

May 01, 2006

Parents of chronically ill children: exploring the experiences of partnered and unpartnered parents

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Recommended Citation

Russo, Vanessa L., "Parents of chronically ill children: exploring the experiences of partnered and unpartnered parents" (2006). *Honors Junior/Senior Projects*. Paper 5. <http://hdl.handle.net/2047/d10006345>

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Running head: HONORS PROJECT PROPOSAL

Honors Project Proposal: Parents of chronically ill children: Exploring the experiences
of
partnered and un-partnered parents

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Project Purpose

While conducting a secondary analysis of previously collected data (Dylis, 2003) on parents of children with a chronic illness, significant differences were discovered between partnered and un-partnered parents on the major study variables. Specifically, these groups seemed to adopt different coping methods. The purpose of this project is to review current literature in order to explore what is known about this difference and use this literature as part of a manuscript regarding issues facing partnered and un-partnered parents and specific nursing interventions to support these parents.

If the difference in coping methods is found to be accurate, this could have great implications for nursing practice. This knowledge would allow the nurse to more adequately prepare the parents and provide them with appropriate and effective resources for coping, based on their individual coping methods.

Review of the Literature

Upon reviewing 32 articles, 19 were found to be on point, reliable, and seemingly accurate. Two articles focused on parental role relating to coping method, three articles focused on support relating to coping method and the remaining articles focused on general gender differences in coping with no insight into the cause of these differences. Overall, it became evident that there is a lack of research regarding partnered and un-partnered parents of chronically ill children. Only one article contained specific data relating to the coping mechanisms of partnered and un-partnered parents. Several other articles discovered themes such as spousal support and parental roles which affect coping and could be related to marital status of parents. However, the authors either mentioned this relationship briefly or not at all.

There was considerable evidence surrounding gender differences in parental coping. Therefore, due to the lack of data on partnered and un-partnered parents of chronically ill children, the focus of this project was expanded to include the gender differences as this was also a theme that found in previous data analysis (Dylis, 2003). Seven research articles related to gender differences in coping are reviewed in this paper.

Of the reviewed articles, Grant and Whittell (2000) were the only researchers to include single mothers in their sample to differentiate coping strategies among parents. This was as a result of stratified and purposive sampling of random active case files in two unitary authorities in Wales, England. Through semi-structured interviews, they found that all of the 10 single parents (9 women and 1 man) relied on cognitive coping strategies.

Indeed, *all of them* found the following coping strategies useful: seeing the funny side of the situation; realizing that their offspring was not to blame for things; taking one day at a time; accepting the situation as it was; believing in themselves and their ability to handle the situation; and looking for the positive things in each situation. (Grant and Whittell, 2000)

Moreover, they found that the single parent families felt overwhelmed with all of their responsibilities and did not often seek assistance from their other family members.

Parental Role Related to Coping Methods

Through their research, Grant and Whittell (2000) also discovered coping differences among the genders. Overall, women used more coping strategies than men and felt more confident in their abilities than men. This was possibly related to the traditional woman as caregiver role and man as breadwinner. The men in this study simply felt they did not feel experienced in their caring roles. Grant and Whittell (2000) attributed the apparent gender differences to parental role rather than gender specifically. It seemed that the more time the parent spent in the care-giving role, the more confident they felt, and therefore the more coping strategies they felt comfortable using. Therefore, it can be postulated that in single parents, their means of coping depends partly on the role that they fulfill as a parent/caregiver and not necessarily on their gender or their marital status.

Gray (2003) also found that parental role impacted the way that their child's illness affected them and also how they coped with that illness. 32 mothers and 21 fathers of children who were diagnosed with high functioning autism or Asperger's syndrome at an autistic treatment center in Brisbane, Australia were interviewed using semi-structured

interviews. The families had traditional gender roles with the mother primarily caring for the child and the father primarily working. Fathers viewed going to work as a coping mechanism because they were able to “escape” from the home environment for long periods each day. “As a rule, however, the fathers were much more likely to see themselves as being a reserve source of support for their wives.” (Gray 2003) They were not directly involved in care and were able to escape as a way of coping with their child’s condition.

Because of the mothers’ constant exposure to the chronically needy child, they coped quite differently than the fathers. Most of the mothers were either part-time employed or full-time moms and most of the responsibility of talking to medical staff, attending appointments and maintaining domestic order fell to them. Therefore, it makes sense that one of their most popular coping strategies was keeping the autistic child separated from siblings while the father preferred to either keep the child busy or go to work. The mothers and fathers did agree that the most important way to cope for them both was to anticipate difficulties and plan a response in case they actually happened. However, it is clear through this example that coping strategies are affected by the role that the parent plays rather than necessarily gender or marital status.

Support Related to Coping Method

Another common theme that affected coping behaviors was support. It is possible that a presumed lack of support for single parents could negatively affect their coping behaviors. According to Patistea, Makrodimitri, & Panteli (2000): “Hope, social support and the marital relationship were the most helpful resources in managing the multifaceted problems caused by the diagnosis.” Without social support or a marital

relationship/partner, coping is a more difficult process that involves different mechanisms. Through a semi-structure interview of 42 families randomly sampled from an oncology clinic in Athens, Greece, Patistea et al found that two-thirds of the parents said their spouses were the most important source of emotional support and assistance with practical problems. They also found that the fathers felt the need to project the traditional strong, protector type role whereas the mothers showed greater distress and anxiety regarding their child's health status. This is all fitting with previously reviewed data.

Through a six-part questionnaire given to a group of 80 fathers of children with chronic illness and 80 fathers of health children, Katz and Krulik (1999) found that social support in fathers was tied to self esteem and coping. "Although generally important in everyday life, it appears that social support is more crucial to fathers when coping with stressful situations such as chronic illness of the child." (Katz and Krulik 1999) If the father lacks this social support from a spouse, this could compound the negative effect on his self esteem and his coping behaviors.

Overall, as evidenced in the above review, there are many gaps in the literature regarding partnered and un-partnered parents of children with chronic illness. Although one can speculate that social support and parental roles are connected with marital status, the only way to prove this is through further research. Despite the lack of literature on coping differences relating to marital status, literature abounds relating to specific coping differences between the genders.

The following themes were discovered upon reviewing seven articles related to gender differences in coping: 1) Fathers used problem solving coping skills whereas

mothers used more emotion based coping skills; 2) Mothers saw that the illness affected them greatly whereas the fathers saw a lesser impact; 3) Mothers and fathers both experienced role conflict but related to their own, often differing, roles and this conflict correlated with decreased marital satisfaction; 4) Fathers were more likely to use avoidance to try to regain control of the situation.

Fathers Using Problem Solving vs. Mothers Using Emotion

Through the use of a questionnaire sampling 48 fathers of children with chronic conditions, Hovey (2005) found that fathers used concrete, problem solving coping methods. These included: 1) trying to figure out what to do; 2) looking at options; 3) reading about the problem; 4) getting information; and 5) weighing choices. (Hovey 2005) The fathers in this study perceived that they used more problem based coping whereas their wives used more emotional/psychological based coping such as talking to friends/family.

In another descriptive comparison design study involving a questionnaire filled out by 48 fathers of children with chronic conditions and 51 fathers of well children, Hovey (2003) found that although fathers used less emotional coping strategies than their wives, they were actually more likely to use crying as a coping method than the fathers of well children. This suggests that the chronic illness does illicit emotional coping responses from the fathers, but perhaps to a lesser degree than their wives.

Cayse (1994) found that among 23 fathers of children with cancer the two most commonly used strategies were praying and getting information. Praying is actually considered an emotional coping mechanism which contradicts with previous stereotypes suggesting that fathers do not use emotional coping mechanisms. It is important,

however, to look at the second coping mechanism: getting information. Getting information is clearly a problem-solving based coping mechanism. Therefore, although fathers do use some emotional coping mechanisms, they do not use as many as their wives and they do not seek support from others as a way of coping which is traditionally a major coping mechanism of mothers. This could be related to the fact that mothers see that the illness affects them greatly whereas fathers saw a lesser impact.

Varying Perceptions of the Impact of Chronic Illness

As mentioned above, women perceive that their child's condition significantly affects them whereas fathers see a lesser impact on their lives/emotions. In 2000, Knafl and Zoeller researched this theme via individual, in depth interviews with 43 couples and 7 women who were coupled but their partner did not participate in the interview. They found that although parents in the same family are likely to have a shared view of the illness and its impact on the family, in the families that did have discrepant views, it was usually the mother who emphasized the impact of the illness. They also found that the mothers were more likely to view the child as abnormal, express a lack of confidence in their ability to manage the illness, and describe themselves as transformed through having a child with a chronic illness. (Knafl and Zoeller 2000) Mothers also noted that their child's condition affected their mood and disposition more than their husbands.

In a review and critique of the literature related to cystic fibrosis and the family, Mohlman Berge and Patterson (2004) found that mothers actually had more psychological distress, particularly depression and anxiety. This is consistent with the literature that suggests a child's illness has a greater psychological impact on the mother rather than the father. However, it should be considered that fathers have a tendency to

avoid emotional situations in order to regain an image of control. This may mean that although it appears that mothers experience more psychological distress, fathers may just not express it in the same ways. This concept of avoidance will be discussed later in the paper.

In a similar study interviewing 48 fathers of children with chronic conditions and 51 fathers of well children, Hovey (2003) found that fathers perceived that the mothers worry about the same issues as themselves but not to the same degree. They felt that the mothers worried excessively and did not cope well with the lifestyle alteration of having a child with a chronic illness.

In 2005, Hovey sampled 48 fathers of children with chronic conditions and through the Family Perception Index questionnaire, she again found discrepancies about the perceived impact of the child's illness. "98% of fathers perceived that feeling worn out was a huge concern for their wives but only 73% saw it as a concern for themselves." (Hovey 2005) Fathers also thought that this concern impacted their wives' desire to be intimate with them. "87% of the fathers said that sexual relationship with their spouse was a concern for them but only 72% reported that they thought this was a concern for their wife." (Hovey 2005) It is important to note that this data is based on the fathers' *perceptions* of the mothers' feelings so this data may differ when the mothers are asked what their perceptions are.

Hovey (2005) also goes on to suggest a possible reason for the discrepancy of perceived impact. She notes that the fathers' concerns were more focused on the positive aspects relating to normal family activities such as going to the park together or spending time together as a group. Mothers' concerns were more focused on family-care

responsibilities and fatigue. This could be related to a difference in roles, but this was also a concern in families where there was an equal sharing of responsibilities. Further research on this topic would be beneficial.

Role Conflict Related to Different Roles and Resulting Decrease in Martial

Satisfaction

Upon a review and critique of the literature on cystic fibrosis and the family, Mohlman Berge and Patterson (2004) found that mothers experienced role strain especially when they took on the majority of caregiving needs of the child. This role strain was related to decreased martial satisfaction and decreased desire for intimacy. “When mothers assumed caregiving roles, they felt less support and love from their spouse and the fathers withdrew both physically and emotionally from the child’s caregiving tasks which further related to the mothers’ decreased desire to be sexually intimate with the father.” (Mohlman Berge et al 2004)

Mohlman Berge et al (2004) further found 7 studies that reported decreased martial satisfaction due to less communication and less time spent together in recreational activities. As nurses, it is important to note this and educate families on ways to balance the child’s complex needs with their own marital and psychological needs. Although decreased martial satisfaction was related to increased treatment compliance, it is more important for family functioning to find a balance between the child’s treatment needs and the parent’s needs. This is not to say ignore the child’s complex needs, but working together as a team and communicating is probably the best way to prevent a decrease in martial satisfaction post diagnosis.

When teaching families about role equalization and conflict resolution, it is important to consider the average varied roles of mothers and fathers. Hovey (2003) found that fathers of children with chronic conditions found role conflict with the roles of protector, communicator, and breadwinner. Teaching should be directed at these roles for the fathers and in situations where mothers do most of the caregiving, teaching should be related to the caregiving role.

Fathers Use of Avoidance

There is large agreement in the literature that fathers frequently use avoidance as a “coping” mechanism in order to regain an appearance of control. Although Sigmon and Stanton (1995) did not interview fathers, upon interviewing 55 male and 75 female college students, they found that males were more likely to “cope” by avoiding and women were more likely to use emotion based coping strategies. They also found that avoidance coping correlated positively with depressed mood and psychological distress whereas acceptance coping correlated negatively with depressed mood. (Sigmon et al 1995) This suggests that although males perceived that had greater control over stressful situations, they actually could be more depressed than females but they may just hide it more effectively.

The male desire to hide their emotions thereby regaining perceived control was also recognized by Hovey (2003). She determined that fathers of children with chronic illnesses had greater concerns regarding lack of control than the fathers of well children. In fact, this was one of their major concerns. This is probably related to the traditional image of the strong male/father who can protect and provide strength to his family.

While sampling 8 fathers whose infants had severe congenital heart disease, Clark and Shandor Miles (1999) also found that two of their major concerns included trying to maintain control and providing strength while hiding emotions. They also had a fear of attachment because it was a situation that they did not have control over. Clark et al (1999) further note that nurses need to address these issues because it is shown that fathers' responses to the diagnosis may negatively impact future infant-father interactions.

The most important message for nurses to extrapolate from the above literature is the large need for family teaching upon a child's diagnosis with a chronic illness and throughout their care. In order to ensure good family functioning, families should be taught: how to balance roles/responsibilities; how to express feelings and communicate with each other; that each partner will respond in a different way to the illness; healthy coping strategies rather than defense mechanisms; finally to *support* their spouse especially when their perceptions and feelings differ.

Preliminary Project Outline

1. Introduction
 - a. Intro to parents of children with chronic illnesses and also the Dylis 2003 neurofibromatosis study
2. Review of current literature relating to partnered and un-partnered parental coping
 - a. Partnered vs. un-partnered
 - b. Support relating to coping
 - c. Gender roles relating to coping
3. Review of the current literature relating to specific coping differences among the genders
4. Use all of this evidence to customize nursing interventions in order to improve coping and quality of life for parents of children with chronic illness
 - a. It is important to know parental characteristics in order to adequately and appropriately develop a nursing plan

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Summary of Proposal

While conducting a secondary analysis of previously collected data (Dylis, 2003) on parents of children with a chronic illness, significant differences were discovered between partnered and un-partnered parents on the major study variables. Specifically, these groups seemed to adopt different coping methods. It was also found that the genders coped differently and used different coping strategies. The purpose of this project is to review current literature in order to explore what is known about this difference and use this literature as part of a manuscript regarding issues facing partnered and un-partnered parents and specific nursing interventions to support these parents.

Preparation/Qualifications

As a senior BSN nursing student at Northeastern University, I am qualified to conduct this research based on my clinical experience at Children's Hospital Boston and my classroom experience in Pediatrics, Pediatrics in the Community, Nursing Care of Vulnerable Populations, Mental Health Nursing and Maternal-Child Health Nursing. I have also completed Advanced Writing for the Disciplines, Statistics, Ethics and Health Care Research. I am also a member of the Honors Program at Northeastern University through which I participated in honors adjuncts which included numerous research papers and coordination with faculty. I feel that the above, coupled with my desire to improve the quality of life of patients and their families, qualifies me for this research.