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Facing mortality

Facing mortality: exploring the mechanisms of positive growth and the process of recalibration

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Abstract

Interviews with 11 participants who had suffered a range of traumas 5 or more years ago were analysed using thematic analysis to explore the impact of a negative event and the mechanisms involved in subsequent changes and adjustment. Participants described a sense of mortality reflected in a feeling that life was fragile as though the intellectual knowledge of their future death had been turned into an emotional reality which had offered them opportunity to make changes across a number of life domains. For some, however, these changes were hindered through ongoing issues such as physical and psychological symptoms and legal action. The final theme reflected a process of recalibration and many described achieving a state of relative contentment. Transcending these themes were a series of mechanisms facilitating change including downward comparisons to friends and abstract others, active remembering involving forced reflection, self talk and reading diaries, shifting priorities and a focus on the positives and lowered expectations. Overall, it is suggested that growth following trauma is achieved through a shift in the object of comparison whether it be others or themselves as either in an alternative life trajectory or even death. This may result in a greater appreciation of life, but rather than being achieved through growth in one's sense of self per se it reflects a generalised lowering of expectations and growth in comparison to a new lowered set of points of comparison.

Key words: illness and disease – life threatening; illness and disease – responses; thematic analysis

Introduction

Over the past few decades researchers have explored not only the negative consequences of trauma but also the ways in which an individual may find benefit or show growth. Such research has been framed within a number of different theoretical perspectives and has been given a range of names resulting from extensive debates about the nature of the construct. For example, research has focused on stress related growth (Park, 2004), benefit finding (Tennen and Affleck, 1999), meaning making (Park and Folkman, 1997), growth orientated functioning and crisis growth (Holahan et al, 1996) and existential growth (Janoff-Bulham, 2004). Tedeschi and Calhoun (2004) developed a self regulatory model of post traumatic growth in an attempt to draw together the existing literature on trauma and coping and described the role of factors including personality, optimism, social support and meaning making. Such approaches are also in line with Taylor's cognitive adaptation theory (Taylor, 1983), research exploring realistic acceptance (Reed et al, 1994) and find reflection in a movement known as 'positive psychology' (Seligman and Csikszentmihalyi, 2000). Research focusing on the experience of positive growth, its role in predicting patient outcomes and the predictors of growth will now be described.

Primarily, research has explored the ways in which individuals make sense of trauma and their experiences of growth or thriving. In particular, Tedeschi and Calhoun have carried out much work in this area and their synthesis of the literature concluded that post traumatic growth was a more progressed form of positive adjustment than either just resilience or optimism and involved a process of transformation. Further, they highlighted five main areas of growth which were perceived changes in self; closer family relationships; changed philosophy in life; a better perspective in life; a strengthened belief system (Tedeschi and Calhoun, 2004; 2006). Recently, Hefferon, Grealay and Mutrie (2009) carried out a

systematic review of the qualitative research and highlighted four key themes across the different studies. These were reappraisal of life and priorities; trauma equals development of self; existential re evaluation and new awareness of the body. In addition, they concluded that the latter theme, in particular, was unique to internal rather than external trauma and that although they found common elements to positive growth across traumas there were also differences.

Research has also explored the role of different factors in predicting positive growth after trauma. For example, Tedeschi and Calhoun (2004) argued that the degree of post traumatic growth relates to symptom severity, time elapsed since the event, age, gender, social support and a clear cause to the event. Similarly, McMillen (2004) emphasised the role of available support for recovery and Harvey et al (2004) highlighted the positive and negative responses of others. Research has also addressed growth following non illness related trauma. For example, McMillen, Smith and Fisher (1997) explored growth following a mass killing, surviving a tornado and a plane crash and reported that growth was predicted by being able to find benefit in the event and a stronger fear of death during the event.

In contrast, other studies have explored the role of post traumatic growth in predicting patient outcomes. For example, Milam (2006) concluded that growth following a diagnosis of HIV was protective against certain physical illnesses and Reed et al (1994) reported how ‘realistic acceptance’ of their HIV diagnosis illustrated by statements such as ‘I tried to accept what has happened’ and ‘I prepare for the worst’ was related to a higher chance of death at follow up.

Research has therefore explored positive changes following trauma or diagnosis. To date, however most studies have neglected the processes involved in facilitating such change and have tended to concentrate on homogenous events. In their systematic review of the qualitative research, Hefferon, Grealy and Mutrie (2009) highlighted differences and similarities between internal and external events and emphasised the need for further research exploring the mechanisms of change rather than descriptions of such change. Accordingly, the present qualitative study aimed to address the mechanisms involved in growth across a range of traumatic situations and to explore commonalities and differences across both internal and external events.

Method

Design

The study involved a qualitative method with in depth interviews.

Participants

Eight women and three men ranging in age from 23-56 years were interviewed. All participants were Caucasian and English speaking. Nine were English, one was American and one was German. The circumstances surrounding their traumatic experiences are shown in Table 1.

-Insert table 1 about here -

Procedure

The University email system, which is open to all staff (academic, administrative, support etc) was used to access individuals who had experienced either an internal or external trauma 5 or more years ago. The University is large, campus based and located in the South of

England. A traumatic experience was defined as being life- threatening and could include an accident or a diagnosis. Twenty eight individuals responded who fitted the inclusion criteria. A sample of 11 was selected to represent a range of both internal and external events and to target those which were considered the most serious in terms of psychological, physical impact and threat to their life.

Interview schedule

Questions focused on the following: i) Can you tell me first what happened to you? ii) What effect did your experience have on your relationships with others? iii) How has your outlook changed over the years since the experience? iv) How do you think you have changed as a person compared to before the experience? Participants were not asked to describe their beliefs about the mechanisms of change but these were derived from the data. The interviews lasted between 25 minutes and 1.5 hours. Two were conducted over the phone and the remaining nine took place face to face in a small room on a university campus.

Data analysis

The interviews were transcribed and analysed using Thematic Analysis (Miles and Huberman 1994; Braun and Clarke 2006). All 11 transcripts were read and re read in order to become familiar with each individual's account. After initial annotation the transcripts were loaded into NVivo 8 for data management. Preliminary analysis produced 17 broad areas containing the relevant quotes across all transcripts. The transcripts were re read and those areas which appeared less significant or less consistent across transcripts were discarded. Once it was agreed between researchers that these themes appropriately reflected the original data, a set of sub themes and overarching themes was established.

Results

The main themes emerging from the data were **i) facing mortality ii) opportunity for life changes iii) ongoing issues and iv) recalibration** which reflected an ongoing dynamic process as participants experienced and made sense of their traumatic event. Transcending these themes were a series of **mechanisms** identified as facilitating growth following trauma. These will now be described with the use of exemplar quotes.

i) Facing mortality

Participants described how the traumatic event, whether it had been a serious accident or a diagnosis of a life threatening illness, made them face up to their own mortality which was described as ‘glimpsing my mortality’, ‘a bloody bombshell’ and ‘game over’.

For example, Sean said:

‘when I first found out he told me the words, as I said the world just seemed like it’s such a lonely place, there is nobody around.’ (Sean)

Participants who had received a life threatening diagnosis in particular expressed feelings of ‘anger,’ ‘disbelief,’ ‘uncertainty,’ and ‘desperation,’ Susan spoke about her experiences of being told she had cancer and said: *‘I felt like it was a huge scarlet letter there for a while’* as everyone responded with shock to her diagnosis.

For most, life was described as ‘unpredictable’ and they talked about the ‘fragility of life’, how it ‘can be over so quickly,’ and described life as the ‘main event’ and not a ‘rehearsal’.

ii) Opportunity for change

The appreciation that they had escaped death resulted in a sense that this was an opportunity for change, to ‘do things differently,’ to stop ‘umming and ahing’, and put them in a position of ‘questioning,’ where they were able to undergo a ‘reassessment’ of their choices.

For many, this meant no further delaying of plans and in some cases this was related to their careers. For example, Paula decided to go back to University and Pam decided to take up a nursing degree following her breast cancer:

‘I think it made me (sighs) feel that you know if there are opportunities for me to go and do anything that I should which is one of the reasons why I went in to do my nurses training.’ (Pam).

Others were motivated take more holidays, move house, retire or spend more time on their hobbies. As Sean said:

‘you don’t know what’s round the corner...I always wanted to go on holidays and what have you - but now um I’m going to do it... I had the opportunity to take early retirement last year which I just jumped at.’ (Sean).

Many also described the ways in which their trauma had made them more committed to their relationships. Terry described how his stroke had encouraged him to reassess the time he spent with his son and to build on this and Melanie took the opportunity to look at the way she treated her friends and family and said ‘I need to appreciate these friendships I have got’ reflecting on her new efforts to reconcile the arguments she was involved in. Several also described how they actively used their own experiences to support others.

Not all change was seen in such a positive light. Terry also described changing his job and spoke about ‘rationalising’ his stroke and looking at it ‘positively’ as an opportunity to do something new and not so ‘boring.’ There was, however, a clear feeling of loss of his work identity and the skills he had built up as a successful self employed consultant for 30 years. He talked about his experience being ‘discounted’ and ‘not relevant’ in his new role.

iii) Ongoing issues

Many participants described a number of ongoing issues including ‘constantly negotiating’ with symptoms, new injuries, ongoing legal battles and side effects. This was powerfully described by Susan who had had lung cancer:

‘anytime I am anywhere around cigarette smoke the scar tissue will just start aching like really hurting...on my side and I still feel it when I get a cold. And I work really hard to NOT get colds because the scar tissue is very intense in there and it really holds infection.’ (Susan).

Susan described her scar as a ‘neon sign’ which affected her both immediately after the operation and now 11 years later.

Scars were seen to be particularly important for women and Susan, Melanie and Carol all described feeling uncomfortable wearing certain clothes especially ‘bathing suits’ and Melanie described how she avoided wearing fitted dresses because of her altered body shape following her hip fracture. Carol also described how she had become much more conscious of her scars as she got older and that she couldn’t ‘get away from it.’

Mike also described the ongoing issues with his shoulder which he had damaged when hit by a van. He described how his loss of function was coming into 'his daughter's life now' and he felt that through no fault of his own he couldn't have the positive relationship with his daughter and was unable to lift her feeling 'like a 70 year old really.' His accident was affecting his identity as a father and the role he associated with this. Others reported numerous psychological problems such as depression, anxiety and relationship problems in the years following their trauma. Mike also reported loss of confidence relating to his change of career and status at work. He described conflicting feelings about the continuing court case which he hoped would help him 'turn things around' whilst at the same time was causing him 'stress'. Further, despite saying he would feel 'relieved' after the court case he commented that the stress of it was 'masking' the pain of his shoulder and he was worried about what would happen after a legal ruling.

iv) Recalibration

The fourth theme to emerge from the data related to a sense of recalibration with participants' describing how facing mortality had influenced their views of life. Many described how coming so close to death through accidents or diagnoses enabled them to be more appreciative and to take greater enjoyment from the simple things in their lives, recognising that their lives could have been over much sooner using words such as 'lucky' and 'fortunate' and phrases such as 'but it's better than being dead', 'I have to be grateful for what I have' and 'so I try and look on the bright side of things'.

'sometimes I think 'wow I could have been dead 9 years ago' and instead I am sitting here eating this incredible thing in Italy ... things like that just make me appreciate I am still alive and I'm able to enjoy as much as I can you know.' (Susan).

For many, this shift in perspective was described as having changed them making them 'wiser,' 'less naive,' less of 'a worrier,' and more 'determined.' Pam commented she had 'become stronger through it,' saying 'it was probably something I didn't realise I had within me'.

For others, however, the process of recalibration seemed incomplete. This was particularly the case for those still receiving treatment. For example, although Pam described how after her breast surgery she felt she had to not *'let it rule you because I do feel you can't live your life looking over your shoulder to see what is coming up behind you - you have got to look forward'* she felt she hadn't *'fully come to terms with it yet'*. Pam's mixed feelings were embedded in an ongoing process of a further two years of treatment and a sense that there were *'no guarantees.'*

v) Mechanisms of change

Participants therefore described their responses to a number of different traumatic events in terms of a sense of mortality, an opportunity for change, ongoing issues and a process of recalibration. These themes were inter related in a dynamic and circular fashion as participants appraised and reappraised what had happened to them in the context of new and ongoing experiences and events. Transcending these themes were a series of mechanisms which emerged as facilitating this journey.

One key mechanism was a process of social comparisons and several participants used the misfortunes of others to reduce their own self pity using statements such as *'you realise how there's always someone a lot worse off.'* For some this involved focusing on friends and family who had also experienced a negative event. But some made social comparisons in the abstract by focusing on people they didn't know:

'I just think ... I am not deformed ...you know – you read in the papers people who have had car accidents lost you know half your face you know I think I am - still got everything.' (Melanie).

Participants also described an effortful process of active remembering and making themselves reconsider what had happened in order to feel better about the present. For example, Anna described how she would make herself remember how she felt in hospital in order to stop herself complaining if she now feels ill. Melanie also tried to reactivate her memories of what it had been like after her car accident as a means to help her to take a more positive view of current life events. She said when discussing these diary entries:

'..yeah reading back and just reflecting over it just makes me think that everything is OK and you still have a whole life ahead of you so don't focus on the past... I keep everything next to my bed in a little box so I just sometimes at night pick it up and read a little bit..' (Melanie).

Another key mechanism involved focusing on the positives in their lives including their relationships with others and the newer aspects of their careers. This also reflected a shifting of priorities and a recognition that some aspects of balance may have been missing in their

lives prior to the event. Pam commented *'you cannot underestimate the, you know, love and support they give you'* and Melanie described how she now tried to find more value in what she may have previously taken for granted.

Susan also described how she had shifted the emphasis in terms of how she evaluated her career. Having been a professional dancer before her lung cancer she said:

'before the surgery I was thinking you know 'I am meant to be a dancer' ...I still dance but you know not, you know with the fever...things didn't seem so dramatic anymore it wasn't such a do or die thing because I had already survived.' (Susan).

This account also finds reflection in the most common mechanism used – that of shifting expectations. Many participants, who described feeling more positive about their lives after the trauma, did so through a mechanism of lowering their expectations. For example Susan also said:

'so many things are just not as important as they used to be to me ..you know what things are important are to be with my husband to you know make sure you know, feel good at home, you know, simpler things really although I still have ambition but you know I am just not I am not as hungry now.' (Susan).

Similarly after her diagnosis Pam realised that serious things did happen and comparing her views to before her diagnosis said:

'I am much more, well you have got to live your life. You can't worry about what's going to happen and erm there is no point being, you know, ultra careful and never doing anything. I kind of think well whatever is going to happen is going to happen but I am going to enjoy what I have got.' (Pam).

Further, David also described settling in his relationship and taking major career changes.

This 'reassessment' resulted in less pressure and more balance for him in his life.

Discussion

This study aimed to explore the impact of traumatic events, both internal and external, and highlights a number of key themes as participants experience initial shock and a sense of mortality, seeing the event as an opportunity for change, the need to manage ongoing issues and show a process of recalibration. These find reflection in much of the work on positive change following trauma (eg. Park and Folkman, 1997; Holahan et al, 1996; Tedeschi and Calhoun, 2004; Hefferon et al, 2009) and illustrates the ways in which a negative event can result in growth. The present study, however, also aimed to address the mechanisms facilitating this growth process and provides some insights into the nature of this shift and how this shift occurs. In particular, participants described using a process of downward comparison involving focusing on others who they perceived to be worse off than themselves which has been reported as a mechanism for coping with both illness and stress and sense making (eg. Taylor, 1983; Taylor et al, 1984). They used active remembering involving forced reflection, self talk and one reported reading her old diaries as a means to increase the salience of her sense of being lucky and several described shifting their priorities and making themselves focus on the positive aspects of their lives. Finally, most also described actively lowering their expectations of life as a means to improve their relative sense of contentment.

Much previous research describing change following a traumatic event emphasises a renewed appreciation of life and positive shifts in an individual's perception of their life which is conceptualised as growth. The results from the present study provide some insights into the mechanisms of such change and illustrate that much growth may be due to a reduction in what they believe they want and what they believe they can achieve; by lowering their points of comparison, whether it be others or themselves and reducing their expectations, the gap between what they have and what they aspire to is closed and they are rendered calmer and more settled in their life.

In summary, the present indicated that trauma is experienced in terms of an increased sense of mortality, seeing the event as an opportunity for change, the role of ongoing issues and, for many, a resulting state of recalibration. The present research however, also addressed the mechanisms of such change and highlighted a role for downward social comparison, active remembering, shifting priorities and lowered expectations. Accordingly, although the terms 'existential growth', 'post traumatic growth' and 'growth orientated functioning' suggest an improvement in ones' sense of self per se, the mechanisms identified in the present study indicate that this growth is achieved through a shift in the object of comparison whether it be others or themselves as either in an alternative life trajectory or even as dead. This may result in a greater appreciation of life, but rather than being achieved through growth in one's sense of self per se it reflects a generalised lowering of expectations and growth in comparison to a new lowered set of points of comparison.

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Table 1: Participants (pseudonyms) and characteristics of traumatic experience

Participant name	Traumatic experience	Years since experience
Susan	Characinoid tumour in right lung – non metastasised	11
Melanie	Car accident – caused by her speeding	5
Anna	Meningococcal Septicaemia in combination with Waterhouse-Friderichsen-Syndrome	5
David	Car accident, other driver resulting in fractured deltoid peg vertebrae	10
Pam	Breast cancer with breast reconstruction	5
Terry	Trauma induced stroke	5
Sean	Prostate cancer operation	9
Louise	Liver failure following spinal fusion	12
Carol	1 failed kidney transplant at 17 then successful transplant 4 years later	18
Mike	Accident – hit by a business van whilst cycling resulting in 13 corrective operations	5
Paula	Breast cancer tumour removed - radiotherapy	5