

## Narratives of Exceptional Survivors Who Work with Aboriginal\* Healers

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### ABSTRACT

**Background:** The commonalities are described of 47 people who sought traditional aboriginal healers for help with their cancer. All had 10% or less chance of survival at 5 years given the site and stage of their cancer from actuarial table calculations.

**Subjects and design:** The subjects were compared to a similar group of people who were also working with aboriginal healers and who did not survive past 5 years. Narratives were obtained from the people before and after their work with the healer. These stories were enriched through interviews with family members, friends, health care providers, and the healers themselves, whenever possible. Panels of naïve medical students, graduate students, patients, and health care providers were used to evaluate the stories and to pick themes that consistently emerged (dimension analysis). Once stable dimensions emerged, scenarios were developed to rate patients along these dimensions from “1” to “5.” New panels did the ratings, with at least 3 panels of 3 people per narrative. Comparisons were made between these 2 groups of people, and differences emerged on the dimensions of Present-centeredness; Forgiveness of others; Release of blame, bitterness, and chronic anger; Orientation to process versus outcome; Sense of Humor; Refusal to accept death as immediate prognosis; Plausible (to the patient, his or her family, and the healers) explanation for why he or she got well, including a story reflecting a belief about how he or she can stay well; Supportive community who believes in the person’s cure and protects the person from outsiders who think the person will die; People experience a quantum change, in which major improvements in self-esteem and quality of relationships occurs; and Spiritual transformation.

**Conclusions:** The 2 groups of people reported equal increases on the dimensions of Sense of Meaning and Purpose and Faith and Hope, which may be intrinsic to the style of healing of aboriginal elders.

### INTRODUCTION

Gotay et al.<sup>1</sup> have defined exceptional survivors as people who have survived at least 5 years with less than 25% actuarial probability of doing so, given their site and stage of cancer at diagnosis. They compared exceptional survivors of cancer to nonexceptional survivors with the same cancers and sites (but with greater than 25% actuarial probability of living 5 or more years), and with normative data

for the instruments used from the general population. They found that both types of survivors had high levels of well-being compared to the normative populations; cancer survivors exhibited higher levels of coherence and resiliency, but not optimism with few differences between the 2 types of survivors.

Widespread interest exists in “exceptional survivors” and how they come to be so. The conventional oncological argument holds that they are merely the end of the bell-shaped

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\*The term “aboriginal” is used (instead of “Native American” or “American Indian”) since the author works in Canada where the term is used for the original inhabitants of a place (as it is similarly used in Australia, New Zealand, and other British Commonwealth countries). This term is preferred by the people themselves, as is also the term First Nations people. “Native North American” would be clumsy and would have a different meaning within the British Commonwealth as a person born in North America, and not necessarily a descendant of one of the original inhabitants of North America.

curve and are not different psychologically or spiritually from any other survivor. O'Regan and Hirshberg<sup>2</sup> documented more than 1000 cases in which cancer apparently went into spontaneous remission. Some of these fascinating cases and others were described in a best-selling book 2 years later.<sup>3</sup> While it is difficult for some to understand how nonmedical healing might affect an organic disease such as cancer, these intriguing reports suggest this possibility. Survival is not necessarily of more importance than quality of life, but clear demonstrations of such an effect might compel us to consider changing our management of patients with cancer. The potential of the mind to influence the course of cancer is of theoretical interest, and any effects might apply to other chronic diseases.

Work with animal models has clearly shown a relationship between psychological determinants and tumor growth.<sup>4-6</sup> Research on the relationship of human personality to cancer has not yielded clear correlations.<sup>7</sup> Prospective studies have implicated a number of possible risk factors, the most consistent finding being repression of emotion or depression,<sup>8-14</sup> a conclusion disputed by Kreitor et al.<sup>15</sup> Other, larger studies have failed to show a connection between cancer and depression.<sup>16-18</sup> Factors that some have found to be protective include social support<sup>19-21</sup> (disputed by Funch et al.<sup>22</sup> and Cassileth et al.<sup>23</sup>), greater expression of distress,<sup>24</sup> smaller numbers of severe or difficult life events,<sup>25</sup> and fighting spirit.<sup>26</sup> Other investigators, however, have not found these relationships.<sup>23,27</sup> Fighting spirit, measured psychometrically, did not affect survival in a recent analysis of 578 patients done by Watson et al.<sup>28</sup>

Evidence from controlled trials of psychologic interventions is mixed. At the time of writing, there are 9 published trials with randomized, case-control, or sequential cohort designs. Four (4) showed a positive effect of an intervention on survival. In the best-known of these, Spiegel et al.<sup>29</sup> demonstrated an 18-month average prolongation of life in women with metastatic breast cancer who attended a weekly support group for up to 1 year. However, the control group in this experiment might have been anomalous, since, as pointed out by Fox,<sup>30</sup> its members died more rapidly than similar populations of patients who were not in therapy. Richardson et al.,<sup>31</sup> using a sequential cohort design, found significant effects of a psychologic intervention in patients with hematologic malignancies. Fawzy et al.,<sup>32</sup> in a randomized trial, similarly demonstrated a significant survival advantage to patients with malignant melanoma who had taken a brief, group psychoeducational course 6 years before. Ratcliffe et al.<sup>33</sup> found a small but marginally significant difference in survival of patients with lymphoma who received training in relaxation compared with randomized controls who did not.

All trials specifically designed to test effects on survival have given negative results. The first of these, by Linn et al.,<sup>34</sup> was a randomized comparison of the lifespan of patients who had a variety of late-stage cancers and who ei-

ther received or did not receive individual counseling (for an unspecified time). The second, by Morganstern et al.,<sup>35</sup> was a case-controlled study, which showed a nonsignificant trend in favor of longer survival in patients in group therapy. Two more recent studies were randomized clinical trials (RCTs) using interventions similar to those of Spiegel and of Fawzy, respectively. Cunningham et al.<sup>36</sup> gave 35 sessions of group-supportive and psychoeducational therapy to women with metastatic breast cancer: These subjects did not live significantly longer than controls. Edelman et al.<sup>37</sup> used a brief, 11-session, cognitive behavioral intervention that also failed to prolong the life of patients with metastatic breast cancer, by comparison with controls. One further published study, not designed to test for survival and with a weaker design, has also given negative results in a *post hoc* analysis.<sup>38</sup>

Further RCTs may eventually yield a consensus about the mean effects of psychotherapy on survival, although adequate experiments are likely to be large and expensive, especially since we do not know how to stratify subjects for such trials. We do not know the characteristics of patients who are susceptible to remarkable healing, psychologic, social, or genetic. Others have argued that qualitative data may be needed to detect a mind-cancer link.<sup>13,39-42</sup> This qualitatively based approach, although labor intensive, has a further advantage, in that it facilitates assessing complex constellations of variables (e.g., "Application to self-help work," which requires more than just listing behaviors, e.g., the individual's dedication or intensity of self-help work must also be captured).

The study of exceptional survivors could also shed some light on possible connections between efforts at mental self-help and cancer remission or prolonged survival and has a literature.<sup>43-49†</sup> The picture emerging from these studies is consistent with findings from Cunningham's<sup>50</sup> pilot work; patients who lived longer than expected were flexible, self-motivated, and usually reported significant changes in behaviors and attitudes. However, in all these accounts, patients were selected retrospectively, so that there was no way of knowing how many patients showed similar characteristics but failed to survive. All have other serious methodological defects as well: medical documentation was almost nonexistent, and in some cases subjects who had medically curable cancers were included. Most collected data were from a single interview only, usually years after recovery, and only 2 used standard qualitative methods. In recent years, there have been a number of randomized, controlled trials, which have yielded mixed results on psychologic interventions and cancer survival. In particular, all trials specifically designed to test the hypothesis that psychologic change prolongs survival have so far given negative results, suggesting that any effect that exists is likely to be small. Yet there is an accumulation of clinical experience pointing to the existence of a minority of patients with cancer who make strong efforts to help themselves psychologically and

appear to live longer than expected.<sup>43–46,49,51,52</sup> How can we reconcile this divergence between the inconsistent results of these trials and the clinical observations, or are the latter simply the result of therapists' desire to attribute efficacy to their interventions?

While there is still little known about the detailed mechanisms of cancer regulation, we can put forward a logical hypothesis. Any effects of the mind would necessarily act through neurological or endocrine pathways on biological response modifiers, such as immune mechanisms or cytokine activity that might, in turn, influence tumor progression.<sup>53</sup> It would follow that the size of effect on the regulators of cancer growth would reflect the degree of change at higher levels of the pathway, and ultimately, the degree of initial psychological change. We might therefore expect to see a relationship between the extent of work and change patients exhibit, and effects on tumor-retarding mechanisms, and hence lifespan.

This line of reasoning leads to a conclusion that is potentially important for studies on the possible prolongation of life by psychological therapies in patients with cancer. If only a small proportion of the patients in therapy group become strongly involved in trying to help themselves psychologically (as we observe), and theirs are the only lives substantially prolonged, this effect may be "diluted out" when group means are calculated. An RCT would thus need to be large to produce a reliable treatment effect (all so far published have been small).

In order to detect any subpopulation of patients whose psychological work leads to longer survival, we need to ask: "Is the way patients respond to therapy or treatment of any kind, particularly in their degree of involvement with proposed self-help strategies, related to duration of survival?" To know what to ask, we need to find long-term survivors who attribute their survival to nonmedical means and who would not be predicted to survive on medical grounds alone.

Because of the author's position as a connector between traditional aboriginal healers and people who wished to consult traditional aboriginal healers, his clinical practice provided a unique opportunity for accumulating stories of exceptional patients with cancer who used aboriginal healing as part of their path to wellness. This paper reports on some of these patients.

## METHODS

Since 1980, the author has been helping people who wish to work with traditional healers to find them. He has also done his own "neotraditional" healing work in the manner of traditional healers, but in a more modern context.<sup>54–56</sup> Stories from this work are not included in this series. Rather,

the author reports upon stories collected from patients in his practice for whom his primary role was supportive and to facilitate the patients in finding a traditional healer. Forty-seven (47) stories were selected of patients who met the definition of exceptional survivor. These people's stories were matched (for comparison purposes) with 47 patients who had cancers of the same site and stage, but who did not live 5 years.

A more stringent definition of exceptional patients was used than provided by Gotay et al.<sup>1</sup> in that people included had less than 10% actuarial likelihood of surviving 5 years given the site and stage of their cancer at diagnosis. This prediction was confirmed by 3 oncologists. Stories from the people themselves were enriched by the parallel accounts of family members and friends. Whenever possible, local health care providers were also contacted for further details of the story. Some of these exceptional patients were legendary in their community, often called upon as examples of healing.

Qualitative studies such as these cannot speak to the prevalence of such patients. When the author gives lectures, he finds that 25% to 40% of audiences know at least 1 person who has had a "miracle cure" from cancer. The author suspects that the so-called "outliers"—which these patients clearly represent—are more common than conventional medicine expects. Outliers may be especially more common outside of mainstream culture, where beliefs in the wisdom of conventional physicians are not so strong. The purpose of this paper is to report commonalities among these patients, understanding that this methodology provides no support for the argument of causality.

Questions asked to compile people's stories included (and were not limited to) the following:

1. Why do you think you developed cancer?
2. Do you think working with the medicine man (woman) helped you?
3. What do you think allowed you to get well?
4. What did the healer tell you to do?
5. What did the healer do with you?
6. Did you think it would work?
7. How do you explain your wellness?
8. What do members of your family think?
9. What do members of your community think?
10. What was your prior experience with Native American spirituality and ceremony before your work with the healer?
11. What has been your past exposure to spirituality? Religion? Ceremony?
12. How would you describe your past spiritual experiences? Have they been positive, neutral, or negative?
13. What role does spirituality and/or religion play in your life? What is your religion? How do you define spirituality?
14. Have you had any extraordinary or unusual spiritual experiences?

<sup>†</sup>Huebscher RR. Spontaneous remission of cancer. Ph.D. thesis. U.M.I. Dissertation Services, Ann Arbor, MI. 1992.

15. Have you ever had a period of intense suffering? When? How did you get over it?
16. When people talk about spiritual transformation, what do they mean?
17. Have you ever had a spiritually transforming experience? How about a peak experience? When was that? What happened?
18. Do you have a daily spiritual practice? What do you do?
19. What are your important relationships? Who do you love? Who loves you? Do you feel loved?
20. What do people mean when they talk about spiritual growth? In what areas would you like to grow?
21. Have you had any particular sensory experiences that seemed remarkable (visual, kinesthetic, olfactory, smell, etc.)?
22. How did your mental state change from when you were first diagnosed until today?
23. How did your sense of self change from diagnosis until now?
24. What did you think the healer was intending to do when he or she worked with you?
25. What was your favorite part of your work with the healer? Your least favorite part?
26. Did your sense of the sacred and what is sacred change? If so, how? How much?
27. Did your sense of how to pursue the sacred (your own particular path toward the sacred) change? If so, how? How much?

All people were followed at least 5 years after diagnosis or until the time of death, though in an important sense, the focus of this paper is upon the stories told and not the actual people themselves, for the raters had no access to the people, only to their stories.

## QUALITATIVE METHODS

### *Analytic method*

Schatzman's<sup>57</sup> (1991) grounded method of "dimensional analysis," as interpreted by Kools et al.<sup>58</sup> and Cunningham et al.<sup>50</sup> was used. The first 5 to 8 stories were used to develop a "vocabulary" of concepts or categories encompassing issues important to subjects from interviews. The key process in dimensional analysis is naming the main components and describing their various attributes ("dimensionalizing"). The goal is to cluster the final number of categories into a smaller number of dimensions. Prior knowledge is acknowledged as an important part of theory building in dimensional analysis, unlike the "blank slate" approach assumed in some grounded methods.<sup>59</sup>

The author wished for more of a "Wittgensteinian ordinary people" rating. Thus, stories were distributed at re-

treats, trainings, and workshops (with proper nouns changed so that the people could not be identified). Participants were invited to read the stories and identify what they thought were the major themes present. We discussed methods and prior work that had been done in the field, since we did not believe anyone could actually be a blank slate. Assessment was done by groups of 3–5 people with each story having at least 3 groups rate them. The work was done by patients with cancer, health practitioner students, and health practitioners meeting in workshops or retreats as part of the learning about the mind and cancer process. Twenty-four (24) such sessions were held. The 12 categories listed below appeared at least 70% of the time in different sessions and appeared stable. Other categories that appeared less than 70% of the time are not reported in this paper, although some were quite interesting. Consensus was reached in each session about the categories that the entire group believed to be relevant.

### *Rating of categories*

Once 12 stable dimensions had emerged, the same procedure was used to develop a quantitative rating of these dimensions, following examples in the text on qualitative data analysis by Miles & Huberman.<sup>60</sup> For each of the themes that emerged and that were suitable for quantitation, scenarios were written describing the patterns of behavior and thought that qualified for a score of "1," "3," or "5" on a five-point scale. The scenarios were developed in the same manner as the dimensions. Ratings of "2" and "4" were applied when data fell between scenarios. Once consensus had been reached on rating scenarios, they were applied in future sessions by participants until all stories had been rated on all 12 dimensions with at least three groups rating the stories at least three times.

### *Reliability and validity of the process*

*Reliability.* Once scenarios were developed, inter-rater reliability by members of each team remained above 0.7 for each dimension and between teams above 0.75. This happened readily without training and was related to the scenarios being clear and being developed by ordinary people

TABLE 1. AGE RANGES OF PEOPLE FINDING "MIRACLE CURES"

<i>Age range</i>	<i>Number of exceptional survivors</i>
20–29	12
30–39	23
40–49	30
50–59	29
60–69	2
70–79	1
80–89	2

TABLE 2. SUMMARY OF PATIENTS WITH CANCER

<i>Type of cancer</i>	<i>Number of patients</i>	<i>Average years disease free</i>	<i>Average years to death nonsurvivors</i>
Lymphoma	4	9	3
Metastatic breast cancer	12	9	3
Prostate cancer	4	5	3
Metastatic ovarian cancer	4	17	1
Malignant melanoma	1	5	4
Colon cancer	9	14	4
Brain cancers (glioblastoma, astrocytoma)	7	6	1
Esophageal cancer	1	13	2
Lung cancer	2	11	1
Pancreatic cancer	1	21	1
Multiple myeloma	1	6	4
Non-Hodgkin's lymphoma	1	12	3
Total cancers	47		

over multiple passes. The rating scenarios are available upon request.

**RESULTS**

The modal age range of the patients interviewed was the fifth decile of life (ages 40–49; Table 1). Patients came from a wide range of cancers (Table 2).

The theoretical categories that emerged as potential candidates for explanatory factors for these patients dramatic outcome are the following:

1. Present-centeredness.
2. Forgiveness of others.
3. Release of blame, bitterness, chronic anger.
4. Acceptance of death.
5. Humor.
6. Reduced attachment to outcome versus commitment to a process of life change, with resulting increase in sense of life-meaning and dignity.
7. Faith and hope in something.
8. Refusal to accept death as immediate prognosis.
9. Plausible (to the patient, his or her family, and the healers) explanation for why he or she got well, including a story reflecting a belief about how he or she can stay well.
10. Supportive community who believes in the person's cure and protects the person from outsiders who think the person will die.
11. People experience a quantum change, in which major improvements in self-esteem and quality of relationships occurs.
12. Spiritual transformation

TABLE 3. COMPARISONS BETWEEN EXCEPTIONAL SURVIVORS AND NONSURVIVORS FOR RATING SCENARIOS OF IDENTIFIED DIMENSIONS IN THEIR STORIES

<i>Identified dimension</i>	<i>Rating for exceptional survivors</i>	<i>Rating for nonsurvivors</i>
1. Present-centeredness*	3.8 (0.8)	2.8 (0.9)
2. Forgiveness of others*	4.1 (0.9)	2.0 (0.4)
3. Release of the past*	2.7 (0.7)	1.6 (0.6)
4. Process orientation*	4.4 (2.0)	3.4 (2.5)
5. Humor*	3.4 (0.8)	1.9 (0.3)
6. Life-meaning and dignity	3.6 (1.0)	3.2 (0.5)
7. Faith and hope	3.0 (0.9)	3.1 (1.0)
8. Refusal to accept death*	4.3 (0.3)	3.3 (0.7)
9. Plausible explanation*	3.2 (1.0)	1.9 (1.1)
10. Supportive community*	3.1 (0.9)	2.0 (0.9)
11. Quantum change*	3.0 (0.8)	1.8 (1.0)
12. Spiritual change*	3.2 (1.0)	1.8 (0.8)

\*Denotes statistical significance of at least  $p < 0.05$  and standard deviations are included in parentheses.

Review of the life stories of 50 patients with cancer who died did not reveal anywhere near the same degree of these qualities, lending possibility to the hypothesis that these may be attributes of the "states of mind" that are most compatible with "miracle cures."

Dimensions were identified that were different between the two groups. Two (2) dimensions were not different among the two groups and are probably at the heart of aboriginal healing regardless of outcome: meaning and dignity and faith/hope. The survivors seemed more present-centered, forgiving, disconnected from their past, and humorous. They had more plausible explanations to both self and community for why they healed, had more supportive communities, changed more, and had more spiritual change. That naïve raters could identify these differences is important.

## CONCLUSIONS

These results are preliminary and constitute more of a pilot study to guide further investigation than a definitive answer to the mind-body problem in cancer. These findings suggest that raters can read stories and identify differences between exceptional survivors and nonsurvivors, all of whom were working with traditional aboriginal healers. This suggests that exceptional survival could involve a change in these attributes that could be called healing and could be nonrandom, though the frequency cannot be assessed. Further research should be undertaken to determine whether stories and their qualitative analysis could be used prospectively to identify longer-term survivors and discriminate them from shorter-term survivors.

These data provide preliminary support for the argument that states of mind/relationship are associated with lengthened survival. The actual dimensions identified, however, may not be as important as the gestalt impressions that the raters made and assigned to the dimensions as the best way they knew to convey their impressions. In other words, the stories may contain more richness than the raters intuitively used than the dimensions identified would suggest.

Belief in the plausibility of the explanation for survival seemed particularly important. Roberts et al.<sup>61-63</sup> concluded that if both patient and physician believed in the effectiveness of a treatment, outcomes closely approximate one third excellent results, one third good results, and one third poor results. Belief in treatment and plausibility of the story about how the cure occurred are both important preliminary proposed variables for the state of mind associated with healing. Roberts studies of biologically ineffective treatments in which patients and doctors believed showed combined average reported effectiveness of 40% excellent results, 30% good results, and only 30% poor results, for a mean total of 70% positive outcomes.

Miller and deBaca<sup>64</sup> have proposed that quantum change is important for dramatic physiologic changes. Quantum changes are sudden, permanent, major shifts that sweep

through the whole life of a person. Native American healing philosophy teaches that such quantum changes are often necessary to change the tide in a patient who is deteriorating. Participation in ceremony can be one catalyst of quantum change.

The faith and hope of most persons covered in this study rested in spiritual resources and supernatural beings, along with their faith in the skill of the traditional healer. Spiritual healing has remained an untapped resource in our health care even though research has begun to document its effectiveness.<sup>65</sup>

One could call the treatment that took place "spiritual healing." Spiritual approaches are not completely foreign to the American mainstream. They are frequently used in the treatment of addiction disorders. Among patients suffering from depression, those receiving a spiritually oriented therapy had better scores on measures of post-treatment depression and life adjustment than did those whose treatment did not include a religious content.<sup>66</sup> Patients' religious commitment has been shown to improve their treatment outcomes and recovery rates, decreasing their length of stay in hospitals, and reducing the need for costly drugs or follow-up care. Recovering schizophrenic patients who attended church or were given supportive aftercare by religious caregivers had lower overall rates of rehospitalization.<sup>67,68</sup> Patients with hip fracture who are religiously committed have been found to suffer from less depression after their injury and recover more rapidly than patients with lower levels of religious commitment.<sup>69</sup>

Among 232 patients undergoing elective heart surgery, 6 months later, 9% had died.<sup>70</sup> None of the 37 who described themselves as deeply religious before surgery had died. Although only 5% of those who attended church as infrequently as every few months died after the operation, 12% of those who rarely or never attended church died during the same 6 months after their operation.

Thus, traditional spiritual healing could have played a role in helping these people to become exceptional survivors. Further study is indicated.

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