

A revised model for coping with advanced cancer. Mapping concepts from a longitudinal qualitative study of patients and carers coping with advanced cancer onto Folkman and Greer's theoretical model of appraisal and coping

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ABSTRACT

Objective: To explore whether the Folkman and Greer theoretical model of appraisal and coping reflects the processes used by people living with advanced cancer.

Methods: Interview data from a longitudinal qualitative study with people with advanced (stage 3 or 4) cancer (n=26) were mapped onto the concepts of the Folkman and Greer theoretical model. Qualitative interviews conducted in home settings, 4-12 weeks apart (n=45) examined coping strategies, why people thought they were effective, and in what circumstances. Interviews were coded and analysed using techniques of constant comparison.

Results: Mapping coping strategies clearly onto the problem- or emotion-focused elements of the model proved problematic. Fluctuating symptoms, deterioration over time and uncertain timescales in advanced cancer produce multiple events simultaneously or in quick succession. This demands not only coping with a single event but also frequent repositioning, often to an earlier point in the coping process. In addition, there is substantial ongoing potential for some degree of distress rather than purely 'positive emotion' as the final stage in the process is death with several points of permanent loss of capability in the interim.

Conclusions: The Folkman and Greer theoretical model is helpful in deconstructing the discrete 'problem-focused' or 'emotion-focused' coping mechanisms participants describe but its formulation as a linear process with a single, positive, outcome is insufficiently flexible to capture the evolution of coping for people with advanced cancer.

Keywords

Cancer, coping, oncology, well-being

Background

Coping with long-term, progressive or fluctuating chronic illness is complex and challenging, yet important to wellbeing^{1,2}. For people facing serious life limiting or life threatening illness coping can be particularly challenging, sometimes because of the absence of previous direct experience of the stressor³⁻⁶. Individuals may believe they are a 'burden'⁷ and cope with illness by internalising responses to difficult events even where challenges are tangible or external. However, people experiencing difficult circumstances may still cope effectively and experience well-being^{3,8-12}.

Coping is a central concept in many theoretical approaches to well-being, resilience and adaptation to serious illness, and can be understood with reference to behaviour, cognition and emotion¹³⁻¹⁷. One theoretical model of appraisal and coping processes to maintain psychological well-being during illness was developed by Folkman and Greer^{18,19}. It shares some common concepts with other models (e.g. Common Sense Model of Illness Representation^{17,20,21}, Model of Restorative Wellbeing^{14,22}) such as event/threat, appraisal and coping, but has a focus on outcomes of positive emotion. Coping theory has traditionally focused on distress¹⁹, but the emphasis of this model on positive psychological states resonates with the focus of the research reported here on coping well with advanced cancer^{23,24}, and is commonly used to guide empirical work in cancer and other serious illness^{25,26}.

Folkman and Greer posit that coping is developed along a timeline where an event triggers responses which lead to a positive outcome which supports subsequent positive emotion. The core constructs they present are presented diagrammatically in Figure 1 and a narrative summary provided in supplementary online materials.

< Insert Figure 1 around here >

In this paper we take findings from a qualitative study of coping with advanced cancer and use them to interrogate the Folkman and Greer theoretical model of appraisal and coping to see if it is captured by these empirical data.

Methods

Research Questions

Data from a study on coping with advanced cancer are used to explore whether the Folkman and Greer model reflects the coping processes they used. These data are from a serial interview study designed to answer the following questions:

- a. What do people do to cope well when living with advanced cancer?
- b. Why and when do they perceive these coping strategies as effective?
- c. How can health care professionals support effective coping strategies?

Study Design

The protocol and main findings from this longitudinal qualitative study are published^{23,24}. Informal carers were involved in the study, their data are not used here.

Sampling

Eligibility criteria:

- i) Adults > 18years. No upper age limit.
- ii) With advanced cancer, defined as those with metastatic disease at diagnosis, and/or where disease is progressing following treatment (local or metastatic spread) and/or where the prognosis is estimated to be less than a year²⁷.
- iii) Those whom their health care professionals judge have capacity to give informed consent to participate in the research.

Recruitment

People with advanced cancer were recruited from outpatient clinics within two cancer centres in North West England, purposively sampled for variability in tumour group, age and gender²⁸. People were identified by research nurses and approached between May 2012 and April 2013, with recruitment ceasing when data saturation was reached²⁹. Written consent was taken and participants could withdraw at any time.

Data Collection

Data were collected through audio-recorded interviews conducted in home settings by DR, with recordings and transcripts shared with CW. Interviews examined coping strategies, why people thought they were effective, and in what circumstances. Serial interviews enabled changing and evolving perceptions to be explored^{30,31}. An initial topic guide developed iteratively. Mean first interview length was 64 minutes (range 42 – 106 minutes).

Data analysis

Interviews were independently coded by DR and CW using NVivo 10™ and analysed drawing from techniques of constant comparison³². An analysis matrix was constructed to compare and contrast coding for people with advanced cancer at and between first and second interviews, and to focus on change occurring over time. Data were mapped onto Folkman and Greer's theoretical model, identifying coded data themes which represented the constructs in Figure 1, described in online supplementary materials.

Ethics and governance approvals

NHS Research Ethics committee approval was given by NRES North West – Cheshire (11/NW/0739) and governance approvals given by both cancer centres.

Results

Table 1 shows details of participants.

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The findings from the study are mapped on to Folkman and Greer's theoretical model. These are summarised in table 2.

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Events

For those living with advanced cancer, we found that disruption to the fabric of ‘normal’ life creates a series of events related to disease and its treatment. The ‘event’ could relate not only to ‘milestones’ such as diagnosis but also to adverse test results or reaching the stage at which cancer became regarded as incurable. While participants were able to recall their initial shock and chaotic thoughts at receiving a diagnosis of cancer they differentiated between ‘that day’ and their current daily lives when ‘events’ are multiple, multifaceted, fluctuating and evolving:

I was just shocked that after 20 years breast cancer had come back ... So it took me a while to accept it and not doing as much as I did. But now I’ve come like, this is how it is and this is what I can do, and live with it, basically.(P06, IV1, Female)

The model reflects recollections of coping with the initial impact of diagnosis but there are anomalies when applied to the reality of living with advanced disease. Participants describe coping with fluctuating symptom severity, or where the manageability of symptoms is affected. Participants find ways of ‘making sense’ of these impacts but effective coping strategies are not always based on perceptions which could be defined as ‘positive emotion’. Rather, coping appears to result from stoic acceptance of negative impact where emotional outcomes are mediated by meaning-based coping:

... some days I feel like I can go and cut the grass, I can walk up to the village, I can do what I want to do. ... And sometimes by half nine in the morning we’ve [mother and self] sort of agreed lazy day... (P04, IV1, Male)

When daily lives are disrupted by events such as clinical results then the pathway between event and outcome can shift towards or away from the positive emotion assumed to be the final outcome of the Folkman and Greer model.

Person Characteristics

In the model, person characteristics are assumed to be an individual blend of traits and experience. In our study participants emphasised experiential learning in developing their own coping strategies. Participants outlined how personal beliefs and outlook contributed to coping strategies and were integral to managing the everyday impacts of symptoms and side effects:

I suppose my philosophy in life is, get on with things and look for the blessings, and if you look back over a day there’s always things that you can be grateful for; just the fact that you’ve been able to get up, you have been able to have some breakfast, somebody has rung you unexpectedly. (P26, IV1, Female)

Our data shows that the ability of individuals to cope tends to be referenced by a positive self-perception a ‘coper’. Participants used phrases such as ‘*I don’t do negative*’ as a way of explaining how and why they were able to continually adjust. This need for frequent adjustment and for ‘*making sense*’ of fluctuating events demands not only a high capacity for reflection but also supports conceptualising coping as a non-linear process.

Appraisal

Within the context of serious illness it is relatively simple to classify events as ‘harm’, ‘threat’ or ‘challenge’, but these are assessed with greater complexity in daily life. For example, the unwelcome challenge of managing fatigue could be converted into an opportunity for forms of relaxation which are enjoyed but usually limited by the obligations attached to ‘normality’:

...I do more reading now than I had time to before, so that's been a bit of a bonus really and I finished off a few little projects that I had on the go, that I hadn't finished, so that's been quite nice,... (P01, IV1, Female)

Coping

While some events could be labelled as ‘problem’ or ‘emotion’, others are presented as simultaneously both and neither, depending on personal characteristics. An example is hair loss due to chemotherapy. For women the physical symptom of losing hair is likely to be perceived as physically problematic and emotionally challenging. Nevertheless, some developed coping strategies which simultaneously address the problem-focused threat or harm and the emotion-focused challenge.

‘...and if I put the wig on, or the scarf, then we can go out but they're not comfortable to wear so, really, I like to be here [home] where I can just lie about with nothing on my head’ (P23, IV2, female)

For men, hair loss when already experiencing male pattern baldness may not be problematic *per se* because they have existing coping mechanisms for the physical problems it presents. Their emotional response is contextualised as an extension of a ‘natural’ development even though it is the result of therapy:

‘...I'm losing my hair but that was happening anyway so it's not a problem really, I just shaved it off because it went tufty ... I'm just bald before I expected to be!’ (P04, IV1, male)

There is overlap and blurring between the foci of coping which may also require some meaning-focused coping to be employed in order to decide whether the ‘event’ is a problem or generates an emotional response.

Event outcome

The model may oversimplify the ways in which people approach ‘events’, their impact and their resolution. We found the same ‘event’ may create a different progression with coping strategies revised to accommodate the change:

‘... the [grand]kids love me to play with them and I love to do it – I think they think I'm one of them ‘cos I'm little! – and I DO even though its not what I would USUALLY do ... I can't do that[usual] and I hate it, but I find ways even though its hard.’ (P03, IV1, male)

The complexities of managing fluctuating energy and ‘wellness’ can produce multifaceted events which are simultaneously harm, threat and challenge.

Emotion outcome

The ‘emotion outcome’ phase of the model may not fully address coping with more complex events. By dividing potential outcome scenarios between ‘positive emotion’ and ‘distress’ it excludes a number of aspects of living with advanced cancer that we found with no clear distinction. The chronic symptoms which pose everyday harms, threats or challenges often do not fit easily under a discrete heading and, as a result, may cross between subsequent headings in later stages of the model:

... [after chemo] you just want to get home. So luckily we’ve got a car. [but] to get to [clinic] and back you get about £5 something. [and if you try to claim benefits] it’s frustrating ... (P03, IV1, Male)

... and the fella came and helped us fill it out so we get some more money now ... means we can use the car and go for a run on the way to the clinic ... loads better! (P03, IV2, Male)

In addition, when ‘events’ occur concurrently, the nature of appraising individually and in association and coping with mix of results is unlikely to fit neatly into the event and emotion outcome categories or to clearly produce either positive emotion or distress.

Meaning based coping

Individuals in this study frame, appraise and respond to the experience in a variety of ways including finding or revising its perceived current and/or future meaning. As a result, even where responses remain tempered by some measure of ‘distress’, each may lead to effective coping if not clear ‘positive emotion’:

... when they diagnosed my cancer as stage four advanced, I panicked because I might die a few months ahead. But I feel great. But I panicked myself. (P16, IV1, female)

I feel at peace, I’m ready. I don’t care, just at least my relatives or my friends would not worry where they get the money for my burial, everything is arranged. (P16, IV2, Female)

Positive emotion

The model is premised on the production of positive emotion as the sustaining element in the coping process but mapping these data raises questions as to whether its production is always possible. If the production of positive emotion is the only basis on which coping can be considered effective then many people living with advanced cancer or other chronic, fluctuating conditions are unlikely to achieve it in any consistent way:

I was feeling really down, really emotionally down, not angry in any way ... once I’ve had a good cry and then I actually start focussing on the positives in life,

well, I'm not dead yet, I'm, touch wood, these tablets are doing some good, touch wood, if that doesn't happen and the tablets don't do the job, I've still got the chemotherapy and radiotherapy ... once I've got whatever it is out of my system, the bee out of my bonnet, whatever, I'm not too bad, I start thinking more rationally, again, instead of all doom and gloom.(P18, IV1, Male)

As a result, 'positive emotion' may be combined with 'distress' yet remain integral to the development of a coping strategy against similar future events.

Conclusions

Principal findings

This study reveals that people with advanced cancer develop ways of 'living around' and 'living with' events and repeatedly revisit, reframe and redevelop coping strategies in response to repeated, fluctuating events and event clusters. The coping process for people with advanced cancer appears non-linear, fluctuating between positive and negative constructs of coping, and 'looping' as people recover from additional events, threats, harms and challenges. People may revert to earlier forms of coping to assimilate change, or develop new strategies. The Folkman and Greer model is a useful conceptual tool in defining elements of the coping process, but has limitations and may not be sufficiently flexible for people living with advanced cancer. The additional elements of repeated events and event clusters, sense-making, repositioning and adjustment, and use of meaning based coping at different stages in advanced cancer, looping and transitioning between stages are presented in figure 2.

<Insert figure 2 around here>

Comparison to existing research

The Folkman and Greer model is valuable in exploring how people cope with specific and separate events yet important questions emerge about its applicability to terminal disease where there are aspects of illness which constitute a chronic condition while others produce an acute event. With a terminal diagnosis, no matter how coping is achieved or sustained in the interim, there is only one eventual outcome. This alters individuals' responses to the impact(s) of illness and their perception of these as a series of 'events'

Research with people with advanced cancer describes the type of coping that they deploy, although the results are equivocal. Some suggest that emotion focused coping may be used more than problem focused coping for those with advanced cancer³³, although there are suggestions that problem focused coping may be particularly adaptive⁴. People who appraise cancer as a threat may be more likely to use problem focused coping, whilst those who appraise it as a harm/loss more likely to use avoidance coping. Other research highlights the use of meaning based coping such as prioritising, downplaying, and self-preservation^{9,34}. Our

data suggest that meaning-based coping makes a greater and potentially earlier contribution to the coping process than suggested by Folkman and Greer.

Known important aspects to coping are the necessary adjustments for those with advanced cancer³⁵, recognition of the individuality of experience³⁶, and that factors external to the experience of advanced cancer (e.g. health of carer) can affect wellbeing and coping strategies³⁷. Our data found that living with the symptoms and impacts of advanced cancer meant that ‘events’ repeat, overlap, fluctuate or accumulate and cannot be easily identified as discrete or separate ‘problem-focused’ or ‘emotion-focused’ challenges. A linear process does not capture the evolution of coping for this group of participants. There is a need to reflect ‘looping’ within the process to accommodate a scenario where challenges are met, repeated, re-evaluated and met again.

Strengths and limitations

The strengths of this study are its size and longitudinal nature, enabling tracking of the development of coping strategies over time. Whilst participants varied in their personal characteristics, we did not capture the experiences of young adults or the very old in this study and the way they use and develop coping strategies could be different. This study used Folkman and Greer’s model as a theoretical lens, but was not designed specifically to interrogate the model. It is possible that data were not collected which could be relevant, although this is unlikely due to the unstructured and iterative nature of the relatively lengthy multiple interviews.

Clinical implications

Our data suggest that Folkman and Greer’s theoretical model is a useful conceptual tool, but requires more flexibility for people living with advanced cancer. The re-presentation of the model based on these data highlights the impacts of multiple rather than single events, with feedback loops at each stage. This has implications for the therapeutic program which Folkman and Greer propose¹⁸, with flexibility needed in suggested activities of identifying and setting goals so that these are continually re-appraised and adjusted to take account of the impact of new events such as fluctuating symptoms and deteriorating physical ability. People with advanced cancer require support to enable them to accept the sense making and repositioning inherent in these adjustments to enable re-attainment of positive emotion.

Declarations

This research was funded by Dimbleby Cancer Care, but they played no part in the analysis or presentation of these data. The University of Manchester was the sponsor of the research.

The authors declare no conflicts of interest.

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Table 1 Participant demographic information

	Participants
Number	n = 26
Gender	M= 17 F = 9
Age	Age range 32 – 82 Mean 56.9
Recruited from tumour group clinic	Breast = 4 Prostate = 3 Lung = 8 Colorectal = 9 Other = 2
Occupation	Retired = 12 Working = 13 Home maker = 1
Total number of interviews completed	45

Table 2. Mapping study findings on to Folkman and Greer's theoretical model

Element of Folkman and Greer's model	Key findings from the study mapped on to the model
<i>Event</i> An identifiable and possibly traumatic experience.	Recognises that complex everyday experience may produce multi-faceted or rapidly consecutive 'events' which form simultaneous or parallel clusters. <i>'Its just everything...the hospital, being sick, worrying about the future...you think it'll get easier but then something else comes along...'</i> (P03, IV1, Male)
<i>Personal characteristics</i> Psychological traits Previous experience of event	Acknowledges the broader impact of individuals' perceptions, constructs and interpretations arising from traits, history, environment and context. <i>'I'm not someone who gives in...I'm miserable sometimes, of course I am, but I've got through things before...'</i> (P05, IV1, Female)
<i>Appraisal</i> a. Harm b. Threat c. Challenge	Considers how appraisal in the context of living with a life-threatening illness may be difficult to categorise as anything other than a psychological 'challenge'. <i>'Its scary! I know I'm going to get more ill and die but its no use wasting days...just got to find ways of enjoying what time I have.'</i> (P04, IV1, Male)
<i>Coping</i> Problem focused coping response to physical or tangible events Emotion focused coping response to emotive events	Questions that coping can be clearly defined as either problem-focused or emotion-focused. <i>'My hair's the worst. I need to wear the wig or a scarf outdoors so I do but it doesn't feel right. I'm comfortable without them at home ...my husband's very good about it ... even though he used to love my hair'</i> (P23, IV2, Female)