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Adjusting to illness and other major life events

How can GPs help?

BACKGROUND

General practitioners often see patients who are struggling with a change in their life circumstances. When this change involves illness, the GP is well placed to provide support and practical assistance. However, research in this area has tended to concentrate on the patient who is overwhelmed and unable to cope, focusing on the negative consequences of anxiety and depression.

OBJECTIVE

This article is designed to demonstrate the process of coping, and successful strategies that can be encouraged in the primary care setting.

DISCUSSION

The process of coping involves thoughts and behaviours. A patient with a new diagnosis, or a threatening change in their health, will assess the situation and determine how much it threatens them (primary appraisal) and how well they feel they are able to cope (secondary appraisal). They will then begin their preferred coping strategies. The GP can provide support and encouragement throughout this process.

Case study

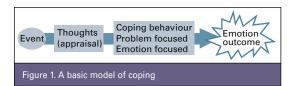
Anna, 59 years of age, is a physiotherapist who had a left mastectomy 15 years ago for breast cancer. At that time, there was no evidence of lymph node involvement and Anna remained fit and well for a long time. She became a passionate advocate for cancer care. She presented to you recently with a painful hip, and X-rays confirmed a metastatic lesion in the femur. Anna was understandably upset at this news, but coped well with her treatment with characteristic fortitude. You have not seen her much, but you are shocked to see her in the surgery, pale, listless and unkempt. She tells you her husband died suddenly a few weeks ago of a haemorrhagic stroke and since then she 'just can't cope any more'.

People experience many challenging circumstances

in life. Severe physical illness is one of them, and one that provides the general practitioner with a special opportunity to assist patients to adapt in the crisis and at the same time explore major issues that affect wellbeing. A medical model that emphasises psychopathology is not necessarily the most helpful. In contrast, a model that focuses on the normal process of grief and emphasises the positive aspects of coping will assist the person to make a successful transition to the next stage of their life.

What can you offer?

One of the great privileges of general practice is the invitation to share major and sometimes devastating events in the lives of our patients. As GPs we provide practical support where we can, a caring relationship, and a guide to resources. This is particularly relevant when the crisis involves a major illness. In these situations, doctors have a special entrée; patients want and expect guidance and reassurance from the doctor when the problem is clearly a 'medical' one.



People recover from acute illness; the upset is temporary. Severe and chronic diseases however, pose continuing threats and challenges.¹ Patients experience uncertainties about their future physical capacities, their ability to continue their former lifestyle, pain and other symptoms, and their value as a person.² These real and potential life changes create ongoing stress and require significant adaptation in order to adjust to a new way of life, to maintain balanced mental health, and to make good decisions for the future.³

We are naturally aware in medicine of negative outcomes – as Anna's case, when coping is overwhelmed, and of possible depression and anxiety. Patients can however, experience psychological wellbeing under very difficult circumstances – some perhaps even finding new meaning in life. Understanding the various ways people cope and adapt to major life events will help GPs to support this adaptive process. An approach to understanding the situation so as to be able to facilitate improved psychological wellbeing involves: fully empathising with the person, and specifically analysing the thinking and behaviour (*Figure 1*).

Empathically understanding the situation

Through empathy we seek to fully understand what is going on – the whole picture – particularly focusing on the circumstance and the patient's experience of it, which importantly includes their feeling state (*Figure 1*). There will always be negative emotion, but is it adequate to simply label this depression or anxiety? We want to, by empathically listening, get an understanding of the experience that will tell us what is going on psychologically and how we can best help. For instance, we may ask is the prominent experience one of:

- worry about the future uncertainty about the outcome
- grief and sorrow with pining and pangs of grief like a bereavement or death
- helplessness, feelings of incompetence, not knowing what to do.

Of course there may be mixtures of these in a single circumstance. In Anna's case, her experience may involve worry about her own future, grief and sorrow at the death of her husband, and of her own health and feelings of helplessness – but the correct understanding is important because the way we help will be different. For the person with overwhelming helplessness we will try to strengthen their level of control, for the person in grief we will comfort

and aid the grieving process. With empathic listening we tentatively reflect back to the patient our understanding of what they are describing – the patient will then likely confirm or correct.

Behaviour and thinking analysis

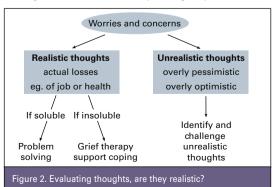
Following a proper empathic understanding, we can now break up the experience into its not so obvious components and analyse the thoughts and behaviours associated with the experience (the middle two parts in *Figure 1*).

Thoughts

When patients experience an illness, symptoms or crisis, they will make an assessment of its importance or significance for them. Perhaps this is not done consciously, but automatically. They will, for instance, interpret the event as a threat or a challenge, or perhaps a 'loss'. This process is called appraisal – technically called 'primary appraisal'. This is very individual and depends on a person's past experience and beliefs. For instance, if a person has had a harsh childhood they may well have grown up with a general sense of pessimism and tend to see things as a threat. It also depends on their current circumstances – a diagnosis of cancer is different for a young person compared to an older person.

A person will also, again quite intuitively, make an evaluation of their resources to cope with the circumstance. This includes internal resources – strength of character and coping mechanisms, and external resources – social network, finances, information. This is called a secondary appraisal. Again, past experiences and personality, as well as current social supports and circumstances, will influence whether a person feels they have adequate resources for the situation or not. One can easily see how these appraisals will lead a person to feel confident on the one hand, or fearful and demoralised on the other.

An important assessment that the doctor makes is how realistic these appraisals are. For example, if the patient is expressing grief (or what we might call anticipatory grief) because there is nothing that can be done – is it true that nothing can be done? Are they feeling helpless because



they see themselves as incompetent? - 'nothing ever works out for me'. Are these self evaluations realistic? Or, is the patient pursuing an unrealistic search for a diagnosis or cure, not facing up to the reality, and as a result not attending to important things? Is he being overly optimistic and not bothering to pursue treatments as you think he should?

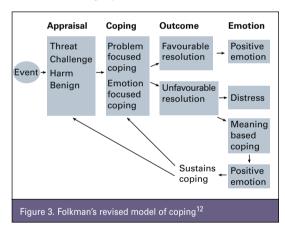
These evaluations are fraught - doctors make mistakes in their evaluations. Heijmans et al4 demonstrated in patients with diabetes and arthritis, that doctors and patients frequently differ in their perceptions of the stresses associated with illness. Doctors are also prone to feeling the same emotions as their patients - anger, helplessness, false optimism. So while this assessment might be difficult, it is important, as it will guide our interventions (Figure 2).

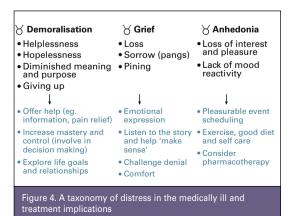
Coping behaviours

Two types of coping behaviours have traditionally been distinguished:

- problem focused coping, and
- emotion focused coping.5

Problem focused coping is defined as coping efforts focused on the environment and the problem at hand (eg. efforts associated with control and actions to directly solve the problem). In contrast, emotion focused coping is involved more with reducing exposure to the stressor and associated





emotion - escape and avoidance, distancing, distraction, seeking social support, and cognitive reframing (Table 1).

In general, it can be expected that a problem solving approach will lead to a favourable event outcome, which in turn is likely to lead to a positive emotion outcome. But in chronic or terminal illness, or after bereavement, a totally favourable outcome is not always possible.

Susan Folkman⁶ recently studied a group of people experiencing an unfavourable event outcome but who had a favourable emotion outcome, ie. were not becoming depressed. These were patients dying with AIDS; but they had carers. From her observations she described a third type of coping: meaning based coping. In meaning based coping people:

- used positive reappraisal (interpreted the situation positively)
- found meaning in daily life events
- revised goals for the future, and
- activated spiritual beliefs.

The use of each of these seemed to generate a sense of meaning and purpose, leading to positive emotional states (Figure 3). This is an important adaptation to the traditional model of coping because it acknowledges that there is another level of coping that is important and ultimately determines wellbeing in difficult circumstances. A consideration of what is really important (eq. particular relationships, goals in life, religious beliefs and contemplation) is necessary for patients to adapt to new circumstances and to develop resilience for difficult situations.

What can GPs do to assist patient adaptation?

McWhinney et al7 have emphasised the importance of making a patient centred assessment in parallel with our doctor centred assessment. The above considerations all work toward understanding the predicament of the patient in their terms, in other words, a patient centred assessment. We will discuss later the usefulness or otherwise of making a diagnosis of depression or anxiety (arguably doctor centred diagnoses). Studies in patients suffering from severe or terminal medical illness have shown that demoralisation, characterised particularly by helplessness and hopelessness, is the common experience,8 and that demoralisation, grief and adhedonic depression can be distinguished from each other (Figure 4).9 Severe demoralisation is evidenced by a general loss of meaning or purpose in life and a 'wanting to give up.¹⁰ From the information we have so far about Anna, it appears she is experiencing demoralisation and grief. These need to be explored as well as identifying any features of adhenonic depression.

A patient derived taxonomy such as this will assist a GP to respond specifically and individually to the needs of a patient

(Figure 4). In Anna's case, if she is feeling demoralised, feeling overwhelmed and helpless, offering a mixture of practical help (adequate pain relief, increased supports to help her while undergoing treatment), advice (information about the disease, treatment options, probable outcomes, available resources) and involving her in the 'problem solving' (treatment decisions) will restore some degree of control and mastery. To assist Anna with her grief, not striving to give immediate relief (this is not possible in grief) but offering a listening and sympathetic ear and supporting her through the process is what is needed. Grief in the end requires a person to face the consequences; but this is a process that happens gradually. In the meantime, a bereaved person struggles to make sense of it all and, in some cases, of life itself. Anna, like all people experiencing grief, needs comfort, reassurance and support. Loss of interest and pleasure requires strategies to help her stay engaged with life, such as pleasant event scheduling or reconnecting with people who are important to her.

Using a 'coping' framework allows us to think about in what ways we can assist a person to use resources available to them. To the extent that a person is able, we will want to encourage them to use practical problem focused strategies while acknowledging their need to use a degree of minimisation and withdrawal in the early stages of adaptation. Mobilising social supports is important, while at the same time recognising the emotional strain that family and loved ones are under. Anna has demonstrated in the past that she is able to marshal both problem focused coping skills (her matter of fact management of her treatment) and meaning focused coping (her passionate cancer advocacy). Although feeling that her coping skills have been exhausted, over time her GP may be able to assist her in developing other meaning based coping strategies such as discovering meaning in every day activities with children, grandchildren or friends, re-evaluating goals and priorities in her life, or activating spiritual beliefs.

What can be done when there is nothing that can be done? Well, there is never a time when nothing can be done. But what do we do when there is no further curative treatment available for the person with cancer, or there is nothing that is working to halt the pain and disablement of arthritis? Recent work in the area of meaning based coping provides some evidence based guidance. Situations such as this challenge many of the myths we hold about ourselves11 (Table 2).

We can explore a number of these existential issues at the cognitive level. There may be grief involved in realising that life is not what was hoped for. Acceptance of this will also involve examining what can be done or achieved with what remains. General practitioners can help their patients reconsider their values and goals for their remaining life

Table 1. Common coping strategies

Emotion focused coping

- seeking emotional support and understanding
- using humour
- venting negative emotions
- denying or minimising the problem reframing
- using alcohol in excess

Problem focused coping

- concentrating efforts on doing something about the situation
- planning
- getting help and advice

Meaning focused coping

- seeing something positive in circumstances (eg. becoming advocate for cancer screening
- discovering meaning in every day activities (spending time with self or with grandchildren)
- re-evaluating goals and priorities for life being more goal directed
- · activating spiritual beliefs and practices

- to examine what is important to them. One patient may decide to retire from work, not because they have to, but because work is not now a priority. They want to spend more time with the family. Another will become an advocate for a cause or a community volunteer. For patients near the end of life, reviewing their life history helps to remind them of important relationships and achievements and their value to people. Taking an interest and inviting patients to bring along photographs will reinforce their sense of worth. And finally, treating patients with respect and dignity will allow them to experience their value to the very end.

When do we diagnose clinical depression?

Perhaps this is not an important question. We have already discussed the use of most nonpharmacological treatments for depression. Of relevance though is the question of when to use antidepressants. Unfortunately, there are no black and white indicators for the use of medication. The GP needs to implicitly weigh up many factors, including potential negatives of prescribing antidepressants. In general however, antidepressants are more likely to be useful when:

- depression is severe there is less evidence for their efficacy for the mild to moderate depression
- depression is persistent
- there is prominent anhedonia, guilt or self deprecation, psychomotor retardation, early morning wakening or worsening of mood in the morning (in other words, symptoms more typical of an 'endogenous' depression).

The giving of an antidepressant may of itself, give hope and reassurance.

Table 2. Universal human existential myths and fears		
I am in control	vs	fear of helplessness
I am confident	vs	fear of failure
I am lovable, acceptable	vs	fear of rejection
My life is meaningfull	vs	fear of futility

Conclusion

In this article we have explored some of the experience of, and psychological states associated with major life change. The example used is of a patient concurrently experiencing a diagnosis of metastatic cancer and death of her husband. An approach to the patient that seeks to understand the patient's experience, for instance of helplessness (demoralisation) and/or grief, will enable an appropriate response reflected from the GP, for instance, one that reduces helplessness, acknowledges and facilitates normal grieving, and maximises adaptive coping. Such an approach restores personal esteem and meaning in life where it has been challenged, and helps return a sense of wellbeing.

Conflict of interest: none declared.

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