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Developmentally appropriate social and mental health support could improve quality of life for children receiving cancer treatment

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Commentary on: Jibb L.A., Croal L., Wang J., Yuan C., Foster J., Cheung V., Gladstone B.M. Stinson J.N. Children's Experiences of Cancer Care: A Systematic Review and Thematic Synthesis of Qualitative Studies. *Oncology Nursing Forum* 2018; 45(4):527-544.

Commentary

Implications for practice and research

- Developmentally appropriate conversations with children receiving cancer treatment can ensure timely referrals to the wider team through early identification and understanding of impact and needs.
- The benefits of on-going social support during cancer treatment whilst wideranging may not be optimally facilitated or utilized in care settings and therefore an area for future research.

Context

As the overall long-term survival rate for children's cancer increases,¹ recognition of the wide-ranging (physical, psychological, emotional and social) impacts on the quality of life for these children and young people is important.^{2,3} The systematic review undertaken by Jibb et al.⁴ focuses on the experiences of children receiving cancer treatment with the aim of improving their quality of life through informing practice.

Methods

A systematic review of four databases (MEDLINE, EMBASE, CINAHL, PsycINFO) focusing on articles published 2000-2016 was conducted.⁴ The search strategy was reported to be wide-ranging: the search terms were not documented but available on request from the authors. Identified studies used either qualitative or mixed methods, were written in English and reported on the experiences of children and young people (under the age of 18 years) during cancer treatment.

The authors appraised and synthesized articles exploring the experiences of children receiving treatment for cancer. Two authors independently screened for inclusion with any disagreements resolved with a third person. Reporting was independently assessed by two authors using an adapted version of the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist.⁵ Data from selected papers were extracted and tabulated and NVivo was used to facilitate thematic analysis. Two researchers initially

independently assigned codes and then agreed consensus (involving a third person where discrepancies arose). Identified themes were discussed collectively.

Findings

Findings from 51 studies were included in the analysis. These studies reported an average 14 of the adapted 31 COREQ items.

Five distinct themes were identified. The suffering experienced (younger children highlighting physical and older children emotional and social impact) was the predominant topic area raised. Adaptive (resilience) and maladaptive (denial) coping strategies were found to be adopted in response to the fluctuating uncertainty a cancer diagnosis can bring. Awareness of the wider impact on their family and peer group relationships, and perceived responsibility, resulted in assumed new roles, such as provider of comfort. Children highlighted practical interventions, including support, information and individualised care as beneficial.

Commentary

This review synthesizes literature on the experiences of children receiving cancer care drawing on a range of international studies. It informs understanding of the impact of cancer treatment and identifies some important implications for practice that could improve the quality of life for the children receiving treatment for cancer.

The identified range of suffering and adopted roles, informed by the uncertainty a cancer diagnosis can bring, provides additional context to the recognized impact on these children's emotional well-being and need for targeted mental health support.⁶ Understanding the impact of cancer care from the perspectives of both the child and the family as a whole, is important and can inform timely targeted referrals with the associated benefits of early intervention. Revisiting these developmentally appropriate conversations with the child, alongside wider conversations with the family, across the cancer trajectory is important. Although children were found to adopt new roles and responsibilities as a direct result of the experience⁴ not all developed resilience and coping skills over what could be prolonged treatment periods.

Whilst nurses were identified as key providers of social support directly enhancing the cancer experience, there is an identified need for more research into the provision and impact of social support (external to the care team) during cancer treatment.

References

 Melissa M. Hudson, Michael P. Link, and Joseph V. Simone Milestones in the Curability of Pediatric Cancers. *Journal of Clinical Oncology*. 2014; 32(23):2391-2397

- 2. Bitsko, M. J., Cohen, D., Dillon, R., Harvey, J., Krull, K., & Klosky, J. L. Psychosocial late effects in pediatric cancer survivors: a report from the Children's Oncology Group. *Pediatric Blood & Cancer*. 2016; 63(2):337-343.
- 3. Quinn, G. P., Gonçalves, V., Sehovic, I., Bowman, M. L., & Reed, D. R. Quality of life in adolescent and young adult cancer patients: a systematic review of the literature. *Patient Related Outcome Measures* 2015; 6:19-51.
- 4. Jibb L.A., Croal L., Wang J., Yuan C., Foster J., Cheung V., Gladstone B.M. Stinson J.N. Children's Experiences of Cancer Care: A Systematic Review and Thematic Synthesis of Qualitative Studies. *Oncology Nursing Forum*. 2018; 45(4):527-544.
- 5. Tong, A., Sainsbury, P., & Craig, J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007;19(6):349-357.
- CLIC Sargent (2017). Hidden Costs: The Mental Health Impact of a cancer Diagnosis on Young People [On line] Available from https://www.clicsargent.org.uk/sites/files/clicsargent/CLIC%20Sargent%20Hidde n%20Costs%20report.pdf

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Competing interests

None