Fostering Resilience in Siblings of Youths with a Chronic Health Condition: A Review of the Literature

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An accumulating body of literature points to the potential for successful outcomes among families who have a child with a chronic health condition. Resilience research has catalyzed a reconceptualization of the experience of such families from a deficit, pathological perspective to a growth-enhancing opportunity. However, scant data available about the specific risk and protective mechanisms influencing the psychosocial outcomes of well siblings in these families are lacking. This article draws on the literature addressing resilience in youths experiencing adversity to inform social workers about how to better promote positive outcomes among well siblings. Implications for future research and suggestions for social work practice to target the unique needs of well siblings are discussed.

Key words: childhood chronic health conditions; family-centered care; resilience; siblings

Advances in medicine and technology have enabled youths with chronic health conditions to live longer and remain in the care of their families (Hollidge, 2001). Data suggest 10 to 20 million children and adolescents residing in the United States have some form of a chronic condition—a health impairment that “has lasted or is expected to last more than a defined period of time, usually three months or longer” (American Academy of Pediatrics, 1993, p. 876). Although there is literature on the impact of mental illness or life-threatening illness on siblings and the caregiving role that some adult siblings assume, the intent of the following review is to broadly capture the experience of school-age youths who have a sibling with a chronic physical (for example, spina bifida), medical (for example, diabetes), or developmental condition (for example, Down syndrome).

The increased number of youths with a chronic health condition has resulted in more opportunities for social workers and other health professionals to assist this population (Brown, Krieg, & Belluck, 1995) and a greater appreciation for the importance of family-centered assessment and intervention (Strohm, 2001). Attending to the individual strengths, capabilities, and needs of the affected youths, parents, and siblings is fundamental to helping families successfully adjust to the ongoing and often unpredictable journey of childhood chronic conditions (Bergman, Lewiston, & West, 1979).

Despite widespread agreement about viewing the impact of the child’s health condition as a shared experience, data are limited on the specific risk and protective factors influencing the adjustment of siblings and perhaps most significant, how to foster resilience in this special population. Drawing on the literature related to resilience in youths and families, we aim to help prepare social workers to identify and address the needs of school-age siblings, possibly preventing the onset of psychosocial difficulties.

Childhood Chronic Health Conditions and Relevance to Social Work

Social workers are uniquely prepared with the knowledge, skills, and value base to provide family-centered intervention in the context of childhood chronic health conditions (Bergman et al., 1979). An emphasis on family theory in social work education, and especially the principle that a stressor affecting the well-being of one member will likewise influence the psychosocial outcomes of other members, clearly establishes social workers as likely professionals to assist this population (Andreae.
Social workers are schooled in a person-in-environment approach to understanding individual and family strengths and risks that influence psychosocial outcomes (Bronfenbrenner, 1979). By integrating ecological and developmental theories with a strengths-based approach, practitioners draw out individuals’ and families’ abilities, competencies, and resources (Walsh, 1998). Finally, social workers’ interactions with youths and families across diverse service settings, such as hospitals and clinics, schools, and other community agencies, provide multiple opportunities for family-centered services inclusive of well siblings.

**IMPACT OF A CHILD’S CHRONIC HEALTH CONDITION: A SHIFT IN PERSPECTIVE**

The growing body of literature on risk and resilience offers social workers and other health professionals a medium to reconceptualize the experience of families living with a child’s chronic health condition from a pathological, deficit-laden perspective to a growth-enhancing, resilience lens (Walsh, 1998). This perspective affirms and builds on individual and family resources and simultaneously attends to the multiple and varied forces affecting the youth and family (Patterson, 2002).

Although acknowledging that families of youths with a chronic condition may encounter major stressors and challenges, such as daily caregiving demands, financial strains, concerns about access to adequate services, and future health uncertainties, researchers and practitioners observe that some family members and the family as a whole often emerge stronger and more resourceful from their experience (Walsh, 2002). The increased awareness that having a member with a chronic health condition does not condemn family members to poor outcomes challenges health professionals to account for why some “stay healthy and do well in the face of risk and adversity and others do not” (Patterson, 2002, p. 350). Ultimately, the process of understanding what helps families and their members adapt, perhaps even thrive, in response to challenges associated with the child’s condition is a study of resilience (Fraser & Galinsky, 1997).

**CONCEPTUALIZING RESILIENCE**

Appreciation of positive outcomes in the face of adversity, coupled with a growing dissatisfaction with pathology-focused intervention strategies, steered researchers away from an exclusive focus on risk factors to a search for mechanisms promoting resilience (Walsh, 1998). The literature is rich with descriptions and axioms on resilience, but presently, there is no single, universally held definition of just what resilience is. Some researchers describe it as a set of positive behavioral patterns and internalized capacities demonstrated under adverse circumstances (Gilgun, 1996), and others hold that resilience ought not be defined as a static set of strengths or qualities (Kirby & Fraser, 1997). An accumulating body of evidence suggests there is no singular characteristic or attribute that is protective across all life experiences, thus lending support to conceptualizing resilience as an evolving process (Glantz & Sloboda, 1999).

Also, although there is general agreement about resilience as emerging from an ongoing interplay between risk and protective factors (Rutter, 2000), the exact nature of the interaction remains a source of debate (Kirby & Fraser, 1997). **Risk factors** are defined as variables, including individual attributes, familial characteristics, and environmental conditions, that “increase the probability of onset, digression to a more serious state, or the maintenance of a problem condition” (Fraser & Galinsky, 1997, p. 265). In comparison, **protective factors** are described as assets that eliminate or decrease the negative consequences of being at risk and are likewise observed in individuals, families, and the environment (Garmezy, 1985; Gilgun, 1996). Data increasingly suggest an interactive model whereby protective factors exert a positive effect only in combination with risk factors through three types of mechanisms: buffering, interrupting, or preventing the occurrence of a risk factor (Kirby & Fraser).

**Points of Consensus in Resilience Literature**

Despite these inconsistencies in the literature, widespread support for several key components for resilience research exists. First, an individual must be exposed to significant adversity that is associated with a major increase in the probability for emotional, behavioral, social, or psychosocial difficulty (Rutter, 2000). Second, the quality of adaptation or outcome must also be evaluated (Masten & Coatsworth, 1998).

Another area of agreement is the importance of ecological theory in understanding resilience. The inclusive characteristic of ecological theory, a multisystems theory that focuses on the interaction
between the individual and contextual influences (Bronfenbrenner, 1979), is particularly attractive for theorists considering resilience as developing from the complex interplay among individual characteristics, family processes, and environmental conditions (Kirby & Fraser, 1997). Walsh (1998), in particular, embraces ecological theory for its capacity to account for how culture shapes individual responses to adverse life experiences.

Sensitivity to cultural differences appears central, therefore, to fully appreciating resilience as a phenomenon of unexpected and positive outcomes in the face of adverse circumstances. Consequently, universal benchmarks of psychosocial functioning ought to be considered (Greene & Conrad, 2002) as well as culturally relevant expectations for development (Masten & Coatsworth, 1998). Clearly, “what constitutes a positive outcome is frequently a subjective matter of perspective based on often controversial values [and] cultural biases” (Glantz & Sloboda, 1999, p. 117). For example, through research with youths from 14 countries, Grotberg (1995) noted the importance of faith in encounters with adversity for some cultures while problem solving was emphasized in others. Social work practice texts introduce students to the importance of culturally sensitive practice (Smith, Gabriel, Lott, & Hirano, 2000); other resources focus more specifically on culturally competent practice (Fong & Furuto, 2001; Lunn, 2003). Still others address multicultural awareness in the health care professions (Julia, 1996). Ultimately, a meaningful understanding of resilience in youths, including siblings of youths with a chronic health condition, rests on the capacity of social workers and other health professionals to embrace an ecological and developmental approach that is grounded in a culturally sensitive, strengths-based tradition.

THE EXPERIENCE OF WELL SIBLINGS

An At-Risk Population?

Why must special attention be paid to siblings of youths with a chronic health condition? Some literature suggests well siblings tend to be vulnerable to poor psychosocial outcomes (Patterson, 1991a; Williams et al., 1997). The chronic condition may require the reallocation of assets, including financial, physical, and emotional resources; the adjustment of family timetables around condition demands; and the minimizing of the developmental needs of other family members (Patterson, 1991b; Reiss, Steinglass, & Howe, 1993; Rolland, 1999). Changes in family structure and roles (Patterson, 1991a), decreased emotional and physical availability of parents (Tritt & Esses, 1988), and parental stress related to caregiving responsibility may likewise yield an adverse effect (Feeman & Hagen, 1990). Finally, unpredictable medical exacerbations, potentially resulting in crisis states for the family, may be stressful for well siblings.

Although a general understanding of potential stressors experienced by siblings has been established, research on factors protecting against or heightening risk of psychosocial difficulties among school-age siblings is an area that “continues to receive little attention” (Wallander & Varni, 1998, p. 38). A survey of resilience research in the context of childhood chronic health conditions results in rich data on the affected youths (for example, Patterson & Blum, 1996; Vessey, 1999) and parent caregivers (for example, Knafl & Zoeller, 2000; Wallander & Varni) but few investigations specific to siblings. Such a lack of knowledge of factors leading to adaptation versus maladaptation for well siblings is alarming, especially when siblings may at times experience greater stress than their brother or sister with the health condition (Strohm, 2001).

Scant available data suggest that some siblings are vulnerable to poor adjustment outcomes. Compared with siblings of well youths, those whose siblings have a chronic condition are more likely to demonstrate psychosocial difficulties such as emotional problems (Taylor, Fuggle, & Charman, 2001) and behavioral problems (Tritt & Esses, 1988). More specifically, siblings of youths with a seizure disorder exhibited greater conduct and academic difficulties than peer comparisons (Feeman & Hagen, 1990), and siblings of youths with diabetes reported lower self-esteem and more depressive symptomology than youths with healthy siblings (Adams, Pevel, Stein, & Dunger, 1991).

Additional research has examined the effect of sibling demographic factors, especially gender and age, on adjustment outcomes. Although some data support perceiving male siblings as being at greater risk of differences than female siblings (for example, Ferrari, 1984; Lavigne & Ryan, 1979), the opposite pattern has been observed in other research (for example, Daniels, Miller, Billings, & Moos, 1986). A third group of data highlights no reliable difference in adjustment outcomes as a function of sibling gender (for example, Gallo, Breitmayer, Knafl,
The effect of sibling age on adjustment outcomes is likewise inconsistent, with findings of younger siblings manifesting more difficulties (Ferrari, Lavigne & Ryan) as well as reports of no difference (Gallo et al.). However, in a study of anxiety and loneliness of siblings of youths with cancer, Bendor (1990) observed different themes of impact in focus groups with younger siblings (eight- to 13-year-olds) and older siblings (14- to 19-year-olds). Whereas younger siblings expressed feelings of deprivation, displacement, anger, and vulnerability to illness, the older siblings described conflicted feelings of burden around caregiving and a need for independence.

In summary, although the exact etiology of poor adjustment outcomes remains an area in need of further investigation, there is considerable empirical and theoretical support for perceiving siblings of youths with a chronic condition as vulnerable to psychosocial difficulty (Leonard, 1991). Strohm (2001), for one, definitively argued “these children fit into an ‘at risk’ category” (p. 49). Fortunately, some progress toward family-centered care in which siblings’ unique concerns, needs, and strengths are addressed in research and clinical settings has been evident.

Fisman and colleagues (1996) specifically examined protective factors influencing the psychosocial adjustment of siblings of youths with developmental disabilities. Marital satisfaction, lack of parental depression, a cohesive family environment, and a positive sibling relationship emerged as protective correlates for siblings of children with Down syndrome but not for siblings of children with pervasive developmental disorder. Interestingly, these data are suggestive of differential risk and protective mechanisms as a function of condition type, necessitating both broad-based sibling investigations inclusive of a range of conditions as well as targeted research focusing on unique sibling groups.

Although prevention models for siblings likewise remain early in development, two recent studies tested the effectiveness of programs designed to promote favorable outcomes among siblings. Williams and colleagues (1997) piloted an intervention using psychoeducation and group social support, and regarded the substantial increase in mean score on a knowledge-of-illness measure as indicative of a positive outcome for sibling participants. The importance of interventions targeting siblings is corroborated by findings of significant improvement in socioemotional adjustment for siblings participating in a program designed around social support and recreational activities compared with matched, wait-listed peers (Phillips, 1999). Although initial findings appear promising, the effectiveness of any intervention program fostering resilience rests on an accurate understanding of the key risk and protective factors experienced by siblings.

**Evidence for Resilience**

Balancing some findings of psychosocial difficulties for siblings is evidence of general positive outcomes. What do we know about well siblings who exhibit no favorable adaptation? Noll and colleagues (1995) observed no significant difference in the social competence of siblings of youths with sickle cell anemia and a comparison group of youths with well siblings. Others have found no reliable difference in risk of adjustment difficulties between siblings of youths with a range of chronic conditions and comparison peers (Gallo et al., 1992). More significantly, some data support a growth-enhancing aspect for siblings, including the development of empathy and compassion (Kiburz, 1994) as well as patience and sensitivity (Tritt & Essex, 1988). It is also important to point out that youths who demonstrate difficulties in one area of developmental competencies may simultaneously manifest positive outcomes in other aspects of functioning. Empirical support for this position comes from the work of Hollidge (2001) who found siblings of youths with diabetes to be vulnerable to anxiety and low self-concept but demonstrate high levels of behavioral competence.

Of note, a continuum of psychosocial outcomes, including the capacity for positive sibling adjustment, is also evident in the hospice literature. Although Robinson and Mahon (1997) reported a range of short-term outcomes of fear, guilt, and anxiety to long-term reactions like social withdrawal, they also found evidence for psychological growth among well siblings. Similar to findings about youths with chronically ill siblings, the experiences of children and adolescents who have a sibling receiving hospice services is an area in need of further investigation (Lehna, 2001). To offer social workers and other health professionals practice suggestions when working with siblings, we draw on the larger, more established body of literature on resilience on youths in general.
PRACTICE IMPLICATIONS: FOSTERING RESILIENCE IN SIBLINGS

Individual-Level Correlates of Resilience
With extensive work in childhood adversity, Garnezy (1985) is considered a pioneer in resilience research and has identified key individual attributes, familial characteristics, and environmental conditions fostering resilience in youths that have consistently corroborated by research over the past decade. Knowledge of these correlates of resilience may guide development or prevention or intervention models for siblings of youths with a chronic condition. Social workers are well equipped with the skills to enhance individual-level protective qualities such as communication skills, self-esteem, and overall sociability (Masten & Coatsworth, 1998; Walsh, 1998).

Family-Level Correlates of Resilience
Siblings’ immediate adjustment and long-term adjustment are also influenced by relationships characterized by mutual support, collaboration, and commitment (Leonard, 1991; Patterson, 1991b). Another prominent theme noted in family health literature is the importance of balancing the needs of the affected child with those of the surrounding family, including siblings. Mallick (1979) observed that “the family must find a way of balancing demands made upon them for rearranging their lives, so as to be able to provide special care to the patient...and to advocate for the other needs of family members” (p. 124). Clearly, practitioners and families must be cognizant of how the developmental needs of siblings are immediately influenced, and secondly, consider how their psychosocial development will be attended to in the future (Rolland, 1999).

A need for information about the chronic condition has consistently been reported as a significant concern of well siblings. Drawing on rich data from focus groups, conversations with parents, siblings and health care providers, Strohm (personal communication, November 5, 2002) developed a comprehensive list of psychosocial concerns specific to the experience of school-age siblings. Distress was noted in the following areas:

- feelings of guilt about having caused the illness or being spared the condition;
- pressure to be the “good” child and to protect parents from further distress;
- feelings of resentment when their sibling with special needs receives more attention;
- feelings of loss and isolation;
- shame related to embarrassment about their sibling’s appearance or behavior;
- guilt about their own abilities and success;
- frustration with increased responsibilities and caregiving demands (Strohm, 2001, p. 49)

Age-appropriate, accurate information about their sibling’s health condition and the natural responses to their experience, both positive and negative, are acknowledged as fostering sibling resilience (see for example, Bendor, 1990; Williams et al., 1997).

Another area of consideration is the system of family beliefs, including appraisal of the impact of childhood illness, family identity, and overall worldview. For example, resilience appears to be related to a family’s capacity to normalize adversity and to define challenging experiences as manageable and surmountable (Patterson, 1991b; Walsh, 1998). Appreciation of how spirituality may strengthen or support families in their efforts to cope with a child’s chronic health condition is likewise an important function for social workers assisting families caring for youths with chronic conditions. Walsh (1998) aptly observed, “many of our most fundamental beliefs are founded in religion and spirituality” (p. 70). In addition to bolstering support systems—internal and external to the family—social workers are wise to acknowledge the potential healing and comforting aspects of religion and spirituality that may undergird resilience. In summary, fostering resilience in siblings is undoubtedly tied to bolstering the inherent strengths, resources, and functioning of the surrounding family unit.

Specific suggestions for social work practice include acknowledging siblings as important members of the family, especially during periods of parent physical or emotional unavailability (Bendor, 1990) and involving the siblings in the family’s natural adjustment process to the child’s condition by providing ongoing psychosocial support and accurate information about their sibling’s health needs (Strohm, 2001). Other important roles for social workers include encouraging parents to support expression of emotions and feelings by well siblings (Kiburz, 1994); developing supportive relationships between healthy siblings and members of the health care team (Bendor); and increasing participation of
siblings during hospitalization and rehabilitation periods (Drotar & Crawford, 1985). Such practices are consistent with comprehensive, inclusive family-centered assessment and intervention that has a preventive quality, anticipating and buffering the potential onset of difficulties for siblings.

Environment-Level Correlates of Resilience

External support systems form the third category of factors fostering resilience (Garmezy, 1985). A family's capacity to mobilize extended family members, as well as formal community supports, to manage crisis periods and chronic stressors related to a child's health condition enhances positive psychosocial outcomes for siblings. Leonard (1991) observed a family's ability to meet its needs by tapping into community resources may affect its ability to be successful in managing family functions such as providing nurturance to all of the children. Conversely, the absence of community resources to support families in balancing the needs of the affected youths with those of other family members may ultimately undermine resilience (Patterson, 2002).

Although the home environment serves as the central domain for the psychosocial development of youths, community contexts, such as the neighborhood, school, or church, may also reinforce a child's self-esteem and self-efficacy, support the development of positive values, and foster strengths (Greene & Conrad, 2002; Werner & Johnson, 1999). To enhance protective processes at the community level, social work intervention should prioritize connecting siblings to available resources during crisis periods as well as for long-term support. One such resource, the Sibshop model advanced by Meyer and Vadasy (1994), is particularly effective in addressing the unique stressors and opportunities engendered by childhood chronic health conditions. The program provides a comforting space for siblings to share stories of common joys and concerns and to learn from each other's experiences in a supportive climate. Importantly, the overarching mission of validating experiences, bolstering coping skills, and highlighting talents is substantiated by research (Strohm, 2001).

In summary, the diversity of adjustment outcomes exhibited by siblings debunks an assumption of the inevitability of dysfunction or maladjustment. To the contrary, their experience may catalyze siblings to tap into inner resources or develop new capacities in their efforts to adjust and adapt. The discussion of protective correlates of adjustment—manifest in individual, familial, and environmental contexts—offers social workers and other health professionals a range of practice options to guide siblings toward such favorable outcomes.

CONCLUSION

To both lessen potential stressors encountered by siblings and assist these youths in maximizing their strengths, more research into the salient risk and protective factors is needed. It is the hope of researchers and practitioners working with at-risk youths that more studies on resilience may spur development of preventive programs to assure favorable adjustment outcomes (Glantz & Sloboda, 1999). That is, if health professionals develop a more advanced understanding of the complex factors fostering resilience in siblings of youths with a chronic health condition, then development of interventions that simultaneously reduce risk and promote protection is a real possibility (Fraser & Galinsky, 1997). Masten and Coatsworth (1998) caution, however, that because youths typically possess multiple risk and protective factors influencing their adaptation “it is unlikely that a magic bullet for prevention or intervention will be found” (p. 214).

Research informing the development of interventions for well siblings ought to carry a bifurcated focus. First, bolstering adaptive psychosocial outcomes is predicated on an understanding of the broad risk and protective mechanisms affecting this population as a whole. Second, to flesh out condition-specific risks and protections, targeted investigations exploring the unique experiences of siblings of youths with a particular health condition are crucial. Such a comprehensive research agenda is needed so that appropriate resources and interventions may be established to foster resilience in all family members as they individually and collectively adjust and cope.

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