Cancer patients’ experience of positive and negative changes due to the illness: relationships with psychological well-being, coping, and goal reengagement

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Abstract

Objective: Most studies in cancer patients on psychological changes focused on positive changes (so-called ‘posttraumatic growth’), with surprisingly little attention on the possibility that patients may experience both positive and negative changes. This study investigated the relationship between positive and negative changes, and their association with positive and negative affect. We also examined the correlates of positive and negative changes, specifically the role of coping and goal reengagement.

Methods: This cross-sectional study was conducted in 108 patients. We used Pearson correlations and Regression analyses to examine the research questions.

Results: Positive and negative changes were relatively unrelated to each other. More positive changes were related to more positive affect, whereas more negative changes were related to more negative affect and less positive affect. Approach coping by more positive reappraisal and goal reengagement was significantly associated with more positive changes. More use of avoidant coping by self-distraction was related to more negative changes.

Conclusions: Patients experienced both positive and negative changes as a result of cancer. These changes were significantly related to patients’ well-being, as well as to their coping and goal reengagement strategies. This knowledge may be incorporated in psychological interventions. Cancer patients can be assisted to learn to acknowledge both positive and negative changes in their life and to approach rather than avoid difficult situations. Patients may also be supported to engage in alternative meaningful goals in life. This is likely to help them find positive meaning.

Introduction

A growing body of literature suggests that stressful events may not only lead to psychosocial problems, but may also be a catalyst for positive changes [1]. The concept posttraumatic growth refers to ‘the positive psychological changes experienced as the result of the struggle with highly challenging life circumstances’ [2,3]. Other terms that have been used for such positive changes are benefit finding, stress-related growth, or adversarial growth [1,4]. In this paper, we will use the term positive changes to refer to changes regarding oneself, relationships with family and friends, and priorities and philosophy of life [5,6]. Among cancer patients, it has been found that the majority experience such positive changes due to the illness [7]. Specifically, patients frequently report better relationships with others, altered priorities and life goals, and a greater sense of meaning and appreciation of life [8–12].

Are patients who experience more positive changes better off in terms of less distress and more positive well-being? The cognitive processing theory of posttraumatic growth assumes that positive change is an outcome of adaptation to stress [3], independent of well-being [4]. Thus, positive changes and well-being are regarded as relatively unrelated outcomes and may therefore co-occur. The findings among cancer patients on this issue, however, are conflicting. One study found that patients who experienced more positive changes reported less distress [13], while other studies found a weak or no concurrent relationship between positive changes and distress [7,14,15]. A recent longitudinal study showed that positive changes were not significantly related to negative affect, but they were significantly related to improved positive affect [16]. This finding suggests
that it is important to distinguish negative and positive affect, as they may be differently related to positive changes.

One limitation of earlier studies on positive changes is that they overlooked the possibility that patients may also experience negative changes regarding oneself, relationships, and priorities and philosophy of life. Only a handful of studies have examined this topic, showing that a significant minority of cancer patients experience negative changes, particularly worsened relationships with others and a heightened awareness of physical limitations and uncertainty in life [12,16–18]. Little is known about the association of these negative changes with positive changes. Do cancer patients who experience more positive changes experience fewer negative changes? One study found that patients’ experience of positive change was unrelated to their experience of negative change [16]. Similar to positive changes, it can also be asked to what extent negative changes are related to well-being. Pinquart et al. [16] found that negative changes were strongly related to worsened negative affect, but not to decreased positive affect. Clearly, these findings merit further investigation. The aim of this study was to validate and extent these findings, by examining the relationships among positive and negative changes, and their association with positive and negative affect. In order to overcome one of the limitations of Pinquart et al., that is the use of open interview questions which is likely to yield incomplete reports of change, we used a standardized multi-item self-report questionnaire to measure psychological changes.

The second aim of this study was to address the question why some cancer patients experience more positive and negative changes than others. Such research, driven by theory, is needed to enhance our understanding of underlying mechanisms [4]. In the cognitive processing theory of posttraumatic growth, Tedeschi et al. propose that cognitive coping processes play a crucial role in the development of perceived positive changes [3,19]. The theory assumes that stressful events may challenge personal goals and beliefs. Through the deliberate and effortful use of cognitive strategies (in terms of recurrent thinking, positive reappraisal, and formulating new goals), people may be able to find positive meaning in the event. This line of reasoning integrates concepts from stress-coping theory, which considers behavioral and cognitive coping strategies to be central in the adaptation to a stressful event [20] and self-regulation theory [21,22]. Self-regulation theory proposes that life circumstances may strongly interfere with the attainability of personal goals and that in such circumstances, it might be adaptive to formulate and reengage in new goals [23,24].

There is empirical evidence that cognitive and behavioral coping strategies indeed play a role in psychological changes due to stressful events. A recent meta-analysis found that positive changes were strongly related to coping by positive reappraisal and acceptance [25]. A review on positive changes following adversity found a similar finding, with more use of approach coping (i.e. acceptance, positive reappraisal, and problem-focused coping) related to more positive change [1]. In cancer patients, such approach coping has also been related to positive changes [26]. Especially, cancer patients’ use of positive reappraisal has been related to positive changes [7,13,15,27,28]. Less is known about other approach strategies, with some evidence that active problem solving and acceptance also play a role [13,15,27]. Results regarding avoidant coping strategies are mixed. One study did not find a significant association of avoidant coping (e.g. denial and behavioral disengagement) with positive change [26]. Widows et al. [15] found that greater use of seeking alternative rewarding activities was related to more positive changes, whereas Urcuyo et al. [13] found that such self-distraction was not significantly related to positive changes. Regarding the associations of coping with negative changes, we only found one study that showed that negative changes were strongly related to avoidant coping and unrelated to approach coping [26]. As far as we know, the adaptive role of reengaging in new goals, as proposed by theory, has not been tested in cancer patients. Therefore, this study examined the role of both coping and goal reengagement strategies in cancer patients’ experience of change.

In conclusion, the central focus of this paper is cancer patients’ experience of positive and negative changes due to the illness. First, we examined the relationships between these two types of changes and the associations of these changes with patients’ well-being. Changes and affect are both regarded as outcomes of the process of adaptation. We expected positive and negative changes to be relatively independent of each other. Moreover, we expected positive changes to be significantly related to positive affect and negative changes to be significantly related to negative affect. Second, we examined the associations of coping and goal reengagement with positive and negative changes. We expected positive changes to be significantly related to approach coping, by positive reappraisal, active problem solving, and acceptance, as well as to goal reengagement. We also expected negative changes to be significantly related to avoidant coping, in terms of self-distraction.

Method

Sample and procedure

Participants were recruited with the assistance from the Comprehensive Cancer Centre, West Netherlands (IKW), and the Dutch patient association for
lymphoma patients. A researcher and two assistants were present on two psychoeducational meetings, which were attended by 200 and 75 cancer patients, respectively. The goal of these meetings was to inform patients about the illness and its consequences. During the meetings, patients were informed about the study and its purpose (i.e. to obtain more insight into the factors associated with psychological well-being in cancer patients). Those who wanted to participate filled in an informed consent and received a written questionnaire and return envelop. In total, 140 patients signed the informed consent. A total of 108 patients (77% of the 140) returned a complete questionnaire (39 male, 69 female). The mean age was 53 years (SD = 11.9), ranging from 23 to 77 years. A large group was married or living with a partner (68%). Other patients were divorced (12%), widow (8%), or single (12%). A relatively high percentage had a higher vocational or university education (51%). Other patients had finished primary education (4%), lower vocational or secondary education (17%), or middle vocational or secondary education (28%). Most patients were diagnosed with lymphoma (67%), followed by breast cancer (12%), leukemia (5%), colorectal cancer (3%), lung cancer (3%), and prostate cancer (3%). The mean time since diagnosis was 7.3 years, with 25% being less than 2 years after diagnosis, 24% between 2 and 5 years after diagnosis, and 51% 5 or more years after diagnosis. Compared with other studies, relatively many patients were diagnosed with stage III (20%) and stage IV (31%) cancer. Other patients had a better prognosis, as indicated by stage I (16%) or stage II (22%). Some patients (11%) did not know their stage. Most patients had surgery (46%). Radiotherapy (55%) and chemotherapy (67%) were also frequently mentioned. About one-fifth of the patients (22%) reported a cancer recurrence in the years following diagnosis.

Instruments

Positive and negative psychological changes
Positive psychological changes were measured with the 17-item Benefit Finding Scale [29], which has also been used in other studies in cancer patients [11,13,30]. The items refer to positive changes in perceptions regarding oneself (e.g. ‘My illness has helped me become a stronger person, more able to cope effectively with future life challenges’), social relationships (e.g. ‘My illness has brought my family closer together’), and meaning in life (e.g. ‘My illness has helped me become more focused on priorities, with a deeper sense of purpose in life’). Response options ranged from 1 (I disagree a lot) to 4 (I agree a lot). Scale score can be obtained by adding up all items (scale range 17–68), as earlier studies found that the scale can best be treated as unifactorial [13,29]. Cronbach’s α-coefficient in this study was 0.89.

Negative psychological changes were measured by a 9-item self-report scale, which we developed based on the study by Fromm et al. [17]. The scale refers to negative changes regarding oneself (e.g. ‘My illness has decreased my self-confidence’), relationships (e.g. ‘My illness has worsened my relationships with others’), and meaning in life (e.g. ‘My illness has made me doubt the meaning of life’). Response options ranged from 1 (I disagree a lot) to 4 (I agree a lot). Scale score can be obtained by adding up the nine items (scale range 9–36). Cronbach’s α-coefficient was 0.84.

Well-being
The Positive and Negative Affect Schedule was used to measure positive and negative affect [31]. Positive affect reflects the extent to which a person feels enthusiastic, active, and alert. In contrast, negative affect reflects a variety of negative mood states, including anger, sadness, guilt, and nervousness. The two scales have shown to be largely uncorrelated. Both scales consist of 10 items. Patients were asked to rate the extent to which they had experienced each mood during the past 2 weeks. Items were scored on a 5-point Likert scale, ranging from 1 (not at all) to 5 (very much). Scale scores can be obtained by adding up the ten items, with higher scores reflecting higher positive or negative affect (scale range 10–50). The scales have been found to be internally consistent and to have good validity. We found Cronbach’s α-coefficients of 0.87 for positive affect and 0.86 for negative affect.

Coping strategies and goal reengagement
The Cognitive Emotion Regulation Questionnaire (CERQ) was used to measure cognitive coping strategies [32]. CERQ consists of 36 items, measuring nine distinct subscales (each by four items). We used the subscales acceptance (e.g. ‘I think that I have to accept the situation’) and positive reappraisal (e.g. ‘I think I can learn something from the situation’). Cancer patients were asked to rate how they are coping with the consequences of the illness. Items can be answered on a 5-point Likert scale ranging from 1 (almost never) to 5 (almost always) (scale range 4–20). Research demonstrated good reliability and validity of the scale [33]. We found Cronbach’s α-coefficients of 0.63 for acceptance and 0.88 for positive reappraisal.

In addition, two subscales of the COPE were used to measure the behavioral coping strategies active coping and self-distraction/mental disengagement [34]. The COPE consists of 60 items, measuring 15 distinct subscales (each by 4 items). Again, cancer patients were asked to indicate the
extent to which they are using these coping strategies to manage the consequences of the illness. An example item of active coping includes: ‘I take additional action to try to get rid of the problem’. An example item of self-distraction/mental disengagement includes: ‘I go to movies or watch TV, to think about it less’. Items can be answered on a 4-point Likert scale ranging from 1 (don’t do this at all) to 4 (do this a lot) (scale range 4–16). We found Cronbach’s $\alpha$-coefficients of 0.75 for active coping and 0.63 for mental disengagement.

Reengagement in new goals was measured by the Goal Disengagement and Goal Reengagement Scale (GRS) [23]. Earlier research has demonstrated the reliability of this measure. The 6-item GRS assesses the extent to which patients reengaged in other new goals when they faced an unattainable goal due to cancer (e.g. ‘When I could no longer pursue this goal, I put effort toward other meaningful goals’). Each of the items has a 5-point Likert scale, ranging from 1 (almost never true) to 5 (almost always true). Scale scores can be obtained by adding up the items (scale range 6–30). We found $\alpha$-coefficient of 0.86.

**Statistical analyses**

Descriptive analyses were performed and means and standard deviations will be presented. For the first research question, concerning the relationships between positive and negative changes as well as the relationship between these changes and positive and negative affect, we used Pearson correlations ($p<0.05$). We also used Pearson correlations ($p<0.05$) to examine the second research question, concerning the associations of coping and goal reengagement with positive and negative changes. Next, we used hierarchical regression analyses (method: enter) ($p<0.05$). In step 1, we entered the four coping strategies and goal reengagement. In step 2, we added positive and negative affect. This latter step was included in the model, in order to examine whether the associations of coping and goal reengagement strategies with positive and negative changes were not the result of concurrent associations of coping and reengagement with affect and of affect with positive and negative changes.

As earlier research has suggested that patients’ demographic and medical characteristics might affect the report of psychological change [15,35], we first tested these relationships in our sample, using $t$-tests, ANOVA, and Pearson correlations. We found no significant associations of age, gender, education, cancer site, time since diagnosis, type of treatment, stage of disease, and cancer recurrence with perceived positive and negative changes ($p>0.05$). Therefore, these characteristics were not included in the analyses.

**Results**

**Descriptives and correlations among study variables**

Table 1 presents the means, standard deviations, and ranges of the study variables. In Table 2, the relationships among the study variables are shown. Regarding the first research question, we found a nonsignificant relationship between positive and negative changes ($r = -0.13$). A greater experience of positive changes was significantly related only to more positive affect ($r = 0.35$) and not to negative affect ($r = -0.15$). More negative changes were significantly related to more negative affect ($r = 0.53$) and less positive affect ($r = -0.42$).

**Associations of coping and goal reengagement strategies with positive and negative changes**

More use of positive reappraisal ($r = 0.58$), goal reengagement ($r = 0.40$), active coping ($r = 0.27$), and acceptance ($r = 0.25$) was significantly related to more positive change (see Table 2). More negative changes were strongly related to more use of self-distraction ($r = 0.32$), and also to less use of positive reappraisal ($r = -0.21$) and less goal reengagement ($r = -0.21$).

Two separate hierarchical regression analyses were performed to examine the predictive value of coping and goal reengagement for the experience of positive and negative changes. As can be seen in Table 3, in the first step, coping and goal reengagement strategies explained 44% of positive changes ($F(5, 86) = 13.78; p<0.001$). More use of positive reappraisal and goal reengagement significantly predicted a greater experience of positive changes. In order to examine whether these results were not confounded by concurrent associations of positive reappraisal and goal reengagement with positive affect and of positive affect with positive changes, we added affect in the second step of the model. Affect only explained an additional 1% of the variance. Both positive reappraisal and goal

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reengagement remained significantly related to positive changes (see Table 3).

Coping and goal reengagement explained 20% of the variance of negative changes ($F(5, 86) = 4.22; p < 0.01$). Self-distraction was the only coping strategy significantly related to negative changes. In order to examine whether this result was not confounded by the concurrent associations of self-distraction with negative affect and of negative affect with negative change, we added affect in the second step of the model. Affect explained an additional 18% of the variance of negative changes, with both positive and negative affect significantly related to negative change. When controlling for affect, the relationship between self-distraction and negative changes remained significant.

**Discussion**

This cross-sectional study focused on cancer patients’ report of positive and negative psychological changes due to the illness. On the one hand, we examined whether such changes were related to patients’ well-being in terms of positive and negative affect. On the other hand, from an integrated coping self-regulatory perspective, we examined possible correlates of patients’ experience of positive and negative changes. Specifically, we investigated the role of patients’ coping strategies and their ability to reengage in new goals. The results showed that positive and negative changes are relatively independent phenomena, each having its own correlates with well-being as well as with coping and goal processes.

The finding that positive and negative changes were not significantly related to each other is in line with an earlier study [16] and underscores the idea that positive and negative changes are relatively independent and may co-occur. This disconfirms the idea that positive and negative changes are opposites of each other and points out the need to bring an end to the exclusive focus in research on positive changes. Future research needs to take into account that cancer patients may experience both types of change. So far, only a few studies have examined cancer patients report on negative changes [12,17–18]. Therefore, little is known about the occurrence of negative changes in cancer patients over the course of the illness and why some patients are more likely to report negative change than others.
A greater experience of positive changes was related to more positive affect and not significantly to less negative affect. This finding is in line with a recent meta-analysis on benefit finding and growth [23] as well as with the findings of Pinquart et al. [16] in cancer patients. A greater experience of negative changes was strongly related to more negative affect and to less positive affect. This is in contrast to our expectations and Pinquart et al. who did not find a significant relationship between negative changes and positive affect. A possible explanation for this discrepancy may be the differences in the instruments and study design. Pinquart et al. used an open-ended interview and a longitudinal design, looking at the association of negative changes with changes in affect. We used a standardized self-report questionnaire and studied the concurrent associations of negative changes with affect. In line with our results, an earlier cross-sectional study among cancer patients also found a strong relationship between negative changes, and both negative mood and positive indicators of well-being [12]. These findings provide evidence for the notion that negative experiences may be more heavily related to overall well-being than positive experiences [36].

Regarding the role of patients’ coping and goal reengagement strategies, we found that more use of goal reengagement and approach coping by positive reappraisal, and to a lesser extent by acceptance and active coping, was significantly related to more positive changes. Avoidant coping by means of self-distraction was not significantly related to positive changes. These results are intriguing for several reasons. First, they show that approach coping, which has been related to positive changes due to trauma and adversity in general [1,25], is also adaptive for cancer patients. Second, the results add to the small amount of empirical evidence regarding the nonsignificant role of avoidant coping in positive changes. Park et al. [26] also found that avoidance coping, such as denial and behavioral disengagement, was not significantly related to the experience of positive change. Third, this is the first study among cancer patients to indicate that, in addition to coping, goal reengagement is associated with cancer patients’ experience of positive changes. As it has been shown that a chronic illness, such as cancer, may strongly interfere with the pursuit of personal goals [37,38], it can be imagined that, precisely under such circumstances, it is beneficial for patients to seek and put effort in new meaningful goals that are attainable. In healthy adults, such goal reengagement has been related to less stress and more positive affect [23]. Our results expand this finding by showing that goal reengagement is not only related to psychological well-being, but also to the experience of positive psychological changes.

To a lesser extent, less use of positive reappraisal and goal reengagement was also related to a greater experience of negative changes. Yet, the strongest correlate of such negative changes was avoidant coping by use of self-distraction. Among cancer patients, coping efforts to avoid thinking about a problem have consistently been related to less psychological well-being [39]. Our study indicates that such avoidant coping is also associated with the experience of negative changes, such as a decreased self-confidence, worsened relationships, and less meaning in life. This finding is in line with Park et al. [26] which also indicated that avoidance coping was significantly related to negative changes. The fact that the experience of negative changes was related to different coping and goal reengagement strategies than positive changes, suggests that positive and negative changes are not simply the opposite of each other, each having its own mechanisms.

When interpreting these results, several limitations need to be taken into account. The study was cross-sectional, thus questions about causality cannot be answered. For instance, the relationship between positive changes and positive affect may indicate that positive changes induce positive affect, as suggested by earlier longitudinal studies [16,30]. Yet, it can also be reasoned that positive affect brings on the experience of positive change. In addition, based on the cognitive processing theory of posttraumatic growth [3,19] as described in the Introduction, we regarded both psychological changes and affect as outcomes of adaptation to cancer, whereas coping and goal reengagement were regarded as predictors. However, alternative models can also be reasoned. Based on the fact that we measured ‘coping with the consequences of cancer’, it can be argued that the experience of positive and negative changes leads to particular types of coping, which in turn influence positive and negative affect. Therefore, our study warrants future longitudinal studies that examine coping and goal reengagement processes in relation to psychological changes and well-being over time. Such research might shed more light on the causal relationships between these mechanisms and outcomes. A second concern is the recruitment of patients from a patient organization. In our sample, there was a relatively large group of patients with a higher stage of disease, more extensive treatment, and greater occurrence of cancer recurrence. This may affect the generalizability of the results to other patient groups. A third limitation is the use of two different scales for measuring positive and negative changes, rather than one with neutral items answered on a scale from positive to negative, as other studies have done [18,40]. It can be reasoned that different domains of changes were being assessed, which may influence the comparisons we made between positive and negative changes. However, tapping negative and positive changes on the same item
also has its limitations, as it is unclear whether negative scores should be added to positive scores or whether they should be examined separately [4]. In addition, this strategy assumes that positive and negative changes are opposites, whereas our results and those of others suggest that this might not be the case. Finally, it should be noted that coping and goal reengagement explained about half of the variance of positive changes, but only one-fifth of the variance of negative change. This suggests that other factors may be involved as well, such as patients’ personal resources (e.g. optimism and self-esteem) and social resources (e.g. support from significant others).

Given these limitations, this study is an important step forward, as it adds to the small body of literature that patients may experience both positive and negative changes as a result of cancer, and that these experiences are related to their well-being. Both coping and goal reengagement strategies were found to be important correlates of these changes. This knowledge may be incorporated in psychological interventions. In order to assist patients in their adaptation to cancer, strategies to decrease patients’ avoidant tendencies may best be combined with strategies that stimulate an active approach of difficult situations. In addition, rather than explicitly telling patients to look for a ‘silver lining’, health care professionals may use cognitive and mindfulness-based techniques to assist patients in recognizing and acknowledging both negative and positive changes in their lives. This may shift their attention to a broader perspective, including positive aspects of the situation. Furthermore, patients may be assisted to become more aware of their personal goals and possible disturbances herein, and stimulated to reengage in alternative meaningful goals. This is likely to help them find positive meaning.

References


