

# Cancer Storytelling: A Study of Well-Being Expressions Made by Patients

Journal of Pastoral Care & Counseling

2018, Vol. 72(1) 37–44

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DOI: 10.1177/1542305018754796

journals.sagepub.com/home/jpcc



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## Abstract

Many cancer patients tell their story to help others. This paper reports a study of 160 such stories, which were processed using a grounded theory methodology.

The stories were rich in emotional words and in metaphors and these, along with self-talk and meaning-for-life, provided the commonest indications of the patients' well-being. Cancer patients, through the process of telling their story, help themselves and enhance their well-being. The method of active listening is described, with associated risks for professionals.

## Keywords

Cancer, grounded theory, metaphor, storytelling, wellbeing

## Introduction

Many cancer patients tell their story. These are found published in books, articles published on Cancer Society web sites and through internet blogs. This paper is a study derived from such cancer storytelling. For working purposes, we follow Carol Haigh and Pip Hardy in defining storytelling as “the effort to communicate events using words (prose or poetry) images, and sounds often including improvisation or embellishment” (Haigh & Hardy, 2010). All of these methods of communication are found in stories told by cancer patients that are available in the public domain.

In this research, it was our desire to process the stories in a manner that respected what the patient was saying. The stories told are factual, or *narrative*, but some authors may have concealed the more painful aspects of their cancer experience. A distinction between the terms storytelling and narrative is acknowledged but, in oncology stories, the factual aspects of the account (narrative) were often hidden due to the emotional language of the storytelling.

Each story studied arose from an individual's lived experience of cancer. Mostly the stories published by the cancer patients contain useful information and are

presented in positive ways designed to inform and help others recently diagnosed. We treated the stories as storytelling because many contain very emotional language and self-talk that often extended the communication well beyond a simple statement of facts. The stories are rich in metaphors, poetry, and spirituality: providing opportunity to understand what was influencing the well-being of the patient and how it shifted during the trajectory of the cancer. A patient's cancer trajectory is often uncertain to both the patient and professional alike (Rosenblum, 2007). We saw that researching the stories could expand the existing knowledge of the impact of cancer on patients' well-being.

The widespread availability of modern communication technologies, has resulted in what can be described as a valuable repository of lived cancer experience. Tina Koch concluded that the collection of patient stories is a valid research data set and that the study of storytelling is really research (Koch, 1998). Consequently, the narrative aspects of storytelling offer the potential to understand patients'

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cancer experience in ways that could be of value to professionals involved in diagnosis, treatment and care; this is because it lets us go beyond an understanding that is typically limited to the medical aspects of our professions. It offers us a means to improve the quality of our professional practice, be it diagnostic, therapeutic or pastoral, by listening to patients (O'Connor, 2011). An earlier study that analyzed the experience of cancer patients concluded that it is important to listen to the stories people tell of their lives and illness (Tuffrey-Wijne & Davies, 2006). The data for most other formally reported studies were initiated by the researcher and these studies are typified by Halldorsdottir and Hamrin (1996), which was based on in-depth interviews of just nine patients, representing six different types of cancers. Our data set was larger at 160 patients, with equal numbers of men and women, represented a larger range of cancers, contained larger representation within each cancer type and placed no constraints on how the story was told and demanded no responses from the patient. Brad Zebrack noted that similar research based on understanding what cancer patients were saying comprises "a small yet burgeoning survivorship literature" (Zebrack, 2000). Our study adds to this small body of research whose conclusions are derived solely from the lived experience of cancer patients.

## Aim

The storytelling of the patients revealed influences on their well-being that extended beyond what we knew from our extensive combined clinical and pastoral experience. In this paper, we describe the findings of our research for its potential to benefit those engaged in providing spiritual care.

## Methods

The methodology of this research is grounded theory (GT). Already published cancer patients' stories were the data for this research. Such stories constitute a form of qualitative data. Thus, the most appropriate methods or tools used are those of qualitative data analysis (QDA). And although numbers arose from the data and are used in the analysis, they are processed differently than they would be had they arisen within a quantitative data analysis study. At all times, this research method strives to understand the lived experience of people and concentrates on their stories in the findings and discussion. The validity of any conclusions arises to the extent that this grounding can be achieved. This is both a strength and limitation of this methodology: a strength because the conclusions are validated by being contained within the data; a weakness because GT limits conclusions to the data.

## Qualitative Data Sources

Of the 160 cancer patient stories studied, 70% of the content was derived from four sources: books, National Cancer Societies, newspapers, and private websites; the remaining 30% came from public websites. Every story was published in some form and thus had been subjected to the scrutiny of a publisher. They are all in the public domain.

How representative is the collection? The patients' cancer types were selected to represent the International Agency for Research in Cancer incidence statistics for the worldwide top 10 cancer sites. We continued adding stories to the data set in order to achieve an equal number of stories (80) by women and by men. Children's cancer stories were excluded from this study because their cancer experience differs from adults, their means of expression are vastly different and too few were found published to constitute a representative sample.

## Grounded Theory

Prior professional experience of the authors indicated that such a large representative sample of patient storytelling could be expected to contain useful information for those providing diagnosis, treatment and care. This would particularly be so if the research method allowed any hypothesis to emerge solely from the stories. Using a survey method, focus group, interview or the like was not a possibility because the data already existed as published material; thus, the study is retrospective. Only a few researchers had studied this rich repository of stories from the perspective of a person experiencing cancer, allowing the patient to control the dialogue. Of those that did, breast cancer is almost alone (Sherman, Rosedale & Haber, 2012). Our intention was to study a larger, more heterogeneous sample that better represented the diversity of cancer incidence than exists in reported research. GT methodology in the form described by Anselm Strauss and Juliet Corbin offered the tools suitable for researching this dataset (Strauss & Corbin, 2008). A full description of the diversity of GT methodology and of the associated controversies is outside the scope of this paper; interested readers can consult books and journal articles such as those referenced in the book by Pat Bazeley (2013). For us the key concern was not to force descriptive findings, but rather to allow any findings to emerge entirely from within the data. We saw GT both as a method, a process to achieve this, and also a means to address the issue of rigor (quality) that emerged as this research progressed.

We used computer aided qualitative data analysis software (CAQDAS) to help with the organizational and analytical aspects of managing the large quantity of qualitative data. Through a study of suitable computer programs, the tools found in NVivo 10<sup>®</sup> were found best for the CAQDAS and fully compatible with a GT

approach: NVivo tools enabled storing data, conceptual thinking, recording decisions, and links between memos, documents, nodes, and models, all assisting in developing a dynamic audit trail to meet the criterion of transparency (Bringer, Johnston & Brackenridge, 2004a).

### CAQDAS With NVivo

The logical sequence we followed moved from classifying (coding) through analyzing to conclusion modifying the inductive/deductive process model for business (Fernández, 2010). Operationally the CAQDAS processes were iterative and involved constant comparison.

### Coding

Stories were entered progressively into NVivo and coded in a first round of coding. Coding is the process of assigning a name to a passage of text which is used to provide subsequent access to that text. NVivo calls this a *node*. In practice, a node can be visualized as a box whose contents are thematically similar. GT requires that coding should emerge from within the data. Anselm Strauss and Juliet Corbin (2008) allowed that prior professional experience be used provided that such discipline-based knowledge fits the data and is appropriately applied. Thus, the extensive clinical experience of the authors was used in performing the first round of open coding in which expected descriptors were used (Bringer, Johnston & Brackenridge, 2004b). Beyond this initial use, all further coding was derived from the data alone. The data rapidly validated the initial open code selection and subsequent coding rounds provided many more open codes. Descriptors for axial coding (which are like sub-sets of text coded as open nodes) soon emerged. Finally, the coding iterations made on the 160 stories established 244 nodes containing 4313 references. This was a large quantity of data, for which CAQDAS offered a practical means of researching.

### Data Saturation

An important methodological question was why were 160 stories deemed sufficient to determine the end of theoretical sampling? The answer is that data saturation was reached. Word frequency queries of the most frequent 100 words exceeding 5 characters were made regularly during data entry. Both when the entry of data failed to add to the content of the 100 most frequent words, and also when coding revealed that no new categories were occurring, data saturation was declared. The rationale was that adding new stories contributed nothing new.

### Analysis With NVivo

Data analysis involved using the *query* functions of NVivo particularly (a) cluster analysis, (b) visualizations

(dendrograms and tree maps) and (c) similarity metrics based on word similarity within coding matrices. No statistical generalizations were made in the way that they are when numbers are used in quantitative analysis. The data analysis performed led to identifying our conclusion (Bazeley, 2013). The NVivo memo function was also used to achieve constancy in coding and for the validation of processes as described by Tina Koch for quality in QDA (Koch, 1994).

## Results

A graph (Figure 1) is presented to show the results of the CAQDAS analysis of the patients' stories of interest to practicing medical and pastoral care professionals. Eight parameters of well-being were identified, of which *feelings* was the commonest. Others in order of popularity (determined by frequency of coding) were *self-talk*, *advice to and from others*, *meaning for life* and the *best parts of having cancer* and *worst parts of having cancer*. Few references were found to the *concept of well-being* in its abstract sense. There are findings related to other influences on well-being, especially prayer and professional education, that fall outside the scope of this paper.

### Metaphor

A number of patients used metaphors either explicitly or implicitly in their words that provided insight into their well-being. The commonest metaphor found in the stories was a *war metaphor* in which the cancer is seen as the enemy to be killed. The diagnosis and treatment were battles with the assisting professionals seen as skilled allies who could locate and kill the enemy. A few patients were able to place the experience within their habitual metaphor. Approximately one-third of patients expressed a spirituality that was typically associated with good well-being, although three examples of bad or unhealthy prayer were found in which the cancer was seen as punishment of former sins. The self-talk of atheists was generally associated with good well-being.

The node *best and worst of having cancer* contained just 5 references to patients who said that their well-being was adversely affected by doctors and other professionals who dealt with them aggressively, preferring their own personal metaphor and ignoring the patient's habitual metaphor.

### Feelings/Emotions

Feelings were found to be the most frequent expression of well-being. The analytical process commenced with a word frequency analysis and followed with a comparison of the top ten feelings. Stronger and darker terms were found in women's expressions of their feelings than in those of men.

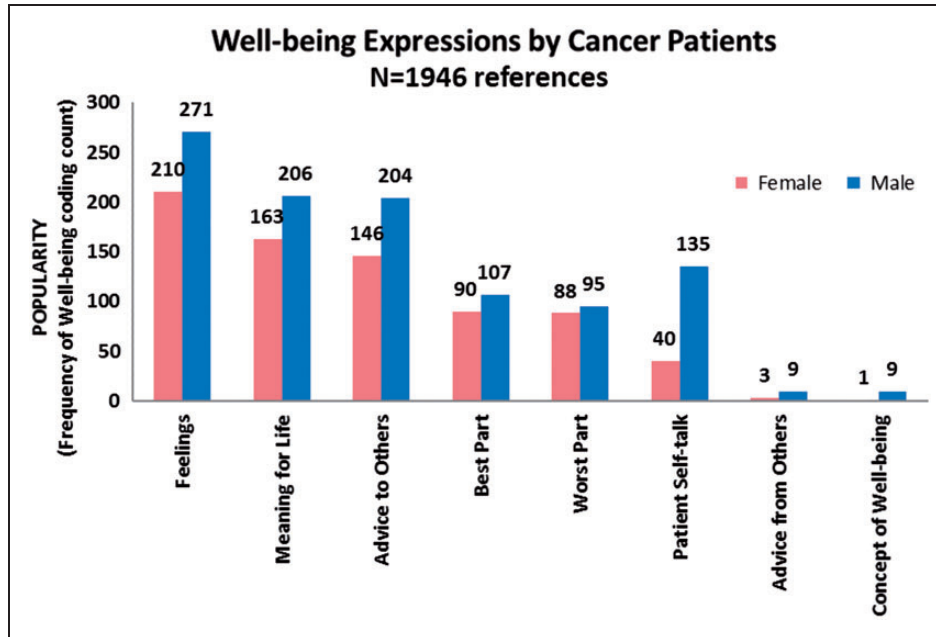


Figure 1. Well-being expressions by cancer patients.

The top two feelings for women were *fear* and *devastation*, whilst for men they were *happy* and *acceptance*. A deeper analysis, performed by clustering the feelings around similarity of their words, showed eighteen common expressions. The quotations and observations were presented in two groups based on the Krishna Mohan definition of well-being as *needs more satisfied* and *needs less satisfied* (Mohan, 1988). The strongest feelings in the *needs more satisfied* set included *comprehension*, *acceptance*, *happy*, *confident*, and *determination*. Among the *needs less satisfied* set were found feelings of *denial*, *of being cheated*, *of shock*, *being overwhelmed* and *of depression*.

### Patients' Self-Talk

The CAQDAS tools provided confidence in recognizing the elements of patients' self-talk as valid indicators of well-being. The analysis produced results showing that the patients wrote their stories primarily, in the words of one patient, to "detoxify" their personal cancer experience. There were also the concomitant benefits of providing information and hope for others and of receiving empathic encouragement for themselves. Some patients improved their well-being through their self-talk by gaining a measure of control over their treatment, despite difficulties that arose because of miss-matches in the cancer and treatment metaphors of medical specialists and of the patients themselves. Double the number of male patients ( $n=31$ ) compared with females (15) made a positive association between their self-talk and their well-being.

### Meaning for Life

The CAQDAS results on *meaning for life* showed that those patients who found a new or altered meaning for life through their cancer described better well-being (206 references by males and 163 by females). Most patients valued family relationships and volunteering whilst they developed either a restoration of their old lives or embarked on a new life. Relatives and friends were affected too. Most visualized their role as helping the person with cancer: they were in it together, accepting change in intimate relationships. For their relatives, lives would never be the same again either.

### The Best And Worst Of Having Cancer

References found in the *best and worst of having cancer* subset of well-being stories were almost equally distributed between males and females. Generally, the references to what the patients described as the *best of having cancer* referred to the remission period that they enjoyed when their treatment was complete or nearly so, whereas the term *worst of having cancer* included adverse changes during this period but was particularly concerned with the period around the diagnosis and the uncertainties surrounding developing treatment plans and their implementation.

### Advice To And From Others

A few patients took messages of hope from these stories, which contained much existentially validated wisdom. Stories exhibiting a spirituality were significantly associated with enhanced well-being. A minority of storytellers, who

blogged to the internet, achieved bonding with respondents despite sometimes receiving inappropriate advice, due to the unmoderated nature of the internet. However, significantly more advice was found to be given ( $n = 350$  references) than taken up ( $n = 12$ ).

## Practical Sequelae For Professionals

What do these results give rise to for professionals? From the results of our research shown in Figure 1, cancer patients, through the process of telling their story, help themselves and enhance their well-being. Thus, medical and pastoral/spiritual care professionals can contribute to such improved well-being: first, through the practice of *active listening* which facilitates the patients telling their story, and second, by providing communication that understands and respects each patient's metaphor.

### Active Listening

Professionals engaged in care who bring a true and complete patient centered *presence* to each meeting with the patient, helping the patient tell their story, are contributing to their well-being (Saunders, 1967). Such patient-centered listening is called *active listening*. And, because of its contribution to the healing process and well-being, active listening is as important as any other part of the diagnosis, treatment, and care. It does not replace medical treatments but is more than just a complimentary therapy. Active listening goes past the medical components of the patient's narrative to more completely take in spirituality, the psycho-social and existential aspects of their illness.

The evidence of this research and a burgeoning literature is that active listening that affords such primacy to the patient's story is as potent as current treatment and pastoral modalities in improving the patient's well-being. Trisha Greenhalgh and Brian Hurwitz wrote that "narrative reveals existential qualities such as hurt, despair, and hope that can assist the process of healing" (Greenhalgh & Hurwitz, 1999, p.48–50). Alun Jones said that the "therapeutic value of storytelling arises by allowing a person shifts of consciousness and so embrace the present and decide how to live whatever life is left" (Jones, 1998, p.1195).

These are some of the comments anonymous people made about **not listening**

- You do not care about me.
- You have an answer for my problem before I've finished telling you what my problem is.
- You cut me off before I've finished speaking.
- You finish my sentences for me.
- You are dying to tell me something.
- You are communicating with someone else in the room.

- You refuse my thanks by saying you really haven't done anything.

However, you were listening when:

- You come quietly into my private world and let me be me.
- You grasp my point even when it's against your own sincere convictions.
- You allow me to deal with my problem in my own way.
- You hold back your desire to give me good advice.
- You give me enough room to discover for myself what is going on.
- You accept my gift of gratitude by telling me how good it makes you feel to know that you have been helpful. (Jamieson, 2004, p.45)

### Listening Taxonomy

We define active listening as: "bringing an understanding presence to the patient that assists them tell their story." *Listening* is more than just hearing. *Presence*: it's not all about my problems; but it's all about my patient. Forrest Lang and his colleagues provided a taxonomy of active listening. Paraphrasing this, the approach to the patient should realize a patient's perspective on illness (PPI) facilitating:

- Expression of feelings. . .
- Attempted understanding of symptoms. . .
- Look for speech clues underscoring concerns. . .
- Personal stories linking the patient with the condition. . .
- Look for behaviors suggesting unresolved concerns or unmet expectations. (Lang, Floyd, & Beine, 2000, p. 222)

Our research showed that this PPI focus on the patient was good but it ignored the person of the active listener. But it is not so simple as providing a mindful presence to prevent failed communication. More is required. Our research showed that 27 patients made 139 mostly unfavorable references to their professionals:

- The professional's cancer paradigm dominated the consultation,
- communication lacked centering on the patient,
- "cookie-cutter" approach was resented,
- trust and confidence were lacking, and
- emphasis on money and/or research recruitment was resented.

These were roadblocks to effective active listening and adversely affected the patient's well-being. Katherine Robertson identified that *judging*, *suggesting solutions* and *avoiding patient concern* acted as roadblocks to good



communication (Robertson, 2005). Attention to Robertson's roadblocks would have resolved the unfavorable references made by the patients studied.

## Discussion

### Research Findings

At the outset of this study we set out to discuss what we found within the stories told by cancer patients that contributed to their well-being and were of likely interest to medical and pastoral care professionals. This paper is derived from PhD research with wider findings than can be reported in a single journal article (Brown, 2015). Results of immediate relevance to the professionals are reported above and are shown in Figure 1. They reflect the diversity and interconnectedness that existed in the stories. Also, the fact that feelings and metaphor were so commonly expressed by patients contributed complexity in understanding what was influencing their well-being. Some words or metaphors could not be taken literally but were interpreted in the context of the story.

### Metaphor use

The results showed that a *war metaphor* was the commonest in use. This is consistent with findings by Ulrich Teucher (2003) who described common use of metaphor by cancer patients. He ranked the *war metaphor* as dynamic and tangible, penetrating both the external and internal existential domains. Susan Sontag (1979) also identified the war metaphor usage and cautioned against it. She saw that it had the potential to confuse or conceal the genuine experience of the patient. Catherine Czechmeister (1993) agreed with Sontag about the adverse effects of this metaphor use but saw some positive effects that were absent from Sontag's work. Catherine Czechmeister saw that people who fought back improved their well-being by gaining a sense of control. The general sense of our research was that the war metaphor is better avoided if well-being is considered. It was never the habitual life metaphor of any of our storytellers.

Teucher reported other clusters of metaphors which he named *intrusion*, *oppressive surroundings* and *growth inside*. Other metaphors found in our research included a bike race, a car ride, sliding on black ice and a journey.

Five references in the *worst part of having cancer* node stated that disregard of their metaphor or asserting the professional's personal metaphor affected the patient adversely. Although this is a small number of references, it is important to understand where the patient is emotionally and to act accordingly, and not to attempt to move the patient into a state that is more comfortable for the professional.

The evidence of this research is that patients were seen to experience enhanced well-being through the process of

telling their stories. The benefits to well-being were real, as indicated by our results above through the text coded to the nodes: *feelings*, *self-talk*, expressions of the *best part* of having cancer, and *meaning for life*. Such narrative therapy is reported in more general medical and spiritual literature. MacIntyre (1984) likens narrative for the author to a journey during which the meaning of life is revealed. The process of writing impacts strongly on the writer. Trisha Greenhalgh and Brian Hurwitz said that narrative by a person can reveal inner existential qualities such as hurt, despair, hope that can assist the process of healing (Greenhalgh & Hurwitz, 1999). The findings of our research are similar but raise a paradox.

### A Paradox

Most patients indicated that they told their story to help other people, evidenced by the *advice to others* parameter (86% of the patients said that they wrote to help others). Ramsey and Bleizner had written that reading positive narratives can provide both hope and inspiration for others (Ramsey & Bleizner, 1999). But there is a paradox here. A vast reservoir of good information exists because of the storytelling and yet the evidence is that very little of the advice is taken up (only three females and nine males took such advice). Why? This question can be answered if it is postulated that the very telling of the story contributes to the well-being of the patient. This conclusion is supported by researchers typified by John Kearsley, who wrote that narrative "alleviates suffering and promotes healing" (Kearsley, 2010). Further he urged that "listening proactively be recognized as a therapeutic tool."

This indicates that professionals wishing to enhance each patient's well-being through their care can do so by bringing a presence to the contact that results in active listening. Thomas Hart wrote that "listening is not always easy. It takes time, and the time may be inconvenient besides. It demands really being for the other during that period, fully present and attentive, one's own needs and concerns set aside" (Hart, 1980).

### Carer Take Care

The patient encounter during active listening can be psychologically laden for a pressured and/or fatigued and/or time poor carer. Our research showed that this focus on the patient in active listening, whilst good for the patient, ignores the person of the listener. Respect for the patient's metaphor too, resulting in sublimation of the carer's personal metaphor, can be extremely stressful for the carer. Austin Cooper described the reasonableness of keeping the length of the listening session within the attention span of both patient and professional alike (Austin Cooper, 2013, personal communication). A "fifteen minute" hour is recommended by Stuart and Lieberman

(1986). Halifax reminded us that the amount of time spent with the patient is less important than what transpires within that time (Halifax, 2008). Laurence Savett cautioned about “burnout” that can arise from compassion overload (Savett, 2007). Despite this ever-present risk of compassion overload, care professionals can enhance their personal well-being through the presence they bring to active listening. John Kearsley described a mutual healing effect on both storyteller and the listener (Kearsley, 2010).

## Limitations

Patients often forget to report the worst aspects of their cancer experience in their storytelling, especially when its purpose is to encourage others. Such potential omission was always in the forefront during the hermeneutic aspects of this research. It does not in any way invalidate or minimize any of the conclusions that were based on more positive aspects in the stories.

## Conclusion

From our research, cancer patients, help themselves and enhance their well-being through the process of telling their story. Medical radiations and pastoral professionals can contribute to such improved well-being: first, through providing the quality of presence needed for *active listening* which facilitates the patients to tell their story, and second, by providing communication that understands and respects each patient’s metaphor.

## Ethics

Every effort has been made to respect what the narrator intended cognizant of the warning of Gunter Eysenbach and James Till that these narrators (the cancer patients) did not expect to become research subjects when they published their stories (Eysenbach & Till, 2001). This was respected in the research and became a strength of the process because the content of the stories was not influenced by manipulations of the researchers. That noted, all stories existed in the public domain before this study commenced. The Ethics Committee of the University of Divinity considered this and gave approval for the research to proceed.

## Funding

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

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## Recovery of Soul in the Clinical Pastoral Movement



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