

## Report from the Canadian Association of Psychosocial Oncology Annual Conference

### **Pediatric cancer**

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#### LONG-TERM SURVIVORS

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#### **SUMMARY: Parental distress and child quality of life**

Racine N, Khu M, Reynolds K, Guilcher G, Schulte F. Quality of life in pediatric cancer survivors: contributions of parental distress and family psychosocial risk, 2017 CAPO Conference, Vancouver, British Columbia.

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The purpose of this study was to evaluate the relationship between family psychosocial risk factors and parental psychologic distress on the health-related quality of life (HRQL) of long-term pediatric cancer survivors. Patient-parent dyads (n=52) consisting of one long-term survivor and one parent were recruited from the Alberta Children's Hospital Long-Term Survivor Clinic. This cross-sectional study invited participants to complete a set of questionnaires used to measure psychosocial risk of the family (Psychosocial Assessment Tool 2.0 [PAT2.0]; parent report), parental distress (Brief Symptom Inventory [BSI]; parent self-report), and survivor HRQL (Pediatric Quality of Life Inventory [PedsQL]; parent-proxy report, survivor self-report).

**COMMENTARY:** Medical and demographic variables such as treatment type and intensity, age at diagnosis, and time since diagnosis have long been recognized as contributors to long-term HRQL in pediatric cancer survivors. Less well understood is the contribution of psychosocial factors, such as parental and sibling distress, and overall family functioning. When a child is diagnosed with cancer, families are uniquely challenged by an abrupt change in

The most significant finding from this study was that family psychosocial risk moderated the effect of parent psychologic distress on parent-proxy ratings of survivor HRQL. Parents with high psychologic distress and high family psychosocial risk evaluated their child's HRQL as significantly worse than parents with high psychologic distress but low family psychosocial risk. Thus, low family psychosocial risk acted as a buffer for parents with high psychologic distress. This trend did not persist for survivor self-reports of their HRQL; survivors' self-reported HRQL scores were negatively predicted by family psychosocial risk, but unaffected by parental psychologic distress.

Dr. Racine concludes that it remains important to consider parents' perspectives, as they are intricately involved in their children's healthcare and treatment trajectories. These results support the practice of assessing family psychosocial risk, as well as parent psychological distress and survivor HRQL, during regular routine screening visits. Screening information can then be used for targeted intervention for families at risk.

day-to-day functioning, responsibilities and role identification.<sup>1</sup> Some families may find the adjustment to life with a critically-ill child particularly challenging, however little is done to systematically identify families at greatest risk.

Research has found that the quality of the relationship between parent and child, as well as overall family functioning (i.e. problem-solving, communication, affective responsiveness and involvement, and behaviour control) predicts the

# LANDMARKS

HRQL of adolescent patients undergoing active treatment for cancer, above and beyond the effect of treatment intensity.<sup>2</sup> A growing body of literature aims to examine the contribution of parental psychologic distress on the HRQL of pediatric cancer survivors. This work has found that parental psychologic distress is negatively related to parent-proxy reports of HRQL in pediatric oncology populations.<sup>3</sup> This relationship does not necessarily hold true for child self-reported HRQL. It is noteworthy that there is a common discordance between parent-proxy and self-reported HRQL. A number of theories may explain this difference: parental distress may affect perception of their child's well-being, or younger patients may have less understanding of the magnitude of their health status and concerns.

## IN BRIEF

### Already known

- Medical and demographic variables contribute to health-related quality of life (HRQL) in long-term pediatric cancer survivors.

### What this study showed

- Family psychosocial risk predicts the HRQL of survivors, as rated by parents and survivors.

### Next steps

- Integrate screening for family psychosocial risk and parental psychologic distress into the followup of pediatric cancer patients.

Racine et al's research is the first to demonstrate that family psychosocial risk predicts HRQL of survivors, as rated by both parents and survivors themselves. The study measured psychosocial family risk using the PAT2.0 — a tool that was created to specifically screen for psychosocial family risk in pediatric oncology. This tool calculates psychosocial risk based on family structure and resources (e.g. number of individuals living in the family home; financial difficulties), family social support (e.g. can anyone provide emotional support to family), family problems (e.g. child custody disputes), parent stress reactions (e.g. nightmares about ill child), family beliefs (e.g. we are going to beat this), child problems (e.g. patient has difficulty making or keeping friends), and sibling problems (e.g. sibling appears sad or withdrawn).

Building on previous research, this investigation makes a significant contribution by demonstrating that family psychosocial risk moderates the effects of parental psychologic distress. Because parents are so intimately involved in their child's healthcare decisions, from treatment trajectories to followup care, it is imperative to evaluate and understand their perspectives. This research highlights the importance of screening for family psychosocial risk and parental psychologic distress to effectively target at-risk families for intervention.

### References:

1. Long KA and Marsland AL. Family adjustment to childhood cancer: A systematic review. *Clini child famil psychol rev.* 2011;14(1):57-88.
2. Barakat LP, Marmer PL and Schwartz LA. (2010). Quality of life of adolescents with cancer: family risks and resources. *Health Qual Life Outcomes.* 2010; 8(1):63.
3. Malpert AV, Kimberg C, Luxton J, et al. Emotional distress in parents of long-term survivors of childhood acute lymphoblastic leukemia. *PsychoOncology.* 2015 24(9):1116-23.