



Post Traumatic Growth in Cancer Survivors

By Shefalika Sahai, 2nd year, BA(Hons) Psychology, Lady Shri Ram College

trauma of the like of chronic or fatal illness like cancer is bound to result in psychological and even physical distress, it is also essential to not ignore the possibility of experiencing positive personal change following a crisis. Systematic research in this area especially since the 1990's has revealed that major life disruptions of varying nature have elicited growth experiences which is now studied as 'post traumatic growth' (PTG).

Through this paper an attempt is made to understand the concept of Post traumatic growth (PTG) as described by previous research and the subsequent theories put forward to explain the phenomenon by particularly looking into cancer survivors. The present paper deals with the concerns regarding the concept of PTG, methodology, designs and tools used to examine the concept along with the drawbacks of such researches and further directions of future researches.

Cancer, is a class of diseases in which a group of cells display uncontrolled growth, invasion that intrudes upon and destroys adjacent tissues, and sometimes metastasis, or spreading to other locations in the body via lymph or blood. These three malignant properties of cancers differentiate them from benign tumors, which do not invade or metastasize. Cancer afflicts all communities worldwide, approximately 10 million people are diagnosed with cancer and more than 6 million people die of the disease every year. The burden of cancer is distributed unequally between developed and developing countries, with particular cancer types exhibiting different patterns of distribution. The total cancer burden is highest in affluent societies, mainly due to a high incidence of tumor associated with smoking and western lifestyle, i.e., cancer of the lung, colorectum, breast and prostate.

In light of the many stressors associated with the diagnosis and treatment of cancer, it is not surprising that psycho-oncology researchers have concerned themselves primarily with documenting its negative sequel. Psychological distress, including depression, anxiety, confusion, and anger, disrupted interpersonal relationships, vocational difficulties, and worsened body image and sexual functioning may be present following cancer (Holland & Rolland, 1989; Meyerowitz, Leedham, & Hart, 1998; Welch-McCaffrey, Hoffman, Leigh, Loescher, & Meyskens, 1989).

Any stressful or traumatic event such as cancer along with negative, distressing repercussions may also have positive consequences and this isn't a new idea. A number of theories have been put forward to explain traumatic life experiences.

Joseph and Linley in their 2006 paper discussed three important formulations- the functional descriptive model (Tedeschi and Calhoun, 2004), the person centered theory and organismic valuing theory (Joseph and Linley) and the biopsychosocial evolutionary perspective (Christopher, 2004). Tedeschi and Calhoun (1999, 2004) proposed that for any event to instigate growth in a person, it has to take seismic proportions i.e. be of a nature so intense and grave that the victim experiences shattering of his/her basic assumptions about life and the world. Such an intensely traumatic event will make the person engage in ruminative thinking about the event and its implications which may be automatic in the beginning but gets more deliberate later. With the presence of positive social support and new coping behaviors, the ruminative thinking gives way to the development of a new narrative that allows the victim to build a new meaning for his life and thus experience growth following adversity.

The person centered perspective on the other hand (Joseph 2003, 2004, 2005) borrows heavily from Roger's theory of a fully functioning person. It proposes that when a severe trauma strikes, a process of disintegration of the self structure results, which is conceived as a normal psychological manifestation of a process of breakdown. However, as humans, we are intrinsically motivated to grow and are cognitively capable of accommodating even distressing life events. Hence, according to this theory, when we restructure our self to accommodate for the distressing experience, we move towards becoming more fully functioning. Christopher (2004) attempted to integrate biology as evidence for post traumatic growth to be a natural consequence of trauma. He argues that "... the normal trauma response is better understood as an evolutionary inherited mechanism for meta-learning, which shatters and reconstitutes the meta-schema (i.e., concepts of self, society and nature), in which learning normally takes place..." (p.76). He goes on to say that the "... negative or maladaptive outcomes of trauma appear to be the result of a failure to adequately modulate the normal adaptive trauma response..."

These theories provide insights into the complex nature of growth and possibilities of human growth following an adversity. While they differ on how growth comes about or what propels it, each supports the view that PTG is a reality and does occur with human beings experiencing trauma. However, there has been research that does not conform to this view and thus offer interesting alternative explanations for the phenomenon that gets termed as PTG. Prior to discussing new possibilities in research with PTG, it is imperative to argue out its validity- is the conceptualization of PTG as a phenomenon and its indicators accurate enough?

Conceptual Reconsiderations of PTG: Is it a valid concept?

Tedeschi and Calhoun (2004) defined PTG as 'the experience of positive change that occurs as a result of the struggle with highly challenging life crises. It is manifested in a variety of ways including an increased appreciation of life in general, more meaningful interpersonal relationships, better understanding of oneself, an increased sense of personal strength, changed priorities and richer spiritual life'. Maercker and Zoellner (2004) suggested that PTG has a transcending, constructive side as initially proposed by Tedeschi and Calhoun and a self-deceptive, positive illusory side too. Not ascribing a negative connotation like denial or maladjustment to the positive illusory component, they explained its presence as a component of PTG by indicating that it may co-exist with deliberate ruminations of the trauma and as such, serves an acute coping and short-term palliative function only with no long term benefits or

adverse repercussions. Maercker and Zoellner said that this self deceptive component of growth is a natural initial response to the traumatic event and serves the purpose of acute coping which is not necessarily maladaptive. However, they, or any other research does not offer a technique to weed out this component from the assessment of growth. The models that emphasize the illusory nature of the processes of PTG identify assimilation as the main mechanism in operation. They question the presence of positive identity changes, understanding PTG as a coping strategy. It is claimed that this strategy aims at counteracting or defending the subject from the distress caused by the calling into question of the coherence, sense and self esteem of the subject's identity, as a result of the illness.

Another view that attacks the exclusivity of growth and benefit finding in the aftermath of trauma is the developmental perspective to growth offered by Aldwin and Levenson (2004). They suggest that growth, re-prioritization and enhanced interpersonal intimacy may also occur following certain events in the developmental cycle of human life. For instance, becoming a parent can also induce the positive changes mentioned above although it is a developmental phase and not a traumatic, negative event. Here again, one finds evidence of growth in terms of enhanced wisdom in the absence of any traumatic event. (Aldwin and Levenson, 2004).

It is perhaps this lack of refinement in the conceptualization of growth that is responsible for disparate findings of its indicators, while Tedeschi and Calhoun (1996, 1999) suggested five dimensions of growth- greater appreciation of life and changed sense of priorities; warmer, more intimate relationships with others; a greater sense of personal strength; recognition of new possibilities or paths for one's life; and spiritual development; other researches propose different indicators of PTG. For example Armeli, Gunthert, and Cohen (2001) proposed six dimensions of PTG-affect regulation, treatment of others, self-understanding, belongingness, personal strength, and optimism. These contrasting indicators of PTG found in different studies as well as the attention deserving questions on the very conceptualization of PTG illustrated above offer an appealing debate on the validity of scientifically and methodologically studying it.

Research Methodology

This section points out some of these concerns regarding the research designs and methodology adopted in studies investigating PTG.

There have been inconsistent findings regarding the incidence of PTG as well as its indicators and factors affecting its occurrence. The inconclusive nature of research at the very level of conceptualization of the concept of growth following adversity points towards the need for a re-exploration of the phenomena in different contexts. Unfortunately, most research conducted to probe this area has adopted either a descriptive or sometimes an explanatory structure whereas what the field requires is more exploratory work in varied populations and cultures in order to attain clarity on the conceptualization and operationalization of PTG. Growth, as a phenomena need not be rejected, but need to be studied and re-studied using an inductive approach instead of the deductive framework that most researches have adopted lately. As Linley and Joseph (2004) discuss in the implications of their review of literature, most of the research studies are nomothetic implying that their findings may not conform to any individual's personal experience of trauma. Nomothetic study allows only to draw an understanding of

general pattern and this may be conducted when either the phenomena under study is a simple, straight forward one or when the concept has acquired a fair degree of conceptual refinement. Neither is the case with the concept of PTG and thus, the need for idiographic research becomes crucial.

Sample characteristics:

Among the research papers reviewed, most included samples that consisted largely of White Caucasians or Europeans. Majority of them belonged to upper middle class strata of the society, were educated at least up to college and had an easy access to specialised oncology care. For e.g. In the cross- sectional study with breast cancer patients by Lelorain, Bonnaud and Florin (2010), the samples consisted mainly of White Caucasian females.

The representation of minority ethnic groups and other races has been minimal or practically nil. The sample characteristics have been largely limited to a single race. Such a trend has also been noted in researches that enumerate application of PTG for clinical interventions. Moreover, there has been limited research on posttraumatic growth among cancer patients outside of western industrialized nations. The experience of severe illness would be expected to be influenced in important ways by the healthcare system and broader cultural-religious context in which patients are embedded and these factors have not been explored. Apparently, only a few researches have been conducted in the Indian context (for example: Post traumatic growth among cancer patients in India has been studied by Thombre, A., Allen C. Sherman and Stephanie Simonton, (2010). They found that perceived growth was associated with greater meaning-focused coping (sense making, benefit-finding), and with reappraisal of worldviews and not related to subjective appraisals regarding illness threat or stressfulness.

The Indian healthcare system presents significant challenges for many cancer patients. Access to specialized oncology care is more limited than access to general medical services, and there are notable geographic and socioeconomic disparities in treatment (Chopra 2001; Kurian 2007; Okonkwo et al. 2008). Psychosocial support services are uncommon. At the same time, PTG might be facilitated by distinct aspects of Indian culture. Strong kinship bonds are often an invaluable source of support for patients (Mehrotra and Sukumar 2007). Religious beliefs may offer an additional resource.

Hence, there is a need for additional research regarding perceived growth in distinctive cultural contexts (Abraido-Lanza et al. 1998; Ho et al. 2004; Taku et al. 2008), such as India. Another trend that has been noted in researches dealing with PTG in cancer survivors is that most of them include adults. Most of the researches available focus on adults and demonstrate how they grow and evolve when confronted with an adverse situation. It is noted that almost no or very little information is available on children or adolescents. Of the few researches done in this field using children or adolescents, the study on Posttraumatic Growth in Adolescent Survivors of Cancer and Their Mothers and Fathers by Barakat, Alderfer and Kazak in 2006 is worth mentioning. The study investigated PTG in adolescent and their parents using a semi structured interview. The results showed that a majority (84.7%) of adolescent survivors of childhood cancer reported at least one positive consequence of having cancer. The researchers concluded that adolescent survivors who are more likely to recall their treatment experiences

(e.g., were age 5 or older at diagnosis) appear to perceive both challenging and adaptive aspects and impacts of the cancer. These patients are likely to understand and appreciate the support and encouragement they received during treatment and to understand that they showed strength in the face of treatment-related adversities, resulting in more positive outcomes (PTG). These findings are consistent with the developmental tasks and challenges of adolescence and suggest the importance of understanding how adolescent survivors process their experiences and formulate longer term cancer-related beliefs.

Thus, clarification of the concept and measurement of PTG after childhood cancer is warranted, as are prospective studies of the association of PTG and PTSS and the role of demographic variables and illness-specific appraisals.

Another variable that is most likely to influence the study of PTG is gender. However, gender as a variable hasn't been addressed properly in the investigation of PTG. Majority of the researches conducted has used women. But, it will be inaccurate to conclude that no research has been done considering gender as an influencing factor. For example: Tedeschi and Calhoun (1996) have reported significant associations between gender and PTG. It was observed that women tend to experience more stress related growth than their male counterparts. They showed the tendency of women to score higher than men on the Post traumatic growth inventory (PTGI) suggests that men and women differ in their responses to trauma. These authors also found that women have a tendency to utilize more of emotion focused coping mechanisms. Hence, again for better conceptualization further research is recommended.

Similarly, personality is also a factor that is of utmost importance and hasn't been addressed in researches pertaining to PTG. Tedeschi and Calhoun (1996) reported that there were many relationships between PTGI and personality. The PTGI scores were positively related with optimism, religiosity and all other major dimensions of personality except optimism. But, they or any other research does not offer a technique to weed out this component from the assessment of growth.

Sampling techniques:

Analysis of the papers selected for this review points out another anomaly in research on PTG- inappropriate sampling techniques and restricted nature of sample chose. Practically all research studies reviewed for this paper as well as the papers included in the meta analysis paper by Helgeson, Reynolds and Tomich (2006) have used non probability sampling and typically judgmental or convenience based sampling. While it is perfectly acceptable to use non probability sampling and it doesn't necessarily imply an unscientific approach, the severe lack of random sampling in research related to PTG is striking and makes one question the generalizability of the results obtained.

Only Schroevers, Ranchor and Sanderman's (2006) longitudinal study examined the long-term impact of a diagnosis of cancer on physical and psychological functioning, by comparing 8-year cancer survivors to a randomly selected sample of similar-aged references without cancer. This study utilised a matched control-group design to assess stress related growth in the victims thereby allowing an essential comparison between the actual victims and matched

group and thus helping with drawing valid conclusions. However, the authors reported that at 8 years after diagnosis, survivors' levels of psychological functioning and resources were similar to those in references. These results stand in stark contrast to most other research conducted to investigate PTG wherein prevalence rates of endorsement of positive items in the questionnaires used ranged from 3% to 98%- different rates for different kinds of trauma (Linley and Joseph, 2004). Thus, although Weiss (2004) reported low responses to growth statements in husbands of women suffering from breast cancer, some growth has always been reported in the target population. Likewise, most research studies conducted, (except the above mentioned study) support the presence and the high prevalence of PTG as a natural consequence of trauma.

The possibility that this consistent reporting of presence of some, if not all domains of growth in populations studied till date may be attributed to the absence of any true baseline and lack of reference point appears more real. Schroevers, Ranchor and Sanderman's findings thus, contest the popular notion that growth is possible only in the aftermath of intensely traumatic incidents and urge researchers to consider conducting more studies utilizing a controlled group design that can offer accurate understandings of what growth is.

Time frame:

Researches done so far to understand the aftermath of trauma have largely adopted a cross sectional design. Cross sectional studies are a form of research method that involves observation of all of a sample of population at one specific point in time, that is, these studies evaluate individuals or victims at a one-time assessment. This is usually administered using questionnaires. Also, out of the several studies conducted, many researchers have found that the time since trauma emerged as being related to positive well being. One study that explored the relationship between posttraumatic growth and several demographic and medical variables found that only time since diagnosis (positively) associated with PTG (Cordova, Cunningham, Carlson, & Andrykowski, 2001). But, again not all researches point towards the same conclusion. Many studies also reject time as a moderate variable and hypothesize that PTG is negatively correlated with time. Therefore, the relationship between posttraumatic growth and variables such as time should be examined in researches so that these variables can be controlled for if necessary.

The best way then to address this issue and the notion of PTG is to adopt longitudinal designs. Longitudinal studies involve repeated observation of the same variables over a long period of time-often decades. They are often used in psychology to study the developmental trends across the life span. Though, only few research studies have incorporated this study design, each of them offers an important contribution towards the subject matter. For example: Schroevers, Ranchor and Sanderman (2006) carried out a longitudinal study examining the long term impact of diagnosis of cancer on physical and psychological functioning by comparing 8 year cancer survivors with randomly selected healthy individuals. The results showed that, cancer survivors and references do not differ significantly on many dimensions.

Tools of Measurement of PTG:

Virtually all research on PTG has been based on self-perceptions of change, which may or may not correspond to veridical change. Researchers most frequently use self-report instruments of positive change following an adversity and sometimes also utilize coding of interviews and open ended questions to explicate PTG. Very little research has attended to the issue of demonstrating instrument validity i.e, checking whether an instrument score corresponds to real-life changes. With the presented debate on validity issues of PTG, these self-report instruments may provide little more than individual's perception of growth. Frazier et al. (2009) wished to enquire this very same issue- does self-reported PTG reflect genuine positive change? They collected data from undergraduate students who completed standardized measures tapping typical domains of PTG at two different time spots which was compared with their scores on the PTGI. Interestingly, results showed no relation between PTGI scores and the actual PTG domains, thus leading the researchers to suggest that the PTGI, and maybe even other retrospective, self-report measure do not actually measure pre- to post-trauma growth. The most commonly used tools for assessing PTG include Post Traumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996) and the Stress-Related Growth Scale (SRGS; Park et al., 1996). Data derived from questionnaires such as these are required to establish relationships between the subjective experience of growth or benefits and other variables.

All these measures share common features. They ask victims to report on whether they've made changes in a number of domains on a Likert-type scale. Items are summed and scores are considered to indicate the extent of growth. But there are many drawbacks of such forms of assessments. Firstly, each tool proposes different number and different names of domains of growth. Hence it is not possible for any single instrument to measure such an exhaustive list of domains. Also, response biases on the part of the participant due to social desirability or other factors may affect the results obtained. Many a times, although instructions were devised to minimize demand characteristics for endorsements of positive change, response bias may have occurred. Hence, other ways of assessing actual growth needs to be adopted.

Further Directions and Research

Culture permeates every action, gesture, spoken word and even one's beliefs regarding oneself and the world around. Yet, its study in literature of PTG is largely absent. Though many researchers have discussed about the inescapability of culture in truly comprehending PTG (Tedeschi and Calhoun, 2004; Pals and McAdams, 2004), culture as a variable has not been operationalized in the examinations of PTG. A handful of studies have been conducted on Eastern populations which allow valuable insights into how the experience of growth following an adversity is constructed differently from Western populations. A single study on PTG in Indian patients was identified. Thombre, Sherman and Simonton (2010) offered an examination of PTG and its cognitive correlates in an Indian sample of cancer patients. Unfortunately, neither of these researchers conceptualize culture in terms of beliefs, values etc. to grasp its association with the personal construction of growth. The above mentioned researches simply conducted an examination of PTG in different racial samples but did not operationalize the important variable of culture to grapple with its permeation into the experience of PTG.

The experience of severe illness would be expected to be influenced in important ways by the healthcare system and broader cultural-religious context in which patients are embedded. What gets classified as traumatic or distressing is itself a cultural construction. Hence, what is needed is that more researches are undertaken that extend beyond the western population. Now, more studies need to be conducted on Eastern populations that can allow researchers to examine how growth is experienced differently from a Western society.

Also it was noted that variables such as time, age, income etc have been found to have different correlations with PTG. In some instances a positive correlation was found, while in some a negative correlation was found. Such inconsistent results are indicative of lack of theoretical conceptualization or inappropriate tools being used to capture aspects of growth. Hence, a more concrete conceptualization is needed to study PTG in specially cancer survivors along with advancement in the tools of measurement. Another trend that was observed in almost all articles reviewed for this paper was that most of them have limited their research to a specific type of cancer- breast cancer. Only a handful of them have examined any other type of cancer. But again even these researches have listed their results while taking into consideration only breast cancer.

A major problem with this approach is that the type of cancer one has can also influence the type of growth (if at all) one experiences. Moreover, the site and stage of the diagnosis may also take a toll on one's life. For example: 2 people suffering from cancer can have totally different views on the positive or negative outcomes they experience. The experience not only depends on the gender but also the site of cancer. Person A might have pancreatic cancer while Person B may have lymphoma. But since pancreatic cancer is more likely to be malignant, chances are high that person A might appreciate or enjoy life more thinking that he/she may not survive. However, since most researches don't address this aspect it will be beneficial if future researchers take this into account and conduct researches and increase our understanding of the subject matter.

Conclusion

Post Traumatic Growth is a concept that needs to be explored in depth because of the consequences that it has on victims of a traumatic event, be it a deadly disease like cancer or any other episode. There are several compelling reasons for examining benefit-perception or growth in the context of the cancer experience. In many ways, cancer is a prototypical stressful event. It strikes without warning and poses a serious threat to current and future wellbeing. Cancer is also a particularly difficult diagnosis to reckon with because the processes involved in its etiology and development remain elusive. Although researchers have identified several risk factors for various cancers, the precise mechanisms and constellation of factors involved in their onset and progression are complex, and disease-management can be difficult. It would beyond doubt be a wealth to the society if further researches that would be carried out are more accurate with its findings and if it could address to the various aspects concerning it. It has a strong promise in its field and is of concern to more or less every individual around.