Families Coping With Chronic Pain:
A Summary of the Research Study

Moderate to severe chronic non-cancerous pain affects approximately 9% of Americans and their families and significantly impacts healthcare, social, economic, and national issues. Most research studies have focused on understanding the individual family member diagnosed with chronic pain rather than examining the family's role in responding to and managing an enduring illness. The purpose of this study was to explore coping, including religious coping, from the perspective of the family as it relates to family functioning when another adult in the family has been diagnosed with chronic pain.

Research Questions

1. How do families use religious coping in managing the stress of being closely involved with the adult family member diagnosed with chronic pain?
2. Is there a significant relationship between family functioning in families with a family member diagnosed with chronic pain and their use of religious coping?
3. Is there a significant relationship between the demographics of both family members and the family member diagnosed with chronic pain and religious coping as reported by the Brief RCOPE?
4. Is there a significant relationship between the demographics of both family members and the family member diagnosed with chronic pain and family functioning as reported by the Family Environment Scale?
5. Is there a significant relationship between the scores of the Moral-Religious Emphasis, a Family Environment Scale subscale, and the scores of the Brief RCOPE?

Open-ended Survey Questions

1. What major coping methods have families found helpful in managing the stress of being closely involved with the adult family member diagnosed with chronic pain?
2. What major coping methods have families tried that have not been helpful in managing the stress of being closely involved with the adult family member diagnosed with chronic pain?
3. What methods of religious and/or spiritual coping have families found helpful in managing the stress of being closely involved with the adult family member diagnosed with chronic pain?
4. What methods of religious and/or spiritual coping have families tried that have not been helpful in managing the stress of being closely involved with the adult family member diagnosed with chronic pain?

Survey Method

Adult family members were recruited through announcements placed on the following Internet websites: AARP, The Arthritis Foundation, National Fibromyalgia Association, National Headache Foundation, Reflex Sympathetic Dystrophy Syndrome Association, Senior Net, The TMJ Association, and Trigeminal Neuralgia Association. Participants were also recruited through the distribution of flyers at waiting room locations that included pain management clinics, doctors' offices, hospitals, and offices

of counselors who work with chronic pain patients and families in Texas as well as Colorado, Georgia, and Washington.

A secure, anonymous, Internet website survey provided the following quantitative data: demographic information concerning the family member and the adult family member diagnosed with chronic pain; family functioning in chronic pain families using the Family Environment Scale (Moos & Moos, 2002); and religious/spiritual coping in chronic pain families using the Brief RCOPE (Pargament, Smith, Koenig, & Perez, 1998). In addition, four qualitative questions enabled participants to report specific coping strategies, including religious coping, that families have found helpful or not helpful in managing the stress of being in close contact with the family member diagnosed with chronic pain.

Family Members and Family Members Diagnosed With Chronic Pain

Of the 88 family members who completed the survey, 73 met the following study criteria: an adult family member not currently diagnosed with chronic pain who was closely involved with an adult family member diagnosed for a minimum of 6 months with chronic non-cancerous pain. Family members ranged in age from 18 to 79 years old with a mean age of 45. The family member sample was almost evenly divided between females (51%) and males, 60% were spouses, and 73% were living with their chronic pain family member. The majority (95%) of family members who participated in the survey were Caucasian, over three-fourths (77%) had some college education, 63% were employed full-time, and 81% responded they had never participated in a chronic pain management program with educational or family therapy sessions. Although the majority (49%) of family members reported there were no children living in the chronic pain family, almost a third (30%) indicated there were children 18 years old and younger in the family, and 69% responded this was a first marriage for the couple.

The age range of chronic pain members was 20 to 88 years old with a mean age of 48, and the years since pain diagnosis ranged from less than one year to 44 years with a mean of eight years. Almost three-fourths (71%) of the chronic pain family members were females, and the majority were Caucasian (91%), with some college education (68%), and diagnosed with Fibromyalgia (29%), Arthritis (15%), Reflex Sympathetic Dystrophy (12%), Chronic low back pain (11%), and headache/migraines (10%). Twenty-three percent reported 11 other diagnoses. Over a third (37%) were disabled, slightly less than a fourth (23%) were employed full-time, and a majority (55%) had not been involved in a pain management program.

Family members rated the stress, during the last month, of living with or being in close contact with the adult family member who was diagnosed with chronic pain, and 16% considered the stress as minimal, 44% as moderate, and 40% as very stressful. Thirty-six percent reported the family managed the stress better than at the diagnosis, 47% indicated the family managed the stress the same as at the diagnosis, and 17% responded that the family managed the stress worse than at the diagnosis.

Discussion of Quantitative and Qualitative Analyses

Family stress

A small group of family members in this study, who described their family environment as minimally stressful during the last month, used a higher number of positive religious coping methods. In contrast, a larger group of family members, who indicated their family environment was very stressful, used more negative religious

coping strategies. Pargament (2002) distinguished between positive and negative religious coping methods that were used in this study's survey in the following way:

> The pattern of positive religious coping methods…are derived from a secure relationship with God, a sense of spirituality, a belief that there is meaning to be found in life, and a sense of spiritual connectedness with others. Positive religious coping methods include benevolent religious appraisals of negative situations, collaborative religious coping, seeking spiritual support from God, seeking support from clergy or congregation members, religious helping of others, and religious forgiveness. In contrast, the pattern of negative religious coping methods grows out of a general religious orientation that is, itself, in tension and turmoil, marked by a shaky relationship with God, a tenuous and ominous view of the world, and a religious struggle in the search for significance. Negative religious coping methods include questioning the powers of God, expressions of anger toward God, expressions of discontent with the congregation and clergy, punitive religious appraisal of negative situations, and demonic religious appraisals. (p. 171)

Thus, the degree of stress, in the chronic pain family during the last month, distinguished between the patterns of positive and negative religious coping that families were using to manage the stress. In this study, several family members explained their family's faith and spiritual turmoil: "church…trying to talk to a pastor…nobdy realy understands…" "My [chronic pain family member] blames God for the injury so [the chronic pain family member] will not let me talk about spiritual coping." "…expectations to attend church when things are difficult at home can add to guilt and hurt and stress." In contrast, 23% of the family members spontaneously reported using religious and/or spiritual coping as methods that helped manage the stress of chronic pain.

Family Functioning and Religious Coping

This study indicated that chronic pain families, who placed a high emphasis on ethical and religious issues and values, also used positive religious coping methods a great deal. Families, who functioned with a low degree of commitment, help, and support for one another (Cohesion), and families, who indicated they were highly organized in their activities and responsibilities, both used more negative religious coping strategies. Denying realities and ignoring changes was one coping method that chronic pain families in this study indicated was not helpful in managing stress. One family wrote about coping methods that had not helped, "Trying to continue as if nothing is wrong." Another wrote, "not letting [the chronic pain member] hurt, thinking [the chronic pain member] can keep up." Therefore, chronic pain families, who are highly structured in their planning of family life, may be too inflexible to make the necessary changes for better family functioning under stress.

Religious Coping and Chronic Pain Families

This study found that older family members with more education used more positive religious coping strategies, whereas families, with a young adult as their youngest child still living at home, sought fewer. Families, with a disabled chronic pain family member, and remarried chronic pain families had more of a religious struggle, and older chronic pain family members placed less emphasis on moral and religious values.

Family Functioning and Chronic Pain Families

Life stage and chronic pain. Families in this study, who did not have children living in the family, were more competitive in their activities and stressed the importance of

planning family activities. Families, with an adolescent as the oldest child, were less assertive and self-sufficient but were more likely to set rules and procedures in family life. Chronic pain families, with adolescents, were more interested in intellectual, cultural, and recreational activities, whereas families, with a young adult as the youngest member living in the house, did not place a high emphasis on these activities, nor were they concerned with ethical and religious matters.

Family type and chronic pain. In this study, chronic pain families, in which this was the first marriage for the couple, set fewer rules and procedures (less control), and remarried families functioned with more organization and planning. Despite the low number of participants who represented divorced chronic pain families, results indicate they were more committed to helping each other, encouraged each other to express their feelings more, participated in more intellectual, cultural, recreational activities, and expressed less anger in their families. Also, a small sample of two-generation families provided less support for each other, did not encourage open expression of feelings, and expressed more conflict openly, indicating low family functioning.

Chronic pain families. Chronic pain families, in which the family members diagnosed with chronic pain were disabled, were less supportive of each other, less encouraging to openly express their feelings, and did not place a high priority on planning family activities. Family members in this study, who wrote about their use of coping strategies, confirmed the beneficial effects of open communication. One family member wrote, “We found that the best way to manage the stress is to talk, talk and more talk. You have to keep the lines of communication open regardless of how much at times you want to block everything out.”

In this study, older well-educated family members had chronic pain families that set more rules and procedures to run their family life and had less openly expressed anger and conflict in their families. Chronic pain families, in which the family member did not live with the chronic pain family member, had less feelings of togetherness. Both family members and family members diagnosed with chronic pain, who were responsible for full-time household duties, had family environments that were less supportive of each other and had more set ways of doing things in the family. Chronic pain family members, who were responsible for part-time household duties, did not give as much time and attention to each other, and family members, who were responsible for part-time duties, placed a high emphasis on following the rules in the family. These findings support the results of other studies (Dura & Beck, 1988; Romano, Turner, & Jensen, 1997) in which lower cohesion and higher control have also been family functioning characteristics of chronic pain families. However, to the researcher’s knowledge, this is the first study to discover a link between the responsibility of household duties and a chronic pain family profile of low cohesion and high control. One possible explanation might have come from a comment written by a family member, “The term ‘household duties’ for employment really would be ‘caring for spouse’ because I cannot leave [the chronic pain member] for more than a couple hours at a time, and usually not more than once a day. I think it should be more identified because I know that from my experience, not being able to work – loss of my own independence.” Another family member remarked that future research should include the question, “What extra responsibilities fall to you because of [the chronic pain person’s] situation? Do you resent this?” Therefore, this study expands the understanding of how the changes in responsibility and the increased

burden of household duties, both full-time and part-time, impact the functioning of chronic pain families.

Coping Methods, Including Religious Coping

In this study, universal themes of acceptance and change emerged from the following eight coping methods (listed in descending order mentioned) concerning helpful ways their families managed the stress of being closely involved with a chronic pain family member: Building Relationships; Accepting Realities and Managing Changes; Using Religious and/or Spiritual Coping; Focusing on Family Health; Seeking Therapeutic Alternatives; Having a Family Focus; Accessing Support Systems; and Seeking Knowledge. In addition, the following three coping methods specific to religious and/or spiritual coping (listed in descending order mentioned) contributed to the universal themes of acceptance and change: Having Faith or a Belief; Accessing Support Systems; and Seeking Knowledge.

The universal themes of denial and ignoring change emerged from the following seven coping methods written by over half of the family members (listed in descending order mentioned) concerning coping methods their families had tried that had not helped to manage the stress of chronic pain in the family: Not Building Relationships; Denying Realities and Ignoring Changes; Seeking Therapeutic Alternatives; Exceeding the Limits; Accessing Support Systems; Ignoring Family Health; and Seeking Knowledge. In addition, the following three coping methods specific to religious and/or spiritual coping (listed in descending order mentioned) contributed to the universal themes of denial and ignoring change: Feeling Conflicted; Having Faith or a Belief; and Blaming.

Conclusions

This study was unique in that it explored the experiences of the chronic pain family rather than the chronic pain patient. Chronic pain in the family influences family relationships in many ways, and this research study provided insights into the methods that families use to cope, including their reliance on religious coping strategies to manage the stress of chronic pain. Based on the quantitative and qualitative data analyses, the following conclusions are reported:

1. Family functioning is not necessarily affected adversely by the presence of stress caused by chronic pain in the family. A majority of families who reported the experience of moderate to severe family stress during the last month also reported managing their family stress the same or better than when the chronic pain was first diagnosed.
2. Although some chronic pain families seem to have trouble coping with the stress of chronic pain, nearly all of the families have found beneficial ways in which to cope and many do not appear to be adversely affected.
3. Religious coping, such as, having a faith or a belief, praying and meditating, and accessing support, helps chronic pain families manage the stress of chronic pain.
4. Some families try religious coping methods, such as, having a faith or a belief, praying, trying to get support from clergy and congregations, and find religious methods fail to help them manage the stress of chronic pain.
5. Specific forms of religious coping strategies have a direct effect on family functioning. Families with high cohesion, a marker of more resilient chronic pain families, have less of a religious and/or spiritual struggle.

6. Positive religious coping is a specific form of religious coping linked to better family functioning in chronic pain families. Families, who place a high emphasis on ethical and religious issues and values, access a greater number of positive religious coping strategies.
7. Chronic pain families with certain family functioning and religious coping profiles could be at risk for using more negative coping strategies. Chronic pain families, in which the family member diagnosed with chronic pain is disabled and who also have low cohesion, low expressiveness, and low organization, were an identifiable profile in this study. In addition, chronic pain families, who report very stressful family environments, low cohesion, and the need for more organization, could be at risk for using more negative religious coping strategies.
8. The responsibility of full-time and part-time household duties could be a factor to identify at risk family functioning. Low cohesion and high control were both factors related to the responsibility of household duties.

Therefore, the results of this research study indicate there are identifiable coping methods, including positive and negative religious coping strategies, which can help or hinder family management of the stress from being in close contact with an adult chronic pain family member and can contribute to either resilient or disruptive family functioning.

Implications

Implications for Family Science Professionals

1. Recognize that chronic pain will have a lasting impact on the family system so that the professional needs to understand the specific characteristics of the effects of an enduring illness on the family.
2. Investigate peer reviewed research literature and attend seminars for information concerning the evolving methods of pain management.
3. Consider a target chronic pain family population and devise programs that help chronic pain families learn beneficial coping strategies and improve stress management within the family.
4. Become an advocate for increased research concerning the family and chronic pain management.

Implications for Health Care Agencies and Providers

1. Recognize the need and include all family members, who consider themselves closely involved with the chronic pain family member, in multidisciplinary chronic pain programs.
2. Prepare programs that target better family management of the stress of being in close contact with the adult family member diagnosed with chronic pain.
3. Increase community awareness of programs offered and facilitate family interaction with pain management professionals and pastoral counselors who understand the implications of religious coping strategies.
4. Use multiple and valid measurements to profile at risk families and provide assistance in making the changes necessary for healthy family functioning.

Implications for Religious Institutions

1. Recognize the changes families need to make in family life due to the effects of chronic pain and provide educational opportunities for pastoral staff to be trained to understand and respond to the specific needs of chronic pain families.

2. Consult with chronic pain families concerning their particular needs and provide methods for accessing institutional support specifically related to their situation.
3. Reevaluate institutional religious requirements and make adjustments for the unique needs of chronic pain family members.
4. Consult with chronic pain families concerning their particular religious coping strategies and the degree of stress in the family. Be aware of the possible negative effects of long-term use of negative religious coping methods.

Implications for Policy Makers

1. Recognize the impact that chronic pain has on the family.
2. Adopt, fund, and evaluate programs that promote family management of chronic pain with better family functioning.

Recommendation for Future Research

1. Influence of gender in managing chronic pain
2. Spouses vs. non spousal influence in family functioning and coping
3. Families with disabled chronic pain family members vs. non-disabled
4. The relationship of chronic pain diagnoses and family functioning and coping
5. The role of household duties in the management of chronic pain stress
6. Chronic pain family rituals and family functioning
7. The effects of support or non-support from the extended family on coping and family functioning
8. Comparison of a program specifically designed for chronic pain families based on beneficial coping methods with comparison pre- and post-testing of family functioning with control group
9. Non-traditional families and cross cultural chronic pain families
10. Financial impact on family functioning and coping

Limitations

This study was a self-report survey, and generalizing the results must be done with caution. Limitations of this research include the following:

1. Sample size: while 73 is a respectable number, this researcher would have liked to have had more participants.
2. Participants were recruited by self-selection using the web and may not represent a generalizable chronic pain family population.
3. This research study was cross-sectional and participants were studied at only one point in time, thus limiting a broader view.
4. Reactivity to the sensitive nature of the subject of religious and/or spiritual coping may have affected the participants' responses.
5. The lack of a control group prevented comparison of outcomes with a non-pain sample.

References

Dura, J.R., & Beck, S.J. (1988). A comparison of family functioning when mothers have chronic pain. *Pain, 35,* 79-89.

Moos, R.H., & Moos, B.S. (2002). *Family Environment Scale manual: Development, applications, research* (3rd ed.). Redwood City, CA: Mind Garden.

Pargament, K.I. (2002). The bitter and the sweet: An evaluation of the costs and benefits of religiousness. *Psychological Inquiry, 13,* 168-181.

Pargament, K.I., Smith, B.W., Koenig, H.G., & Perez, L. (1998). Patterns of positive and negative religious coping with major life stressors. *Journal for the Scientific Study of Religion, 37,* 710-724.

Romano, J.M., Turner, J.A., & Jensen, M.P. (1997). The family environment in chronic pain patients: Comparison to controls and relationship to patient functioning. *Journal of Clinical Psychology in Medical Settings, 4,* 383-395.

Copyright© Barbara Kirk Jackson, Ph.D., 2005
All Rights Reserved