ENDURING PSYCHOLOGICAL IMPACT OF CHILDHOOD CANCER ON SURVIVORS AND THEIR FAMILIES IN IRELAND: A NATIONAL QUALITATIVE STUDY

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Background Five-year survival after childhood cancer has improved in Ireland in recent decades and is currently 81%. There are thousands of adult survivors of childhood cancer (ASCC) living in Ireland, but little is known about their psychological and social needs. Ireland’s National Cancer Strategy 2017–2026 highlighted the need to establish the psycho-social needs of ASCC. This study aims to establish the major expressed psycho-social needs of this group for the first time.

Methods Seven focus groups were conducted with ASCC and parents in Dublin, Cork and Galway in 2018. Focus groups were promoted through social media, print media, radio, voluntary organisations, and clinical networks. Survivors were invited to participate if they were diagnosed with cancer before age 18. Braun & Clarke’s Framework for Thematic Analysis was used to identify semantic and latent themes. Member-check was undertaken to confirm that participants’ views and experiences were accurately recorded.

Results The 33 participants (15 ASCC, 18 parents) had experienced a range of haematological and solid tumours in childhood. Five overarching themes were generated: (1) Enduring psychological impact on survivors; Many ASCC experience high levels of psychological distress as adults, including delayed trauma which can precipitate mental health crises in adulthood. (2) Enduring psychological impact on family members; Parents and siblings have unmet psychological needs relating to their experience of childhood cancer. (3) Enduring impact on family dynamics; ASCC and parents expressed high levels of fear and guilt relating to their cancer experience, which impacted on their family interactions. (4) Challenges accessing support; Psychological support services are inadequate to meet the needs of ASCC and their families, and are often only available through private providers. ASCC are not routinely offered psychological support during follow-up. (5) Desired model of care; No single service model appeals to all ASCC, and flexibility is required in the delivery of psychological support (individual vs. group, formal vs. informal).

Conclusion ASCC and their family members experience enduring psychological effects relating to their diagnosis and treatment. Psychological support services are inadequate to meet the needs of this growing population in Ireland. The study was limited by its participants who were self-selected, majority female, and may have experienced psychological distress regardless of their previous experience of cancer. The findings are being used to guide development of enhanced psycho-oncology services in the Irish public healthcare system, in line with the National Cancer Strategy.

A SYSTEMATIC REVIEW OF POPULATION-BASED QUALITY INDICATORS FOR END OF LIFE CANCER CARE

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Background Improving the quality of cancer care throughout the disease trajectory is an international priority. Population-based quality indicators (QIs) are key to this process yet remain predominantly used for evaluating care during the early, often curative, stages of disease. Aim To identify all existing QIs for cancer patients with advanced disease and/or at the end-of-life, and to evaluate each indicator’s measurement properties and appropriateness for use.

Methods We searched five electronic databases from inception to February 2019 for studies describing the development, review and/or testing of QIs for adults with advanced cancer and/or at the end-of-life. For each QI identified we extracted descriptive information (numerator; denominator; benchmarking data; care domain) and assessed six measurement properties (acceptability; evidence-base; definition; feasibility; reliability; validity). Assessments were based on previously established criteria with four possible ratings: positive; intermediate; negative; unknown. Ratings were collated, and each QI classified as either: appropriate for use; inappropriate for use; or, of limited

Abstracts