

The Development of a National Paediatric Psycho-Oncology Service

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Abstract

Aims

To investigate the psychological care provided to children and young adolescents with cancer and their families within the National Children's Cancer Service (NCCS), Ireland, in respect of the national and international standards of care.

Methods

A retrospective audit of 316 referrals made over 32 months by the NCCS to the psychology service in malignant haematology and oncology was performed.

Results

The audit revealed that out of 316 patients, a yearly average of 189 (50%) of urgently referred patients received psychological support within the NCCS between January 2013 and August 2016. Furthermore only 20 (22%) undergoing haematopoietic stem cell transplantation (HSCT), 14 (22%) referred to the paediatric palliative care team, and 84 (62%) of teenage patients received psychological input during this timeframe.

Conclusion

The audit revealed that the current psychology service provision is failing to meet the international standards of care. Due to the data provided by this audit, in conjunction with a clinical risk assessment of the service, funds for the post of principal psychologist have been secured. Further psychology posts (HSCT, late-effects and neuropsychology), and development of the psycho-oncology model of care are required to ensure equality of access and evidence-based psychological care for all children with cancer.

Introduction

Approximately 200 children/young adolescents (0-16 years) are diagnosed with cancer annually in Ireland. The role of the National Children's Cancer Service (NCCS) is to diagnose, plan treatment and follow-up care for all children/young adolescents diagnosed with cancer in Ireland¹. In addition to newly diagnosed patients, the service sees an average of 700 patients annually on an outpatient basis. Furthermore, the NCCS also acts as an advisory and response service for 16 shared care centres throughout Ireland. The National Cancer Strategy 2017-2026^{1,2} recognises that current services are under pressure and patient numbers will continue to increase. The National Cancer Control Program (NCCP)¹ identifies the provision of safe, high quality and patient-centred care as the primary aim of all cancer services. This involves care that is evidence-based, timely, efficient, effective and equitable. To achieve this model of care, the Strategy identified the need of establishing multi-disciplinary psycho-oncology teams in each of the eight designated adult cancer centres and the NCCS. Despite an increase in child/young adolescent cancer diagnoses, the psychology personnel provision for the NCCS has been one full-time senior clinical psychologist since 2003.

Psycho-oncology, a relatively new sub-speciality, has facilitated the integration of the psychological domain into the disease-specific speciality of oncology/haemato-oncology³. Psycho-oncology is a sub-speciality within oncology/haemato-oncology that focuses on the: (1) psychological responses of patients, families, and caregivers, to the diagnosis of cancer; and (2) the behavioural, social, medical and psychological factors that may affect the disease process⁴, and impact on compliance and response to treatment. The psychological issues connected to childhood cancer have been well documented, with receipt of a potentially life-threatening paediatric cancer diagnosis having been found to be universally distressing and potentially traumatising for both children and their families⁵⁻⁶. Paediatric psychology has a unique role within the multidisciplinary team⁶ (Table 1).

Table 1. Key roles of paediatric psychologists working within malignant haematology and oncology settings.

Key Roles
Assessing vulnerabilities and promoting resilience, coping and adjustment to cancer and throughout different parts of treatment from diagnoses, treatment, end of treatment and/or relapse.
Supporting the medical team in managing nausea, procedural pain, procedural distress and other side-effects of treatment.
Assessing and increasing adherence to treatment.
Assessing, monitoring, and when possible, reducing and/or rehabilitating neuropsychological effects.
Facilitating transition to palliative care and preparation for end of life.

Empirical evidence suggests that cancer patients who have their psychological needs met during treatment have a greater quality of life (QOL) and better health outcomes⁷. Despite a wealth of research documenting the psychological risks for children and their families faced with a paediatric cancer diagnosis, significant differences have been found in the standard of psychological care offered to patients across services⁸. An international group of professionals worked to develop evidence-based standards for psychosocial care in paediatric oncology, conducting in-depth systematic reviews of the available research evidence: The 15 Standards for the Psychosocial Care of Children with Cancer and Their Families⁸ (Table 2).

Table 2. Standards for the Psychosocial Care of Children with Cancer and Their Families.

Standards
1. Youth with cancer and their family members should routinely receive systematic assessments of their psychosocial health care needs.
2. Patients with brain tumours and others at high risk for neuropsychological deficits as a result of cancer treatment should be monitored for neuropsychological deficits during and after treatment.
3. Long-term survivors of child and adolescent cancers should receive yearly psychosocial screening for: a) adverse educational and/or vocational progress, social and relationship difficulties; b) distress, anxiety, and depression and c) risky health behaviours. Adolescent and young adult survivors and their parents should receive anticipatory guidance on the need for life-long follow-up care by the time treatment ends and repeated at each follow-up visit.
4. Youth with cancer and their family members should have access to psychosocial support and interventions throughout the cancer trajectory and access to psychiatry as needed.
5. Paediatric oncology families are at high risk for financial burden during cancer treatment with associated negative implications for quality of life and parental emotional health. Assessment of risk for financial hardship should be incorporated at time of diagnosis for all paediatric oncology families. Domains of assessment should include risk factors for financial hardship during therapy including pre-existing low-income or financial hardship, single parent status, distance from treating centre, anticipated long/intense treatment protocol, and parental employment status. Targeted referral for financial counselling and supportive resources (including both governmental and charitable supports) should be offered based on results of family assessment. Longitudinal reassessment and intervention should occur throughout the cancer treatment trajectory and into survivorship or bereavement.
6. Parents and caregivers of children with cancer should have early and ongoing assessment of their mental health needs. Access to appropriate interventions for parents and caregivers should be facilitated to optimise parent, child and family well-being.
7. Youth with cancer and their family members should be provided with psychoeducation, information, and anticipatory guidance related to disease, treatment, acute and long-term effects, hospitalisation, procedures, and psychosocial adaption. Guidance should be tailored to the specific needs and preferences of individual patients and families and be provided throughout the trajectory of cancer care.
8. Youth with cancer should receive developmentally appropriate preparatory information about invasive medical procedures. All youth should receive psychological intervention for invasive medical procedures.

<p>9. Children and adolescents with cancer should be provided opportunities for social interaction during cancer therapy and into survivorship following careful consideration of the patients' unique characteristics, including developmental level, preferences for social interaction, and health status. The patient, parent(s) and a psychosocial team member (e.g., designee from child life, psychology, social work, or nursing) should participate in this evaluation at time of diagnosis, throughout treatment and when the patient enters survivorship; it may be helpful to include school personnel or additional providers.</p>
<p>10. Siblings of children with cancer are a psychosocially at-risk group and should be provided with appropriate support services. Parents and professionals should be advised about ways to anticipate and meet siblings' needs, especially when siblings are unable to visit the hospital regularly.</p>
<p>11. In collaboration with parents, school-age youth diagnosed with cancer should receive school re-entry support that focuses on providing information to school personnel about the patient's diagnosis, treatment, and implications for the school environment and provides recommendations to support the child's school experience. Paediatric oncology programs should identify a team member with the requisite knowledge and skills who will coordinate communication between the patient/family, school, and the health care team.</p>
<p>12. Adherence should be assessed routinely and monitored throughout treatment.</p>
<p>13. Youth with cancer and their families should be introduced to palliative care concepts to reduce suffering throughout the disease process regardless of disease status. When necessary youth and families should receive developmentally appropriate end of life care [which includes bereavement care after the child's death]. This includes psychological preparation for end of life.</p>
<p>14. A member of the health care team should contact the family after a child's death to assess family needs, to identify those for negative psychosocial sequelae, to continue care, and to provide resources for bereavement support.</p>
<p>15. Open, respectful communication and collaboration among medical and psychosocial providers, patients and families is essential to effective patient- and family- centred care. Psychosocial professionals should be integrated into paediatric oncology care settings as integral team members and be participants in patient care rounds/meetings. Paediatric psychosocial providers should have access to medical records and relevant reports should be shared among care team professionals, with psychological report interpretation provided by psychosocial providers to staff and patients/families for patient care planning. Psychosocial providers should follow documentation policies of the health system where they practice in accordance with ethical requirements of their profession and state/federal laws. Paediatric psychosocial providers must have specialized training and education and be credentialed in their discipline to provide developmentally appropriate assessment and treatment for children with cancer and their families. Experience working with children with serious, chronic illness is crucial as well as ongoing relevant supervision/peer support.</p>

Within this context, there was a need to conduct a clinical audit of the dedicated psychology provision in the NCCS, to facilitate continuous service development and quality improvement⁹, and to explore whether the current provision was meeting the international standards of care (standards 1,4,7,8,12,13)⁸.

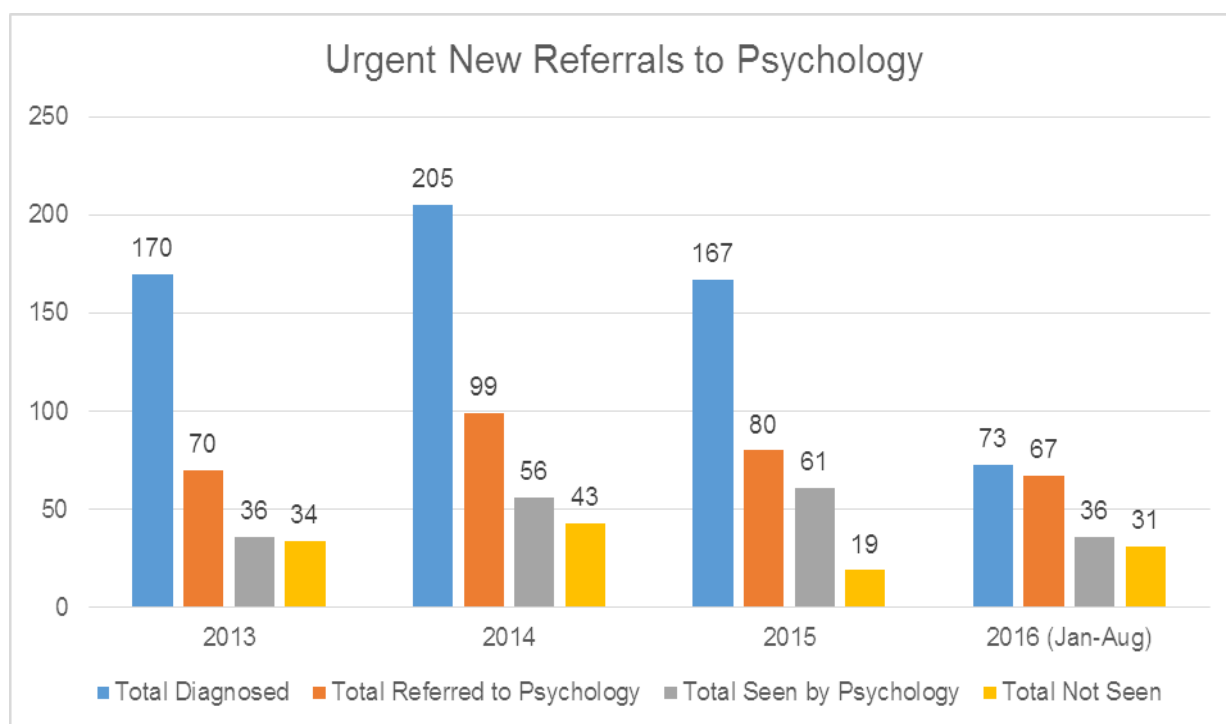
Methods

A retrospective, cross-sectional review of referrals made by the NCCS to the psychology service from January 2013 to August 2016 was performed in September 2016. The data collected was classified into total number of newly diagnosed patients, number of patients undergoing haematopoietic stem cell transplantation (HSCT), referred to palliative care, referred to psychology, seen by psychology and not seen by psychology. The chair of the hospital's research ethics committee was contacted prior to the conduct of this audit, to discuss ethical considerations (to include anonymisation of data), its development and publication.

Results

The total number of patients diagnosed within the NCCS per year, the total number referred for psychological support, the total number who were subsequently seen, and the total number who were not seen are summarised in Figure 1. This data is presented yearly from 2013 to 2016. These statistics exclude active, ongoing, and relapsed cases.

Figure 1. Urgent New Referrals to Psychology.



In 2013, 36 (51%) of urgent, newly referred patients had access to psychological support within that year. In 2013, the NCCS had access to one full-time senior clinical psychologist for oncology and haemato-oncology.

In 2014, there were 205 patients diagnosed with cancer, the highest number recorded in a single year to date and not surprisingly, the psychology service received the highest number of new, urgent referrals for psychological support (99). The total number of patients who accessed psychological support improved slightly upon the preceding year, with 56 (57%) seen by a psychologist in 2014: 43 (43%) of patients were not seen. In 2014, the NCCS had access to two part-time (0.5) senior clinical psychologists, one for oncology and one for haemato-oncology, and both anecdotally reported dedicating more than 0.5 to each speciality to try to fill the gaps of the service.

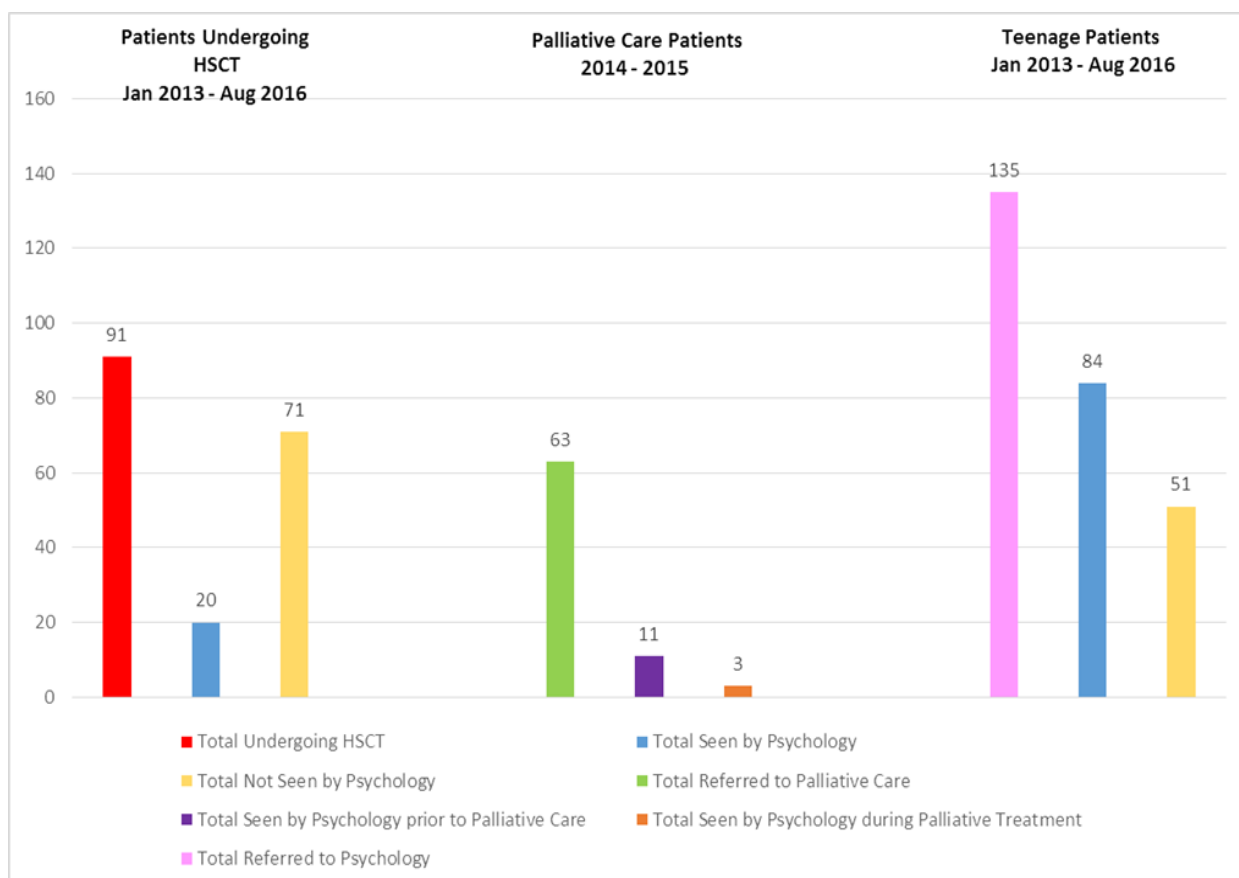
In 2015, the highest percentage of urgently referred patients were seen by a clinical psychologist due to an increase in psychology service provision; 61 (76%) seen: 19 (24%) not seen. For 6 months of that year, the NCCS had access to three part-time (0.5) senior clinical psychologists, two for oncology and one for haemato-oncology.

From January to August 2016, the psychologist saw 36 (54%) of urgent, new referrals, while 31 (46%) remained not seen.

A more detailed analysis of the data was conducted to explore specific areas of clinical need highlighted by the literature⁸: HSCT, palliative care and young adolescents.

The psychological support received by patients undergoing HSCT between January 2013 and August 2016, patients in palliative care between 2014 and 2015, and young adolescent patients between January 2013 and August 2016 (Figure 2).

Figure 2. Patients Undergoing HSCT, Palliative Care Patients and Teenage Patients.



Of the 91 patients undergoing HSCT, approximately 20 (22%) received psychological input. Children, young adolescents and their families received support from other members of the psychosocial multidisciplinary team, including a complimentary therapist, play specialists, and social workers.

Of the 63 patients from the NCCS who were referred to the palliative care team between 2014 and 2015, 15 (24%) were offered psychological input during their cancer treatment. 14 (22%) availed of the psychological support offered; 11 (17%) before they became palliative, and 3 (3%) after they were referred to the palliative care medical consultant.

Of the 135 teenage patients who were referred for psychological support between January 2013 and August 2016, approximately 84 (62%) received psychological input from a psychologist.

Discussion

This audit demonstrates that the current psychology provision within the NCCS is failing to meet international standards of care. This provision creates inequalities in patient care and does not currently facilitate every child/young adolescent diagnosed with cancer to have access to psychological support throughout their cancer journey. The data revealed approximately 189 (50%) of urgent, newly referred patients received psychological support within the NCCS between 2013 and 2016. The only exception was in 2015, where 61 (76%) of urgent, new referrals had access to psychological care. Notably, dedicated psychology provision was increased that year due to additional personnel support within the psychology service, bringing the dedicated provision to 1.5 (WTE) for six months of 2015.

The audit also revealed a significant difference between 2013 and 2016 in the number of patients referred to the psychology service and the number of patients seen. These findings should be interpreted within the limitations of this study, highlighted below. However, the authors feel a possible interpretation of the increase in number of referrals and number of patients seen may be found in the specific psycho-oncology training of the new psychologist, and psycho-educational programme that was introduced in 2016. This result is supported by the National Cancer Strategy 2017-2026¹ and empirical literature, which indicate the need for staff working in this area to have specific training and supervision within the sub-speciality. This is essential to provide staff with the knowledge and skills required to provide safe, high quality and patient-centred psycho-oncological care. The need for more psychological care was already indicated in the National Clinical Programme for Paediatrics and Neonatology¹⁰. Furthermore, the NCCP and the current Cancer Strategy¹ recognise the need to employ multi-disciplinary psycho-oncology teams, including psychologists, who have an appropriate level of seniority and expertise in psycho-oncology to guarantee this appropriate provision of care.

For this reason, there is a need to employ a principal psychologist with expertise in paediatric psycho-oncology¹; a role that is already present in four of the eight designated adult cancer centres in Ireland. This person would deliver specialised interventions for families experiencing the highest level of psychological distress and would offer training and supervision to other psychologists and healthcare staff working within the NCCS, in the 16 shared-care hospital centres, and in mental health community services.

The literature suggests high levels of staff burnout in the field of child/young adolescent oncology/haemato-oncology, and psychological support and supervision for staff may be instrumental in facilitating staff retention within the NCCS¹¹⁻¹⁶. Due to the work of the NCCS in conjunction with the hospital management team, data from this audit, and a clinical risk assessment conducted recently by the psychology department and NCCS, funds for this post have now been secured.

To meet the international standards of psychosocial care⁸, which are more specific to psychology (1, 2, 3, 4, 7, 8, 9, 10, 11, 12, 13, 15) it is proposed that three additional psychology posts are also required: one full time senior psychology post in HSCT, one for the late effects clinic (survivorship programme), and one senior neuropsychologist. This increased provision will facilitate the psycho-oncology service in assessing and providing psychological intervention to every child/young adolescent with cancer receiving active and maintenance treatment in the National Children Cancer Service, at appropriate time for screening and for treatment if/when needed. The medical/nursing team will be asked to automatically refer every child/young adolescent diagnosed with cancer to the Psycho-Oncology Service, using a new referral form that has been piloted in the service, this would provide information to screen with priority the most urgent cases, but every family will receive a formal screening and when needed intervention. In collaboration with Professor Anne Kazak, The Children's Hospital of Philadelphia, the service is ready to pilot an Irish version of the screening tool recommended by the standards of care (Psychosocial Assessment Tool, Standard 1)⁸.

This proposal of three additional posts is based on the current number of newly diagnosed patients entering the service each year for children age 0-16. Together with the NCCP, the NCCS is working to increase the age of treatment and include young adults in the service, creating a Children and Adolescent Service with Cancer (0-23). If this is successful, in the future, the most updated research evidence-based data and service user's involvement, will be used to design appropriate service for this cohort of patients.

The NCCS have identified HSCT as an area of particularly high priority need for increased psychological services. Currently, approximately 20 (22%) of children/young adolescents undergoing HSCT receive psychological input. Although the HSCT programme at the NCCS has previously been accredited by the Joint Accreditation Committee for the International Society of Cellular Therapy (JACIE) and the European Society for Blood and Marrow Transplantation (EBMT), the failings of the NCCS to provide appropriate access to a psychologist before, during and after transplantation¹⁷, specifically due to a lack of psychologists, has been identified. The psychological needs of children, young adolescents and their families are higher during and following transplantation due to the medical complexity of this treatment and the psychological challenges of isolation.

The results of this audit should be interpreted in respect of its limitations. Due to limited psychology resources, a dedicated database for psycho-oncology referrals was not in operation from 2013-2016. Exact data pertaining to the number of newly referred cases who were not seen by a psychologist, who subsequently moved to adult or community-based waiting lists, were re-referred, or who may have died without being seen, is unknown.

A research innovation grant received in 2018 has provided the service with a functional database, facilitating the collection of more precise data in the future and a prospective database has been active since the employment of the Principal Psychologist in January 2020 and in this information is now recorded.

In conclusion, the strong partnership between psychology, and child/young adolescent haemato-oncology/oncology has facilitated, albeit slowly, the genesis of paediatric psycho-oncology. However, the psycho-oncology service will continue to fail to meet the international standards of psychosocial care without additional personnel. With the correct staffing, paediatric psycho-oncology services in Ireland will be able to support children, young adolescents and families, and develop, through clinical research, developmentally targeted clinical knowledge, to inform and integrate within the medical care of children and young adolescents with cancer. This is essential, as evidence suggests that cancer patients who have their psychological needs met during treatment have a greater QOL and better health outcomes⁷. As clinicians looking after children/young adolescents with cancer and their families, we must keep striving to meet this goal.

Declaration of Conflicts of Interest:

The authors have no conflicts of interest to disclose.

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