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Single Parenting and Children with Chronic Illness: An Understudied Phenomenon[1]

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It is estimated that 20% to 30% of the children and adolescents in this country suffer from a chronic disease or health condition. These conditions can affect children throughout their lives and also affect the family unit. The increase in day-to-day caregiving requirements, the complexities of disease management activities, lifestyle, and family dynamics, alone or collectively, may influence long-term health outcomes. Furthermore, chronic health conditions may affect the financial status, and social, community, and school interactions of the child and the family. The child or adolescent is affected personally by the pathology of the disease, side effects or treatment, and by the required lifestyle and health management adaptations. The family is involved in the child's illness management through requirements for care assistance, supervision/guidance, travel and time from work for health visits or hospitalizations, cost of care, and the effect of these requirements on family dynamics and lifestyle.

Over the past several years, many studies have examined the potential impact of childhood chronic illness on parents and families (for review see Kazak et al., 2003). In general, the literature has delineated a myriad of stressors that parents may experience, including financial stress, role strains, separations, adjustment to the various components of the medical system, interruptions in daily routines and plans for the future, and the general uncertainty with regard to the child's prognosis. All of these possible experiences may lead directly and indirectly to anxiety, depression, post-traumatic-stress, hopelessness, and feelings of loss of control. What is not known is how single, or "lone," parents trying to navigate the complex needs of maintaining a home, family, and a chronically ill child adapt to these challenges.

The proportion of children in two-parent families has decreased from 85% to 69% in the last 30 years; thus nearly 3 in 10 children live in single parent homes (Shudy et al., 2006). The most common type of single parent home is one with a mother present, although single father homes are among the fastest growing type of family situation in this country (Garasky, 1996). Single parenthood may occur as a result of loss (death, separation, divorce, or abandonment by one parent) or by choice (adoption, assisted reproductive technology, choosing to become or remain pregnant without a partner).

In general, the field of pediatric chronic illness has not kept pace with the demographic changes that now characterize our society; changes that have the potential to profoundly affect child and family functioning. A recent review of the impact of family structure on family income revealed that financial resources for lone parents were only 55% of those of married-parent families (Thomas & Sawhill, 2007). Even more striking, children in lone-parent families are more than four times as likely to live in poverty than those in married-parent families – across all race/ethnic categories (Thomas & Sawhill, 2007). These findings are particularly salient in

the case of pediatric chronic illness, which frequently taxes the economic resources of the family under the best of conditions.

In response to the increasing number of children growing up in single parent households who must face challenges associated with chronic illness, and the dearth of literature specifically focused in this area, a one-day "think tank" was organized and led by Lori Wiener, Ph.D. (National Cancer Institute, Pediatric Oncology Branch) and Mary Jo Kupst, Ph.D. (Medical College of Wisconsin) in collaboration with the Children's Inn at the National Institutes of Health. The think tank was generously sponsored by the Andre Sobel River of Life Foundation. A distinguished group of multidisciplinary experts in pediatric psychosocial research of chronic illness was invited to attend a one-day meeting that was designed to address three primary questions pertaining to single parents of children living with a chronic or life-limiting illness: "What do we know?", "What do we need to know?" and "Where do we go from here?" Each expert was to respond to these three basic and fundamental questions from his/her own clinical experiences and programs of research. We were humbled by the dearth of knowledge about the complexity and diversity of the variables affecting the needs and adjustment of all parents, particularly those who care for a child with a chronic illness by themselves. Furthermore, while we all recognized the challenges that single parents must endure in negotiating the financial stressors of having a child with a chronic illness, and the caregiving of multiple children in a family, we realized a primary challenge was to define who should be considered a "single parent" and how variables such as socioeconomic status, distance from home to hospital, presence of other children or support figures altered the potential impact on a single-individual meeting the needs of a chronically ill child. As researchers, we also recognized that we had failed to examine systematically the challenges that these individuals must face. Indeed, there was consensus that this is an overlooked population much in need of our careful attention.

While the initial goal of the "think tank" was to develop a limited institutional study to examine the psychosocial correlates of single parents dealing with pediatric chronic illness, by the end of the day it was clear that a need to better understand the complexity of this issue exists, and therefore, the development of a research study was deferred. We now provide an overview of what we learned, including a review of the extant literature in the area of single parenting and chronic illness, concluding with recommendations for investigators who work with chronically ill children and their families.

What Do We Know: Literature Review

Impact of Illness

There is a wealth of information on the impact of pediatric illness on individual family members and family functioning as a whole. The existing body of literature describes an undeniable impact, both positive and negative, of pediatric illness on family dynamics, adult dyadic relationships, finances, employment, and emotional well-being of patients, parents, and siblings. While it is beyond the scope of this article to review all published studies that relate to pediatric chronic illness, parental and family functioning, and psychosocial outcomes, a summary of pertinent and well referenced literature since 1985 is provided in Table 1.

In an extensive literature review, Shudy and colleagues (2006) identified specific stressors, needs, psychosocial functioning, coping, and recommended interventions with families negotiating pediatric chronic illness or injury. Shudy's review revealed that a pediatric critical illness or injury is indeed stressful for the whole family, given many potentially traumatic events that occur at diagnosis and treatment, often mirroring post-traumatic stress disorder (PTSD).

The literature has generally suggested a reciprocal relationship between chronic illness and parental adaptation whereby the child's illness impacts the parents' functioning and parental functioning also influences child adaptation. With the onset of illness, families must initiate a number of changes in family routines, structure, and functioning, including redistribution of roles and responsibilities for family members. Depending on the illness, its severity, and treatment complexity, families may be required to become intensely involved in the care and maintenance of their family member who is ill. Parents have described difficulties maintaining family functioning and a sense of routine as they organize care and fit it into their family schedules with pre-existing day-to-day responsibilities (Jarrett, 1994). In some cases, complex treatment regimens or severity of illness can restrict family activities. As the illness consumes a greater part of the parents' energy and time, many parents report lacking time to spend with siblings and are concerned about the negative impact this might have on them (Coffey, 2006). Indeed, both mothers and fathers have identified giving emotional support to the child with cancer and to other children in the family as the most time-consuming and difficult caregiving activities (Svavarsdottir, 2005). Mothers, in particular, found it difficult to care for their ill child and plan activities for the rest of the family.

Studies examining distress in families coping with a cancer diagnosis, in particular, have repeatedly shown increased levels of depression and anxiety at initial diagnosis (Barrera et al., 2004; Sloper, 2000; Steele, Dreyer, & Phipps, 2004). While studies often show a steady decline in distress levels over the first year following the cancer diagnosis (Steele, Long, Reddy, Luhr, & Phipps, 2003), there is some suggestion that continued levels of distress can exist up to 18-months post-diagnosis (Manne, Miller, Meyers, Woller, & Steinherz, 1996; Sloper, 2000). Mothers of children with cancer seem to represent a particularly vulnerable group, as many studies have shown greater psychological distress in mothers than in fathers of children with cancer (Noll, 1995; Sloper et al., 2000) or when compared to mothers of children with acute illnesses (Barrera et al., 2004; Sahler et al., 1997). Moreover, one recent longitudinal study found that single mothers of children with cancer tended to have moderately high and stable levels of psychological distress over the 6 months following initial diagnosis (Dolgin et al., 2007).

Marital Functioning

When examining the experience of caring for a child with a chronic illness, the literature identifies several themes parents commonly describe, including living with anxiety, carrying the burden, and survival of the family unit (Coffey, 2006). While there does not appear to be a disproportionately high divorce rate among parents of chronically ill children (Cadman, Rosenbaum, Boyle, & Offord, 1991; Sabbath & Leventhal, 1984), some studies clearly describe the negative impact of a chronically ill child or adolescent on the marital relationship (Youngblut et al., 2000), largely associated with significant role strain and changes in marital satisfaction. Other research has found no significant difference in levels of marital satisfaction when comparing parents of chronically ill children with parents of comparison children without a chronic healthcare condition (Gerhardt et al., 2004, Kazak, Reber, & Snitkzer, 1988; Noll et al., 1994. 1995; Reiter-Purtill et al., in press; Spaulding & Morgan, 1986). Some families report greater cohesion and trust and increased communication as a result of the child's illness (Lavee & Mey-Dan, 2003; Philichi, 1989). Similarly, in an examination of changes in marital relationships among 35 parents of children treated for cancer for less than a year to more than five years, Lavee and May-Den (2003) found that aspects of the relationship, such as communication, conflict resolution, and interpersonal trust, were reported to have improved during the child's illness. The greatest negative effect of the child's illness, reported by both mothers and fathers, was on their sexual relationship, with nearly half of the couples surveyed reporting a significant decline in this area. Few changes were reported in leisure activities, parenting, and relationships with the extended family. Clearly, the research examining the

relationship between parenting a child with an illness and marital satisfaction has yielded varying results (Gaither, Bingen & Hopkins, 2000). Furthermore, no studies were identified that addressed patterns of relationship changes within other family constellations, including same sex couples or cohabitating partners.

Carrying the Burden

While both parents may report significant worry and concerns of maintaining family functioning, one parent, typically the mother, is commonly identified as the primary caregiver. The responsibility of making and keeping health care appointments, monitoring illness status, administering medications and treatments, in addition to caring for household tasks such as feeding the family and cleaning the home, has resulted in mothers' describing this phenomenon as "carrying the burden" (Hirose & Ueda, 1990). This burden of care, which has been shown to remain relatively stable across the duration of the illness (Steele, Long, Reddy, Luhr, & Phipps, 2003) has led many mothers to believe they could not have a break from the routine and responsibility of caring for the child, often leading to physical exhaustion (Coffey, 2006). Furthermore, carrying the burden of care may allow for fewer opportunities for community and outside activities, leading to feelings of social isolation and potentially diminished social support. Notably, recent work also has suggested that the burden of care and level of stress that accompanies having a child with a chronic health condition may have significant negative effects at the physiologic level, including premature cell aging, which may culminate in a variety of health problems in the caregiver (Eppel et al., 2004).

Financial Considerations

The financial stress, employment loss, and overall negative economic impact on families with a critically ill child have been demonstrated (Winthrop et al., 2005). Studies have reported the financial burden of illness, particularly in families living with a cancer diagnosis. Previous reports estimate between $5,000 and $17,000 *per year* in medical and non-medical, *out-of-pocket* costs including time off from work, travel expenses, and treatment equipment (Jacobs & McDermott, 1989).

Family income is strongly associated with children's health. Multiple studies have indicated deterioration in finances or job loss as a result of a child's chronic illness. For example, in one study, 30% of families reported a deterioration in finances or loss of job (Montgomery, Ronald, Reisner, & Fallat, 2002). Mothers of chronically ill children have cited concern over the lack of opportunity for employment (Hauenstein, 1990; Wasilewski et al., 1988). In fact, in an unpublished study, Hauenstein (1987) found that 10 of 14 mothers (71%) of chronically ill children were unemployed, whereas only 1 of 11 mothers (9%) of healthy children did not work outside the home.

This brief review only skims the surface of the complicated psychosocial issues that exists when parenting a child with a critical illness. In the best of circumstances and even in the most supportive environment, parents of a child with an illness may have to alter their family roles and routines, struggle with adjusting to and coping with the disease, treatment options, and disease outcomes, and may encounter significant financial difficulties. Single parent families may feel these issues even more intensely. For example, the financial burden on a single-parent home is greater than that of a two-parent home, with the median income of a single-parent home only 47% of that of married-couple families (Shudy et al., 2006). In addition to the possible catastrophic financial issues, being a sole caregiver is likely to be associated with fewer social supports. As more children are being raised in single-parent homes, the burdens and functioning of these families who are raising ill children clearly need the focused attention of our children's hospital and health care system.

What Do We Need to Know?

In preparation for the think tank, we conducted literature reviews of relevant research pertaining to single-parent families on *PubMed, Medline, and PsychINFO*. We also surveyed pertinent book chapters and all of the articles from the *Journal of Pediatric Psychology* since 1987 for articles specifically examining the potential associations of lone parenting versus two-parent households on children's psychosocial functioning and the impact of the child's illness on caregiver functioning. With only two exceptions, we were unable to locate any studies that examined single-parent homes versus two-parent homes as a primary outcome variable and only one book chapter addressed this issue independently (Wiener, Hersh, & Kazak, 2006).

The first exception was a study of adjustment in long-term survivors of pediatric cancer (Mulhern, Wasserman, Friedman & Fairclough, 1989) which found that survivors from single-parent households had twice the risk of school problems and internalizing problems as did children from intact or "blended" homes. A second exception was in the development of a screener for psychosocial risk in families of children newly diagnosed with cancer, the Psychosocial Assessment Tool (PAT; Kazak et al., 2001; 2003; Pai et al., in press). Kazak et al. found that a number of family structure variables are associated with higher risk, including being a single parent, being an adolescent parent, and having four or more children, each indicative of higher strain and reduced resources within the family. While additional quantitative and qualitative research and assessment are needed to fully determine the psychosocial functioning of these families, early data appear to suggest increased psychosocial risk in single parent households raising an ill child.

Knowing the stressors of raising any child, nonetheless one with a chronic illness, raises the question of why there has been little to no systematic examination of single parenting and chronic illness. The lack of empirical work in this area may be due in part to methodological difficulties in recruiting caregivers who are raising their children alone. While no work has thoughtfully examined an association between family constellation and availability, accrual problems may exist due to practical challenges single parents face in fulfilling activities of daily living, not withstanding complications associated with participating in research studies. As such, many single-parent families may not have entered existing studies or may have discontinued the study participation prematurely. Other contributing methodological problems include recognizing that "single parent" is often a fluid concept whereby a parent may be considered single in one situation but this status may change over the course of time and study participation.

As such, in a discussion of single parenting, it must be recognized that there is difficulty in defining the "nuclear family", or in more vernacular terms, deciding what actually constitutes a family. "Marital Status" as indicated on typical demographic inventories does not provide sufficiently adequate information for the purpose of our understanding either who constitutes the household or family, or who contributes to the "marital"/family support system available to the primary caregiver of a child with a serious illness. Simply asking one question on a demographic questionnaire about marital status will not suffice. For example, two separate individuals may identify themselves as "single" on a demographic inventory, but there may be significant differences between a single unmarried parent who lives with a partner or with extended family members, and a single unmarried parent who lives solely with his/her children. These potential gradations of "loneness" complicate the assessment of family composition across time and social contexts. In short, even the definition of a single parent may need clarification, especially as it is reported in the literature.

In previous years, the issue of single parenting was closely intertwined with the issue of social class. Single parents were typically mothers who did not have access to higher paying jobs due

to salary discrimination, lack of educational opportunities among women, or because they were burdened with all of the care for their children and as a result could not access routes to career advancement/increased compensation. Although discrimination with regard to access and compensation continues to exist as evidenced by 28.4% of all female-headed households being at or below the poverty level vs. 5.5% of married couples (U.S. Census Bureau, 2005), there have been significant improvements in employment opportunities for women in general, as well as for single mothers. While social class alone may account for the variance in adjustment and adaptation of a child with a chronic illness from a single parent family, a single woman raising a child with a chronic disease is not necessarily synonymous with poverty. Accordingly, there now exists an opportunity to examine other predictors that may mediate the influence of single parenting and adaptation (e.g., cultural factors, personal, environmental variables, resources) to a child with a chronic illness. The Report of the American Psychological Association Task Force on Socioeconomic Status (2007) concluded that, while socioeconomic status has a major impact on families, “intersectionality” of socioeconomic status with other salient variables, (e.g. gender, race/ethnicity, and disability status) might be more important than simply categorizing socioeconomic status. Similarly, studies of the intersection of family formation and living arrangements with other predictors of outcomes are essential if we are to go forward with meaningful research in this area.

Where Do We Go From Here? Future Directions

A major purpose of this commentary is to point out the gaps in the extant literature with regard to understanding the challenges experienced by single parent families in raising a child with a chronic illness. Undoubtedly, we have limited knowledge about how single parents, or perhaps more appropriately termed a “lone parent”, versus families with two parents and/or other adults involved in childrearing, fair over the course of time with regard to adjustment and adaptation to their child’s illness. As we develop more sophisticated methodology for conducting longitudinal studies, including those that investigate the sequalae of single parenting, this will be a fruitful area of research, particularly in the context of caring for a child with a chronic illness.

Several specific areas for further empirical research are highlighted by the literature review and think tank discussions. These include the need to assess the chronic nature of pediatric illness, the impact of financial hardship on family coping, and the long-term effects on family functioning. The importance of supporting families long after the initial diagnosis when many parents may find that their internal and external resources are depleted was underscored. Additionally, the discussions resulted in a compilation of gaps in current research relating to lone parenting of children with a chronic illness. Table 2 delineates and summarizes specific questions necessitating future investigations in the areas of definition, measurement, demographics, and psychosocial adaptation.

Definition, Measurement, and Demographics

Available demographic data do not capture what a family actually looks like. With the changing and complex landscape of families in this country, it is imperative that “lone” or “single” parent (or caregiver) and single parenting is carefully defined. For research purposes, classifying single parents is complicated by the fluid and informal status of many relationships. Therefore, the astute investigator must think through the measurement of the complexities associated with marital status both at baseline assessments and over the course of time. At a minimum we should know whether this is a single parent who is cohabiting with a partner. Further, we may want to know about the birth history of this child: was this child born to an unmarried mother or were the parents divorced at the time or subsequently? Is there any other actively involved divorced parent and what complications or benefits arise in this context? Being the sole decision-maker for what might, in fact, be major health and well-being decisions, for some

might be a challenge in and of itself, while other single parents may actually find it less stressful to be more autonomous in their decision-making rather than being confronted with conflicting opinions and priorities.

Psychosocial Adaptation

Functioning of caregivers and children prior to the development or identification of a chronic disease is likely to predict psychological adaptation. But, regardless of premorbid functioning, it will be important to conduct longitudinal studies to examine family functioning and single parent adjustment as it is impacted by children's chronic illness as well as by a child's psychological functioning over the course of the illness. Moreover, of importance is the adaptation of other family members, their previous psychological functioning, socioeconomic status, concurrent psychosocial stressors, and quality of relationships, all of which may be posited to interact significantly with the child's current psychological functioning and adaptation to illness. Demographic variables (e.g., rural versus urban environments) also are apt to impact single parents' social supports and access to social services. How these variables in turn impact psychological functioning of the child and coping is in need of systematic and careful investigation.

When studying psychosocial functioning in this population, it will be important to assess the physical proximity of significant others (who may or may not be relatives), as this may provide the opportunity for the single parent to profit from substantial social support. Moreover, quality of familial relationships and the time that the family spends together is likely to influence the quality and quantity of support provided to the child or adolescent with a chronic illness. Critically important is examination of the length of relationships among caregivers in the family system and the degree of parental functioning over the course of time, which can only be assessed within a longitudinal context.

Research design must also be sensitive to how cultural issues may relate to single-parenting and family adaptation. Dolgin et al. (2007) found that Hispanic or Spanish speaking mothers of children with cancer had moderate, stable levels of distress up to 6-months following their child's diagnosis. Among immigrant groups, other factors influencing adjustment and adaptation may include unique challenges such lack of fluent English, ineligibility for social services afforded to U.S. citizens, and low literacy, which might preclude appropriate informed consent for research participation. Other areas of potential inquiry include how living in ethnic and racial cultures where family leadership by grandparents is generally accepted might affect adjustment and adaptation of a single parent; how living in a culture where the church or religious community plays a significant role might affect family adaptation; and if there is an interaction between culture and family structure such that adaptation of the child and the family differ as a function of ethnicity or race.

Despite the enormous stressors associated with caring for an ill child, parents and caregivers may often respond with significant resiliency in the face of prolonged stress and uncertainty. However, stress can certainly negatively influence mental, emotional, and behavioral health. Higher rates of distress and depression have been found in low-income, female-headed households, largely associated with employment problems, housing, and discrimination (APA Task Force on Socioeconomic Status, 2007). Furthermore, the field of psychoneuroimmunology has taught us that psychological stress can and does influence physical health (for review see, Glaser, 2005). Findings suggest lone mothers with the highest amount of perceived stress may be at increased risk for cardiovascular disease, shorter Telomere length[2], lower telomerase activity[2], and higher cellular oxidative stress, leading to premature aging by 10 years (Epel et al., 2004). Whether there are differences in stress processing among single-parent families caring for a chronically ill child versus two-parent families as a function of social support is largely unknown. For example, whether issues of

loneliness, isolation, and limited social supports increase the risk for physical health problems among parents, and even exacerbate morbidities for chronically ill children, are important questions for future research efforts. Thus, it is prudent to provide more careful screening for single parents particularly in the area of psychosocial stressors and mental health problems, and to target specific social, psychological and medical risk factors.

Survivorship research should also contemplate these issues. Current data doesn't tell us how parenting does or does not change as children move into later stages of survivorship. Questions to be considered include whether being a single parent effects the child's health care utilization, the parent's perception of internalizing/externalizing behavior in child, and the child's likelihood to engage in risky health behaviors or adherence to medical regimens.

Summary

We have attempted to underscore the critical need to conduct long needed research among children with chronic illnesses within the context of the changing family demography in this country. Research should encompass the various types of families that exist in our society, including those families that are headed by single parents. It clearly is not possible within the space limitations to delineate all research possibilities. Rather, our plan was to identify some of the more significant gaps in this important and heretofore neglected area of inquiry. We hope that we have stimulated investigators to consider this issue either as part of their existing research programs or as a new area of inquiry.

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Table 1

Summary of studies.

Authors	Sample Description	Instruments & Design	Major Findings	Study Limitations
Best, Streisand, Catania, Kazak (2001)	113 parents of children treated for leukemia	Design: Longitudinal, prospective study Instruments: Langer Symptom Checklist, Perception of Procedures Questionnaire, STAI, IES- R. PTGI, Pediatric Anxiety and Avoidance Scale, CHOP-Self-Efficacy Scale	Anxiety during treatment was a predictor for later PTSS in mothers, but not fathers. Anxiety, self-efficacy, posttraumatic growth, and length of time since treatment ended were associated with parental avoidance.	All parents were familiar with and well connected to the hospital and had participated in a previous psychological study. As such, these parents may have been more willing to participate, resulting in a potential underreporting of avoidance.
Bramlett, Blumberg (2007)	Utilized the 2003 National Survey of Children's Health (NSCH)	Design: Cross-sectional	Children living in single-mother or grandparent-only families had poorer health than children living with 2 biological parents. Children in single-father families did as well (mental health) or better than (physical health) children living with 2 biological parents.	Cross sectional design; the sample survey format of the NSCH was subject to nonrandom error, including coverage bias and non-response bias.
Cadman, Rosenbaum, Boyle, Offord (1991)	1869 families, 3294 children (4–16 years old) with chronic illness or physical disability	Design: Epidemiologic study comparing and contrasting families of healthy children and families of children with chronic illness and/or physical disability Instruments: Checklist of chronic medical conditions, Family Assessment Device	Parents of children with chronic health problem demonstrated increased rates of treatment for "nerves" & increased maternal negative affect scores. Families of children with chronic illness showed no increase in single-parent families, social isolation, or alcohol related problems.	Large-scale surveys limit the detail and numbers of items/ measures used compared to clinic settings and may underestimate family and parents adjustment difficulties that would be more evident in the clinic setting.
Coffey (2006)	Parents of a child with a chronic illness	Design: Metasynthesis of 11 qualitative articles	Seven themes evolved from the studies: living worried, staying in the struggle, carrying the burden, survival as a family, bridge to the outside world, critical times, and taking charge.	Did not investigate themes in single-parent families.
Crosier, Butterworth, Rodgers (2007)	354 single mothers, 1,689 partnered mothers	Design: Cross-sectional Instruments: Data from a national survey – the Household Income and Labour Dynamics in Australia (HILDA) Survey; SF-36	The prevalence of moderate to severe mental disability was more pronounced in single mothers (28.7%) compared to partnered mothers (15.7%). Socio-demographic, household income, financial hardship, and social support accounted for 94% of the association between single mother status and poor mental health, with financial hardship and social support being the strongest predictors.	Cross-sectional design; measures of other factors strongly associated with poorer mental health (physical and sexual abuse) were not accounted for.
Gerhardt et al. (2003)	Mothers (64) and fathers (46) of children with JRA and classroom comparison children, mothers (64) and fathers (40)	Design: Cross sectional Instruments: SCL 90-R, FES, Norbeck Social Support Interview	No significant differences: caregiver distress, family functioning, or social support. More mothers of children with JRA in the "case" range on the SCL-90-R.	Small sample size.
Hauenstein (1990)	Parents of children with chronic childhood illness	Design: Literature review of studies examining the parental dyad	A moderate amount of evidence exists for the occurrence of parental distress as a consequence of managing a chronically ill child found. Evidence also exists for significant emotional distress (i.e. maternal depression) in both parents. Parents with ill children tend to have few social resources, thus increasing parental distress.	
Janzen, Green, Muhajarine (2006)	15,662 Canadian men (ages 15–64) living with at least 1 child < 25 years old.	Design: Secondary analysis of data from the National Community Health Survey – Self- report	Single fathers experienced poorer perceived health than partnered fathers, likely due to the more limited economic and social resources available to single fathers.	Self-report; cross-sectional data could not determine if poorer self-rated health might have contributed to participants becoming single fathers, lower incomes, or poorer levels of social support.
Kazak, Reber, Snitzer (1988)	45 families with children (6 years old or younger) with PKU and 49 healthy controls	Design: Matched comparison Instruments: The Langner Symptom Checklist, The Dyadic Adjustment	There were no group differences in parental psychological distress, marital satisfaction, or parenting stress.	Only examined functioning of intact, 2-parent families

Authors	Sample Description	Instruments & Design	Major Findings	Study Limitations
		Scale, The Family Adaptability and Cohesion Evaluation Scales – Version 2, PSI, CBCL		
Lavee, May-Den (2003)	Mothers and fathers of 35 children (ages 2–16) who were treated for cancer for less than a year to more than 5 years.	Design: Cross-sectional Instruments: ENRICH scale	Some aspects of the marital relationship (communication and trust) were strengthened, while other areas (sexuality) showed deterioration. There was a slight decrease in relationship satisfaction within 1 yr of diagnosis, an increase in marital strength when the child had been ill for 2 or 3 yrs, and a deterioration in the marital relationship after more than 4 years of illness.	Small sample; cross-sectional; only used couples whose marriage were intact and excluded couples whose marriage dissolved during their child's treatment.
Montgomery, Oliver, Reisner, Fallat (2002)	32 families of children who survived a TBI, with a mean time since injury of 3 years.	Design: Qualitative Instruments: 30-item questionnaire designed by the research team	More than 1/3 of families were impacted in a moderate to profoundly negative way. 30% of families reported a deterioration in finances or loss of job. 16% reported a worsening of adult relationships.	Small sample size; no single-parent families were included in study
Noll et al. (1994)	32 families of children with sickle cell disease; 32 families of classroom comparison children	Design: cross-sectional Instruments: SCL-90-R, FES, Norbeck Social Support Interview	No differences: caregiver distress, family functioning or reported social support	Small sample size; nearly all families in both groups were single parent households.
Noll et al. (1995)	2 studies:1. 25 families of children with cancer and 25 classroom comparison families2. 42 families of children with cancer and 42 classroom comparison families	Design: Cross-sectional Instruments: SCL-90-R, BSI, FES, Norbeck Social Support Interview	Study 1. No differences between the 2 groups of families on mother or father distress or family functioning. Study 2. Mothers of children with cancer reported more distress than mothers of comparison youth; no differences for fathers. Fathers reported higher controlling scores; all measures of family functioning in the normal ranges. No differences on reported social support.	Small sample size; no separate analysis for single parent families.
Phililchi (1989)	30 families with children hospitalized in a PICU	Design: Cross-sectional Instruments: Family Adaptability and Cohesion Evaluation Scales (FACES-III) & Family Crisis-Oriented Personal Evaluation Scales (F- COPES)	As a whole, families were well functioning with strong adaptability and cohesion, and utilized a variety of positive coping mechanisms.	Small, homogenous sample; utilized a convenience sample, meaning a true representation of the population was not investigated.
Reiter-Purtill et al., in press	Mothers (54) and fathers (42) of children with JRA and classroom comparison children, mothers (490 and fathers (32)	Design: Cross sectional Instruments SCL-90-R, FES, Norbeck Social Support Interview	No significant differences caregiver distress, family functioning, or social support. Greater neurological severity in children with NF1 was associated with greater distress, more family conflict, less positive mealtime interactions, and less social support from the perspectives of mothers.	Small sample.
Sabbeth, Leventhal (1984)	Families with children who have a chronic illness	Design: Meta-analysis of 34 studies of marital adjustment in families adjusting to childhood chronic illness	In examining elevated divorce rates or poorer marital adjustment, only 6 studies used matched healthy families for comparison. No significant differences in divorce rates between groups were found. However, 4 of 7 studies with comparison groups showed increased marital distress in parents of ill children.	
Shudy et al. (2006)	Families with children who have a critical illness or injury	Design: Literature review of 115 articles examining the impact of critical illness and injury on families	Pediatric illness and injury is a stressful time for families, but effects on the parental relationship and marital cohesion have been variably described. Many existing studies have numerous methodological issues that prevent drawing significant conclusions. There is limited research on the differences in impact on fathers vs. mothers, cultural diversity, and financial burden.	Only examined families in the PICU, neglecting other settings or situations where families may be in equal or greater distress.
Steele, Long, Reddy, Luhr, Phipps (2003)	65 mothers of children with cancer during the initial 6 months of diagnosis and treatment	Design: 6 mo. Longitudinal Instruments: questionnaires regarding parental perceived stress, caregiver	Perceived stress and maternal affective distress decreased over time, but caregiver burden remained high and relatively stable.	The majority of mothers in the study had domestic partners and were of a high SES status, thus limiting the generalizability of

Authors	Sample Description	Instruments & Design	Major Findings	Study Limitations
		burden, affective distress, and parenting strategies		results to single parents and those with lower incomes.
Svavarsdottir (2005)	Parents of 26 children under 18 y.o. with cancer	Design: 2 year longitudinal, descriptive study Instruments: questionnaires regarding caregiving activities, general wellbeing and health perceptions	The most difficult caregiving activity for parents was providing emotional support to the patient and other children in family. Mothers found it hard to manage behavioral problems and plan family activities. Fathers found it difficult to manage work and organize care for the child at the same time, and to give emotional support to their partner.	Small sample size; all families were 2-parent households
Wiener, Vasquez, Battles (2001)	31 fathers of children with HIV	PSI, BSI, and a needs questionnaire created by the authors. Design:	Twenty-nine percent of the fathers were the child's only caregiver. More than half the sample had significantly elevated levels of parenting stress and psychological distress compared to standardized norms. The majority of these fathers (97%) reported the need for supportive services including support groups, help with discipline, disease management, and assistance with planning for the future.	Small sample size; no comparison group.

Table 2

Gaps in Current Research: Questions to be Addressed

Definition

Define “lone” or “single” parent (or caregiver) and single parenting

Measurement

How to quantify and measure “lone” parent, degrees of single parenthood, what being “alone” means, assessing changes in parenting/relationship status over time.

How to define marital status and the fluidity of marital status in longitudinal studies.

Demographics

Currently research not designed to study single families, socio-environmental factors.

How do we piece out the influence of SES and related socio-environmental factors when studying this population? (APA task force on SES Report, 2007).

What are the unique needs of single parents who live in rural parts of the country with limited access to health care systems in general, and/or survivorship clinics?

Adaptation

At what point in the illness trajectory does being a single parent matter most?

Does adaptation for the single parent differ from a partnered parent?

How does adaptation for the single parent change over time?

What are the protective factors enhancing single parenting?

What are the risk factors negatively impacting single parenting?

Who is truly vulnerable? Are single parents actually more vulnerable? If so, are they more vulnerable emotionally, mentally, financially, physically, or all of the above?

What influence does social support, the physical proximity of significant others, and/or the quality of the home environment have on the adjustment and outcomes of this population?

Is there is a difference in how the health care team relates to the single parent versus one that is partnered?

Is sibling adaptation different in a single parent family than in a family with two parents present?

Does culture influence how a single versus two-parent family adapts?

Is there a potential interaction between single parenting with disease outcome?

Are there differences in stress processing among single-parent families versus two-parent families?

Is there a difference in a child’s vulnerability or role in decision making when living in a single parent home?

When is help most needed for single parents? Are there critical time points for this population when dealing with an ill child?