

Integrated psychosocial care of children with advanced cancer and their families

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DESCRIBED IN THIS ARTICLE is the impact of symptom distress on children with advanced cancer and their families. The benefits of timely and appropriate referral to paediatric palliative care are named. The merits of systematic identification of psychosocial risk are given. Finally, an example of an integrated model of psychosocial care is presented by reference to work ongoing at Lauralynn Ireland's Children's Hospice.

Symptom distress and quality of life

Each year in Ireland approximately 210 children under the age of 19 are diagnosed with cancer with the majority surviving beyond five years.¹ Despite increasing survival rates, these children remain at risk for high symptom distress.^{2,3,4} Common physical symptoms associated with distress among children with advanced cancer are pain, fatigue, and drowsiness, whereas irritability and sleep disturbance are highly distressing psychological symptoms.⁴ The effect of these symptoms is to diminish the child's quality of life.^{5,6,7}

Family psychosocial risk

For parents, the stresses associated with the carer role are numerous. Examples include co-ordinating and delivering medical care, decision making, communication with professionals and within the family, containing distress, disruption to family roles and routines, financial costs, and the prospect of losing the child.⁸ Difficulty adjusting to the role as carer is expressed as problems with mood, disturbance of sleep, fatigue, and feelings of fear in relation to the child's symptoms and the prospect of the child dying.^{9,10}

The experience of caring for a child with cancer also places strain on spousal relationships¹¹ and relationships within the extended family.¹² With respect to siblings' psychosocial adjustment to childhood cancer, symptoms of cancer-related post-traumatic stress are prevalent, as is poorer academic functioning and greater absenteeism.¹³

End-of-life and palliative care

A subgroup of children with cancer succumb to their illness, with an average of 24 deaths occurring in Ireland per year due to childhood cancer.¹ At the end of life, the most frequent and problematic symptoms are pain and fatigue, occurring in almost all children.^{10,14} Feelings of sadness, anxiety, irritability, and a range of distressing physical symptoms also feature.^{2,3,15}

Timely and appropriate referral to palliative care services is one way of offsetting some of the burden on the child and family.⁸ Referral to palliative care is linked with improved parental perceptions of children's symptoms, enhanced quality of life and communication, better family support, and greater co-operation between families and healthcare providers.¹⁶ Children who receive palliative care also spend fewer days in hospital, receive fewer invasive treatments, and are less likely to die in the ICU.¹⁷

Psychosocial care pathways

Just as there are obstacles to achieving integrated medical care of children with cancer so are there difficulties in relation to the delivery of psychosocial care to seriously ill children and their

Table 1: Evidence-based screening measures validated in paediatric oncology

Distress Thermometer (DT).²⁰ A brief visual analogue measure of psychological distress from 0 (No Distress) to 10 (Extreme Distress). It has been used in paediatric cancer and other childhood illnesses, generally with a clinical cut-off of 4 or 5 (24). Self- and Parent-Report versions are available.

Psychosocial Assessment Tool (PAT) Version 3.²⁵ Based on the PAT,¹⁸ the PAT 3 is a brief parent report screener of family psychosocial risk based on a social ecological model of families that assesses psychosocial risks across the child's social environment. The PAT generates a total score and seven subscale scores (eg. Structure/Resources, Social Support, Child [Patient] Problems, Sibling Problems, Family Problems, Stress Reactions, and Family Beliefs) by summing the number of endorsed high-risk items (subscale scores) and as a weighted average (total score). The total score, which is a sum of the subscales, maps on to the PPPHM²⁶ with three tiers of risk – Universal, Targeted, and Clinical.

Strengths and Difficulties Questionnaire (SDQ).²⁷ A 20-item measure of adjustment of children from 3 to 17 years old. A total difficulties score (0-40) is derived, with a cut-off of 14. The SDQ has strong psychometrics and has been used in paediatric oncology.²⁸ Self-, parent- and teacher-report versions are available.

families. Psychosocial supports are typically not provided in a systematic or consistent way across or within paediatric oncology settings.¹⁸ Recognising this, the interdisciplinary team at Lauralynn Ireland's Children's Hospice ('Lauralynn'), an organisation that provides hospice and palliative care to children with life-limiting illnesses, including certain cancer diagnoses, developed a pathway which allows for mutual decision-making and organisation of psychosocial care processes that are aligned with best practice. The pathway is adhered to by all staff in order to ensure high standards of equitable and sustainable psychosocial care.

Screening and referral of psychosocial risk

As per the psychosocial care pathway, concerns are flagged in the course of routine screening and, more organically, arising from staff contacts with the child and family members or in the form of external- or self-referrals. In respect of routine screening of psychosocial risk, a semi-structured clinical interview known as the Holistic Needs Assessment (HNA) is carried out with each family at point of admission to the service. Developed by a cross-section of professionals at Lauralynn, the HNA captures data on the child and family across five domains. In addition to detailing the child's physical needs, it collates information relating to the child and family's psychological/emotional wellbeing, social factors, spirituality, and the child's adaptive skills (eg. communication,

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Table 2: A hypothetical case example of psychosocial care at LauraLynn: Ryan

Referral. Ryan, aged 12 years, is referred to LauraLynn Ireland’s Children’s Hospice by his neurologist. Intensive therapies aimed at slowing the growth of Ryan’s brain tumour were unsuccessful. He lives with his parents, Alan and Veronica, and his sister, Annie (seven years).

Screening. At the time of admission to the service a Holistic Needs Assessment (HNA) was undertaken by two experienced clinical nurse specialists in children’s palliative care. This is a semi-structured clinical intake interview that informs the care team at LauraLynn of the family’s main concerns, in qualitative terms. At the time of carrying out the HNA, Ryan’s parents were focused primarily on pharmacological management of Ryan’s pain. No specific psychosocial concerns were identified then. However, some weeks later Veronica related to a member of LauraLynn care staff that she and Alan were experiencing significant strain and that this was expressed as increased conflict. She added that while Ryan was showing great resilience, his sister increasingly ruminated on what would happen to Ryan’s body once he had died. Having conferred with parents, separate referrals were completed by the staff member involved. These were then forwarded to the psychosocial team for multidisciplinary

team (MDT) review. The level of distress in the case of parental discord was rated at 8 out of a possible high score of 10; Annie’s distress was rated as 6 out of 10.

Psychosocial care plan. The MDT review found that as a service LauraLynn was in a position to respond to the needs identified. Based on the high level of distress caused by parental discord, it was determined that the clinical psychologist would offer couple’s counselling. Given that her parents’ coping resources were depleted, it was further decided that direct support would be offered to Annie in the form of play-based therapy. Psychosocial leadership was assumed jointly by the clinical psychologist and the play therapist.

Outcome. Support provided by the clinical psychologist, which included teaching relaxation exercises and assertive communication strategies, helped Alan and Veronica to regulate the intense emotions they were experiencing and to resolve conflict without escalation. It also provided a gateway to subsequent bereavement support provided by the psychologist after Ryan’s death. In her work with the play therapist, Annie prepared in advance how she would contribute to Ryan’s funeral – she wrote a poem about the reasons why she was proud to be his sister.

play/leisure, managing routines, learning). At LauraLynn, the most commonly identified care goals, in order of prevalence, are those relating to the child’s physical needs, child and family psychological/emotional needs, and the child’s adaptive behaviours.¹⁹ In addition to the HNA, annual reviews are carried out, which take stock of both the child’s care needs and the broader needs of the child and family.

Responding to psychosocial risk

At the time of writing this article in June 2019, to augment data collated from HNAs and annual reviews, and to allow for clear identification of psychosocial concerns as they arise over time, the team at LauraLynn have integrated into the care pathway a system of referral that is tailored specifically to a children’s hospice and palliative care setting. A brief psychosocial referral form invites the referrer to describe what the main concerns are, what supports have been accessed/helpful to date, and it incorporates a standardised measure of distress known as the ‘distress thermometer’.²⁰

The information collated by the referral form is then processed systemically in a designated weekly forum by an interdisciplinary team. In this context, consideration is given to, among other things, what is the level of distress caused by the concerns, what offering will achieve the greatest gain, and who is best placed to assume psychosocial leadership of the case? This system provides for evidence-based psychosocial triage so that the team’s resource allocation is purposeful, and responsive to the type and severity of need²¹ (see *Table 1* for examples of screening measures).

In the event that risk is identified in relation to self-harm or suicidality, staff are guided by relevant policies developed within the service.²² Aligned with the principles of evidence-based

practice, the pathway just described means that psychosocial care at LauraLynn is informed by the best available research in the area of assessment, the clinical expertise of the team, and the specific needs identified for each child and family.²³ The process is illustrated above by reference to the hypothetical case of ‘Ryan’ (see *Table 2*).

Summary

Children with cancer are at high risk of symptom distress, particularly so in the case of advanced cancer and at the end of life. This has implications for the child’s quality of life. For parents, the stresses associated with the caring role are numerous and intense, such that it is difficult to meet the competing needs of siblings. Timely and appropriate referral to children’s palliative care services is one way of mitigating the strain on the child and family.

An example of a psychosocial care pathway that allows for mutual decision-making and resource allocation that is purposeful, targeted and sustainable is that offered at LauraLynn Ireland’s Children’s Hospice. In developing pathways of the kind described here care providers can ensure that psychosocial care is informed by the best available research in the area, the clinical expertise of the team, and the specific needs identified for each child and family.

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