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Disenfranchised griever

The GP's role in management

Disenfranchised grief results from a loss that is not or cannot be openly acknowledged, publicly mourned, or socially supported. This article aims to explain the concept and varying presentations of disenfranchised grief and outlines the importance of the general practitioner's role. Preliminary quantitative results of a study of 15 cross cultural workers re-entering Australia are presented, showing more than half experiencing grief during re-entry and all having some form of disenfranchised grief.

Disenfranchised griever present with various symptoms, however, primary care has focused on mental illness, with little recognition of loss and grief issues, especially disenfranchised grief. Further research is required and currently underway to design and formally test a model that can be implemented within an Australian fee-for-service setting.

Case study

Ms DP, aged 55 years, presented to her GP with insomnia, panic attacks and uncontrollable weepiness. She had spent 25 years working as a missionary in a third world country and returned to Australia after conflict with her organisation which resulted in a 'nervous breakdown'. A psychiatrist had prescribed an antidepressant. However, she continued to have symptoms. She described her re-entry as a shameful, isolating experience: 'To the mission and to myself I was an embarrassment... It was as though I had never been away. I needed to catch up on all the family news but they seemed to have no desire to catch up on my news. It was the same with the church.'

Grief is both an expression of distress and a cry for help.¹ Whatever is disenfranchised in grief is not free to experience or to express itself.²

What is disenfranchised grief?

Disenfranchised grief, or hidden sorrow, is a growing issue in the 21st century with millions of people affected.³ This presents a challenge to general practitioners as they consult with patients of whom more than one-third may be suffering from moderate or severe grief. Clark⁴ identified 80% of the losses identified in her general practice sample as disenfranchisement related to loss other than death.

Doka originally defined disenfranchised grief as the grief that persons experience when they incur a loss that is not or cannot be openly acknowledged, publicly mourned or socially supported.⁵ Table 1 outlines the types of disenfranchised grief.³

It is important for the GP to recognise disenfranchised grief for three reasons:

- the physical and mental health of patients may be at risk¹ as disenfranchised grief is a risk factor for complicated mourning⁶ and is also associated with complicated grief
- the usual care agencies are often not involved because of the disenfranchised nature of the grief, and

- the patient may disclose confidential information that is hidden from others.¹

For cross cultural workers re-entering their home country, the GP who recognises their disenfranchised grief may be well placed to prevent the morbidity often associated with the complications of grief.^{4,6}

How are grief and mental illness related?

Over the past 40 years there has been increasing debate about the significance of loss and grief and their relationship to mental illness such as depression, anxiety and post-traumatic stress disorder (PTSD). Medical researchers and clinicians have focused on the importance of the management of these mental illnesses in primary care.⁷ In contrast, the importance of loss and grief, especially disenfranchised grief, in this setting and its appropriate management has had far less attention. Grief is known to be a significant predictor for depressive symptoms^{8,9} and as such merits more emphasis. However, Parkes¹⁰ notes that the consequences of loss are so far reaching that the topic should occupy a large place in the training of health care providers – but this is not the case. There are also significant differences in the management of loss and grief compared to mental illness.⁶

Table 1. Types of disenfranchised grief**Disenfranchisement by the community**

- The griever's relationships are unacknowledged (eg. ex spouse)
- Lack of acknowledgment of the griever's loss (eg. infertility)
- Exclusion of the griever as not being capable of grieving (eg. children)
- Exclusion of the griever due to the circumstances of the loss (eg. suicide)
- Exclusion of the griever due to their way of grieving which is not deemed appropriate by the community (eg. wailing)

Disenfranchisement by oneself

- Self initiated disenfranchised grief where shame plays a significant role

More recently there has been increasing impetus for integration of patient centred medicine with its biopsychosocial roots and evidence based medicine. Clark⁴ has suggested the need for a loss and grief paradigm for general practice. This has led to greater attention being paid to the importance of loss and grief in the management and prevention of illness in the general practice setting and the design of the Grief Diagnostic Instrument (GDI),¹¹ which attempts to measure grief including disenfranchised grief in research and clinical general practice. This instrument includes a validated quantitative tool (GDI score) to measure the extant state of grief.⁴ However, the importance of disenfranchised grief in managing patients in general practice is still being evaluated.

The significance of disenfranchised grief

Disenfranchised grievers may not recognise their distress is grief and may present to the GP with anxiety, depressed mood, insomnia, substance abuse, relationship breakdown⁶ or as part of a picture of generalised psychological distress with somatic symptoms.⁴ This grief results from the lack of recognition, validation and support of the griever, resulting in complicated grief and mourning⁶ with the griever presenting to the GP for management.

As GPs have widespread and ongoing access to communities and are often the first point of contact with the health care system, they may be the only accessible interface for disenfranchised grievers when other interfaces such as family, community, and even their own intrapersonal emotional memories, are unavailable because of the nature of their grief. Patients also value

'humaneness' as the most important attribute of their primary care professional.¹² This may facilitate disclosure to the GP of confidential material and facilitate empathic bridging, which in turn may form part of therapy.

Disenfranchised grief has been increasingly recognised in a number of groups seen regularly by GPs including ex-spouses, caregivers, nursing home staff, pet owners, children, adoptees, individuals with developmental disabilities, and those who may be grieving suicide or AIDS victims or other forms of stigmatised death.³ Other groups continue to be identified, including victims of sexual abuse, indigenous people and prisoners re-entering their original subcultures.¹³⁻¹⁵

General practitioners who are aware of disenfranchised grief and its association with health problems will be well placed to negotiate the way forward with other important groups of disenfranchised grievers as they are identified.

Re-entry adjustment/disenfranchised grief

There has been little identifiable research on disenfranchised grief in cross cultural workers re-entering their home country, although it has been flagged an important issue.¹⁶ With over 100 Australian nongovernmental organisations (NGOs) and mission agencies currently providing aid and personnel to work in over 135 nonwestern countries,¹⁷ the phenomenon of disenfranchised grief associated with re-entry is likely to become significant in the future.

Cross cultural workers may miss out on many of the benefits of primary health care because their mobility and time limited re-entries limit their ability to attend to health needs. Financial barriers, with income in the lower socioeconomic range,¹⁸ may also lessen their access to care;

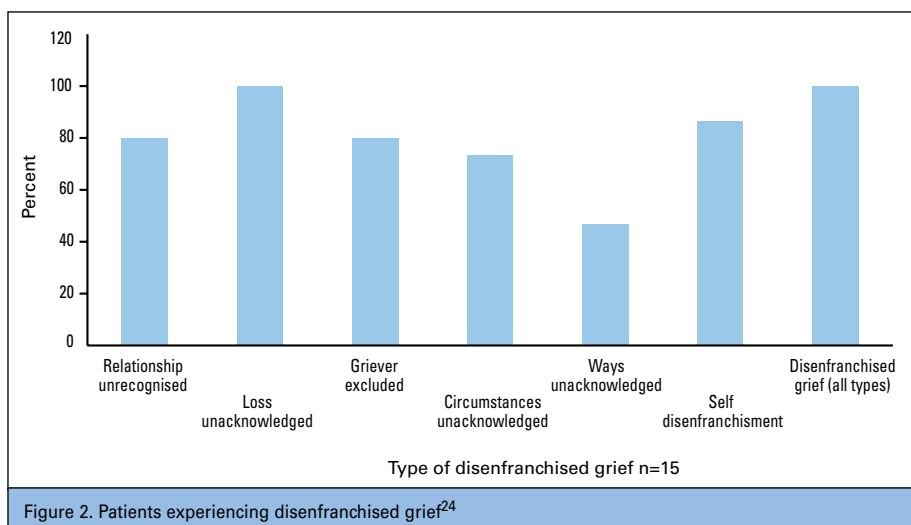
this has been shown to be the case in relation to accessing help for depression.¹⁹ However, appropriate health care provision for those identified as disadvantaged²⁰ may also be an issue, with no intervention currently available to manage loss and grief issues, especially disenfranchised grief, in the general practice setting. The Royal Australian College of General Practitioners 2005 summary report suggests 'Awareness of the needs of special subpopulations may be important for planning interventions in general practice for reducing health inequalities'.²¹

Cross cultural workers may present with a range of symptoms to their GP as a result of the multiple losses they experience from relationships, identity, home, community and cultures. McFarlane²² identified the re-entry period as a time of risk for development of ill health and psychological distress. Lovell²³ showed that over 40% of returned workers had psychological issues with 80% suffering from depression.

Preliminary quantitative data from phase 1 of a study (undertaken as part of the lead author's PhD thesis) investigating loss and grief issues in re-entering cross cultural workers alerts GPs to the importance of disenfranchised grief in this group, with more than half experiencing grief during re-entry and all experiencing disenfranchised grief with each category represented (*Figure 1, 2*).²⁴

Further qualitative analysis of this study is being undertaken, and an intervention for general practice will be designed and tested that can be implemented within an Australian fee-for-service setting in this group. The intervention may be applicable for use with other groups such as indigenous people, prisoners and victims of sexual abuse.

**Figure 1. Patients experiencing grief²⁴**



What can GPs do?

General practitioners are in a unique position to make a difference to outcomes in the area of loss and grief. Recognition of disenfranchised grief, validation and support are vital. They can involve other primary care providers including psychologists, and grief and pastoral counsellors in the management and education, not only of those affected but also of the wider community, including NGOs in the case of cross cultural workers. Although the emphasis has previously been placed on mental health issues such as depression, the development of a separate paradigm of loss and grief in primary care is increasingly important to enable appropriate diagnosis and management. One of the current problems for health providers is the lack of ownership in the area of research, education and service provision for loss and grief issues and the need for a single voice to be created in order to improve the outcomes for those affected. Communities may develop greater awareness of disenfranchised grief in re-entering cross cultural workers and explore the challenges involved in management.

Conclusion

Grief, disenfranchised by the patient and the community, is important in the general practice setting as it may present as physical and mental health problems. The GP may be the only accessible provider of care due to the disenfranchised nature of the grief and financial barriers. Preliminary results from an Australian study have shown that grief, especially

disenfranchised grief, may play an important role in psychological distress in re-entering cross cultural workers.²⁴ Further research is being undertaken to design an intervention which will assist the GP in assessment and management of grief in primary care. As some GPs develop skills in this area, sharing expertise, formalising networks and liaison with other primary care providers will be important. By recognising, validating and appropriately managing disenfranchised grief, GPs can improve patient health care outcomes, prevent complications of grief, and offer significant support to re-entering cross cultural workers as they serve the global community.

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