

Seminar Paper:
Topic 1: Chronic Illness and Families

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FAMILIES SURVIVING GRIEF, TRAUMA AND ABUSE

Experience reveals that families confronted with illness can respond in dramatically different ways. In some families as tension and stress rises members are mobilized to work together to deal constructively with the demands it faces. In other families, such demands will unravel and immobilise the family system (Danielson, Hamel-Bissell, & Winstead-Fry, 1993; Holmes, 2015). By focusing on childhood chronic illness this paper will explore why some families will cope better than other families. In no particular order, differences in how families cope and manage illness will be discussed with reference to the major dimensions of chronic illness. The major protective factors will also be addressed.

Family life cycle research indicates that stress within families is at its greatest in those years when dependent children are being raised. Not surprisingly, research also suggests that families coping with childhood chronic illness are subject to higher levels of stress than families with children developing at a normal rate (Rayner, & Moore, 2007). Illness is considered a stressor when poor health produces demands that require changes within the family system. If the family is unable to manage these changes the strain of the illness stressor will result in family stress (Danielson et al., 1993).

More specifically, stress resulting from illness is thought to be caused by an actual or perceived imbalance between the demands of the illness and the family's capabilities. The imbalance (i.e., changes to the existing family structure) requires family adjustment and adaption. For example, family members may be unable to perform usual tasks or roles calling for the entire family system to adjust and adapt to the emergence of new systemic patterns. Obviously, in the instance of families

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dealing with childhood chronic illness larger demands exist as more long-term adjustment and adaption of family patterns is needed, as compared with an illness stressor that is insignificant, minor, or temporary in duration (Danielson et al., 1993).

Family's with a chronically ill child may be constantly adjusting and adapting in order to balance and manage the needs of the unwell family member and the family. These demands often entail permanent family change as old roles are discarded and new roles emerge, particularly around the physical and emotional care requirements of the ill family member (Danielson, et al., 1993). The family's ability to adjust to a new normalcy requires the application of more complex adaptive behaviours, such as compromise and synergy, whilst systemic implications necessitate family restructuring and consolidation (e.g., realignment of family roles, rules, alliances and boundaries) (Cook, 2015; Danielson et al., 1993).

Thus, families characterised by adaptive interfamilial relationships are seen as possessing a protective factor when dealing with chronic illness (Cook, 2015). The importance of the family system emerges throughout the literature with studies showing that adaptive family relationships and psychological adjustment of parents are good predictors of child adjustment to chronic illness, whilst less adaptive family relationships predict poor child adjustment (Seren-Cohen, 1999).

Family resources are also considered an important factor in determining how well the family system will cope with the challenges of an illness stressor. Chronic illness dictates that the stressor will exist for an extended or indefinite period of time. It could be assumed that the longer an illness exists, the greater its impact, or potential impact, on the family and its members. It could also be assumed that the longer the duration of an illness stressor the larger the affects on family resources.

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Understandably the threat of chronic illness becoming an assault on the family's stability intensifies when considering that the duration of an illness stressor increases the likelihood that family resources will be overextended and depleted (Danielson et al., 1993; Seren-Cohen, 1999).

As resources diminish the threat to the family increases. For example, long-term medical care can be costly and may easily exceed the family's financial capacities. A study of long-term childhood cancer found that one third of the family's gross annual income was spent on illness related costs. This figure was found to be even higher for poorer families. Increased work hours or additional employment was often sought to alleviate the financial burden, compounding the family's stress (Danielson et al., 1993; Rayner, & Moore, 2007).

Of the tangible resources it could be argued that money is the most pertinent to family adjustment and adaption. The necessity of money for providing the family with basic needs means that the presence of a financial threat can rattle the very core of family stability (Danielson et al., 1993). Financial strain related to parents ceasing work out of necessity (e.g., caring responsibilities), expenses of home modifications and non-subsidised medical costs, have been shown to add to the stresses and strains of parents caring for medically vulnerable children (Seren-Cohen, 1999). This burden, or added pressure, known as the "Plus" factors of illness demands (i.e., on top of those faced by a healthy family) has the potential to not only affect the nuclear family but also the extended family, as resources may need to be pooled to meet exorbitant health costs (Danielson et al., 1993).

The extent of the illness stressors impact, whether all family members are affected or only a few, will influence its significance. The nature of chronic illness

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usually requires that the whole family change. As family resources (e.g., monetary, and support from family members) are utilised, tensions may rise increasing the likelihood of family disruption, stress and crisis (Danielson et al., 1993; Hobfoll, 2001). The greater the number of family members involved in the illness experience the greater the potential for the stressor dominating the families system, structure and function. The “illness may demand so much that it becomes the organizing principle of family life” (Seren-Cohen, 1999, p. 1). Chronic illness may cause the family to sacrifice other developmental needs; lifecycles of individual members and the family may be derailed and effective management of the illness compromised (Seren-Cohen, 1999).

In contrast, the responsibilities of an illness may fall unevenly on one family member. Given that mothers tend to be the primary managers of care, the burden of coping with childhood chronic illness is often bestowed on them (Cook, 2015; Danielson et al., 1993). Studies have shown that mothers are more actively engaged in the child’s treatment and provide the majority of home-based care. The ongoing health issues resulting from childhood chronic illness are associated with higher levels of distress among mothers than among fathers. Research into the impact on fathers is limited, yet some findings have shown that fathers report more stress in relation to finances. Father’s will also be affected by the strain caring for an ill child has on the spousal relationship. Compared to healthy controls, couples with an ill child reported greater relational tension, fewer positive interactions and increased conflict over child-rearing (Seren-Cohen, 1999). With more time spent focusing on and attending to the needs of the ill child, the parental relationship is often neglected (Cook, 2015; Seren-Cohen, 1999).

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Although, data indicates that the majority of families dealing with childhood chronic illness cope and children resilient, families facing serious paediatric conditions are fundamentally ordinary families confronting extraordinary stress. Under such circumstances, illness stress is understandably associated with elevated risks to mental health. Research has also found that mothers of ill children report higher levels of depressive symptoms than mothers of well children and that families coping with childhood chronic illness are more vulnerable to developing psychiatric symptoms and stressors (Seren-Cohen, 1999). The family's mental health is therefore crucial for determining how well illness demands are managed. Interpersonal family stress has been shown to reduce treatment compliance among families dealing with cystic fibrosis. Thus, resource demands of the stressor, whether big or small (i.e., medical resources and treatment required), have the potential to negatively affect the management of chronic illness, especially among vulnerable families (Seren-Cohen, 1999).

The severity of the illness may also determine the extent to which family functioning is impacted upon. Likewise, for this dimension of chronic illness the severity of the stressor is determined by the seriousness of the threat to the family's stability or by the amount of significant demands placed on family resources and capabilities. Illness is considered a hardship, however certain illnesses are considered more severe than others. For families with a chronically ill child the prognosis may be vague, and less optimistic. The child may be dependent for many years, or in need of ongoing, permanent care. Lifespan itself may be jeopardised, exposing parents to the possibility of being pre-deceased by their child (Pinquart, 2014; Rayner, & Moore, 2007). Anticipatory grief stemming from anticipatory loss will generate severe stress

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that may consume the family and cause disorganisation (Danielson et al., 1993). This is expected to occur, at least initially, when the illness is terminal (e.g., childhood cancer). Grief and loss will also be experienced by families coping with an illness that impairs the child's ability to achieve normal developmental milestones (e.g., cerebral palsy, congenital heart disease), or return to their former selves (Pinquart, 2014). The severity of the illness will correspond to the level of emotional stress families have to endure and may dictate how well the illness stressor is managed.

Conversely, when an illness is defined as severe families may be more likely to manage the initial crisis (i.e., at the onset of diagnosis) by being receptive to outside support and resources (i.e., health professionals, emotional and financial support). Coping strategies can be utilised in response to the support received, and not necessarily determined by established family patterns. In such cases, a balance between demand and resources reduces the severity of the situation and helps mitigate family stress and crisis (Danielson et al., 1993). Accessing resources acts as a protective factor for managing chronic illness, particularly among less resilient families whose functioning tends to be less adaptive.

Variables relating to illness severity have also been shown to affect how well families manage illness stressors. Illness demands featuring functional limitations (i.e., restrict age-appropriate activity) is a good predictor of family function, or parental adjustment and adaption (Pinquart, 2014; Seren-Cohen, 1999). Levels of parental distress were highest among parents whose children had chronic conditions with functional limitations. Distress levels among parents of children without functional limitations were virtually identical to parents of healthy children (Seren-Cohen, 1999).

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Predictability of the stressor, or level of uncertainty, is another dimension of chronic illness that can dictate how well families manage and adapt. Findings indicate that the unpredictable and less visible nature of seizure symptoms (e.g., epilepsy) creates feelings of helplessness that are generalised to other aspects of family life. For example, research shows that chronic illness with unpredictable variables puts a family at risk of poorer communication, cohesiveness and integration. Given that unpredictable conditions tend to be less understood, negative perceptions abound. Studies have demonstrated that children with epilepsy have a weak self-concept and consider themselves as being problematic to the family. Likewise, teachers rated children with seizure symptoms as less intelligent. Children with predictable more visible conditions led to better adjustment outcomes (i.e., cerebral palsy) (Cook, 2015; Danielson et al., 1993; Seren-Cohen, 1999).

Thus, an illness stressor that is perceived as manageable can contribute positively to a family's sense of control, whereas stressors perceived as unmanageable, can have a negative impact. Studies have shown that certain disease characteristics, such as lack of cure, unknown cause, and seizure symptoms, have a high probability of causing anxiety and depression within the family. Waiting for test results, poor communication between health providers, and disturbed family routines (e.g., hospitalisations) can also contribute to feelings of lost control (Danielson et al., 1993).

This sense of lost control may be compounded if the onset of an illness stressor is sudden as opposed to gradual. As with severe illness, family support and assistance with the sudden onset of an illness stressor may be readily forthcoming. This mobilisation of resources can buffer the threat, helping family's adapt. However,

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crisis may ensue due to the great disruption it produces within the family. The possibility of family stress and crisis may be lowered with the gradual onset of an illness as it affords time to gather information, develop coping strategies, and adjustment to new roles and tasks (Danielson et al., 1993; Hobfall, 2001).

The stigma of the stressor, whether great or small, represents another major dimension of chronic illness that can influence family functioning. Many parents of children with chronic conditions, especially visible conditions, reported experiencing hurtful behaviours (stigmatisation and discrimination) of non-support from family and professionals (Seren-Cohen, 1999). Stigmatisation promotes a sense of isolation intensifying the stress generated by the illness. It also blocks pathways to social support (Danielson et al., 1993).

Conservation of Resources (COR) theory predicts that resource loss is the principal component in the stress process and that stress is induced when important resources are perceived to be threatened, or actually lost (Hobfoll, 2001). Given that access to social support is considered an invaluable resource and protective factor for positively enhancing how the family system will change (adapt) in response to a crisis (chronic stress), stigmatised illnesses that restrict opportunities to access such support may render the system unbalanced (i.e., inadequate resources and skills). The successful (flexible) response to an illness stressor, balancing stability and change, may be fraught with difficulties (Hobfoll, 2001; Olson, 2000).

As with all major dimensions of chronic illness those that relate to the origin of the stressor (inside or outside the family) and the cause of the stressor (natural, synthetic or unknown), have the potential to guide family adaptability. Stressors originating within the family, particularly hereditary diseases that affect children (e.g.,

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haemophilia) can trigger parental guilt (Danielson et al., 1993). Parents have been known to report great suffering and anguish over having passed on a bad gene (inadequacies and imperfections) (Seren-Cohen, 1999). This may have a detrimental affect on the family's self-esteem, a vital resource to successful family outcomes. Illness originating outside the family (e.g., friends), depending on the relationship, tends to place minimal demands on the family (e.g., adjustment and role change). Childhood chronic illness with an unknown cause, such as cancer, may provoke fear causing family disruption and disorganisation. Professionals capacity and the family's ability to devise plans for treatment or disease prevention may be compromised with an illness of unknown cause. Families may cope better with a diagnosis that has a known cause, as it enables explanations, fostering a sense of control (Danielson et al., 1993).

Despite the severity of childhood chronic illness, interestingly studies have shown that parental stress is more strongly associated with the ill child's difficult behaviour than the actual time spent caring for the ill child (illness severity). Likewise, in another study adjustment outcomes for well siblings in families with an ill child were more strongly related to the child's behaviour problems than illness severity (Rayner, & Moore, 2007). Parental distress has been linked with increased behavioural problems in well siblings. This suggests the possibility of a mediating effect between parent's capacity to cope with illness and their ability to parent well siblings. Understandably, compliant child behaviour is considered a protective factor for families dealing with childhood chronic illness, as is the mother's perception of the illness stressor (Seren-Cohen, 1999).

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With mother's being the primary caregivers it is perhaps not surprising that studies have found that mother's perception of the impact the illness stressor is having on the family is the best predictor of maternal mental health and overall family functioning (Seren-Cohen, 1999). Other protective factors include, early intervention, being well resourced (socially, financially and emotionally) and educated, possessing high verbal intelligence, attending to the child's illness demands without sacrificing others, and possessing a parental style that is flexible (authoritative) as opposed to controlling (authoritarian) (Cook, 2015; Rayner, & Moore, 2007).

Overall, it could be argued that illness management will ultimately be determined by the family's perception (appraisal) of their ability to cope with the stressor. As we have seen this will be influenced by many factors (e.g., resources and illness demands), however as mentioned earlier, the inherent intrafamilial patterns of functioning will be a decisive factor in determining how successfully the family system adapts (Danielson, et al., 1993).

For example, a protective strategy called "balanced coping" is when a family system establishes a reciprocal, interactive relationship with the illness. The ill child's needs are attended to without sacrificing individual members' needs or the whole system's needs. Family systems with healthy cohesion (togetherness), flexibility and communication are likely to fare better in activating this strategy than family systems imbued with dysfunctional patterns and processes (e.g., triangulation, disengaged, rigid, poor communication and problem solving skills) (Olson, 2000; Seren-Cohen, 1999). This not only highlights the importance of adaptive family functioning for predicting illness management but how chronic illness in some families can cause renewed growth and closeness (Danielson, 1993).

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In conclusion, the family systems ability to cope with childhood chronic illness is multifaceted, complex and varied. The major dimensions of chronic illness influence family appraisal, sense of control, and confidence in managing the illness stressor. Protective factors will affect how positively or negatively the family adjusts and adapts. Systemic forces, such as flexible (resilient) and inflexible (vulnerable) family patterns and process will determine how successfully the family responds to change, and how well the illness stressor is managed overall.

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