

## ARTICLE

# Paediatric Illness: The Role of Social Context in Childhood Cancer

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The impact and interaction of paediatric illness on child, family and the broader social context represent key areas of concern for both researcher and practitioner. The prevalence of paediatric chronic illness has been estimated at as high as 19% (Newacheck & Stoddard, 1994). In the past many paediatric illnesses were identified, treated, and conceptualised within a biomedical context which left little room for the examination of how other factors such as social context may contribute. This was, in part, due to the dominance of the biomedical model (Ogden, 2004) but also due to the fact that, historically, many paediatric illnesses had survival rates as low as 26% (Patenaude & Kupst, 2005). This resulted in a tendency to focus on mortality and a reduction in attention to psychosocial factors (Eiser, 1994). Paediatric cancer serves as a useful example of this.

There are 1700 new cases of childhood cancer in the UK every year (UK Childhood Cancer Research Group [UKCCRG], 2004). Survival rates have climbed from approximately 30% in the 1960s to 70% today (UKCCRG, 2004). Low survival rates in the past meant that treatment was often seen solely within a medical context and issues such as social influence, education, quality of life, and how they pertain to adjustment were overshadowed by the need for improved medical treatment

(Bessell, 2001). With significant medical advances and increased survival rates came an increase in attention to the role of psychological and social mechanisms that contribute to treatment, adjustment to illness, and outcome (Kazak, 2005; Kazak et al., 2003).

The role social context may play in paediatric illness has long been suggested and a social ecological/systemic framework has underpinned the clinical and research work of many in recent years (Kazak, Simms & Rourke, 2002). Bronfenbrenner's (1979) social ecology model has attracted much attention and suggests the importance of recognising and studying the child's development and adjustment in terms of "the relation between the settings and contexts in which the person is actively involved" (Kazak, 1992, p. 263). The child is said to be at the centre of a series of concentric rings, each representing increasingly larger environments with which the child interacts (Kazak, 1992). Within this model the parents and family are seen as the most significant influence and research has tended to focus therein (Kazak, 2005; Seagull, 2000). In particular, the mother-child relationship has been of primary focus (Seagull, 2000). With outpatient care more common and families taking more responsibility in the care of the chronically ill child the

importance of the wider social context is more pertinent than ever and further evaluation and research is suggested. For the purposes of this article the influence of social context on paediatric cancer will be of primary focus and, more specifically, parental and family influences.

A considerable body of literature has investigated the response to, and impact of, cancer on the child. While several studies have identified an impairment of psychosocial functioning (Bessell, 2001; Koocher & O'Malley, 1981; Stuber et al., 1997), there is also considerable evidence to suggest that the majority of children adjust positively to the disease (Eiser, 1990; 2000; Hoekstra-Weebers et al., 2001; Stuber et al., 1997). In fact studies have also shown the potentially positive impact of cancer on the child such as increased empathy, motivation and maturity (Eiser, 1998). Eiser (1998) has pointed out the problems of focusing solely on a 'deficit-centred' approach.

While there has been an increased recognition of the child's resilience and ability to thrive in the face of adversity (Bugenthal, 2003), it is also realised that research has identified a subset of children and families that experience difficulties in coping and adjusting (Kazak et al., 2003; Kupst & Schulman, 1988; Kupst et al., 1995; Patenaude & Kupst, 2005). While factors such as age and the specific organic status of disease have been identified as significant contributors to adjustment and outcome (Eiser, 1998; La Greca, 1990; Vannatta et al., 1998), they cannot fully explain the considerable amount of variance in outcome among paediatric cancer patients (Eiser, 1998; Kazak et al., 1997). Research has identified a considerable body of evidence suggesting the importance of parental and familial influences on paediatric adjustment to cancer (e.g. Eiser, 1998; Kazak, 2005) as well as several other chronic illnesses such as diabetes (Johnson, 1995) asthma (Kaugars, Klinnert & Bender, 2004) and cystic fibrosis (Coyne, 1997). This is perhaps not surprising given the primary role the parent and wider family play in the child's life and even more so with the increased dependence that accompanies childhood illness.

Throughout any paediatric illness, parents receive large amounts of potentially distressing and complex information which they must

absorb, evaluate and use to make decisions relating to treatment and management. The central caring and decision-making role of parents in the care of the child with paediatric cancer and the complexities and stress it can involve are evident (for a discussion, see Patenaude & Kupst, 2005). The ability and willingness to seek and understand information, and to make informed decisions for the child has obvious implications for treatment and outcome (Schapira, 2006; Thorne, Bultz & Baile, 2005). This is an important point given the multidisciplinary and complex nature of cancer care. Patenaude and Kupst (2005) provide a useful description of the potential impact of communication on parental decision-making and how this can affect the child. They assert that because “most paediatric cancer patients are placed on a clinical trials protocol, parents have more recently needed to make difficult decisions between a treatment with known effects but not completely satisfactory outcomes and an experimental treatment with possibly improved potential for cure or survival but with less sure or potentially more ominous side effects” (Patenaude & Kupst, 2005, p. 10). The role of the parent–oncologist interaction in this process has the potential to impact and possibly determine the child’s treatment and outcome. The information parents receive, their understanding of it, and their awareness (or lack thereof) that treatments may be under a research protocol ultimately affects the child and may cause difficulties (Patenaude & Kupst, 2005). Thus we see an example of how the dynamics of the social interaction between parents, oncologists and their decision-making process and capabilities will affect child outcome.

The parents’ inability to successfully access and share information may result in levels of uncertainty and poorer subsequent adjustment (Koocher & O’Malley, 1981). Communication plays

an increasingly large role in cancer care and can affect understanding, satisfaction (Hagerty et al., 2005; Schofield et al., 2003), hope and psychological morbidity (Schofield et al., 2003) and has led many to suggest that certain cancer patients and families may not be fully equipped to make informed decisions (Gattellari et al., 2002). This is particularly relevant given the evidence suggesting a link between parental and familial psychological morbidity and general functioning, and child functioning, adjustment, and outcome (Banez & Compas, 1990; Thompson et al., 1992). For example, maternal anxiety has been associated with child–reported symptoms in cystic fibrosis sufferers (Coyne, 1997; Thompson et al., 1992).

Family relationships have been identified as influencing childhood adjustment to cancer (Kazak, 2005) and there has been an increasing amount of research reflecting a family perspective (Seagull, 2000). This is however often dominated by the mother–child relationship and the broader family is only just coming into focus (Seagull, 2000). The recognition of the role family can play in adjustment to paediatric cancer has led some researchers and practitioners to suggest the importance of assessing and identifying risk factors. Kazak et al. (2002, 2003) identify factors such as marital status, family size, family history of emotional problems and financial difficulties that may place both child and family at increased risk of adjustment problems. They found that 33% of families studied exhibited these risk factors. They developed an easily administered screening tool to assess these risks at initial diagnosis and found that higher risk at diagnosis predicted higher social work activity (Kazak et al., 2003). As they suggest, this could be an important practical tool, particularly given the fact that research has shown that those families exhibiting most

problems and dysfunction at diagnosis tend to continue in that vein and that initial diagnostic functioning may be predictive of subsequent functioning and adjustment (Kupst et al., 1995).

Parental stress, anxiety and quality of life have been shown to predict adjustment of the child with leukaemia after treatment (Kazak et al., 1997). Family cohesion and adaptability have also been shown to be strongly related to post–cancer treatment psychological adjustment (Rait et al., 1992). These findings are in line with research from other chronic illnesses suggesting the importance of family cohesion and adaptability in coping and adjustment with chronic illness (for a discussion, see Wallander & Thompson, 1992). Without recognising the families’ resources and needs, several authors suggest “it is impossible to provide appropriate and necessary psychosocial services” (Powers et al., 1995, p. 310) on which there has been considerable recent recognition (WHO, 2003).

Family coping strategies have been shown to be related to successful adjustment in several paediatric chronic illnesses (Coyne, 1997). The role and use of social support, coping skills, perceived control and parental anxiety have been shown to be related to the pain and distress of the child with cancer (Zeltzer, 1994, as cited in Patenaude & Kupst, 2005, p. 11) and psychopathology (Helgeson & Cohen, 1996). High levels of social support can lead to better adjustment for both child and parent (Kupst & Schulman, 1988). In his model, Thompson (1985) suggests the importance of several factors in determining adjustment to chronic illness including family functioning and resources. While there are a number of advocates of this approach, in practice the research has tended to focus primarily on maternal influences at the expense of other important relationships such as those of the father and peer. The “paediatric oncology researcher’s persistent lack of



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attention to fathers, siblings, and others in the child's social ecology" (Kazak, 2005, p. 35) has been criticised as limiting our understanding of childhood adjustment to cancer (Seagull, 2000).

Given that as many as 42% of paediatric cancer patients may exhibit consistent social adjustment problems with peers and in the school environment (Bessell, 2001), this is particularly concerning. The child's adjustment to cancer is significantly facilitated by successful peer interaction and adjustment in the school environment and has the potential to create 'feelings of normalcy' or of isolation and difference (Bessell, 2001, p. 355). It is acknowledged that the broader social environment and peer relations play a large part in the child's adjustment and contribute to a healthy notion of self and self-efficacy (Garrison & McQuiston, 1989). Further, in systematically excluding the father's role in facilitating paediatric adjustment to cancer (Seagull, 2000), we exclude a large and important component of the child's life.

Kliewer (1997) asserts that parents influence their child's perception, coping, and responses, which subsequently impacts upon psychosocial adjustment by effectively teaching children to react in certain ways (such as emotionally) and to use particular coping strategies that "create a home environment that either invites open communication and cohesion or stifles them" (p. 283). Stuber and colleagues (1997) found that mothers' perceptions of life threat and treatment intensity in their child with cancer significantly predicted their child's appraisal of life threat and treatment intensity, and that mothers' appraisals also predicted the child's anxiety and distress. Thus we see the importance of parental response and adjustment in creating and maintaining the child's response. The Stuber et al. (1997) findings also indicated that close relationships can add to the overall stress of the child because the child may feel empathy or guilt over a parent's distress.

With recent research indicating that a large proportion of mothers, fathers, and siblings show significant signs of posttraumatic stress disorder (PTSD) (for a review, see Kazak, 2005) this represents an important point and several family-based interventions to improve problem solving and stress have shown beneficial results for both

parent and child (e.g. Kazak, 2005).

The role of parents in facilitating coping with pain and the effects of treatment such as nausea is also a significant one for the child with cancer. Cognitive and behavioural techniques can be useful tools for parents and can improve child coping and adjustment (Barrera, 2000).

The impact and interaction of paediatric illness on child, family, and the broader social context are understandably of concern. We see that relationships such as parental ones have the potential to both positively or negatively contribute to the patient with paediatric cancer's adjustment and outcome. Family and parent characteristics and coping strategies seem to be influential in promoting the child's adjustment. The parents' decision-making abilities and appraisal and levels of anxiety and stress can influence child outcome. Research also suggests that family openness, cohesion and adaptability play an important role and suggests that several factors place the child and family with cancer at increased risk of maladjustment.

However, the findings of the current literature on paediatric cancer must be interpreted with caution. As mentioned earlier, there has been a considerable lack of attention to father, sibling, and peer relations and how they influence the child with cancer. While this seems to be changing, there is still a large gap for family interventions in research and practice (Kazak, 2002).

Further, Eiser (1998) questions the ability of research to directly attribute problems to social factors when the disease and treatment aspects may be significant and, further, that we may need to re-conceptualise adjustment outcome measures. The child with cancer is often compared to the normal population and may show deficits in achievement in comparison. This, however, may reflect changes in the child's or parents' values or perspective rather than an actual deficit: that is, cancer may result in the child reconsidering what is important and paying less attention to academic or social norms.

Another limitation is the fact that the sample size in the majority of paediatric psycho-oncology studies has been small (Patenaude & Kupst, 2005) and there is therefore a problem of generalisability. If the influence of social variables is to be assessed adequately, larger sample sizes are

required. The length of follow up has also been short term in the majority of studies (Patenaude & Kupst, 2005). This is perhaps not surprising given the relatively recent changes in survival rates. However, longitudinal effects of children surviving cancer would be beneficial in the future.

The literature has also been limited by the consistently white American population on which it has focused (Eiser, 1998). This unrepresentative research neglects and limits our understanding of social, cultural, and racial factors important to treatment and outcome in paediatric oncology. The significant influence of socioeconomic status is not adequately considered and, given its potential contribution to the availability and quality of services within the American system, this represents a serious confounding variable.

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