

SH01

Family Management Styles: Updates and Global Perspectives Description

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The purpose of this symposium is to discuss advances in the use of the Family Management Style Framework. The Family Management Style Framework provides a theoretical foundation for many family studies. Investigating how families integrate complex health conditions contributes to the advancement of family science and practice. Family management of complex challenges directly affects patient and family outcomes. With presenters from Australia, Brazil, and the United States, this symposium will provide a global perspective regarding the use of family management as it relates to chronic illness, critical care, palliative care, and end of life care.

SH02

Caregivers of Brain Tumor Survivors: Exploring Family Management of Late Effects

Moderator: Suzanne Feetham, Janet Deatrick¹, Wendy Hobbie¹, Sue Ogle², Kim Mooney-Doyle¹, Maureen Reilly², Erin Mullaney¹, Barbara Beacham¹

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The purpose of this presentation is to explore family management of adolescent and young adult brain tumor survivors from parent's' perspectives. A cross sectional design was used in this single occasion, descriptive qualitative study with 22 parents of 14–30 year old brain tumor survivors who reside at least part-time in the same household as the parent noted. Open-ended cognitive interviews guided by the Family Management Measure (FaMM) were used to query parents about how they managed their children's cancer late effects. The study team analyzed transcribed data using content analysis. Descriptive themes corresponded to components of family management: reacquainting themselves with their child and reacquainting the child with himself, family, and outside world after treatment (child's daily life); foreseeing uncertain, potentially problematic future (view of condition); trying to maintain normalcy despite the condition (family daily life); framing implications of the condition "then" during treatment and "now" (condition management effort); handling the needs of the survivor within a dialectic of loss and recovery (condition management ability); and balancing

Family Management of Children with Chronic Conditions within an Australian Context

Moderator: Suzanne Feetham Speaker: Alison Hutton, Janet Deatrick

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While family management of children's chronic conditions is being intensively researched in the United States (US), the potential application in other countries has not been systematically assessed. Family management is how the family functions to manage (children's) chronic conditions. In Australia today, one in three children between birth and 18 years has a chronic condition and together with their families face many challenges. The ways in which families respond to and manage the child's illness will affect outcomes for those children and their families. In this paper we will explore family management in two separate countries Australia and the United States; with particular reference to processes used to assess cultural appropriateness. It is important that a pilot study is undertaken in the Australian context, as the newly developed Family Management Measure (FaMM) includes questions specifically designed to assess family management from the perception of parents whose ideas about parenting and illness are situated within their cultural beliefs. To determine the appropriateness of this tool in the Australian setting the results of thirty cognitive interviews guided by the FaMM will be described.

SH04

Family Management When a Child Requires Palliative Care

Moderator: Suzanne Feetham Speaker: Regina S. Bousso, Maria D. Misko, Ana Marcia C.M. Castillo, Regina S. Bousso

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Palliative care at home often entails extraordinary parental effort. The literature suggests that providing palliative care in the home may be so demanding and disruptive of family functioning that it is difficult to sustain over time. This study explored family management of palliative home care for a child or adolescent. Data were collected through conducting an oral history with parents of eight youth. The Family Management Style Framework guided data analysis, which focused on understanding how parents balanced the demands of caregiving and other family life responsibilities. The situational context of having a son or a daughter receiving palliative care at home was defined as a "daily challenge". Parents reported developing the necessary skills to manage this new situation in their daily life. They maintained control over their lives by being continuously available and by supporting one another and taking complete responsibility for all of the child's needs. Parental mutuality fluctuated, especially with regard to the need to access palliative home care services. For the