Notes on family's needs and support from a multicultural perspective

Grief and bereavement care cannot be isolated to after the patient's death. This process begins during a patient's illness. Principles of care include:

Seamless care is important for in-patient palliative care units (PCU) to establish a good relationship with community palliative and bereavement support services. In-patient PCUs need to work closely with community services in monitoring patient and families throughout their journey. This also helps to establish the relationship between service providers, the patient and their families, which continues after the patient's death. Establishing this bond is considered vital in supporting patients and their families throughout their journey.

Advance care planning can assist families grieve and relates to a patient having a good/bad death. Families always remember how their loved one died, and they carry this memory with them forever. Knowing that their loved one has had a good death gives them comfort. Disclosure / non-disclosure (of a terminal condition) can be an issue. Often, in Eastern communities there is the request of non-disclosure made to the health care team by families, and in some cultures there is a great reluctance talk about death. Death is seen as taboo.

Families can find comfort in their own family members as well from members of their religious group. Below are comments provided by palliative care consultants from both the community and in-patient setting in Malaysia about the involvement of religious groups.

> *Anecdotally though, I think the extended family system as well as religious communities (church groups, Buddhist groups like Tzu Chi, etc) play a large role in providing support to families while their loved ones are actively dying as well as during the immediate bereavement phase... They would help by bringing food, providing some company, helping with errands, etc*. (PCU, Selayang)

> *In terms of bereavement we do follow up with families and the clinical team does offer basic bereavement support but not much beyond helping to normalise their experience and some basic interventions where there are unresolved, relationships. For more complex needs we refer but options for referral are limited. We make very few referrals. We used to visit all families at 6 weeks however we found that we not picking up very many problems, so now we see only those who have already been identified as higher risk and the others get a condolence card with an invitation to get in touch should they need to... As anywhere family dynamics can be complex and the clinical team plays a role in helping patients and love ones negotiate an understanding of their situation.*(Hospice Malaysia)

> *Our volunteers undergo training with us and if they become involved in patient care are given quite clear boundaries including that they should not bring their own religious*

views into patient care. We do refer to other organisations… for support because they do good social support…We are quite strict about volunteer contact with patients as volunteers often have their own agendas, be it religious, alternative medicine, or selling insurance!" (Hospice Malaysia)

Language is a powerful tool. People from the same culture connect with each other through a shared language. They may only be able to express how they feel or their needs in their own mother tongue (or language which they are comfortable with). A recent article described the experience of a patient from an African background, who kept telling the hospice worker that she was OK every time they asked her how she was doing. However, the moment she was approached by hospice worker who spoke the same language and had the same background, she expressed her true feelings. Further to this, Hardy- Bougere (2008) stated that some patients can appear to be stoic and affected by loss until they interact with someone from the same culture. Therefore, having a 'link person' throughout patient and family's journey is important in helping families through their grief/bereavement process.

Gender may be an issue in some cultures. For example, in some cultures women may only connect with/open up to another woman instead of a man.

Control - giving patients and families a sense of ownership/control in making decisions is important.

References

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Bray, Y., Goodyear-Smith, F. & Gott, M. (2015). Transnationals' experience of dying in their adopted country: a systematic review. *Journal of Palliative Medicine*. 18:1, doi: 10.1089/jpm.2014.0044

Hardy – Bougere, M. (2008). Cultural Manifestations of Grief and Bereavement: A clinical perspective. Journal of Cultural Diversity. 15:2 Summer 2008

Links

Australian Centre for Grief and Bereavement. www.grief.org.au
National Association For Loss And Grief. www.nalag.org.au
Grieflink www.grieflink.asn.au (see http://www.grieflink.asn.au/topicpersondifferent.aspx)
National Centre For Childhood Grief. www.childhoodgrief.org.au

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