

## Parental Chronic Illness: Current Limitations and Considerations for Future Research

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**Abstract:** For the past fifty years, researchers investigating the impact of parental chronic illness or disability on the family have consistently noted the limited work in this area. Citations spanning several decades are included here to deliberately underscore this fact. The purpose of this article is to highlight this ongoing limitation, as well as a number of ongoing points of disagreement. To this end, issues of insufficient research, contested methodologies, assumptions of pathology, and the divided nature of existing research will be presented. Concerning the latter, for years, studies have appeared in two contradictory perspectives: those which view the families and children of chronically ill parents as at risk, and those who find these families and children developing normally despite profound, atypical stressors. These points seem mutually exclusive, but with current research it is difficult to determine how or where these distinctions occur.

**Key Words:** family, chronic, illness

Some life events have little effect on people, other encounters leave longer lasting effects, and still others shift people into fundamentally changed life paths. The onset of a chronic illness or disability certainly holds the possibility of forcing decisions, adjustments, and futures never before considered (Murray, 2005). For all family members, the process of reconciling to this new life course can involve shock, denial, grief, panic, anger, guilt, and despair (Kuyper & Wester, 1998; Power & Dell Orto, 2004; Thorne, 1990). It is predicted that most Americans, as many as 80%, will experience a chronic illness or injury during their lifetime, either as a patient, family member, or friend (Gavaghan & Carroll, 2002; King et al., 2003). This group now consists of more than 54 million Americans (American Association on Health and Disability, 2009), along with their often overlooked families. With medical treatment advances and longer life-spans, this number will very likely increase (Lewis & Hammond, 1996; Morris & Edwards, 2006).

In this field of study—family functioning in the presence of parental disability or chronic illness—strikingly little research has been done. Even with several decades of ongoing but modest interest, studies involving the families of an individual with a chronic illness or disability remains markedly limited. Fewer still are studies that include the perceptions of multiple family members necessary to better understand the impact of disease or injury on parenting and family dynamics (Blank & Finlayson, 2007; Harris & Zakowski, 2003; Newman, 2002; Watson et al., 2006). Although noticeable research has been conducted on the effects of a child's chronic illness on the family and how adults with chronic illness react to their own disorder, much less is known about the effects of parental disability on the individual parenting role or on the larger

family system if this role is modified (Pederson & Revenson, 2005; Peters & Esses, 1985). Certainly, the family experience of child illness and that of parental illness are not identical in coping strategies, shifts in traditional roles, or long-term consequences (Pederson & Revenson).

It is therefore essential to distinguish which member of the family actually has the disability or illness (Ferguson, 2001; Pederson & Revenson, 2005), as family may be modified when specific adult/parental roles are eliminated, expanded, or transferred to other family members. In this instance, family functioning is understood to be the carrying out of the family's day-to-day life, and adjusting individual roles, expectations, and control to accommodate, or failure to accommodate, to new situational demands. When considering a working relationship to parental chronic illness it is quite similar to the concept of family adaptability. Olsen, Russell, and Sprengkle (1984) defined this as the capacity of the family to change its existing power structure or hierarchy, roles, and relationship norms in response to new situational demands.

### A Continuing Call for Research

Almost fifty years ago, Arnaud (1959) commented on a lack of systematic study of the influence a chronic parental illness might have on a child's development. Roughly twenty-five years later, McCubbin and Patterson (1983) continued to report that little work had been done concerning illness-related family stress. This deficit was consistently noted by their contemporaries specifically investigating parental disability or chronic illness and its possible impact on children and family relations (e.g., Buck & Hohmann, 1981; Peters & Esses, 1985).

With the passage of the Americans with Disabilities Act in 1990, the Disability Discrimination Acts in Australia in 1992 and in the United Kingdom in 1995, one would have expected greater research interest. Indeed, Hornby and Seligman (1991) described such an increased interest in the consequences of illness or disability within the family. However others, in apparent disagreement, simultaneously reported no increase in empirical research (e.g., Armsden & Lewis, 1993; Thorne, 1990). Roy (1990) concluded that with the available studies, it was simply not possible to determine the prevalence of physical, emotional, or psychiatric problems in children of parents with a chronic illness as compared to the general population. Furthermore, there was an evident lack of awareness among policy-makers of the fact that adults with disabilities are frequently also parents (Berkeley Planning Associates, 1997). The literature of the time described "a field of study in its infancy" (Armistead, Klein, & Forehand, 1995, p. 420) attempting to address a "rarely studied population" (Stuifbergen, 1990, p. 43). Over the next few years, a many others reported similar findings (e.g., Blackford, 1999; Ferguson, 2001; Mukherjee, Sloper, & Lewin, 2002; Newman, 2002; Sidell, 1997).

Little has changed, with Pederson and Revenson (2005) still describing a dearth of research on families coping with parental illness. Many more recent works have continued to acknowledge this essential need for research (e.g. Duvdevany, Buchbinder, & Yaacov, 2008; Kissil, Nino, Jacobs, Davey, & Tubbs, 2010; O'Connor, McCabe, & Firth, 2008; Sherman et al., 2007). It is no surprise then, despite the fact that the work reflects treatment and a disease experience from 50 years ago, that newer works (e.g. Diareme et al., 2006; De Judicibus & McCabe, 2004) continue to cite Arnaud (1959), offering further evidence of limited available research.

Studies have not only remained few, but have also left many necessary elements unexamined. Coates, Vietze, and Gray (1985) listed several factors that should be incorporated when considering the effect of a parent's illness on a child's development. These included: socioeconomic status, ethnicity, size of the family, and the child's age and gender. Also necessary are multiple informants using well-standardized, norm-referenced assessment measures that are applicable across research studies (Champion & Roberts, 2001) and an improved awareness of prejudicial and negative stereotypes (Buck & Hohmann, 1981; Farber, 2000; Prilleltensky, 2004; Rehm & Catanzaro, 1998). Finally, a comparison group is viewed as often essential to interpreting data concerning these families (Helegson & Reynolds, 2002; Roy, 1990).

### Missing a Familial Perspective

Illness in the family is a very complex experience and the illness effect on all concerned is critical to understanding the full impact on the family (Armistead, Klein, & Forehand, 1995; Gan & Schuller, 2002; Greer, 1985). Whether acute or chronic, illness is pervasive in its effect on the present and future dynamics of the person's family as a whole (Hornby & Seligman, 1991; Kissil et al., 2010; Reiss, 1986; Smith & Soliday, 2001). Stated simply, chronic illness happens to a family and not the individual alone.

Nevertheless, in 1984, Rustad reported a conventional bias in clinical research toward the person with the medical diagnosis and comparative inattention to the family. Greer (1985) concurred, and years later, Korneluk and Lee (1998) reported similarly. Children appear to be overlooked by those studying adult chronic illness and those researching childhood illness have little or no interest in adults (Champion & Roberts, 2001). Possibly as a result, children of a disabled parent have regularly been viewed "within a discourse of disability and not within a discourse of socialization" (Grue & Laerum, 2002, p. 679), with the child's perspective simply inferred (Kahle & Jones, 1999). Bentov (1999) described these children as being treated with *compassionate neglect*. Mothers with a chronic illness have similarly reported that some medical professionals were noticeably indifferent toward motherhood while those who recognized the parent role often failed to understand the implications of illness or disability (Thorne, 1990). Even though the possible reactions to chronic illness are many and difficult to predict (Sidell, 1997), studies have most often relied on a single informant or a single dyad for conclusions concerning family (Banks et al., 2001; Barlow, Cullen, Foster, Harrison, & Wade, 1999; Lewis & Hammond, 1996).

Barrett-Lennard (1981) wrote that knowing about others implies a perception and understanding of individual and unique qualities that comes from a position as "participant-observer" (p. 91). Family members of parents with a chronic illness could certainly be viewed as such participant-observers and therefore their inclusion in research is necessary. Although more than a few studies have used an "anemic perspective" to examine family functioning in chronic illness, fewer have sought perceptions of family phenomena related to parenting from multiple family members (Rehm & Catanzaro, 1998, p. 23). Understanding familial relationships is absolutely essential to any future understanding of chronic illness, and the perception and influence of all family members is vital.

## Consistent Polarity in Research

Research methodology has also been a point of disagreement. Mukherjee et al. (2002) stated that little qualitative work had been done, explaining that most studies have utilized quantitative approach that has been “criticized for being methodologically unsound” (p. 479). Blank and Finlayson (2007) agreed, finding only one qualitative study relative to their work on caregiver burden and spousal chronic illness. Others, however, have described the opposite, seeing current literature as dominated by qualitative work in localized case studies (Romer, Barkman, Schulte-Markwort, Thomalla, & Riedesser, 2002). Later, Kahle and Jones (1999) concurred, citing the existence of very few empirically based studies to guide future work. Consequently, it is difficult to reach trustworthy conclusions concerning the influence of chronic illness on parenting because of the range of methods and goals in the existing literature (Rehm & Catanzaro, 1998). It also appears that the field has quite often studied variables without an interlinked theoretical model or comprehensive perspective (Armsden & Lewis, 1993; Champion & Roberts, 2001; Romer et al., 2002).

Some have also found the field to be divided with regard to findings: those who view children of parents with chronic illness as at-risk, and those who find these children developing normally despite profound atypical stressors. Over the years, many have linked parental disability to the occurrence of common behavioral patterns among non-disabled children (Arnaud, 1959; Barlow et al., 1999; Diareme et al., 2006). Several others have reported that these children have also exhibited higher levels of internalizing behavior, such as anxiety and depression (Compas et al., 1994; Osborn, 2007; Romer et al., 2002). However, contemporaries concluded that there was no difference in the levels of negative internalizing behaviors in the children of chronically ill parents (De Judicibus & McCabe, 2004; Harris & Zakowski, 2003). Certainly chronic illness has the potential to significantly alter the daily routine and future of the family. However, existing research has actually offered little unambiguous evidence of any detrimental effects on children's development originating from a parent's illness or disability (Kahle & Jones, 1999; Rehm & Catanzaro, 1998; Smith & Soliday, 2001).

A comparable diversity of opinion exists concerning the effect of parental illness on overall family functioning as well. In 1991, Hornby and Seligman wrote that chronic illness would very likely initiate an unwanted restructuring within the family and require individual role changes. Perhaps for the best of intentions some family members may then feel that their own personal concerns and comforts were less important than those of the family member with chronic illness. Such a process would very likely interfere with the normal and ongoing needs for autonomy, assurance, support, and comfort of all family members (Basra & Finlay, 2007; Cheung & Hocking, 2004) and leave many necessities unattended (Nichols, 1987; Patterson & Garwick, 1994). When rigidly organized around one parent's illness, family members risk no longer acknowledging the family system as a whole (Reiss, Steinglass, & Howe, 1993). In such a situation, with the aforementioned unwanted restructuring, multiple individual role shifts, and unattended necessities, the parent's illness can become what Reiss (1986) described as a *disembodied tyrant*, a too narrow and inflexible focus that diverts energy and attention from the family system.

Again in contrast, this very same ambiguity can become an impelling force towards a stronger orientation to live in the present and to reevaluate simpler experiences (Cheung & Hocking, 2004; National Institutes of Health, 1996). Although contrary to popular thought and persistent stereotypes, relationships may actually strengthen with the realized threat of their potential loss (Alexander, Hwang, & Sipski, 2002; Segrin & Flora, 2005). Even a serious disability does not automatically rule out the continuation of an intact, interdependent, loving family, with the parent with a chronic illness being able to contribute in work and partake in play at a satisfying level (Mukherjee et al., 2002; Stuifbergen, 1990).

### Supposition of Pathology

Some have suggested that the study of parenting with a disability has revolved around a search for negative outcomes (Alexander et al., 2002; Banks et al., 2001; Olsen & Clarke, 2003; Prilleltensky, 2004). In 1981, Buck and Hohmann recognized that many alarming predictions and assumptions had been made concerning the frightening repercussions of parental disability on family functioning and child development. Ten years later, Hornby and Seligman (1991) recorded a comparable overestimation of the negative impact, specifically on children. For example, Armsden and Lewis (1993), despite noting that existing research was limited, nevertheless assumed that changes in family functioning due to parental chronic illness clearly posed some danger to the psychological development of the child. Roy (1990) and White (1998) agreed, writing that common sense dictates that children of chronically ill parents *must* be more vulnerable, though also stating that the findings were inconclusive. Such vulnerability makes intuitive or superficial sense perhaps, but is nevertheless assumptive. Should that be the case in the face of inconclusive or opposing findings? Certainly not.

In 1990, Stuifbergen described a limited, but noticeable, core belief of pathology in families with a chronically ill parent that was supported only by much earlier research (e.g., Arnaud, 1959) and a common inference of negative effects on family functioning that was not supported by her study. At roughly the same time, Hornby and Seligman (1991) reported a trend in the relevant literature moving away from the common supposition of unavoidable pathology in families with members with a chronic illness, and moving toward identifying representative stressors, support resources, and coping strategies. Even so, disability has been routinely implied in research (Alexander et al., 2002) and untested assumptions of defectiveness concerning these families persist (Crawford, 2003; Kelley & Sikka, 1997). Although researchers have indeed challenged the field not to assume that negative effects are the standard, it seems possible, if not probable, that with the available “speculative literature” (Greer, 1985, p. 141) such “presumptions of deficiency” (Kelley & Sikka, p. 105) and “pathological assumptions” (Crawford, p. 68) will continue.

Additionally, and for quite some time, research has suggested that able-bodied health-care professionals and researchers might actually project their own expectations onto families with a disabled parent (Blechman & Delamater, 1993; Greer, 1985; Romano, 1984). Kahle and Jones (1999) stated matter-of-factly that researchers in this field have habitually found the problems for which they searched. Similar findings continue (Telford, Kralik, & Koch, 2006; Thorne et al., 2002). Consequently, Nichols' (1987) admonition against adopting a purely academic perspective that risks distancing the research from the present reality of family

suffering, described as an especially disturbing attitudinal bias, remains too often unheeded. A more balanced research outlook which “joins the biological reality of living with a disability to an account of human agency and structure, set in time” is necessary (Blackford, 1999, p. 676).

### Supposition of Commonality

Yet another problem in the field has been a focus on chronic illness in general instead of specific diagnoses (Champion & Roberts, 2001). Studies in chronic illness sometimes appear guilty of blending varied and seemingly unrelated diagnoses into samples of convenience. According to Kazak (1986, as cited by Padula, 1995), this overgeneralization of one illness or disability to another is among the most severe shortcomings in the field. Armistead et al. (1995) described such an approach as introducing an *artificial sameness* that can result in distorted conclusions. Diverse symptoms and trajectories require unique individual and family skills for successful coping and effective management (Coates et al., 1985; Crawford, 2003). For example, among those individuals with rheumatoid arthritis, hypertension, and multiple sclerosis, physiological adaptation varied, while psychological adaptation was found to be more similar (Pollock, Christian, & Sands, 1990).

In light of Buck and Hohmann’s (1983) suggestion to measure parental illness and disability separately, it seems wise to examine individual conditions before judging commonalities. Armistead et al. (1995) suggested that future research should seek to determine if varied types of physical illnesses influence child development and functioning differently. They reported that no existing studies thoroughly compared children whose parents were experiencing different levels of a particular physical illness. Differences within families dealing with the same diagnosis should certainly be considered (Armistead et al.; Watson et al., 2006).

### Conclusion

The literature concerning parental chronic illness and family functioning is limited in size but certainly not in findings. Indeed, it has an apparent tradition of being a visibly divided field, at odds in methodologies, findings, and implications. However, five decades of work has continually called for more deliberate, detailed studies of chronic illness in the family. Apparently all agree that research in this field is of critical importance.

This review has included much of what has been identified as important but often unacknowledged in many previous studies. First, there has been a need for more thorough demographic data concerning socioeconomic status, ethnicity, family size, child's age and gender, severity of any disability, parental education, employment status of the person with chronic illness, time since the diagnosis or onset, gender of the individual with chronic illness, and health status of the well-spouse. Such data becomes even more relevant when considering the absolute impossibility of having accurate baseline data before the onset of a disability or chronic illness (Nelson & White, 2002). Secondly, researchers have strongly stated that studies have too often involved a search for assumed pathology. Kelley and Sikka (1997) concluded that the use of measures that have a strong record of detecting unhealthy adaptation in specific areas of family functioning could help to avoid such biased, yet common, assumptions of deficiency. Third, many quantitative studies in the field could benefit greatly from the inclusion of a

comparison group. With the aforementioned lack of baseline data, this would prove essential to interpreting data concerning these families.

A fourth shortcoming has been the focus on chronic illness in general, with much less work relative to a specific diagnosis. There is certainly value in examining parental chronic illness in a more general, or collective, sense (e.g. Lundwall, 2002), perhaps especially as it relates to stigma or stereotyping, social supports, public policy, parenting modifications, adaptation, and questions of gender. But, for reasons stated above (i.e., artificial sameness), careful awareness should be taken in following too general a path with varied diagnoses. Chronic illness can be visible or invisible, stable or progressive, treatable or untreatable, and debilitating to greatly varied degrees. Certainly, fewer studies exist that consider family functioning or parenting in the presence of a single illness, (e.g. multiple sclerosis, breast cancer, arthritis) with even more limited attention to within-group differences and/or similarities.

Fifth, many studies have inferred the absent child's perspective from parents, or the perspective of the person with chronic illness from the well-spouse, and so on. The contribution of future work in this field will be strengthened to the degree that it addresses these too often unacknowledged elements and consciously connects to, and builds on, the existing body of knowledge (Knafl & Gilliss, 2002).

With the variability in findings, future research must continue to question whether any single stressor, in this case parental illness, is the encompassing negative influence on family functioning that some have believed. Although it is more than 10 years of continuing research later, we strongly agree with Kahle and Jones, who in 1999 accurately concluded, "the available literature provides only *scant* information about a *few* factors that *may* influence the effects of parental chronic illness" (italics added, p. 396). Little has changed.

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