ASSUMPTIONS AND ATTITUDES TOWARDS CHILDHOOD BEREAVEMENT.

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Abstract:

Childhood bereavement bas been a matter of intense discussion among the Palliative care providers. Yet, there is little evidence base behind the notions, which are prevalent among the population in general, and Palliative Medicine providers in particular. Among the masses, there is still prevalence of 'protecting the child' phenomenon. Beliefs, like this, create confusion among the providers while recommending the strategy while dealing with the bereaved children. There is definite need to develop plans to deal with this difficult problem, while recognizing some other issues like culture and spiritual mechanisms.

Introduction:

Healthcarebas multiple roles to offer. Caring for death and dying remains a pivotal role for doctors and other hea1thcare professionals. Bereavement support or preparation for families is also a role, doctors should have understanding of. Over the last decade, there has been a growing acknowledgement among the healthcare professionals about the needs of bereaved children. Hospices, in particular, and palliative care providers, in general, have developed programs of skills and resources to meet this demand'. However, it is also of concern that at times, children are excluded from the grieving process as there is not enough appreciation in the wider community that children of a very young age could go through same emotions. The notion of 'protection' can sometimes be overused. At the same time, the published data, agreed standard or guidelines are sparse and although totally sympathetic, even palliative care workers find it confusing to guide families through this difficult time.

Here we will discuss three rea1life case studies with different scenarios dealing with people's assumption about Children's perception of death.

Case Study One 'Not to tell':

Eighty years old Ian was a farmer and was suffering from peritoneal secondaries from unknown primary. He had a very hard earned estate where he lived with his wife Nora, sons Graham and Geoff. Whilst Graham had no children of his own, all the family enjoyed Geoff's young children Josh aged 9 and Amy aged 7. Nora very much enjoyed being the organizer of the family. After successive admissions to the hospice for aspiration of recurrent Ascites, Ian deteriorated and died with his wife and daughter-in law Jane in attendance. Nora had made the decision for the family that Amy and Josh would not visit Ian during the terminal stages. Following his death, there was a huge argument between Nora and Jane about the children coming to see Ian. Jane stated that children loved their grandfather and had made their wishes known that they wanted to see Ian. While Ian was alive, she respected Ian's wish, not to bring in the children in to see him, but now, Jane felt that children had a right to see their much loved Granddad. Nora argued that the children would never be able to understand what was going on and they were better left alone. She felt if the children are allowed to see Ian after his dying, it will be a horrible experience and will leave them scarred emotionally. She suggested that children are told after the funeral that Ian had died.

Case Study Two 'How to tell':

Pauline had colorectal carcinoma and was undergoing palliative treatment only. She had a daughter Lorna who was divorced and had two children Hannah aged 12 and Connor aged 8. As Pauline was in her terminal stage, she wished to see the children. Lorna approached the hospice staff and said that she could not face telling the children and 'was it appropriate to tell them as they will not understand it anyway?' Hospice staff supported Lorna and Pauline and called the Child Bereavement Counsellor, who helped Lorna speak to the children. Pauline died after the children had been in to see her and left.

Case Study Three 'let us tell':

Seventy-seven years old ex-teacher Maureen was suffering from cancer of the pancreas. When she was diagnosed, she was also told of the poor prognosis. Maureen had four children and nine grandchildren with age ranging from 15 to 4. Maureen spoke to the grandchildren openly and they kept visiting their granny with no hesitation. When Maureen died, her eight years old granddaughter Jade drew a picture of her understanding of Maureen's death and was happy to share it with hospice staff.

Discussion:

The case histories described reflect different attitudes among the society towards childhood grief. While in the case history one, the elderly lady had a notion of 'protection' of the child, lady in case history two, though agreed to tell the children but found it hard. Both of

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these attitudes come from the background that putting children through grief may cause them more 'harm than good'.

There is no national collection of statistical information of the number of children and young people bereaved in United Kingdom. However, an unadvertised telephone service from St Christopher's Hospice in London experienced what was described as 'the tip of an iceberg regarding an unmet need for basic advice, support and resources", There is another interesting conflict of opinion among the healthcare professionals, where some papers suggest that the death of a parent causes children to be at risk of developing psychiatric problems", other papers suggest that these concerns are probably complicated with the methodological problems as well as the experiences which went on alongside bereavement e.g., lack of adequate parenting", Some authors have even identified that in fact bereaved children, in fact show resilience and have coped remarkably well under this severe form of trauma i.e., bereavement', Another paper actively looked at the two theories by interviewing adults who were bereaved as children . The debriefing interviews showed that there were four distinct types of experience: appreciation, frustration, enmeshment, and ambivalence. Depression was not found to be an inevitable outcome.

It is though agreed that children require time to come to terms with their loss and mar need external support to be allowed to grieve. Whether this 'external support' is from the family or friends or professionals, it is open for discussion. Although many people still believe that children do not have full understanding of death, but it was found many years ago by Lansdown and Benjamin that 59% of 5 years old and 73% of 6 years old had an almost complete understanding of the concept and process of deaths. Their reactions vary from acting strange and showing physical signs to keeping their feelings and experience of bereavement of a parent to themselves, which can hinder the process of coming to terms with their loss". Systemic controlled studies of bereaved children have been few but data suggests that majority of children do not show serious symptoms or dysfunctional behaviour'", It is also suggested that as compared to adults, the episode of intense grief is shorter but the total grieving period may last longer.

Another argument among the healthcare professionals is that of the level of intervention provided to the children to help them cope with the bereavement. Some providers believe that providing intervention can make it difficult for the children and their families to use their own resources in the community around them, making them dependent on protessionals[11].

Conclusion:

Though, there is very little written evidence based material on the childhood bereavement, there are still very good grounds to support the theory of 'being open to children of young age'. It also corresponds to the ethos of holistic care and honesty. It is not uncommon to find perplexed children where the truth was hidden. Children, if not told, find the situation difficult and unstable and often imagine the situation to be worse than it really is[12].Inthe United Kingdom, Personal, Social and Health Education (pSHE) program was introduced in 1999, which enables 11 to 14 years old children to learn to recognize emotional stages of grieving process and how to adapt in these circumstances[13]. Although some teachers are undergoing training to help children deal with dying, there is till a gap in the service as it will take time and also often palliative care services have to deal with children younger than that age group. Another important factor to influence the decisions, like any other issue in palliative care, is the cultural and spiritual background. In Pakistan, communities rely on family support or other community networks. This can suit the model but further research is needed to find out if it does[14].

We suggest that:

- There is need to recognize the fact that there still is the notion of 'protecting the child' while actually what is happening is the 'harm to the child' by being dishonest and making them unable to open up.
- We also need to find more evidence to help us channel the resources in the right way, whether it is to support the parents or to set up support groups. It is without doubt that all of these may have their own role. Given the confusion we have, due to lack of data about the childhood bereavement, it is hard to support one strategy over the other.
- We also need more evidence to know whether there are any long terms psychological influences left with the bereaved children. It will help us plan our programs as well as provide information to the family, although it needs to be emphasized, in a very sympathetic manner.
- We also need to recognize the fact that bereavement is influenced directly by social, spiritual and cultural issues, while setting up any such program, we will have to consider the local implications based around the needs of the particular situation.

References:

1. Monroe B. Social work in Palliative care. In D Doyle et al (Eds) Oxford Textbook of Palliative Medicine 867-880: Oxford University Press 1999
2. Stokes, Pennington, Monroe et al. Developing services for bereaved children: a discussion of the theoretical and practical issues involved. Mortality 1999;4: 291-306
3. Weller RA, Weller EB, Fristad MA, Bowes IM. Depression in recently bereaved prepubertal children. Am J Psychiatry 1991; 148: 153~ 1540
4. Quinton D. Adult consequences of early parental loss. BMJ 1989; 299: 694-5

5. Harrington R, Harrison L. Unproven assumptions about the impact of bereavement on children. Journal of Royal Society of Medicine. 1999; 92: 230-233

6. Hurd RC. Adults view their childhood bereavement experiences. Death Stud; 1999: 23: 1741

7. Hurd RC. Adults view their childhood bereavement experiences. Death Stud; 1999: 23: 1741

8. Lansdown R. and Benjamin G. The development of the concept of death in children aged 5-9. Child care and Health Development; 1985: 11: 13-20

9. Fell M, Helping older children grieve: a group therapy approach: Health visit; 1994 Mar 67: 92-4

10. Silverman PR, Worden JW. Children's reactions in the early months after the death of a parent Am J Orthopsychiatry 1992;62: 93-104

11. McCord 1. A thirty years follow-up of treatment effects. American Psychologist 1978; 33: 284-9

12. Landry-Dattee N, Dalaigue-Cosset MF. Support Groups for Children. European Journal of Palliative Care 2001; 8:107-110

13. Department of Education and Skills. A Teacher's guide to personal; social and health education. London: The Stationary Office, 1999.

14. Gatrad AR, Sheikh A. Palliative care for Muslims and issues before death. International Journal of Palliative Nursing 2002; 11: 526-531.