

Creating Moments and Memories: An Evaluation of the Starlight 'Moments' Program for Palliative Children, Adolescents and Their Families

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Abstract : The Starlight Children's Foundation (Starlight) is an Australian non-profit organisation that delivers programs, in partnership with health professionals, to support children, adolescents, and their families who are living with a serious illness. While supporting children and adolescents with life-limiting conditions has always been a feature of Starlight's work, providing a dedicated program, specifically targeting and meeting the needs of the paediatric palliative population, is a recent area of focus. Recognising the challenges in providing children's palliative services, Starlight initiated a research and development project to better understand and meet the needs of this group. The aim was to create a program which enhances the wellbeing of children, adolescents, and their families receiving paediatric palliative care in their community through the provision of ongoing, tailored, positive experiences or 'moments'. This paper will present the results of the formative evaluation of this unique program, highlighting the development processes and outcomes of the pilot. The pilot was designed using an innovation methodology, which included a number of research components. There was a strong belief that it needed to be delivered in partnership with a dedicated palliative care team, helping to ensure the best interests of the family were always represented. This resulted in Starlight collaborating with both the Victorian Paediatric Palliative Care Program (VPPCP) at the Royal Children's Hospital, Melbourne, and the Sydney Children's Hospital Network (SCHN) to pilot the 'Moments' program. As experts in 'positive disruption', with a long history of collaborating with health professionals, Starlight was well placed to deliver a program which helps children, adolescents, and their families to experience moments of joy, connection and achieve their own sense of accomplishment. Building on Starlight's evidence-based approach and experience in creative service delivery, the program aims to use the power of 'positive disruption' to brighten the lives of this group and create important memories. The clinical and Starlight team members collaborate to ensure that the child and family are at the centre of the program. The design of each experience is specific to their needs and ensures the creation of positive memories and family connection. It aims for each moment to enhance quality of life. The partnership with the VPPCP and SCHN has allowed the program to reach families across metropolitan and regional locations. In late 2019 a formative evaluation of the pilot was conducted utilising both quantitative and qualitative methodologies to document both the delivery and outcomes of the program. Central to the evaluation was the interviews conducted with both clinical teams and families in order to gain a comprehensive understanding of the impact of and satisfaction with the program. The findings, which will be shared in this presentation, provide practical insight into the delivery of the program, the key elements for its success with families, and areas which could benefit from additional research and focus. It will use stories and case studies from the pilot to highlight the impact of the program and discuss what opportunities, challenges, and learnings emerged.

Keywords : children, families, memory making, pediatric palliative care, support

Conference Title : ICHPC 2020 : International Conference on Hospice and Palliative Care

Conference Location : Sydney, Australia

Conference Dates : December 03-04, 2020