable window into the future by serving as means of predicting one's future emotional states, also known as affective forecasting (Loewenstein, 2000). Applying this concept to the context of TJR, individuals considering surgery may seek the perspectives of others who have previously undergone joint replacement to limit projection biases (failure to predict one's present state onto one's future state; Loewenstein, 2005) and determine their preferences based on others' prior experience with TJR.

We have pointed to a number of theories leading to predictions regarding the social

structural (relationship to the patient) and experiential (similarity in undergoing TJR) characteristics that may influence TJR patients' patterns of support seeking. Below we review the available evidence from empirical studies of TJR decision-making to illustrate how these predictions map onto prior research and inform our hypotheses regarding patients' preferences for the types and sources of decision support they desire and receive when considering TJR.

### *Empirical Evidence*

Both structural and experiential factors have been shown to predict patterns of support seeking and receipt among individuals considering TJR. With regard to informational support, qualitative research exploring arthritis patients' decision to pursue one of two surgical treatments found that patients turn to medical providers for their professional opinion, but rely on others who have previously been through TJR for personalized guidance (McHugh & Luker, 2009; Zaidi, Pfeil, Macgregor, & Goldberg, 2013). Other qualitative studies have documented a similar pattern of effects, where the perspectives of individuals who have previously undergone TJR are highly influential in shaping patients' attitudes toward surgery, both in lieu of (Clark et al., 2004) and supplementary to physician guidance (Dosanjh, Matta, & Bhandari, 2009; Zaidi, Pfeil, Macgregor, & Goldberg, 2013). Although qualitative research has established that older adults considering joint replacement rely extensively on others who have been through the procedure (Clark et al., 2004; Dosanjh, Matta, & Bhandari, 2009; Parks, Herbert-Beirne, Roja, Tuzzio, Nelson, & Boutin-Foster, 2014; Zaidi, Pfeil, Macgregor, & Goldberg, 2013), it is unclear whether this reliance is systematically linked to patients' desire for specific support types.

Quantitative research has suggested that simply knowing someone who has undergone a successful joint replacement may positively influence patients' willingness to consider the

procedure themselves (Hawker, Wright, Badley, & Coyte, 2004), but that patients may be deterred from pursuing surgery if the procedure did not go well for the other (McHugh & Luker, 2009). Because individuals who have been through a *successful* versus *unsuccessful* surgery appear to bear differential influences on prospective TJR patients' decisional outcomes, our study considers these two sub-groups of experientially similar others separately.

In addition to informational guidance, the decision to pursue surgery almost inevitably requires practical assistance by others (Showalter, Burger, & Salyer, 2000). Yet, with rare exceptions (McHugh & Luker, 2009; Toye, Barlow, Wright, & Lamb, 2006; Sjöling et al., 2005), studies exploring joint replacement have overlooked the salient component of instrumental support. Critically, concerns about dependency following surgery (e.g. getting to medical appointments, time commitments, trouble with activities of daily living) may be a vital part of the decision (Toye, Barlow, Wright, & Lamb, 2006). Prior to surgery, TJR candidates tend to solicit instrumental support by family members (Sjöling, Ågren, Olofsson, Hellzén, & Asplund, 2005). In turn, the reassurance of having this type of support in place has been linked with patients' sense of control over their decision to undergo the procedure (Sjöling et al., 2005).

With regard to emotional support, a recent review and meta-analysis reported that family members positively influence patient well-being through empathic interactions and compassionate care for their loved one (Martire, 2005; Martire, Lustig, Schulz, Miller, & Helgeson, 2004), which in turn may have implications for patients' treatment decisions regarding surgery. For example, a study of osteoarthritis patients considering TJR found that emotional encouragement by family members facilitated patients' choice to undergo the procedure (McHugh & Luker, 2009). Other research has shown that having emotional support by close

others helped TJR patients maintain continuity throughout the decisional process (Sjöling et al., 2005).

Based on the theoretical considerations and empirical evidence described above, we hypothesize that TJR candidates will primarily desire and receive informational support from their healthcare providers and others who have been through TJR, instrumental aid from close family members, and emotional reassurance from informal network ties including both family and friends.

### **Implications for Decision Conflict and Willingness to Undergo Surgery**

To this point, we have reviewed theoretical frameworks and empirical studies that shed light on the types and sources of support that patients may desire and receive when considering TJR. We further conjecture that the degree of congruence in patients' desired and received support may have important implications for their decisional conflict and willingness to pursuing surgery. Below we offer a rationale for how and why this may be the case.

#### *When Desired Support is Not Received*

Although little research has explicitly investigated the link between social support and pre-operative decisional conflict or willingness to undergo TJR, qualitative research with osteoarthritis patients waiting for surgery offers preliminary evidence of this association. Specifically, this research demonstrated patients' frustration and confusion when they failed to receive the informational guidance they desired from their providers (Sjöling et al., 2005). On the other hand, this study found that having informal support in place (i.e. instrumental assistance by family members) helped patients feel more secure in their decisions. For example, adequate instrumental support by others was described as an "extended arm," providing patients

with a greater sense of control over their decision. In addition, emotional comfort and reassurance by family members helped preserve patients' dignity in decision making and maintain a sense of meaning throughout the treatment process (Sjöling et al., 2005).

In related work, research with primary care patients has shown that when patients' support expectations are met by their health care providers, they report having significantly higher rates of satisfaction in their clinical interactions (Williams, Weinman, Dale & Newman, 1995). In turn, patients' satisfaction with interpersonal communication and shared decision making with their providers has been associated with greater decisional clarity and confidence in patients' decision-making (Edwards et al., 2004). Taken together, these studies suggest a potential pathway by which appropriate support provision by providers may reduce patients' decisional conflict through positive and empathic patient-provider interactions. Other research with arthritis patients similarly suggests that a high quality patient-provider relationship, combined with clear and balanced information is crucial to promoting decision clarity regarding surgical decisions (Zaidi, Pfeil, Macgregor, & Goldberg, 2013). For these reasons, we expect that higher levels of congruence in desired and received support will be associated with lower decisional conflict and greater willingness to pursue surgery among patients.

#### *Unsolicited Support or Pressure by Others*

Although the benefits of social support for patients undergoing surgical procedures have been thoroughly examined (see Rosenberger, Jokl, & Ickovics, 2006 for a review), some researchers argue that it is equally important to acknowledge social support as a "double edged sword," where both positive support and problematic support (perceived as unwanted, despite good intentions of the person who is providing it) may simultaneously exact an influence on the

patient (Revenson, Schaffing, Majerovitz, & Gibson, 1991). Studies examining this possibility have demonstrated that unwanted or unsolicited support may be noxious to patients' well-being. For example, research with rheumatoid arthritis patients has shown that receiving problematic (unwanted) support is associated with increased depressive symptoms in patients (Revenson, Schaffing, Majerovitz, & Gibson, 1991). Similarly, a study of coronary syndrome patients demonstrated that excess support is perceived as an additional source of stress for the patient (Boutin-Foster, 2005).

Importantly, unsolicited medical advice or pressure by others may also have implications for patients' decision conflict (Fitzsimons & Lehmann, 2004). According to the Ottawa Decision Support Framework (O'Connor, Tugwell, Wells, Elmslie, Jolly, Hollingworth, et al., 1998), an evidence-based, transdisciplinary model of medical decision-making, one of the primary determinants of high quality decision-making is patients' "perceptions of others," which includes both pressure and support. Although an adapted version of this decision aid has been pilot tested among patients choosing among options to prevent bone fractures (Cranney et al., 2002), research has yet to address the specific component of pressure, such as coercion, taking over, or removal of (physical) control from the patient in relation to patients' decisional conflict or willingness to pursue TJR.

### **Age-Related Differences in Decision Support Preferences**

In addition to investigating social structural and experiential factors, the present study also considers how patients' age may play a role in their decision-making processes. As a guiding framework, socioemotional selectivity theory (SST) offers a lifespan perspective of how age-related shifts in time horizons may result in age differences in motivation and emotion

(Carstensen, 2006). Specifically, SST posits that in young adulthood, when time horizons are perceived as expansive, information acquisition is prioritized. With advanced age, however, time horizons constrict and individuals prioritize emotionally meaningful experiences and social relationships over knowledge-gathering. Extending this framework to TJR decisions, it may be expected that older patients will show a greater preference for emotional support in the decision to pursue TJR and a reduced desire for informational support.

This developmental pattern of prioritizing emotional meaning over information has been confirmed in a recent meta-analysis considering age differences in information seeking and decision quality: in general, older adults tend to seek less pre-decisional information compared to younger individuals (Mata & Nunes, 2010). However, research has yet to systematically consider the role of age in TJR decisions, which is a critical step in understanding age differences in TJR candidates' decisional preferences.

Importantly, dyadic exchanges between older adults and their social network members may further influence the types of support older adults receive. According to the Social Input Model (Fingerman & Charles, 2010; Pitzer, Lefkowitz, Birditt, & Mroczek, 2008), social network members tend to be more gentle with older adults and offer them preferential treatment, which may stem from a variety of reasons varying from negative stereotypes about aging to respect for one's elders. Empirical work has substantiated this prediction, revealing that social network members often reinforce satisfying and meaningful relationships for older adults (Fingerman et al., 2008).

In the context of TJR, qualitative reports by physicians reveal a pronounced hesitation and reluctance to offer negative feedback to older adults, especially when the patient exhibits

signs of fatigue or concern (Gooberman-Hill et al., 2010). Overall, this dyadic process may contribute to older adults receiving greater emotional and less informational support when considering TJR than younger individuals, but again, this has yet to be tested in TJR candidates. Based on these theoretical frameworks and limited empirical evidence, we hypothesize that the older adults in our sample will seek and receive more emotional support rather than information support from their close social network members.

### **The Present Study**

The present study investigates the types of decision support individuals desire and receive when making the decision to pursue joint replacement surgery. Specifically, we examine the relative influence of structural (e.g., relationship to patient) and experiential factors (e.g., whether the decision network member had been through a *successful* versus *unsuccessful* TJR) in determining the types of social support (i.e., emotional, informational, instrumental) that patients desire and receive when making the decision to undergo TJR. In parallel, we consider potential age differences in patients' preference for emotional versus informational support. We further examine whether the congruence in desired and received support is linked with TJR candidates' subjective decisional conflict or willingness to undergo surgery. As noted, *decisional conflict* is defined as the "state of uncertainty about the course of action to take" (p. 25; O'Connor, 1995) including feeling uninformed, questioning personal values regarding alternatives, experiencing emotional distress as well as perceived pressures from important others; whereas *willingness to undergo surgery* is captured by an explicit measure of how likely the individual is to pursue TJR.

All analyses include several key covariates that were previously found to be associated with decision making and social network structure. Five-factor personality traits have been

linked with social network formation (Soldz & Vaillant, 1999) and health care decision-making styles (Flynn & Smith, 2007). In addition, poor health has been identified as a strong predictor of a weakened social network; therefore, physical health is included as a covariate (cf. House, Umberson, & Landis, 1988). Pain level and pain location (knee vs. hip) are also included as covariates given that increased pain has been linked with patients' willingness to undergo surgery (Brander et al., 2003) and that knee (versus hip) replacement has been associated with less favorable pain outcomes after surgery (Beswick, Wylde, Goberman-Hill, Blom & Dieppe, 2012). Consistent with previous methodology, the total number of decision network members and general social network members was included as a covariate to adjust for differences in respondents' network size (Litwin, & Landau, 2000). Finally, because prior TJR experience may influence individuals' perceptions of and willingness to undergo a second TJR (Ballantyne, Gignac, & Hawker, 2007), this study includes only individuals who have *not* previously undergone joint replacement.

Based on the theoretical considerations outlined above, we propose the following set of hypotheses:

*Hypothesis 1: Composition of Decision Support Network.* Overall, we expect that TJR candidates' decision support networks will be comprised of both formal and informal network ties. Specifically, we predict that TJR candidates will desire and receive decision support from at least one network member from each of the following groups: healthcare providers, family members, non-relatives who have previously undergone TJR, and non-relatives who have not undergone TJR.

*Hypothesis 2: Support Desired and Received.* We expect that TJR candidates will desire

and receive all three types of support (informational, emotional and instrumental), but that their preference for and receipt of each type of support will vary by the type of decision network member providing it. In particular, TJR candidates will desire and receive *informational* support from healthcare providers and from non-relatives who have previously undergone TJR. Further, we predict *instrumental* support will be desired and received from family members, and that *emotional* support will be sought from informal network members, particularly family members and individuals who have previously undergone TJR.

*Hypothesis 3: Decision Conflict and Willingness to Undergo Surgery.* We hypothesize that larger, more diverse networks (i.e. comprised of both formal and informal network members), will be associated with lower conflict and greater willingness to undergo surgery. In addition, we predict that higher congruence in individuals' desired and received support will be associated with lower decision conflict and greater willingness to undergo TJR. Given the limited research in this area, we do not make concrete predictions regarding congruence in specific types of support.

*Hypothesis 4: Age Differences.* With regard to age differences, we expect that increased age will be associated with a tendency to solicit emotional rather than informational support from all sources. In addition, we hypothesize that older adults will rely on smaller decision support networks, with a specific emphasis on close family members.

## **Methods**

### **Participants**

Targeted strategies were used to recruit participants at various stages in the decision-making process, from pre-contemplation (i.e. respondents who were still considering whether or

not to pursue surgery) to active pursuit of joint replacement (i.e. respondents who had set a specific date for the procedure). Individuals were eligible for the study if they were aged 40 years and older and were either considering hip or knee replacement surgery and/or had been recommended for surgery by their physician.

A primary recruitment method was an electronic search of EpicCare health records at two outpatient practices in New York City. Participants were also recruited via flyering at senior centers, senior housing residences, and physician practices in New York State. Recruitment from these sites was supplemented by online advertising through a University affiliated e-list serve, by postings to web discussion boards for arthritis and joint replacement, and by recruitment from the Cornell Institute on Translational Research (CITRA) respondent pool of community-dwelling older adults who reported a history of chronic pain. All recruitment methods as well as the study protocol were approved by the Weill Cornell Medical College and Cornell University Institutional Review Boards. Overall, these diverse recruitment strategies enabled us to capture a broad range of individuals at across the full decisional spectrum (ranging from pre-contemplation to active pursuit of TJR).

Individuals were excluded if they were not fluent in English, had previously undergone joint replacement, or exhibited cognitive impairment, defined by a score of less than 3 on a 6-item screener (Callahan, Unverzagt, Hui, Perkins, & Hendrie, 2002). Of the 107 individuals screened, 57 were excluded due to cognitive impairment or prior joint replacement. The final sample consisted of 50 individuals, 86% of whom were women and all were non-Hispanic White.

## **Measures**

*Sociodemographic characteristics.* Respondent sociodemographic characteristics included age, race/ethnicity, gender, and education.

*Social Network Composition and Function.* Following previous methodology (Antonucci, 1987; Fingerman, Ha, & Birditt, 2004; Fischer, 1982; Pillemer & Suitor, 1996), information on the structure and function of participants' social networks was obtained through a detailed series of name elicitation questions. To respect respondents' confidentiality, they were given the option of identifying social network members by name, by a nickname, or by their relationship to the respondent.

Participants were asked to identify several categories of social network partners: a) individuals who provided decision support, b) individuals who did not provide decision support, but from whom support was desired, and c) other social network members. For each decision network member (DNM) named, data were collected on a) that social tie's *demographic characteristics* including age and gender (0 = *male*; 1 = *female*), b) *relationship to respondent* (open response coded into 0 = *family member*; 1 = *health care provider*; 3 = *non-family close other*), and c) *experiential similarity* regarding joint replacement (0 = *DNM had not experienced a joint replacement*; 1 = *DNM had experienced a joint replacement*). If the DNM had pursued surgery, the respondent was asked to what extent the surgery had helped the DNM (0 = *surgery did not help*; 1 = *surgery helped*).

An overall *DNM relationship* variable was created by combining the *relationship to respondent* and *experiential similarity* variables into the following categories (0 = *family member*; 1 = *health care provider*; 2 = *DNM with TJR that helped*; 3 = *DNM with TJR that did not help*; 4 = *non-relatives who had not previously been through TJR*). Each DNM was coded

into only category; they were mutually exclusive. This variable was used in all analyses.

Participants were then asked to indicate how often they desired and received support from each DNM. They were also asked to indicate a) how often that person had been a source of interpersonal stress (i.e. offered unwanted support or pressure) and b) lack of anticipated support (0 = *never*; 1 = *sometimes*; 2 = *often*; 3 = *very often*). To assess *informational support* desired and received, respondents were asked “How often does [DNM] give you advice or suggestions about your decision to get a joint replacement (never, sometimes, often, or very often)?” Followed by “Now, think about whether you actually want this type of support from [DNM]. If it were up to you, how often would you *want* advice or suggestions from [DNM] (never, sometimes, often, or very often)?” Similar questions were used to examine how often participants received and desired “comfort and reassurance” (emotional support) and “practical aid and assistance” (instrumental support) from each DNM.

As noted, the information above was collected for three types of social network partners: a) individuals who provided decision support, b) individuals who did not provide decision support, but from whom support was desired, and c) other social network members. Given the present study’s focus on decision support, the analyses for the present paper were only conducted for the individuals in group (a): individuals who provided decision support for TJR.

Following previous methodology used to examine social ties and support among older adults (Litwin & Landau, 2000), each type of support (informational, emotional, instrumental) received was summed within each DNM category (e.g. healthcare provider, family member) for each respondent. For example, if two healthcare providers were named by a single respondent, the amount of emotional support received from each was summed within the DNM category

“health care provider.” The same procedure was used for all other DNM categories and types of support desired.<sup>1</sup>

*Decision Conflict.* Participants responded to the low-literacy 10-item version of the Decision Conflict Scale (DCS) (Linder, Swank, Vernon, Mullen, Morgan, Volk, 2011). The DCS targets uncertainty about choosing among alternatives and modifiable factors contributing to uncertainty (e.g. feeling uninformed, unclear about values, unsupported/pressured in decision making). Overall, this scale has been shown to have satisfactory reliability and discriminates between individuals who make and delay decisions. (Present study  $\alpha = .81$ )

*Willingness to Undergo Surgery.* All participants were asked the question “How certain are you that you’ll get a knee/hip replacement?” (1 = *certain I will not*, 2 = *probably will not*; 3 = *could go either way*, 4 = *probably will*, 5 = *certainly will*).

*Personality.* Respondents’ personality was screened using the *10-Item Short Version of the Big Five Inventory* (BFI-10; Rammstedt, & John, 2007). Individuals rated the extent to which each personality characteristic was true of them, ranging from 1 (strongly disagree) to 5 (strongly agree). The BFI-10 is an acceptable measure of personality when time is limited, as in telephone surveys (Rammstedt, & John, 2007). Correlations between the personality characteristics ranged from -.60 to .32.

*Physical and Mental Health.* Two questions from the PROMIS Global Health Scale (Cella, Riley, Stone, Rothrock, & Reeve, et al., 2011) were used to assess overall self-reported health: “In general, how would you rate your physical health?” and “How would you rate your

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<sup>1</sup> Identical analyses were also conducted with averaged, rather than summed support. Results were comparable using both methods.

mental health, including your mood and your ability to think?" (1 = *poor*, 2 = *fair*, 3 = *good*, 4 = *very good*, 5 = *excellent*).

*Pain Level, Function, and Location.* Pain was assessed using an adapted version of the American Academy of Orthopaedic Surgeons Lower Limb Core Hip/Knee Module (MODEMS, 1996), a region-specific scale measuring pain level and ability to perform daily tasks.

Respondents were asked about their pain levels and ability to function when walking on a flat surface, going up/down stairs, sitting/lying down, putting on/off shoes or socks, toileting and bathing, and carrying out light housework. Response options were ranked according to severity, ranging from 0 (no pain) to 5 (extreme pain). The six items were summed to form a pain severity scale (Present study  $\alpha = .81$ ). Participants were also asked three questions (also adapted from MODEMS) to assess whether they suffered from knee or hip pain: "Do you have pain and/or stiffness in the front or the back of one or both knee(s)?" "Do you have pain or stiffness in the top of your thigh or groin?" and "Do you have any pain or stiffness in the top front section of your thigh?" (0 = *no*, 1 = *yes*).

## **Procedure**

After providing informed oral consent, each participant completed a structured telephone interview lasting approximately 60 minutes (range: 30 – 65 minutes) administered by a trained research assistant. During the interview, respondents' sociodemographic information (e.g., age, gender, education, income) was first collected, followed by an assessment of their current pain level and pain location (knee vs. hip). Following these introductory questions, information was next collected on the patient's social network composition and structure as well as the decisional support they desired and received. The final portion of the survey included measures of

respondents' personality. Several additional measures, not related to the core questions of this study were also included in the survey (i.e., patients' health literacy, expectations regarding realistic and ideal pain levels after surgery, aging stereotypes, time horizons, maximizing and satisficing tendencies, and risk tolerance). Participants' responses were entered into Qualtrics software, Version 2013 (Qualtrics, Provo, UT).

### **Data Analysis**

Preliminary univariate analyses were conducted to gain an initial understanding of a) TJR candidates' sociodemographic, pain, and personal characteristics, and b) decision network composition (i.e. percentage of healthcare providers, family members, non-relatives with prior TJR experience, non-relatives without prior TJR experience) (Hypothesis 1).

A one-way repeated measures analysis of variance (RM-ANOVA) examined differences in TJR candidates' desire for and receipt of each type of decision support (informational, emotional, instrumental) as well as differences across the types of support. In addition, bivariate correlations examined associations among respondent-level characteristics (i.e., age, gender, general health, pain level, pain location (knee vs. hip), personality, and network size), decision conflict and willingness to undergo surgery, and support desired and received.

Hypotheses concerning TJR candidates' desired and received support were conducted using a multi-level modeling framework. This type of structure was necessary to allow for simultaneous estimation of respondent-level and network-level effects and to accommodate the uneven distributions of social networks across participants. Two separate multilevel models were estimated for the total (summed) support that TJR candidates desired and received as dependent variables, with *type of support* specified as the index variable. Substantive predictor variables

and covariates that reached significance in preliminary bivariate analyses were entered into each model.

To further explore predictions from Hypothesis 2, an interaction term *type of support x DNM relationship to respondent* was added to allow for comparisons between the types and sources of support that TJR candidates desired and received. To examine Hypothesis 4, a separate interaction term *type of support x respondent age* was then added to explore which type of support older versus younger patients desired and received. In these models, age was dichotomized into individuals 60 years and younger and individuals 61 and older.

If an interaction reached significance, pairwise comparisons were planned to explore associations between *type of support x DNM relationship* (Hypothesis 2) and *type of support x respondent age* (Hypothesis 4). The first set of comparisons would examine the types of support TJR candidates desired from each of the DNM relationship categories (i.e. family members, healthcare providers, prior TJR patients who had undergone a successful surgery, prior TJR patients who had undergone an unsuccessful surgery, and all other non-relative close other). The second set would examine age differences in respondents' preferences for certain types of support over others. The same procedure was planned for support received.

The next set of analyses focused on TJR candidates' decisional conflict and willingness to undergo surgery as outcome variables. Specifically, Hypothesis 3 proposed that larger, more diverse networks and higher congruence between desired and received support would be associated with reduced decisional conflict and greater willingness to undergo TJR. To test this hypothesis, difference scores were first calculated for each type of support by taking the absolute value of the specific support type (i.e. informational, emotional, instrumental) received minus the

support desired. The difference scores were then entered as independent variables into two separate a Generalized Linear Models (GLM) with decision conflict and willingness to undergo surgery as the dependent variables. Each model also included covariates that were found to be significant in preliminary bivariate analyses.

## **Results**

### **Preliminary Analyses and Composition of Decision Network**

Of the total sample, 72% had knee pain and 28% had hip pain. With regard to willingness to undergo surgery, approximately half (42%; n=21) were certain or fairly certain they would pursue joint replacement at some point, 36% (18) were undecided, and the remaining 22% (n=11) were fairly or certain they would not pursue joint replacement. Participants generally reported good mental health and average physical health, aside from their pain condition. See Table 1 for sample characteristics.

Of the 50 respondents, 45 (90%) reported consulting at least one decision network member (DNM) in the decision to pursue surgery. The five respondents who did not list anyone in their decision network were excluded from subsequent multilevel analyses examining types of support desired and received. Of those consulting at least one DNM, 31 (69%) identified at least one healthcare professional, 29 (64%) listed at least one DNM who had been through surgery, and 21(47%) named at least one family member. On average, respondents consulted 6.5 network members regarding the choice to undergo TJR (range: 0 – 8). No one in the sample felt pressured into having TJR. Therefore, this variable is not reported below.

Across the 50 respondents, a total of 160 DNM were consulted regarding the choice to undergo surgery. Of the 160 DNM, 54 were providers (34%), 32 were family members who had

not previously undergone surgery (20%), 30 were individuals who had undergone a successful TJR (19%), 31 were individuals who had undergone an unsuccessful TJR (19%), and 10 were non-family close others who had not undergone surgery (6%).

In the repeated measures analysis, the overall  $F$  statistic was significant in predicting differences across the types of decision support desired and received,  $F(5, 155)=18.0, p < .001$ . Post-hoc comparisons using a Bonferroni correction showed that TJR candidates received less informational support than they desired ( $p < .001$ ), less emotional support than they desired ( $p < .05$ ), and less instrumental support than they desired ( $p < .05$ ). Post-hoc comparisons also indicated that respondents desired and received less instrumental support than informational ( $p < .01$ ) and emotional support ( $p < .001$ ). However, post-hoc analyses did not detect differences in respondents' desire for informational and emotional support, or receipt of informational and emotional support. (See Table 1 for means and standard deviations.)

Bivariate correlations examining associations between respondent-level characteristics (i.e., age, gender, general health, pain level, pain location (knee vs. hip), personality, and network size), decision conflict and willingness to undergo surgery, and support desired and received are presented in Table 2. Covariates that were significantly associated with the primary outcome variables were included in further analyses. Models predicting TJR candidates' desired and received decision support therefore included respondent age, the personality traits Conscientiousness and Neuroticism, DNM network size, and DNM gender (Table 3). The model predicting decision support included respondent age, gender, general health, and DNM network size (Table 4). Finally, the model predicting willingness to undergo TJR included respondent, age, general health, pain, personality traits Conscientiousness and Agreeableness, and DNM

network size (Table 5).

### **Hypotheses 2 and 4: Support Desired and Received and Age Differences**

The estimated fixed effects of each multivariate analysis are presented in Table 3. The significant *F* statistics are described in detail below.

#### *Support Desired*

*DNM gender* was a significant predictor of support desired, suggesting that respondents desired support more often from network members who were women. The personality trait *Neuroticism* was also associated with desired support, such that respondents who scored high on this trait were likely to desire more decision support. In addition, *Type of support* also reached significance, indicating that respondents desired more informational and emotional support than instrumental support. *DNM relationship to respondent* was significant, suggesting that respondents desired more support from healthcare providers compared to the reference group (non-family DNM without prior TJR). In addition, there was a modest association between network size and the desire for more support, such that respondents with a larger network desired more decision support. (Model 1).

Neither of the interactions reached significance (*type of support* x *DNM relationship to respondent*, Model 2; *type of support* x *respondent age*, Model 3). Therefore, post-hoc comparisons were not conducted.

#### *Support Received*

As with support desired, the variable *type of support* was also associated with support received, such that respondents received more support from healthcare providers compared to the reference group (non-family DNM without prior TJR). Compared with instrumental support,

respondents were more likely to receive informational and emotional support (Model 4).

Again, neither of the interactions (*type of support x DNM relationship to respondent, Model 5; type of support x respondent age, Model 6*) reached significance; therefore post-hoc comparisons were not conducted.

### **Hypothesis 3: Decision Conflict and Willingness to Undergo Surgery**

*Decisional Conflict.* In general, women were more likely to experience decisional conflict ( $B = 26.98, p < .01$ ), as were individuals with smaller decision networks ( $B = -5.08, p < .05$ ).

With regard to social support, findings suggest that a greater discrepancy in the emotional support respondents desired versus received was associated with greater decisional conflict ( $B = 6.04, p < .05$ ). On the other hand, congruence in informational ( $B = -2.08, p = n.s.$ ) and instrumental ( $B = 0.84, p = n.s.$ ) support did not significantly predict decisional conflict.

*Willingness to Undergo Surgery.* In general, TJR candidates who were younger ( $B = -.04, p < .001$ ), experienced better overall health ( $B = .47, p < .01$ ), but greater pain ( $B = .07, p < .01$ ) were more certain that they would undergo TJR. Contrary to predictions, a smaller decision network was associated with greater willingness to undergo TJR ( $B = -.07, p < .05$ ). With regard to personal characteristics, individuals who scored high on the personality traits of Conscientiousness ( $B = .24, p < .05$ ) and Agreeableness ( $B = .15, p < .05$ ) were more certain that they would pursue TJR. When considering social support, a smaller discrepancy in the instrumental support respondents desired and received was associated with greater certainty in the decision to undergo TJR ( $B = -0.29, p < .05$ ). Neither of the other discrepancy variables, informational ( $B = -0.08, p = n.s.$ ) or emotional ( $B = -0.05, p = n.s.$ ) reached significance.

## Discussion

The present study investigated the types of decision support patients desire and receive when considering TJR. Analyses also examined whether congruence in desired and received support was associated with individuals' decisional conflict and willingness to undergo surgery. In general, results offer partial support for our hypotheses.

With regard to experiential similarity, nearly two-thirds of respondents consulted at least one social network member who had previously undergone joint replacement. This general finding supports qualitative research documenting patients' reliance on others who have been through TJR (Clark et al., 2004; Parks et al., 2014; Zaidi, Pfeil, Macgregor, & Goldberg, 2013). However, multilevel analyses failed to detect differences among TJR candidates' preferred source of decision support. Respondents were equally likely to desire and receive support from their physicians, family members and others who had previously undergone TJR.

Nevertheless, this finding aligns with previous research concerning health advice-seeking, where family members have been deemed important sources of health information (Cook-Craig, Ely, Flaherty, Dignan, & White, 2012) especially among vulnerable patient populations (Wolff & Roter, 2008). It is also consistent with other research indicating that high quality patient-provider relationships help to promote collaborative decision making through positive interactions (Goberman-Hill et al., 2010). Overall, the lack of differentiation among these groups points to the potential for social network-driven approaches to meet TJR patients' desire for emotional reassurance in their decisions to pursue surgery. Specifically, future studies should assess the benefits of including informal network members, namely family members, in interventions for TJR candidates wishing to make informed and individualized decisions

regarding surgery.

Also contrary to expectation, we found no significant age differences in respondents' desires for and receipt of emotional versus informational support for TJR. However, it is important to note that most studies comparing age differences in information-seeking consider differences between young (ages 18-40) and older respondents (ages 65+). In contrast, our study sought to examine potential differences in support-seeking between middle-aged and older adults. Within our sample, participants' age spanned from 41 to 88 years and the distribution was skewed toward the older age-range. It therefore possible that our multivariate analyses may not have been sensitive enough to detect nuances between middle-aged, young-old and old-old respondents.

Nevertheless, this (non)finding should be acknowledged as a contribution to the growing literature on age differences in health decision support-seeking; one that should be viewed in the context of conflicting research in this area (Mata & Nunes, 2010). For example, there is some evidence to suggest that older and younger patients actually have similar informational and relational needs (Romito, Corvasce, Montanaro, & Mattioli, 2011) as well as similar patterns of advice-seeking from close others (Carlsson, 2000). Moreover, our finding corroborates domain-specific evidence that younger and older adults may not differ in their desires for medical information: In a meta-analysis of research on age differences in information-seeking, the general age effect for information-seeking virtually disappeared when comparisons focus explicitly on health decisions (Mata & Nunes, 2010).

Although our analyses did not detect age differences in TJR candidates' informational or emotional support preferences, it was clear from univariate analyses that respondents showed a

strong desire for emotional support from all network members. This general preference for positive interpersonal exchanges is consistent with predictions from SST regarding an age-related shift toward emotional gratification in later life, and may further reflect the high average age of our sample. It is also plausible that having functional limitations due to pain may have primed limited time horizons, and therefore altered respondents' preference for emotional rather than informational support. It should also be noted that none of the respondents in our sample mentioned feeling pressured and participants only rarely mentioned unwanted support. Again, this trend may be viewed in the context of prior literature suggesting that older adults prioritize harmonious interpersonal relationships by selectively "pruning" their social networks to weed out problematic or conflictual relationship ties (Luong, Charles, & Fingerma, 2010).

Analyses examining patients' decision conflict and willingness to undergo surgery further underscore the importance of matching the support TJR candidates desire and receive prior to surgery. In particular, greater congruence in the emotional support individuals desired and received was associated with reduced decisional conflict. Essentially, having an adequately emotionally responsive network may help to alleviate both emotional distress and feelings of pressure associated with TJR, both of which are salient features of the Decision Conflict Scale used in this study.

Whereas the measure of decisional conflict was designed to tap patients' general values and perceived pressures, the assessment of willingness to undergo surgery allowed us to examine patients' likelihood to pursue TJR. In this case, congruence in the practical support TJR patients desired and received was linked with their perceived likelihood to undergo surgery. It was also interesting that *smaller* network size was associated with a greater willingness to undergo TJR.

Overall, our findings regarding decisional conflict and willingness to undergo surgery suggest that, whereas emotional reassurance is critical to supporting patients' feelings and emotions regarding TJR, adequate practical assistance may be the ultimate determinant of whether or not surgery is a tenable option for the patient.

#### *Limitations and Future Directions*

Overall, the results from this study should be viewed in light of several limitations; namely, the modest sample size, cross-sectional design, and restricted sociodemographic focus. To address the issue of cross-sectionality, longitudinal assessments of the present sample are currently underway to determine whether congruence in individuals' received and desired decision support predicts their decisional regret at a 6-month follow up. The present study also sets the stage for other longitudinal investigations. One specific line of inquiry would be to follow joint replacement candidates across the decisional trajectory, starting at the first treatment discussion of TJR, to track their decisional conflict and certainty over time. This method would enable researchers and clinicians to ascertain the specific factors (e.g. decision support, self-efficacy in pain management) that may predict at what point individuals come to a decision. Subsequent interventions could then target the modifiable factors (e.g. sufficient emotional and practical support or access others who have already had the procedure) to promote a timely decision. This is an important line of work given prior literature demonstrating that the timing of TJR has strong implications for patients' recovery at a 2 year follow-up (Fortin, Penrod, Clarke, St-Pierre, et al., 2002).

A second consideration for future research will be to include measures of specific psychological (e.g. patients' coping styles, locus of control) and relational (e.g. relationship

quality, attachment) factors that could partially explain individuals' decisional network selection and need for emotional reassurance. For example, patients who have high self-efficacy in pain management or motivation may rely on internal resources, and therefore may not turn to others for emotional reassurance or comfort. Similarly, patients with poor relationship quality or low attachment to certain network ties may also perceive emotional support as unnecessary or unwanted from those individuals. Although prior research has examined several psychosocial characteristics in relation to post-operative outcomes (Ayers, Franklin, Trief, Ploutz-Snyder, & Freund, 2004; Kendell, Saxby, Farrow, & Naisby, 2001), a better understanding of these variables in pre-operative contexts would shed light on alternative patient-level characteristics associated with decision support selection.

Future investigations should also aim to compare knee versus hip replacement candidates with regard to decisional network composition and decisional conflict regarding TJR. A recent systematic review of prospective cohort studies of TJR found that a significantly greater proportion of knee replacement patients (20%) as compared to hip replacement patients (9%) report unfavorable pain outcomes after surgery (Beswick, Wylde, Gooberman-Hill, Blom & Dieppe, 2012). Surgical candidates may be aware of these pronounced differences in treatment outcomes, especially if they draw upon the experience of others or knowledge of healthcare professionals. Hip and knee replacement candidates may therefore differ with regard to their decisional conflict and desire for practical assistance as they weigh the benefits and drawbacks associated with each procedure. As such, adequately powered studies should aim to examine the unique role of experientially similar others in hip versus knee replacement candidates' decisional conflict and expectations regarding treatment.

Despite the clear need for future research to address the caveats noted above, our study extends prior research in several ways. Unlike other studies, we did not restrict our sample to patients who were referred for evaluation for TJR or who were scheduled to have surgery. Instead, we included patients who fell at any point on the decisional spectrum from *pre-contemplation* (i.e. individuals who were unsure of whether or not they will have the procedure) to *active pursuit* of TJR (i.e. individuals who had set a date for the surgery) to *complete rejection of the procedure* after it had been proposed by a physician. This design allowed us to examine the types of support necessary for individuals at any stage in the decision-making process. Our study is also unique in its focus on decision support networks for TJR patients. To our knowledge, no other studies have quantitatively investigated this area. Moreover, assessing all three support types (informational, emotional and instrumental) offered a more holistic perspective than prior studies which have predominantly focused on advice-seeking, generally neglecting the salient component of instrumental aid. A final key contribution of this work was assessing whether congruence in desired versus received support was associated with TJR patients' decisional conflict.

### *Practice Implications*

Our findings also have several implications for patient care. In this study, both family members and others who had been through a successful TJR were key sources of information for individuals considering surgery. As liaisons between patients and their social networks, healthcare providers can assist patients in receiving adequate decision support by asking patients about the support they desire from non-medical sources, and involving family members in treatment encounters, as appropriate. Given that family members may be important non-medical

sources of informational, emotional and instrumental support, it is critical that they not only have accurate information about the procedure, but also the ability to provide emotional support and practical aid throughout the decision-making process. Instrumental support by family members may be especially vital to set in place prior to surgery. Physicians should therefore work with the patient and family to ensure adequate practical assistance leading up to and following the procedure.

In addition, clinicians should emphasize compassionate interactions with their patients and familiarize themselves with the resources and clinical tools available from the Physicians for Compassionate Care Education Foundation (Oregon, 1996). A final recommendation for physicians, especially orthopedic surgeons, is to follow up with former TJR patients about their interactions with friends or acquaintances considering surgery. This is critical given that former patients may in turn be informational resources for individuals considering the procedure.

Taken together, the findings from this study may help physicians to understand why certain patients may or may not be ready to pursue TJR. Moreover, given that both formal and informal decision network members were sought for a spectrum of support functions, future research should aim to incorporate these various perspectives in subsequent studies of TJR decision making. Overall, this research provides an initial understanding of TJR patients' decisional preferences and points to the need for social network-driven strategies to involve both medical and non-medical providers in TJR discussions.

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Table 1. Respondent Characteristics ( $N = 50$ )

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Demographics	
Age ( <i>SD</i> )	68.0 (11.7)
% Women	81.4%
% White	80.0%
% with college degree	60.3%
Physical health	3.2 (1.0)
Mental health	3.8 (0.9)
# Decision Network Members	6.5 (2.9)
Diagnosis and pain location	
% knee pain	82.4%
% hip pain	17.6%
% considered surgery	95.6%
% recommended for surgery by physician	67.6%
Personality	
Extraversion ( <i>SD</i> )	5.2 (1.4)
Agreeableness ( <i>SD</i> )	7.2 (1.4)
Conscientiousness ( <i>SD</i> )	8.0 (1.0)
Neuroticism ( <i>SD</i> )	5.1 (1.5)
Openness ( <i>SD</i> )	7.5 (1.5)
Support Desired and Received (summed across DNM)	
Informational support desired ( <i>SD</i> )	2.6 (0.8)
Informational support received ( <i>SD</i> )	2.3 (0.9)
Emotional support desired ( <i>SD</i> )	2.6 (1.0)
Emotional support received ( <i>SD</i> )	2.4 (1.0)
Instrumental support desired ( <i>SD</i> )	2.1 (1.1)
Instrumental support received ( <i>SD</i> )	1.9 (1.0)
Decision conflict ( <i>SD</i> )	29.3 (25.9)
Decision certainty ( <i>SD</i> )	2.3 (1.1)

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*Note.* Pain diagnosis was coded from open-ended question (multiple responses possible). Decision certainty was assessed on a 5-point Likert scale from 1 = certainly will not pursue surgery to 5 = certainly will pursue surgery. The Decision Conflict Scale ranges from 0 = no decisional conflict to 100 = extremely high decisional conflict.

Table 2. Correlations between Respondent Characteristics, Decision Certainty and Conflict, and Support Desired and Received

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	
1 Respondent Age																					
2 Respondent Gender	-.16																				
3 General Health	.18	-.45**																			
4 Total Pain	.03	.29*	-.25																		
5 Pain Location (knee)	-.06	.05	-.11	.09																	
6 Extraversion	.19	-.09	.01	-.15	.42**																
7 Agreeableness	.16	.09	.16	.11	-.13	-.10															
8 Conscientiousness	-.12	.23*	.10	.07	.03	-.20*	.16														
9 Neuroticism	-.14	.32**	-.14	-.02	.14	.22*	-.16	-.09													
10 Openness	-.24*	-.04	-.06	.22*	-.24*	-.60**	.04	-.02	-.16												
11 Willingness to Undergo Surgery	-.44**	.06	.28**	.93	-.08	-.16	.23*	.31**	-.06	.10											
12 Decision Conflict	-.20*	.36**	-.23*	-.14	-.05	-.17	.14	.11	-.03	-.19	-.02										
13 Informational Support Desired	-.07	.04	-.00	.15	.06	-.04	-.14	-.02	.15	.06	-.09	-.05									
14 Informational Support Received	-.02	.07	.04	.08	.01	-.05	-.08	-.02	.11	.07	-.03	-.09	.89**								
15 Emotional Support Desired	-.17	.06	-.05	.08	-.06	-.15	-.11	.01	.14	.17	-.08	-.10	.81**	.80**							
16 Emotional Support Received	-.14	.07	.01	.04	-.13	-.11	-.01	-.01	.11	.15	-.08	-.13	.73**	.78**	.95**						
17 Practical Support Desired	-.15	.11	-.02	.13	-.13	-.14	-.12	-.01	.25*	.20*	-.04	-.07	.68**	.66**	.82**	.77**					
18 Practical Support Received	-.09	.16	.00	.12	-.16	-.07	-.02	-.04	.25*	.12	-.07	-.06	.63**	.64**	.78**	.76**	.94**				
19 DNM Age	-.13	-.10	-.12	.06	-.07	-.05	-.00	.02	.06	.09	-.12	-.07	.03	-.03	-.05	-.04	.05	-.12			
20 DNM Gender	.39**	-.02	.06	-.02	.12	.13	.14	-.16	.12	-.08	.30	-.11	-.24*	-.16	-.15	-.12	-.19	-.13	-.13		
21 Network Size	-.06	.06	.06	.07	-.08	-.08	.01	.01	.14	.08	-.14	-.12	.86**	.85**	.88**	.85**	.73**	.73**	-.09	-.14	

\* $p < .05$  ; \*\* $p < .01$  .

Table 3. Multilevel Models Predicting TJR Candidates' Desired and Received Decision Support ( $N=50$ )

	Support Desired			Support Received		
	Model 1	Model 2	Model 3	Model 4	Model 5	Model 6
<i>Parameter Estimates:</i>	<i>F(df 1, df 2)</i>					
Intercept	1.59 (1, 37)	.55(1, 15)	1.03 (1, 41)	1.04 (1, 36)	.38 (1, 15)	1.20 (1, 40)
<i>Respondent Characteristics</i>						
Age	.71(1, 34)	.98 (1, 13)	.10 (1, 33)	.09 (1, 33)	.50 (1, 14)	.03 (1, 32)
Conscientiousness	.01 (1, 37)	1.38 (1, 14)	.04 (1, 37)	.10 (1, 37)	.56 (1, 15)	.08 (1, 36)
Neuroticism	2.09(1, 32)*	3.67 (1, 13)†	2.43 (1, 32)	1.90 (1, 32)†	1.88 (1, 14)	2.04 (1, 32)†
DNM network size	2.68 (1, 31)†	3.08 (1, 13)	2.71 (1, 32)	2.54 (1, 31)	1.16 (1, 14)	2.56 (1, 31)*
<i>DNM characteristics</i>						
Gender (female)	.98 (1, 267)	.742 (1, 2541)	.94 (1, 268)	1.42 (1, 262)	.63 (2, 240)	1.14 (1, 268)
DNM relationship to respondent	2.52 (4, 263)*	2.56 (4, 239)*	2.54 (4, 266)*	1.05 (4, 268)†	1.53 (4, 239)†	2.31 (2, 266)†
Type of support	4.12 (2, 231)*	2.78 (2, 227)†	4.16 (2, 229)*	3.20 (2, 231)*	2.54 (2, 227)†	3.36 (2, 266)*
Type of support x DNM Respondent	--	.96 (8, 227)	--	--	.94 (8, 227)	--
Type of support x respondent age	--	--	.49 (2, 230)	--	--	.59 (2, 229)

† $p < .10$  ; \* $p < .05$  ; \*\* $p < .01$  ; \*\*\* $p < .001$ .

Table 4. General Linear Model (GLM) Predicting Decision Conflict (N=50)

<i>Variable</i>	$\beta(SE)$	<i>t</i>
<i>Respondent Characteristics</i>		
Age	-0.26(0.19)	-1.37
Gender (female)	26.98(6.52)**	-4.14
General health	1.86(3.14)	0.59
Decision Network Size	-5.08(2.44)*	-2.24
<i>Difference Scores in Support Desired vs. Received</i>		
Informational Support	-2.08(2.17)	-0.50
Emotional Support	6.04(2.82)*	2.14
Instrumental Support	0.84(2.95)	0.28

† $p < .10$  ; \* $p < .05$ . ; \*\* $p < .01$

Table 5. General Linear Model (GLM) Predicting Willingness to Undergo Surgery ( $N=50$ )

<i>Variable</i>	$\beta(SE)$	<i>t</i>
<i>Respondent Characteristics</i>		
Age	-0.04(0.01)**	-5.39
General health	0.47(0.11)**	4.40
Pain level	0.07(0.02)*	1.16
Conscientiousness	0.24(0.10)*	3.00
Agreeableness	0.15(0.64)*	2.64
Decision Network Size	-0.07(0.03)*	-2.02
<i>Difference Scores in Support Desired vs. Received</i>		
Informational Support	-0.08(0.09)	0.33
Emotional Support	-0.05(0.12)	-0.41
Instrumental Support	0.29(0.12)*	2.52

† $p < .10$ ; \* $p < .05$ .; \*\* $p < .01$

## CHAPTER 4

### IMPLICATIONS FOR FUTURE RESEARCH

This dissertation compiled three papers that seek to examine the social and interactive nature of chronic pain. The first chapter presented a conceptual framework of hypothesized risk factors for adult children of parents in pain. Specifically, this framework sought to address the questions: does chronic pain in older parents affect parent-child relationship quality, and what factors may moderate the association between chronic pain and parent-child relations? The second and third chapters focused on the social and decisional preferences of older adults who were considering various treatments to manage their pain. In the latter of the two papers, we specifically examined the high-stakes treatment decision of joint replacement surgery. In this final chapter, I attempt to draw connections between the three papers and propose directions for future research.

The studies presented in this dissertation point to three overarching themes concerning CMP patients' social networks and treatment decision making. Specifically, they speak to the importance of 1) positive pain communication and empathic understanding by close others, 2) matching patients' desired and received decision support, especially during high stakes treatments, and 3) involving social networks beyond the patient-provider dyad in pain treatment decision making.

*Positive pain communication and empathic understanding by others.* The theoretical model proposed in Chapter 1 described the importance of positive communication and empathic interactions within parent–adult child dyads coping with chronic pain. Using empirical data, the subsequent chapters illustrated patients' need for emotional support when making pain treatment decisions. Together, quantitative and qualitative analyses exposed patients' desires for reassurance throughout the treatment decision making process, further emphasizing the need for compassionate interactions in their treatment visits. Moreover, these findings highlight that

medical providers are critical sources of emotional support, and not simply informational guidance regarding treatment options.

*Matching patients' desired and received decision support.* In a similar vein, alignment between the emotional support individuals desired and received was shown to be a vital determinant of CMP patients' perceptions of the decision-making process and internal conflict regarding the decision itself. Specifically, the qualitative reports in Chapter 2 revealed pain patients' desire for harmonious interactions with their social networks. Similarly, the quantitative analyses in Chapter 3 found that congruence between the emotional support TJR candidates desired and received was linked with their decisional conflict regarding joint replacement. Overall, matching the emotional support individuals desired and received was critical for a positive experience in the treatment decision making process.

In addition, Chapter 3 tapped the under-researched support dimension of instrumental assistance. Importantly, greater alignment between the practical support individuals desired and received was linked with TJR candidates' willingness to undergo surgery. This finding further suggests that even beyond reassurance and encouragement, having structural aid in place prior to TJR may enable patients to commit to the procedure.

*Social networks beyond the patient-provider dyad.* In addition, the chapters presented in this dissertation suggest that CMP patients' desires to involve others in their treatment decisions may depend upon who the "other" is, both in terms of his or her social structural role (e.g. healthcare provider) or similarity (e.g. pain condition) to the patient. In Chapters 2 and 3, social network members both within and outside of the traditional patient-provider dyad were deemed critical to patients' decision-making processes. As expected, healthcare providers were important conduits of informational guidance. However, non-medical network ties were equally vital to the

pain treatment decisions made by CMP patients; specifically, experiential similarity was a key factor in patients' social selection when considering treatment options for their pain. As a whole, these chapters illustrate the value of considering both formal and informal social networks and different types of decision support in pain patients' treatment decisions.

Despite the contributions of the three papers to the current literature, more research is needed to extend these findings. Based on the results and limitations of these papers, I propose the following directions for future research.

1. *Explore innovative and diverse methods to examine pain communication*

Chapters 2 and 3 of this dissertation presented a multimodal approach to examining patients' social and decisional preferences in managing chronic pain. Although the use of qualitative interviews and survey measures offered novel insights into individual patients' perspectives, both studies were limited by their reliance on self-report and a singular time point of assessment. Given the dynamic nature of chronic pain, innovative and varied methods are necessary to capture the diverse interpersonal interactions and exchanges among patients, their family members, and health care providers. For example, Ecological Momentary Assessment (EMA) has been proposed as an optimally-suited method to assess dyadic patterns of communication and interaction (Martire, 2013) and has been used to gather in vivo data from pain patients and their spouses (Sorbi et al., 2006). This method would also be appropriate for use with pain patients and their adult child caregivers, and could be used to capture how patient-caregiver dyads develop treatment plans and make important treatment decisions across the illness trajectory.

Another promising approach would be to conduct real-time studies of treatment discussions involving triads of older patients, providers, and caregivers over one or multiple

treatment visits. Previously, observational schemes (e.g. Roter Interaction Analysis System; RIAS) have been developed to capture socioemotional and instrumental behavior in problem solving groups, and they were recently adapted for medical dialogue (Sandvik, Eide, Lind, Graugaard, Torper, & Finset, 2002). This analytic technique has been used to code real-time communication between oncology patients and their physicians (Eide, Graugaard, Holgersen, & Finset, 2003), and could easily be implemented to examine triadic decision making around pain treatments. For example, microanalytic coding systems (e.g. Observer System, 1996) could be paired with self-report measures to examine the specific communication elements that influence patient satisfaction with the treatment decision-making process.

2. *Conduct longitudinal studies to assess the concordance in treatment goals and decisions over time*

In addition to gathering real-time data both within the medical encounter and in naturalistic settings, an important future direction for research is to examine the extent to which patient-physician-confidant triads agree on pain treatment goals for the patient. Given that treatment goals and priorities may vary across the illness trajectory, longitudinal assessments are imperative. The initial assessment should take place when a patient is first diagnosed with osteoarthritis or similar pain condition, and would enable researchers and clinicians to establish a baseline understanding of patients' and caregivers' treatment goals. Subsequent assessments would allow clinicians to tailor their treatment recommendations, as needed, to the preferences and priorities of the patient and caregiver throughout the course of care. Moreover, a better understanding of each stakeholder's perspective would help enhance shared decision making within patient-physician-caregiver triads.

A brief inventory has been developed to examine and compare the treatment goals of

family caregivers and physicians of frail, cognitively impaired older adults (Bogardus, Bradley, Williams, Maciejewski, van Doorn, & Inouye, 2001), but research has yet to test this measure within triadic encounters or in the context of chronic pain or with cognitively intact patients. Indeed, although a wide body of research has explored the perspectives of family caregivers and surrogate decision makers for dependent, cognitively impaired individuals (Wendler & Rid, 2011), much less is known about the role of close confidants for independent and cognitively intact older adults. An adapted version of the Bogardus (2001) questionnaire could be piloted with pain patients, their family members and physicians to examine a) concordance in patient-physician-confidant pain perception, b) agreement on the most important treatment goal for the patient with regard to pain management, and c) whether greater triadic agreement is associated with higher treatment satisfaction among patients and lower feelings of burden among family caregivers.

### *3. Examine age differences in pain treatment decisions*

In Chapters 2 and 3, we set forth to examine age differences in individuals' social and decisional preferences. However, given the sample composition, analyses focused primarily on age differences in late midlife and beyond. Future studies are needed to examine whether and how younger versus older adults differ with regard to their decision network preferences when considering pain treatment decisions. At the individual-level, a focus on the decision-making processes of younger (18-40 year old) versus older (60+) adults may offer a broader understanding of pain patients' decision support selection; one that we were unable to capture in our quantitative comparison of middle-aged versus older adults.

At the family-level, an intriguing next step would be to investigate differences in the treatment decision-making processes of early versus later life families in pain. This work should

consider the shift that occurs in social norms and reciprocity in young versus late life families; specifically, that parents typically provide care and support for their children during the early years of life, whereas adult children typically take on a caregiving role for their parents in later life (Antonucci & Akiyama, 1987). One potential line of inquiry would be to assess how this shift in role structure affects patients' decisional networks (e.g., who assumes decisional control in early versus later life dyads?) as well as the decisional strategies employed in early and late life families. In addition, future work could investigate how the normative versus non normative perception of pain in early versus late life affects the nature and type of support offered and received across generations.

#### *4. Identify ethnic differences in decision network structures*

Chapter 2 revealed distinct cultural and ethnic differences in individuals' preferences for formal and informal decision support. The present research along with prior studies (Kroll et al., 2007; Parks, Herbert-Beirne, Roja, Tuzzio, Nelson, & Boutin-Foster, 2014) highlights the need to examine the pain experience from the perspective of diverse ethnic groups. Although CMP conditions disproportionately affect minorities (National Institute of Arthritis and Musculoskeletal and Skin Diseases, 2010), these groups have been neglected in previous studies (Green et al., 2003) and interventions (Martire et al., 2007, 2008; Turner et al., 1990). As demonstrated in Chapter 2, individuals from different ethnic and cultural backgrounds may show distinct preference for formal versus informal treatment. This study merely scratched the surface of understanding the differences between Hispanic versus non-Hispanic Whites' decision styles, especially given the vast heterogeneity across Latino cultures (Baca Zinn & Wells, 2000). Nevertheless, the findings from this study extend theoretical perspectives suggesting that familism and filial piety (cultural beliefs and preferences regarding parental care and respect) play an important role in individuals' preferences for kinship versus formal medical care (Kao &

Travis, 2005; Schwartz et al., 2010). In light of NIH's emphasis on addressing health disparities (National Institutes of Health, 2012), an explicit focus on racial and ethnic minorities should be prioritized.

5. *Develop family-based interventions for the pain sufferer and adult child*

Although more basic research is clearly needed to disentangle the complex interpersonal processes underlying CMP patients' joint decision making with their social networks, a longer-term goal for research would be to expand and strengthen the existing intervention literature for pain patients and their relatives. At present, the intervention research on pain patients and their family members remains limited, with a notable dearth of studies exploring whether family-oriented programs provide any benefits to family members themselves (Martire, 2013; Martire, Schultz, Helgeson, Small, & Saghafi, 2010). Even more striking is that studies tend to focus on the spousal relationship and none of the interventions that assess caregiver outcomes have incorporated adult children. As we note in Chapter 1, adult offspring provide a disproportionate amount of informal care for their older parents; they comprise the largest group of those providing informal assistance to individuals age 65 or older (Center on Aging Society, 1999). Interventions should therefore consider, if not prioritize, this group in family-based approaches to treating older chronic pain sufferers.

A logical step would be to explore how previously implemented approaches could be modified for use with adult children (Keefe et al., 1996). Specifically, differences between spousal and adult child caregivers could be evaluated to determine how future interventions could be tailored for each group. More broadly, studies should explore particular characteristics of caregiver groups (e.g., gender, relationship to the patient, frequency of contact, relationship quality) and patients (e.g., years lived with pain) and their respective associations with specific intervention outcomes (e.g., caregivers' relational, emotional, and physical well-being).

Interventions specifically aimed at patient-provider or patient-provider-caregiver communication should also be emphasized. Although formalized protocols have yet to emerge, pilot testing is underway to ascertain the feasibility and potential efficacy of an innovative intervention program targeting pain communication between arthritis patients and their relatives (Keefe & Somers, 2010). Acknowledging the psychological factors in pain management, this work paves the way for the development of novel and innovative family-oriented approaches for pain sufferers and their relatives.

Taken together, the information presented in this dissertation merits the attention of physicians and researchers interested in improving the quality of shared decision making and treatment for chronic pain patients and others involved in their care. Given the recent emphasis on Patient-Centered Outcomes Research as part of the Patient Protection and Affordable Care Act (2010), a targeted focus on CMP patients' social and decisional preferences is both timely and necessary to advance clinical care and effectiveness. As an initial step, the research conducted for this dissertation sets the stage for future initiatives aimed at addressing patient-centered dialogue, and ultimately, informing broader implementation of individualized decision support for chronic pain sufferers.

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