

## Supporting children and young people before a death: selected references

BEALE, E. A., and SIVESIND, D. (2004)

Parents dying of cancer and their children. **Palliative & Supportive Care**, vol.2, no.4, p403-408. (The authors reviewed their experience with 28 consecutive children referred for assessment and intervention. These were the children of patients with terminal cancer referred to the Palliative Care and Symptom Control Service. In all cases the dying parent was a biological parent. Eleven parameters were assessed in each of 29 children and their incidence was calculated. The children and their parents were seen in a semistructured interview, together as well as separately. The parameters were: seeking reassurance (82), becoming a caretaker (79), inability to separate from parent (79), anger about feeling abandoned (68), despair (57), guilt (54), discipline problems, aggressive behavior (46), denial (39), blame of others (21), and fear for the child's own health (18). The results suggest that children with dying parents manifest significant distress as well as a greater understanding of their parent's illness than is usually suspected. Timely intervention by a child psychiatrist or other mental health professional with proven competence in working with children can help children to better cope with the death and dying of their parent and ameliorate the process of bereavement following the parent's death. Because of the small sample, the authors cannot generalize about all of the findings and suggest that further research is required to characterise the level of distress in the children and the long-term impact in their overall adjustment to life).

BUGGE, K.E., and HELSETH, S. (2008)

Children's experiences of participation in a family support program when their parent has incurable cancer. **Cancer Nursing**, vol.31, no.6, pp426-434. (For a child, facing the imminent death of a parent is a highly stressful situation. This study assessed a preventive support program for children aged between 5 and 18 years and their families when a mother or father has an incurable form of cancer. Bugge and Helseth chose a family-based approach to reduce risk factors and enhance protective factors by increasing positive interactions between parents and children and by increasing their mutual understanding of the illness and its family impact. In this article, they focus especially on the children's experiences of how the Family Support Program met their needs and supported their coping. The qualitative study involved collecting descriptive data via in-depth interviews with children of cancer patients in palliative care after participation in the Family Support Program. The program helped the children to feel more secure; increased their knowledge and understanding; helped them become aware of their own role, their family's strengths, and whom they could approach for help; and helped them realize that it was good and helpful to talk about the illness situation. They needed to talk in private without having to think about other family members' reactions, but they also needed to be in dialogue with other family members).

CHOWNS, G. (2008)

'No, you don't know how we feel': groupwork with children facing parental loss. **Groupwork**, vol.18, no.1, pp14-37. (Groupwork with bereaved children has become increasingly common, with closed and open groups, day and residential programmes, and even online chat rooms offering different approaches and purposes. However,

working with children anticipating potential bereavement has received much less attention. Similarly, research within this area in palliative care has been notable for two things - its paucity and its failure to address the perspective of the children themselves. As a palliative care social worker, whose remit was to support children whose parents were receiving palliative care, Chowns searched unsuccessfully for research that was child-centred and child-friendly, and which would enable children to articulate their beliefs and experiences effectively. Thus, for her doctoral thesis, she turned to the action research paradigm for an approach that would more effectively engage with and illuminate these children's experiences, and undertook a collaborative inquiry - where the research is conducted with rather than for, on, or about the participants - with nine children aged from seven to fifteen. Collaborative inquiry raises - and challenges - many key issues in both research and groupwork, such as voice, power and identity, ethics and competence. This article addresses a number of these issues, with a particular focus on identity).

CHOWNS, G. (2009)

Swampy ground: brief interventions with families before bereavement. *In: Monroe, B., and Kraus, F. (Eds) Brief interventions with bereaved children.* pp37-51. 2<sup>nd</sup> ed. Oxford: Oxford University Press. ISBN: 9780199561643

CHRIST, G.H., and others (1993)

Impact of parental terminal cancer on latency-age children. **American Journal of Orthopsychiatry**, vol.63, no.3, pp417-425. (The underlying psychological and emotional components of distress were examined in 87 children with a parent in the terminal phase of cancer. Common fears, concerns, misperceptions, and behavioral consequences are analyzed, as are more severe psychological and behavioral reactions. Implications for psychoeducational parent-guidance intervention are discussed).

CHRIST, G.H., and SIEGEL, K. (1994)

Impact of parental terminal cancer on adolescents. **American Journal of Orthopsychiatry**, vol.64, no.4, pp605-613. (Psychological and emotional concerns of adolescents during a parent's terminal cancer are described. Compared to younger children, the adolescents' greater cognitive and empathic capacities allowed them to be more aware of losses and of the parent's physical and emotional pain. Parental illness also precipitated conflict around issues of developmentally appropriate separation. The capacity to use intellectual defenses, search for meaning and deeper understanding, and seek help were potent coping abilities. Contrary to the prevailing view, most of the adolescents coped with stress without resorting to severe acting out).

COULDRICK A. (1993)

'Do you mean that Mummy is going to die?' Caring for bereaved children. **Professional Nurse**, (Dec), pp186-189. (Children need to be prepared for a terminally ill parent's death. They should be separated from the family for as little as possible. Children who have been through this experience valued being included in the care and given information in a way that could be understood. Carers who can rely on support and know how to get in touch with health professionals feel more confident about handling the children's uncertainties about the situation).

DAVENPORT, D. S. and MACPHERSON, C. (2005)

Telling children their ill parent is dying: a study of the factors influencing the well parent. **Mortality**, vol.10, no.2, pp113-126. (This study explores the issues and difficulties that influenced surviving parents when they were faced with telling their children that their ill parent would die. In-depth semi-structured interviews were carried out with nine participants who had been through this experience. Thematic analysis was used to highlight the internal experience within the well parent, in relation to the dying parent and to their children. Participants' experiences were shown to be inherently related to holding paradox, specifically in terms of their own conflicting needs and conflicting needs

within the family. The importance of following the lead of the dying parents and the implications of this for therapeutic practice are considered).

DAVIES, B., and others (2005)

Children's perspectives of a pediatric hospice program. **Journal of Palliative Care**, vol.21, no.4, (Win), pp252-261. (Little attention has been paid to documenting the experiences of children in pediatric palliative care programs, both those who are ill and their siblings. In this evaluation study of Canuck Place, a Canadian, free-standing hospice program, 26 ill children and 41 of their siblings completed mail-out questionnaires. In addition, four ill children and 10 siblings participated in face-to-face interviews. Results indicate that nearly all children were enthusiastic about the program's activities and the physical environment at Canuck Place. Engaging activities, physical amenities, and the social climate promoted by staff, volunteers, and other families were important contributors to the children's satisfaction. Suggestions for better serving adolescents included: a wider range of age-appropriate activities, games, and toys--especially for teens and older children; more trips and tours outside the building and around town; and caring staff and volunteers who are "attentive-in-the-moment". From the children's perspective, the key to Canuck Place's success is its social climate of caring, safety, friendliness, acceptance, and variety).

DEHLIN, L., and MERTENSSON, R.G. (2009)

Adolescents' experiences of a parent's serious illness and death. **Palliative and Supportive Care**, vol.7, no.1, pp13-25. (Adolescence is characterized by increasing liberation from parents as the young person evolves into an independent individual. Experiencing the serious illness and death of a parent during this phase implies great stress. Serious illness involves uncertainty, worry, and hope at the same time that it is necessary for everyday life to function. This study sought to describe adolescents' experiences in the serious illness and death of a parent. The study was carried out using a qualitative method. Data were collected in interviews with five adolescents who were 14-17 years of age when one of their parents died. The results show that the parent's illness was a strong threat, as the adolescents understood that their own and the family's lives would be greatly changed by the illness/death. The incomprehensibility of the parent's serious illness and death was a threatening condition on its own. The adolescents strived to make the inconceivable more conceivable to understand what was happening. They also described the necessity of finding different ways of relating to and managing the threat, such as restoring order, seeking closeness, adapting, gaining control, avoiding talking about the illness, not accepting and counting the parent out. The adolescents described feelings of being alone and alienated, even though they were close to family and friends and they did not actively seek support. The lives of the adolescents were changed by their experiences, beyond their bereavement over the parent. They felt that they had become more mature than their friends and that there had been a change in their thinking about life, changes in values, and changes in their views of relationships with other people. The results of the present study can form a basis for developing a support program whose purpose would be to prevent effects on health).

DUNNING, S. (2006)

As a young child's parent dies: conceptualizing and constructing preventive interventions. **Clinical Social Work Journal**, vol.34, no.4, (Dec), pp499-514. (The impending death of a parent with young children in the home presents a family with often overwhelming challenges. Social workers and other mental health professionals are in a position to assist such families if they understand the misperceptions, beliefs and veiled presentation of affect in children. Dunning discusses the framing of proposed interventions in cognitive, affective and behavioral spheres and along with many clinical examples and vignettes, presents guidance for parents which is critical to the overall success of the intervention).

FEARNLEY, R. (2010)

Death of a parent and the children's experience: don't ignore the elephant in the room. **Journal of Interprofessional Care**, vol.24, no.44, (Jul), pp450-459. (This paper explores two interlinked components of practitioner's support to children when a parent or carer is at the end of life or has died. The primary issue relates to communication and the competence and confidence of practitioners when working with this community of children. Fearnley suggests that related to this is the lack of training practitioners receive, both as students and through continual professional development, within the fields of social care and health. The metaphor of the elephant in the room is used to delineate how practitioners avoid such discussions and thereby miss opportunities to support children experiencing potentially the most traumatic life event they have faced. Drawing on current research and the author's experience and reflections as a researcher and practitioner the paper suggests that children experiencing the death of a parent or carer are not being recognized as children in need but rather requiring interventions from specialist services).

FULTON, R. (2003)

Anticipatory mourning: a critique of the concept. **Mortality**, vol.8 no.4, pp342-351. (This paper undertakes a critical review of two concepts, "Anticipatory Grief", introduced into the literature by Eric Lindemann in the 1940s, and "Anticipatory Mourning", recently proposed by Therese Rando in her book *Clinical Dimensions of Anticipatory Mourning*. The introduction of the term "Anticipatory Mourning" allows us the opportunity to re-examine our ideas about human response to loss through death. Presently, controversy surrounds the theories associated with grief and mourning. Recent research challenges long held assumptions. Beyond directing the attention of the physician or other caregiver to the emotional state of the survivor serious reservations are expressed regarding the theoretical or practical value of either concept).

GIESBERS, J. and VERDONCK-DE LEEUW, M. (2010)

Coping with parental cancer: web-based peer support in children. **Psycho-Oncology**, vol.19, no.8, pp887-892. (Objective: To investigate the use and content of web-based peer support in children coping with parental cancer. Methods: In children aged above 12 years, 158 forum discussions on the Dutch website [www.kankerspoken.nl](http://www.kankerspoken.nl) in a time-period of 3 months were investigated. Age, gender, number of discussions, participation and main activities on the website were quantitatively assessed. Contents of the discussions were qualitatively analyzed. Results: In total, 129 children and 8 adults participated on the website with an average age of 15.3 years. The majority was female (80%). On average, a child was on-line for 3 days and participated in 4 to 5 forum discussions. Main activities on the website were sharing personal experience, providing encouragement/support, providing and seeking information or advice and seeking contact outside of the website. Qualitative content analysis revealed that children regularly faced emotional problems and experienced a lack of understanding and communication in their direct environment. Conclusions: In dealing with parental cancer, children experience a variety of difficulties. This study offers a window into the use of web-based peer support by children dealing with parental cancer).

GILROY, C. and JOHNSON, P. (2004)

Listening to the language of children's grief. **Groupwork**, vol.14, no.3, pp91-111. (This qualitative study, utilizing participant observation, explored children's expression of grief in a peer support group of five, eight to ten year old children - with a life-threatening illness in their family. The research took place at The Center For Grieving Children, a specialized grief center in New England, which provides grief services based upon a peer-support model. The themes arising from the participant observation of the study group were: (a) connection and cooperation; (b) attempts to understand and explain; (c) physical expression and play; (d) view of self, and (e) avoidance of feelings and (f) regression of language. A crucial need of a grieving child is being able to have a safe space in which they can express their own feelings, thoughts, and behaviors, without feeling judged by adults who may hold different or contradictory views. The

availability of such a space in combination with supportive adults, who can provide age-appropriate activities and interests, appears to be of paramount importance).

HELSETH, S., and ULFSAET, N. (2003)

Having a parent with cancer: coping and quality of life of children during serious illness in the family. **Cancer Nursing**, vol.26, no.5, pp355-362. (Little research has addressed how a parent's cancer affects young children. The purpose of this study was to explore the well-being and coping of young children during a period of cancer illness in the family. An explorative design was chosen, and data were collected through qualitative in-depth interviews with children (ages, 7-12 years) and their parents. Data were analyzed and interpreted within a phenomenologic-hermeneutic frame of understanding. Four major themes emerged in the findings: illness ruling in the family, reactions over and under the surface, many efforts to manage the situation, and feeling good most of the time. This report discusses how children's reactions and their management of such a difficult life event affect their quality of life. By going in and out of the situation, both literally and emotionally, the children cope with the situation and maintain a balance in life. In general, the children reported feeling good, but they put a lot of effort into it, and their quality of life appeared to be fragile. Their well-being was especially vulnerable at the time of the diagnosis and when the illness situation changed).

KARNS, J.T. (2002)

Children's understanding of death. **Journal of Clinical Activities, Assignments & Handouts in Psychotherapy Practice**, vol.2, no.1, pp43-50. (Children and parents anticipating the death of a loved family member or friend experience anticipatory grief. Parents may become so focused on their own grief and the care of the dying person that they cannot recognize the needs of children experiencing the same grief. These guidelines explain children's understanding of death and provide developmentally appropriate terminology and activities to assist a child through anticipatory grief, the dying process and the death of a loved person).

KENNEDY, K.C. and others (2008)

Supporting children and families facing the death of a parent: part 1. **International Journal of Palliative Nursing**, vol.14, no.4, pp162-168. (Presents findings from a review of key literature and from a scoping of current provision of support for children facing the death of a parent. A summary of the findings from these is reported here. To set out the background and context to the evaluation of a new service aimed at supporting children and families facing the loss of a parent from cancer, key literature was reviewed and a scoping of current bereavement support for children and families was conducted using online searching, telephone and face-to-face communications. The review processes uncovered a range of national and local bereavement services. Bereavement was reported as a normal life event and part of human experience. Health, education and social services personnel need to respond to individual needs, accepting that not all bereaved children require complex, long-term interventions. At national and global levels there was recognition that the needs of bereaved children require careful assessment. A complex range of initiatives have been developed across the UK aimed at supporting children facing the death of a family member. The fragmented nature of provision makes it difficult to be comprehensive or all-inclusive when describing service provision in this area).

KENNEDY, C. and MCINTYRE, R. (2008)

Supporting children and families facing the death of a parent: part 2. **International Journal of Palliative Nursing**, vol.14, no.5, pp230-237. (To report on the views of children, parents and key stakeholders of a new bereavement support service for families where a parent is dying from cancer. Study design: A qualitative pre- and post-intervention evaluation design was used. Case study methods allowed multiple perspectives to be accessed so broadening the scope of the evaluation. Sample and setting: A purposeful sample of six families was recruited from the community palliative care service. Each case study comprised a family, a health professional and the family

support worker. Six key stakeholders also contributed data. Methods: Data gathering included individual and family group interviews, non-participant observation and interviews with nominated health professionals, key stakeholders and the family support worker. Analysis of pre- and post-intervention data were supported by QSR NVivo. Findings: Children and families with complex and/or enduring needs benefited from the specialist expertise and interventions provided by this service. Conclusions: Risk assessment procedures should be used to identify need and ensure limited resources are directed appropriately. Many children and families can be supported within the community drawing on their own social networks).

KENNEDY, V. L. and LLOYD-WILLIAMS, M. (2009)

How children cope when a parent has advanced cancer. **Psycho-Oncology** vol.18, no.8, pp886-892. (When parents are diagnosed with cancer, children experience significant distress. There is little information regarding the nature of this distress and how children cope, particularly when a parent is diagnosed with advanced cancer. This study aimed to explore how children cope, and to identify areas where there may be barriers to children accessing support to enable them to cope. Semi-structured interviews were conducted with ill parents with advanced cancer and well parents and/or any children above the age of 7. Interviews were recorded and transcribed fully, and analysed using a constructionist grounded theory approach. Twenty-eight family participants were interviewed. Four major themes emerged from the data including response to diagnosis, mechanisms of coping, life changes, and positive aspects. Children described being distressed by their parents diagnosis and having concerns related to their parents and their own health. Distraction and maintaining normality were described as the dominant strategies of coping for children, and increased responsibilities and decreased social activity were considered to be the most noticeable of life changes. Parents did not recognise the impact on children to the same degree as described by children and focused on limiting the impact by maintaining normality. Positive aspects described by children and parents included strengthening of relationships and learning to value family members and the important things in life. Open communication within the family may lead to more effective coping and a positive experience for children whose parents have been diagnosed with advanced cancer).

KLEIBER, C. and MONTGOMERY, L. A. (1995)

Information needs of the siblings of critically ill children. **Child Health Care**, vol.24, no.1 (Win), pp47-60. (This study explored parental and sibling perceptions and feelings about sibling information needs during a pediatric admission to an intensive care unit (ICU). Using a qualitative research design, parents (n = 14) and school-age siblings (n = 12) of children who were patients in ICU were interviewed using open-ended questions. Themes of information that the parents report having given to the siblings were similar to the themes that siblings report having heard. However, parents reported that the siblings had numerous questions about the reasons for hospitalization and expectations for the future of the family. The findings indicate that parents may neither be aware of the effects of the ICU experience on the siblings nor have the knowledge and skill to assist them. Parents may need counseling to increase their awareness of the siblings' need for information and teaching to increase skill in providing the information).

LELAH, R. (1995)

Children and adolescents during maternal terminal illness: phenomenology and bibliotherapy. **Dissertation Abstracts International: Section B: The Sciences and Engineering**, vol.55(7-B), (Jan), pp2643. (Professional intervention with family members during maternal terminal illness has demonstrated preventive and therapeutic effects. This dissertation provides an integrative framework suggesting measures helpful to young people experiencing this life event. The following bodies of literature are explored: anticipatory grief, complicated grief, death concepts, theories of growth and development, stress and coping, childhood fears, hospice home care, and the psychological and emotional experience of living with terminal illness. Reading stories about a dying parent may be of help to young people, serving the goals of:

normalization, increased knowledge, facilitating insight, and modeling healthy ways of interacting, coping, and adapting. This dissertation includes a story book that offers a comprehensive explication of the experience of a family of children ages 3 to 10 who are living with maternal terminal illness. The story draws upon the theoretical and clinical framework presented in the dissertation).

MACPHERSON, C., and EMELEUS, M. (2007)

Children's needs when facing the death of a parent from cancer: part one.

**International Journal of Palliative Nursing**, vol.13, no.10, pp478-485. (A small exploratory study was conducted to identify the psychosocial needs of children facing the death and subsequent bereavement of a parent from cancer. The focus was on the palliative phase of care through the bereavement period with the aim of identifying the best way forward in further developing a community-based service for children in Fife. This paper selectively reviews the literature related to children's and families' needs when facing and dealing with the death of a parent, bringing into focus some of the work available to inform thinking and planning in this area).

MACPHERSON, C., and EMELEUS, M. (2007)

Children's needs when facing the death of a parent from cancer: part two.

**International Journal of Palliative Nursing**, vol.13, no.12, pp590-597. (A small exploratory study was conducted to identify the psychosocial needs of children facing the death and subsequent bereavement of a parent from cancer. The focus was on the palliative phase of care through the bereavement period with the aim of identifying the best way forward in further developing a community-based service for children in Fife. This paper presents the results and reports the issues which will be considered as a basis for future service development).

MITCHELL, F. (1997)

Tell me again what happens. Edinburgh: Paediatric AIDS Resource Centre (PARC).

(Though intended for use with children whose parents have AIDS, the booklet is equally relevant to any child with a terminally ill parent. The story is sensitive and loving with lively cartoon-style pictures, and there are blank pages interspersed for the child to write or draw his or her own feelings. To be used with a trusted adult).

ISBN: 9781900339049

MONDANARO, J. (2005)

Interfacing music therapy with other arts modalities to address anticipatory grief and bereavement in pediatrics. In: *Dileo, C. and Loewy, J.V. (Eds). Music therapy at the end of life.* pp25-32. New York: Jeffrey Books. (The loss of a loved one is perhaps one of the most traumatic events in life. However, when such incomprehensible loss occurs because of injury or sudden and untimely illness, all involved are placed in crisis mode. At a time when nothing else can be done medically, the clinician identified to meet the psychosocial needs of a family may encounter resistance from both family and staff as to the finality of the situation. Ambivalence in the form of unconscious and misguided attempts to distract children away from the reality of death is, at best, a desperate effort to stave off the inevitable feelings of bereavement felt by all. Although children can be especially vulnerable at such times, they are often not allowed to share in important family communication. This is disheartening because children facing the death of someone they love are capable of grieving very deeply. When given accurate and complete information at an age appropriate level, children from as early as preschool age can gain mastery over feelings related to dying and death. Notably, while symptoms of childhood grief can appear intermittently over a period of years, some of these symptoms can inevitably take on more profound expression and meaning as a child matures. This type of healthy and maturational grief may occur when the onset of bereavement is addressed in an open and nurturing manner. Clinical interventions in the form of creative opportunities can enable a bereaved child's active expression of feelings and can lead to healthy processing and shared grief experiences. Creative arts therapies provide a context in which liberated feelings expressed in artistic form can be interpreted

or clarified, thus enabling emotional catharsis, effective mourning and an eventual resumption of normal living). ISBN: 9780014598038

MOORE, K. (2009)

One woman and her dog. **Bereavement Care**, vol.28, no.3. (Dec), pp25-28. (Personal account of the role of a specialist pre-bereavement support worker for children and young people facing the death of a parent. Her work for the Seesaw charity to help families to communicate is described, including the contribution of her pet dog to supporting the children).

O'BRINE, R. and LINDSAY-SMITH, C. (1995)

Memory book. Ilford: Barnados. 40pp. (The Memory Book was originally part of Memory Store, a system developed by Barnardo's for parents with AIDS, to help them save information that would remain as mementos for their children).

OWENS, D. (2008)

Recognizing the needs of bereaved children in palliative care. **Journal of Hospice & Palliative Nursing**, vol.10, no.1 (Jan/Feb), pp14-16. (Discusses the need for palliative care practitioners to be aware of the effects that terminal illness and impending death can have on surviving children and adolescents. The myths surrounding how children and adolescents cope with loss are discussed).

PETTLE, S. (1998)

Thinking about the future when death is inevitable: consultations in terminal care. **Clinical Child Psychology and Psychiatry**, vol.3, no.1, pp131-139. (Much of the literature about children and death has emphasized the importance of preparation; these consultations arose out of requests from the family practitioners because the parents were seeking specialist advice in helping their children cope with the imminent death of their mother. Two examples are given where a single session explored, with the parents, the children's understanding of what was happening and of death, and the parents were helped to discuss their concerns and dilemmas, and express their wishes and feelings. The framework of systemic consultation was used alongside a psycho-educational model, drawing on, and sharing the findings of relevant research. Guidelines for such work are elicited from the examples).

POPPLESTONE-HELM, S. V. and HELM, D. P. (2009)

Setting up a support group for children and their well carers who have a significant adult with a life-threatening illness. **International Journal of Palliative Nursing**, vol.15, no.5, pp214-221. (St Richard's Hospice provides care and support for adults with a life-threatening illness and their families. Children and adolescents who are facing the loss of a significant adult are often encountered as part of its work. Whereas in the past children and young people have been supported primarily through one-to-one interactions after the adult has died, the expansion of the hospice's facilities has recently enabled it to provide an increasing amount of pre-death support, including the launch of a pre-death child and family support group. This article reflects on the benefits and challenges of setting up and running such a group and the journey the hospice has gone through so far. It is hoped that by sharing experiences, some of the benefits of group work for children and adolescents facing the loss of a significant adult can be demonstrated, and that others in the worldwide palliative care community who are considering running or are already providing such a service will be encouraged).

REITH, M. (2007)

Care of families during and after the death of a loved one. **End of Life Care**, vol.1, no.2 (Jul), pp22-26. (Discusses the role of nurses in caring for relatives during the terminal phase of a patient's illness and in supporting them after the death. The characteristics of good pre-bereavement and bereavement care are identified. Complications relating to unresolved or hidden grief are explained and factors specifically affecting children are discussed).

ROTHERHAM-BORUS, M.J. and others (2005)

Adolescent adjustment before and after HIV-related parental death. **Journal of Consulting and Clinical Psychology**, vol.73, no.2, (Apr), pp221-228. (The impact of HIV-related parental death on 414 adolescents was examined over a period of 6 years. The adjustment of bereaved adolescents was compared over 4 time periods relative to parental death and was also compared with the adjustment of nonbereaved adolescents. Bereaved adolescents had significantly more emotional distress, negative life events, and contact with the criminal justice system than nonbereaved youths; these behaviors did not remain significantly higher after parental death. Depressive symptoms and passive problem solving increased soon after parental death, as compared with nonbereaved adolescents. One year subsequent to parental death, depression and passive problem solving were similar to the levels of nonbereaved peers. Only sexual risk behaviors increased following parental death. These results suggest the importance of early family intervention soon after parental HIV diagnosis, prior to parental death, and sustained over time).

ROTHERHAM-BORUS, M.J., LIGHTFOOT, M. and SHEN, H. (1999)

Levels of emotional distress among parents living with AIDS and their adolescent children. **AIDS and Behavior**, vol.3, no.4, (Dec), pp367-372. (Examined the level and the relationship between emotional distress reported by parents living with AIDS (PLAs) and the emotional distress of their adolescent children. Levels of depression and anxiety were assessed among 268 PLAs (aged 25-60 yrs) and 403 of their adolescent children (aged 12-18 yrs). Compared to normative clinical samples, emotional distress was significantly higher among PLAs; fathers' reports were in the clinical range. In contrast to their parents, adolescents' reports of emotional distress were similar to those of normative same-age peers. The levels of depression and anxiety reported by female adolescents were significantly higher than those of the male adolescents. The level of adolescents' depression and anxiety was significantly related to their parents' depression. In conclusion, a parental diagnosis of AIDS does not appear to be associated with high rates of emotional distress among their adolescent children).

SALDINGER, A.A. and others (1999)

Anticipating parental death in families with young children. **American Journal of Orthopsychiatry**, vol.69, no.1, pp39-48. (Findings from a community study of parentally bereaved children demonstrate that forewarning of death is not associated with more favorable mental health outcomes than is sudden death of a parent. The applicability of the general anticipatory grief literature to the circumstances of children facing the loss of a parent is called into question, and the need to assess more carefully the effect on children of a parent's protracted terminal illness is emphasised).

SALDINGER, A.A. and others (2004)

Facilitating attachment between school-aged children and a dying parent. **Death Studies**, vol.28, no.10, pp915-940. (A qualitative, community study of 58 parentally bereaved children and their 35 surviving parents illustrates how families take advantage of forewarning of death to foster connections between children and dying parents and prepare for youngsters' continued attachment to dying parents after the death. Children and parents displayed strong yearnings to remain connected during terminal illness, but fostering connections for attachment after the death was less intuitive and more emotionally fraught as it undermined coping strategies based on denial of impending death. Thus, although some may benefit from interventions aimed at anticipatory relationship facilitation, clinicians should respect limitations on what family members are psychologically able to bear).

SALDINGER, A.A., CAIN, A. and PORTERFIELD, K. (2003)

Managing traumatic stress in children anticipating parental death. **Psychiatry: Interpersonal and Biological Processes**, vol.66, no.2, (Sum), pp168-181. (Qualitative evidence drawn from a community study of 58 parentally bereaved school-age children (aged 6-16 yrs) and their surviving parents (aged 32-55 yrs) provides a

descriptive exploration of one of the most difficult challenges faced by families in anticipated deaths: managing the stress of a child's exposure to the graphic physical, emotional, and mental deterioration of the dying parent. The concept of traumatic stress is broadly defined to include exposure to the "fact" of impending death itself, that is, the anxiety that comes from knowing that one may lose a close other. Included, as well, is an exploration of secondary traumatic stress, defined here to cover the notion of the stress of watching other loved ones in the family succumb to terror and anxiety about the impending death. Emphasis is placed on a child's unique vulnerability to traumatic stressors and on the role of parenting in mediating child exposure to parental decline. In contrast to the anticipatory grief literature which emphasizes the advantages of forewarning in cushioning postmortem adjustment, this study documents the adverse impact of a child's exposure to graphic stimuli).

SALDINGER, A.A., PORTERFIELD, K. and CAIN, A. (2004)

Meeting the needs of parentally bereaved children: a framework for child-centered parenting. **Psychiatry: Interpersonal and Biological Processes**, vol.67, no.4, (Win), pp331-352. (This article describes the development and deployment of a framework for measuring parenting capacities in the context of bereavement. Grounded theoretical analysis of interviews with a community sample of 41 bereaved spouses with school-aged children elicited a set of nine bereavement-specific parenting tasks. A corollary coding system (covering all nine parenting tasks) was created to transform interview materials into quantitative data, thus permitting systematic empirical investigation of the parenting capacities of bereaved spouses. Parenting behaviors were coded on a 5-point scale ranging from least child-centered to most child-centered. Sex of surviving parent and circumstances of death proved to be significant mediating variables: mothers were more child-centered than fathers, and parents surviving sudden deaths more child-centered than those surviving anticipated deaths. Lengthy illness was associated with less child-centered parenting. The more child-centered the parenting, the less symptomatic the child as measured by parent report (Child Behavior Checklist) and child self-report (Children's Depression Inventory, Revised Child Manifest Anxiety Scale). Child-centered parenting was associated with more positive and fewer negative perceptions of the surviving parent by the child as measured by the Parent Perception Inventory. Implications of findings are discussed).

SAUNDERS, J. (1996)

Innovations in practice: anticipatory grief work with children. **British Journal of Community Health Nursing**, vol.1, no.2, pp103-106. (This paper discusses the work undertaken with children who have a significant person in their family in the final stages of a life threatening illness. The paediatric nurse works alongside members of both the primary health care team and the educational team in helping the family to prepare the child through the various stages of illness and, ultimately, for the expected death of that person. The aims are to form a relationship of trust with the child in order that he/she feels that there is someone available to talk to and discuss fears and anxieties that they may not be able to share with their parents. It is hoped that the child will then be able to make choices about his/her involvement in the actual care of the parent, with the support of those around them).

SEAGER, K.M. and SPENCER, S.C. (1996)

Meeting the bereavement needs of kids in patients/families -- not just playing around... **Hospice Journal**, vol.11, no.4, pp41-66. (Children grieve differently than adults. Although the unit of care in the Hospice is the patient and family, emphasis is often on the grown members of the family and the anticipatory grief and bereavement needs of children and adolescents is sometimes not met adequately. In this paper, hands-on strategies for working with children both before and after a significant death are presented, as well as an appropriate context information on the grieving process for youth under age 18).

SWEETLAND, C. (2005)

The palliative care nurse's role in supporting the adolescent child of a dying patient.

**International Journal of Palliative Nursing**, vol.11, no.6 (Jun), pp294-298.

(Reflection from a hospital-based palliative care nurse specialist on her role in caring for a 15 year old girl whose mother was dying of cancer. The approaches she used, their consequences, and useful support materials are described. The health care professional's role in informing and empowering parents to prepare their children for bereavement is considered).

TURNER J. (2004)

Children's and family needs of young women with advanced breast cancer: a review.

**Palliative & Supportive Care**, vol.2 (Mar), pp55-64. (This article reviews literature about the impact of advanced breast cancer on children and families. It is clear that the adjustment of the family is influenced by disease stage and maternal adjustment, the needs of the particular child relating closely to their developmental stage. Interventions with children and families to promote adjustment when a parent has advanced cancer are also discussed, including implications for clinical practice).

TURNER J. and CLAVARINO A. (2007)

Development of a resource for parents with advanced cancer: what do parents want?

**Palliative & Supportive Care**, vol.5, no.2, pp135-145. (Parents coping with a diagnosis of advanced cancer experience distress and guilt about the impact of the disease on their children but report that there are few resources specific to advanced disease to guide and support them in discussions with their children. Although some resources have been developed to assist parents with advanced cancer, it appears that these are not widely disseminated. To determine the need for a brief resource that could be given to parents at the point of diagnosis of advanced cancer, including its content, in-depth interviews were conducted with eight women with advanced breast cancer.

Women confirmed that they had received minimal assistance from health professionals in discussing the diagnosis with their children, and even when professional counselors were accessed they were not always attuned to the specific needs of parents with advanced cancer. Women felt frustrated that information they did access focused on early disease and lacked the details women felt they needed in coping with advanced cancer. Women felt that there was a need for a brief resource that reassured parents about the impact of the cancer on their children, including practical strategies to help them cope and examples of the ways other parents had responded to difficult questions such as about parental death. A draft resource was developed, critically reviewed by the participants, and their comments incorporated into a final version. This article expands on the themes highlighted by women as important to assist parents with advanced cancer, including the final resource that was developed).

WITHELL, B.B. (2009)

The prebereavement psychological needs of AIDS-affected adolescents in Uganda.

**International Journal of Palliative Nursing**, vol.15, no.3, pp128-133. (In Sub-Saharan Africa, adolescents who live with dying parents are recognized as vulnerable but research into their psychological needs is limited. A small qualitative retrospective study was undertaken in Uganda to gain insight into the prebereavement experiences of AIDS-affected adolescents. Unstructured interviews with ten parentally-bereaved adolescents were conducted and recorded. Following transcription, the narrative data were thematically analysed. The adolescents' level of awareness concerning the parent's illness affected their psychological needs. Four variations of awareness were identified and then categorized as concealed reality, disguised reality, discerned reality and disclosed reality. Most adolescents discerned that their parent was dying as the illness advanced, but they remained psychologically isolated and unprepared. Disclosure is advocated but must include ongoing emotional support and future care arrangements).