Submission to Parliamentary Committee

Health and Community Services Committee

Inquiry into palliative care services and home and community care services in Queensland

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I am making this submission as an individual. I am employed as a Bereavement Counsellor with Metro South Palliative Care Service.

I wish to respectfully draw the Health and Community Services Committee's attention to the lack of availability and paucity of bereavement care services in Queensland.

Introduction

Psychosocial and grief support is identified as an essential component of care for individuals diagnosed with chronic illness, coping with a terminal illness, those with disabilities, and individuals transferring to aged care facility living and approaching the end of their life. In addition, bereavement care is expected for family members. The provision of bereavement care is now an established and integral part of modern palliative care. Australian and State Government policies include bereavement care as a key area for action. [2]

However, access to bereavement support is not easily available or able to be identified clearly at this time by members of the public in Queensland. As a result, from my observation, children, adolescents, extended family members and caregivers are suffering, often in silence. This results in an added cost to society in loss of function, increased need for medical care, delayed development from childhood, deferred mental health issues, suicide, and, in some cases for grieving spouses, early death from illness. [4]

Background

Bereavement care is clearly defined as an essential component and core function of palliative care. [4] According to the World Health Definition, palliative care "uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated" and this is further expanded in the first goal of the National Palliative Care Strategy, 2010, "awareness and understanding of dying, death, grief, bereavement and loss, to support better access to appropriate, timely services". [1, 2]

Grief can be defined as the "response to loss with physical, emotional, cognitive, behavioural and spiritual manifestations". [3] It is ***not*** defined as an abnormal or illness response to loss.

Numerous reports outline the impact of suboptimal and unmet needs of both patients and their families and caregivers. These include the following: increased susceptibility to physical and psychological morbidity, social isolation, financial disadvantage, psychological distress and needs of caregivers at least equal to or greater than the patients themselves. A high proportion, (approximately 50%) of caregivers are found to be below norms for physical health, depression, anxiety, and debilitating grief. [4]

It is important to note that "bereavement" is not equivalent to "illness" or "mental illness" and should not be approached as such. And yet, the common expectation seems to be that people should just see their GP providers if they are not managing during bereavement, that GPs can provide support directly, prescribe medication to assist the bereaved individual or simply establish a Mental Health Plan and refer individuals to generalist psychologists. For some individuals, approximately 20% of those bereaved by non-violent or suicide deaths, grief ***can*** develop into a complicated recovery pattern requiring more intensive interventions. [5, 6] For the majority, the remaining 80%, normal inherent resilience, with the individual's chosen level of support, will enable readjustment to life over the course of a few years. [3]

Current Situation

In Queensland there is no single, established agency as the pre-eminent provider of specialist, bereavement counselling. Often bereavement follow up just simply does not occur.

Various organisations offer varying levels of support to family members who have previously accessed their service for palliative care e.g. Karuna Hospice; St Vincent's Tarmon Palliative Care Centre, Brisbane; Metro South Palliative Care Service. Other organisations are available for support according to their criteria e.g. Canteen for adolescents ages 12-24 if they have lived in the same household as the person who died; Redkite for family members of adolescent cancer patients; Royal Children's' Hospital for parents of children treated at the hospital. Some individual counsellors, psychologists, and social workers are also available in private practice. Please note, these examples are certainly not meant to be conclusive but rather to indicate that people who may be looking for support during bereavement must first search out what, if anything is available to them.

Addressing the Gap

I propose that consideration be given to the establishment of a coordinated centre for grief services in Queensland. This could be similar to centres established interstate, e.g. Australian Centre for Grief and Bereavement, located in Victoria; state branches of National Association for Loss and Grief e.g. NSW, Victoria.

Over time this would enable the following:

A centralised information agency available for members of the public;

Contact lists for professionals to locate suitably trained and experienced grief counsellors;

A training centre for professionals to increase the current small cohort of specialist, professional counsellors;

Facilitated support groups;

Support for individuals adjusting to chronic illness, admission to an aged care facility, or preparing for their own death;

Other causes of bereavement could be supported: intensive care admission, sudden death e.g. heart attack, motor vehicle accidents, suicide, trauma, etc.

Online support programs;

Public education and information sessions;

Telephone help lines;

Roving regional centre programs;

Rapid response in large disaster situations;

Support to the media;

A lending library could be established and lists of other appropriate resources available for professionals and members of public.

Summary

- Bereavement is the normal response to significant loss. Grief should not be medicalised or treated as needing intervention in the majority of instances.
- The overarching principle is that the majority of adults are resilient in realigning themselves and adjusting to a new form of existence following accumulating losses or the death of a significant person with the appropriate availability of bereavement support and counselling when needed.
- Children and adolescents have specific needs. Those bereaved by mass disaster, suicide, traumatic or violent causes have specific needs.
- The most appropriate and effective way to deliver support is by enabling people to reach out when they need help. A centralised agency that is professionally specialised will empower this process in Queensland.
- Other States in Australia have already established specialised services.
- An identified bereavement service, if established with Government support, would be available and accessible in a wider range of circumstances to ensure the health and wellbeing of the population in urban and rural areas of the State.

References

[1] World Health Organization (WHO), http://www.who.int/palliative/definition/en/

[2] National Palliative Care Strategy 2010 – Supporting Australians to Live Well at the End of Life, ibid

[3] Hall, C. 2012. Journal Bereavement Practice in Palliative Care, Winter 2012 p.1

[4] Hudson, P. et al. 2012. *Guidelines for the psychosocial and bereavement support of family caregivers of palliative care patient.* Journal of Palliative Medicine, Vol 15 No 6, 2012.

[5] Bonanno, G. 2004. *Loss, trauma, and human resilience: Have we underestimated the human capacity to thrive after extremely aversive events?* American Psychologist, 59 (1), 20-28.

[6] Prigerson, J. 2004. *Complicated grief: When the path of adjustment leads to a dead-end.* Bereavement Care, 23, 38-40.