

Peer Mentoring and Survivors' Stories for Cancer Patients: Positive Effects and Some Cautionary Notes

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INTRODUCTION

Providing patients with adequate information produces better medical outcomes, less distress, higher quality of life, and better preparation for active involvement in treatment¹⁻³—benefits that have energized research on the effective delivery of information to patients. For the most part, this research has focused on information and statistics relevant to treatment and prognosis.⁴ However, patients are increasingly coming into contact with another form of information about which little is known—namely, information describing the experiences of fellow cancer patients, or experiential information. For instance, the Internet makes this information available through patient-oriented chat rooms, bulletin boards, and a growing number of popular Web sites featuring survivors' stories, case studies, and testimonials. Apart from the Internet, patients learn about other patients' experiences in the popular media and through peer mentoring or buddy programs made available by treatment centers or cancer organizations. These programs enable patients to receive encouragement, support, and guidance from people with first-hand knowledge of the difficulties and fears they may be experiencing. Peer mentors may, or may not, be formally trained and are free to share any aspect of their experience they deem helpful, including information about their treatment decisions, effects of treatment, coping strategies, and recovery obstacles. In so doing, they attempt to communicate both factual information and information about normal or desirable ways to respond to cancer.

Generally speaking, patients like getting experiential information, and many former patients enjoy providing it. At the same time, the informational content of peer mentoring and survivors' stories has the potential to influence patients in significant ways. Yet little is known about how patients use this information or how it affects them. When does it give them hope, and when does it frighten them? Does it facilitate, or com-

plicate, decision making? Under what circumstances is it helpful versus harmful?

To begin investigating the answers to such questions, cancer patients' responses to interview questions assessing how they communicated their thoughts and emotions during treatment were analyzed. Participants consisted of 20 men and 10 women completing a screening protocol for a multisite trial testing a psychological intervention for hematopoietic stem-cell transplant (HSCT) survivors. All study procedures were approved by the institutional review boards at the study sites, and patients provided signed informed consent. All patients had undergone HSCT 1 to 3 years earlier to treat hematologic malignancies such as multiple myeloma, lymphoma, and leukemia, and all were English speakers who were at least 18 years old at recruitment and at least 16 years old at transplantation. They were, on average, 54 years old, married ($n = 25$), white ($n = 25$), and well-educated (22 had college or graduate degrees). Most ($n = 25$) reported an annual household income of more than \$80,000. Content analysis⁵ of their responses to interview questions identified 10 functions of communication. Of the four most commonly mentioned functions, three prominently featured contact with other patients and/or exposure to information about their experiences: preparatory coping, social comparison, and negative effects. This article focuses on results involving these three functions of communication because of their relevance for understanding the effects of experiential information on cancer patients.

PREPARATORY COPING: KNOWING WHAT TO EXPECT AND HOW TO COPE WITH IT

Patients most often described how learning about fellow patients' experiences helped them prepare for transplantation. Experiential information was usually received directly from HSCT survivors before transplantation, and it supplemented information provided by the health care team. Patients specifically discussed learning about people's day-to-day experiences on the transplant unit, physical and

emotional effects of transplantation, treatment decisions, and coping strategies. Many patients who did not have access to this information wished they had. For instance, one man diagnosed with lymphoma and multiple myeloma discussed how experiential information would have helped him, “At the very beginning, I was frightened and I was confused, and we didn’t know what course to take. . . . If I had more knowledge of what the disease was or what other people had experienced, it would have been very helpful. . . . To know what route or what choices. . . were there for me, . . . and to know that really I personally didn’t have to be afraid.”

Of course, each person’s experience with cancer is different. Some patients commented that its variety was a positive feature of experiential information—they felt that hearing about many people’s experiences would help them understand the range of difficulties they might encounter and options they might not have otherwise considered. Conversely, several patients felt that hearing about other people’s experiences would not be helpful because of their differences. Thus, as with other forms of information,⁶ patients differed in their desire for experiential information, and some understood that a single patient’s experience would not necessarily be informative for understanding their own situation.

Patients who spoke with fellow patients most often found them through informal networking with friends, family, or acquaintances. It appeared that these contacts were strongly desired, but not readily available through formal channels. One woman with multiple myeloma described how she sought a fellow patient’s perspective on HSCT, “I did talk to someone who had it—a friend of my husband’s who worked with him. . . . I would tell him how I’m feeling. He would say, ‘Yeah, you’re going to feel this way and then you’re going to get better. It goes away. You’re going to eat this. You’re not going to feel like eating that.’ I spoke with him, and that helped a lot.”

A man with multiple myeloma was particularly adept at making contacts, “My daughter gave me the name of a doctor that was diagnosed 2 years previously with multiple myeloma. So I got in touch with the doctor and his wife over the phone, and he gave me someone else’s name, and I got in touch with that person. And then someone at work gave me the name of someone else, and I got in touch with that person. When we went to the conference last year [held by the Multiple Myeloma Foundation], I met other patients, and I’ve been in contact with them to find out what their experiences were and how they’re dealing, and what their protocol is now.”

Several patients discussed how experiential information helped them make treatment decisions and frame questions for their health care providers. For instance, a man with non-Hodgkin’s lymphoma described how it made him aware of treatment options and helped him feel less overwhelmed by the need to make a decision that could affect his survival, “When you are first considering going through such a procedure, you come in. . . with almost no experience to lean on, to understand, to anticipate what is going to happen to you. You read terrible statistics about mortality and. . . morbidity rates, you read about graft versus host disease. . . You end up. . . playing the odds with your own life and making a decision [about what kind of procedure to have] or, indeed, whether to have the procedure at all. . . . So you’re taking this incredible risk with your life, with your body, and—I think it was on reading further and learning, for instance, about. . . my friend who had a mini [transplant]—but I came to understand that there were other alternatives. It wasn’t just either this or the [autolo-

gous] procedure. . . So it was from reading people’s experiences [with HSCT] that helped me to prepare for the decision.”

Like this man, some patients turned to books, magazines, pamphlets, and the Internet for written descriptions of other patients’ experiences. Several books were mentioned repeatedly, perhaps because materials featuring patient experiences were scarce—especially patients with the same diagnosis. These patients’ use of the Internet is consistent with reports that it is an increasingly important source of cancer-related information.⁷ At the same time, experiential information found on the Internet was sometimes viewed as frightening.

Several patients had not had access to experiential information, but felt that, if they had, it would have helped them realize that HSCT was not going to be as bad as they feared. One woman with non-Hodgkin’s lymphoma said, “If you read about what people go through. . . you know what to expect. When you don’t know, it just feels like there’s this big thing coming around the corner and you don’t know what it is. I think I over-hyped myself, thinking that it was a scarier thing than it really was. There were some nights when I was pretty—you know, when I wasn’t feeling good. But it wasn’t as bad as I expected. I expected it to be much worse than that.”

Clearly, these were patients with good outcomes who were commenting retrospectively. Yet it was common for patients to discuss how learning about others’ experiences helped reduce their uncertainty and distress. Taken together, patients’ descriptions of the emotional and informational value of experiential information before transplantation suggest its promise for supplementing information routinely given to cancer patients as they prepare for treatment.

SOCIAL COMPARISONS: KNOWING WHERE YOU STAND IN RELATION TO OTHERS

In addition to helping patients prepare for HSCT, patients described using experiential information as a basis for social comparisons—gaining a better understanding of threatening situations by comparing oneself with others.⁸ Consistent with reported effects of upward comparisons (comparisons with people perceived to be better off),⁹ patients viewed those who had successfully navigated treatment as role models and derived a sense of hope from their survival. The following comment by a woman with non-Hodgkin’s lymphoma illustrated how both one-on-one interactions and written materials were helpful in this regard: “‘Hey, look, this person’s writing about it, so they survived.’ Just that alone—just that—opens the door. This is a survivor here. Wow. And that gives you a kind of fuel to go to the next step. I think that’s very empowering. . . I mean, this is what they have those survivor meetings for, and this is what I know I take away from these celebrations. . . . Gene Wilder was at two out of the three I attended. . . He’s a little ahead of me. But again, these are all the impetuses to keep going. I mean, wow, look at all these people. They’re here. It gives you a lot of courage, and you know, ‘Hey, I can do this. They did it.’”

Upward comparison was a flexible strategy sometimes used in seemingly unlikely situations. For instance, a woman with multiple myeloma commented that a fellow patient who was ostensibly communicating discouragement was nonetheless a source of hope, “If I sit in the doctor’s office and I see somebody who says, ‘I have been coming back and forth for 10 years with this,’ they think they’re

discouraging me. But what they're really doing is making me feel good. I'm saying, 'They lived 10 years after this. That's great!'"

Patients also mentioned people who were worse off, usually in conjunction with comments on how they felt fortunate in comparison (downward comparisons).⁹ For instance, a man with lymphoma and multiple myeloma stated, "As much as I have gone through, I always see somebody that has had it worse than I have."

Some patients reported a profound sense of isolation and described how simply knowing about others' experiences helped overcome this feeling. Their reactions illustrate how experiential information can help normalize the cancer experience and provide patients with the comforting sense that they share common bonds with others.^{10,11} These experiences were particularly powerful when the other person had the same diagnosis, as described by a woman with amyloidosis who attended a survivor's meeting, "I don't normally go to stuff like this. . . but I was singularly and strongly motivated because I never met another human being with this particular disease and I wanted to so badly. I said, 'Does anybody here have amyloidosis?' I couldn't believe I did that, but I needed to do that. . . Four women said, 'We do.' Well, I became paralyzed to this spot. Tears rolled down my face, and I couldn't speak. As I am speaking to you now, tears are flowing now. I was so deeply connected to them. I never saw any one of them in my life. I had no idea where they came from, how badly sick they were, or what, but I knew that they had gone through this thing. . . Yet somewhere deep inside my heart there was a need to connect with somebody. . . Now, I didn't need to find out anything about their lives, just that they had been there too, and they hugged me."

These findings suggest that experiential information may help address the isolation reported by some cancer patients, while at the same time helping them maintain hope and discover positive aspects of their situation. Research suggests that providing cancer patients with experiential information that enables social comparisons can also increase their self-efficacy, validate their emotions, and increase their subjective understanding of cancer treatment.^{10,12} Yet, social comparisons can also have negative consequences—upward comparisons can be threatening and downward comparisons frightening.⁹ Thus, providing experiential information to patients could backfire unless guided by empirical evidence clarifying circumstances under which it is helpful versus harmful.

NEGATIVE EFFECTS OF EXPERIENTIAL INFORMATION: WHAT CAN GO WRONG?

A substantial minority of patients (23%) mentioned situations in which learning about experiences of fellow patients was unhelpful or even harmful, highlighting potential pitfalls of experiential information beyond those involving social comparisons. Patients who thought it was unhelpful usually commented that others' experiences would differ from their own and thus be uninformative. Harmful effects fell into two categories: stories that were distressing or stories that communicated what patients felt was harmful information. For instance, several patients reported distress after hearing about enduring negative adverse effects (although other patients stated they wanted to know everything). Patients also mentioned being distressed by discouraging communications. One man diagnosed with lymphoma described the following interaction, "I even talked to a neighbor who

had lymphoma and had a transplant. . . She scared me half to death. She just said, you know, 'This is going to haunt you forever' . . ."

An example of information that was perceived to be harmful—in this case, because it seemed to encourage nonadherence—was described by the same man, "Some of the people I talked to had very weird views. Like they said, you know, 'I never went for any of the consolidation. I stopped taking the medicine afterwards.' I think that's a detrimental thing to tell people, because I think those are things you need to do. I wouldn't want to give that as advice."

In this study, patients who reacted negatively to experiential information also appeared to restrict their exposure to medical information, consistent with reports that some cancer patients prefer limited information about their situation, in general.⁶

Although few patients mentioned instances in which experiential information directly influenced their behavior, its effects on adherence, decision making, and self-care may be subtle. For instance, it could affect patients' expectations about cancer or its treatment,¹³ or it could alter their beliefs about what constitutes normal or effective behavior.^{14,15} Indeed, a recent study of prostate cancer patients illustrates its potential impact. Study findings suggested that patients' treatment preferences were more strongly influenced by fears, misconceptions, and anecdotes about other patients' experiences than by population-based information.¹⁶

FINAL THOUGHTS

Experiential information affects cancer patients in a variety of ways, all of which appear to be made more powerful by the strong emotional bond they feel with others who have, like them, been treated for cancer. It is generally welcomed by patients, as is reflected in the positive effects they report. It helps them feel more prepared for treatment and decision making, reduces their fear and uncertainty, gives them hope, forges common bonds, and allows them to feel fortunate in comparison to others. These outcomes suggest that experiential information may be a promising way to supplement medical information. However, there is currently little empirical evidence to guide its provision. The need for such research is made more critical by evidence that experiential information can have negative effects, as well as its increasing availability of experiential information outside of the formal treatment environment, where its effects are difficult to determine or control.

A lingering question is this, if experiential information is so important, why has this fact not been more apparent in studies of the information needs of cancer patients? First, it is noted that the benefits of peer contacts are recognized in the context of social support provided by peers and within support or self-help groups. However, although the supportive functions of peer contacts are recognized, their use as an informational resource is not well-recognized, and their effects in that regard are not well-understood. One reason for the relative lack of attention given to the informational value of experiential information may be that survivors' stories and advice are not viewed by health care professionals, researchers, and patients as information, as such, or even as something the medical community can or should provide in the course of clinical care. To the extent that experiential information is not viewed as falling within the purview of clinical care, researchers' broadly worded questions assessing patients' need for information will not capture their need or desire for

experiential information. A related point is that measurement instruments used in research may not capture the spectrum of patients' needs because the domains assessed are limited by implicit definitions of information held by researchers. Regardless of whether patients and their health care providers think of experiential information as information, however, the current results demonstrate that it serves that function for many patients.

Our intention in presenting these results is to draw attention to this understudied—but increasingly available—form of information. There are potentially three broad benefits of empirically guided provision of experiential information. First, it could give patients a more complete and vivid sense of what they may experience during treatment and recovery, thereby enhancing their self-efficacy for coping with treatment and promoting their active involvement (eg, by helping them formulate questions for their health care team). Second, it could provide therapeutic benefit by normalizing patients' experiences and giving them a sense of predictability, control, and hope. Third, it may address patients' need for information about survivorship and psychosocial issues—central concerns covered relatively poorly by existing approaches.¹⁷ If guided by research, experiential information could have a positive and powerful influence on patients' fears and beliefs about cancer, which could translate into behaviors important to survival and quality of life.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The authors indicated no potential conflicts of interest.

REFERENCES

1. Devine EC, Westlake SK: The effects of psychoeducational care provided to adults with cancer: Meta-analysis of 116 studies. *Oncol Nurs Forum* 22:1369-1381, 1995
2. Meyer TJ, Mark MM: Effects of psychosocial interventions with adult cancer patients: A meta-analysis of randomized experiments. *Health Psychol* 14:101-108, 1995
3. Mossman J, Boudioni M, Slevin ML: Cancer information: A cost-effective intervention. *Eur J Cancer* 35:1587-1591, 1999
4. Rutten LJ, Arora NK, Bakos AD, et al: Information needs and sources of information among cancer patients: A systematic review of research (1980-2003). *Patient Educ Couns* 57:250-261, 2005
5. Krippendorff K: *Content Analysis: An Introduction to Its Methodology* (ed 2). Thousand Oaks, CA, Sage, 2004
6. Miller SM: Monitoring versus blunting styles of coping with cancer influence the information cancer patients want and need about their disease: Implications for cancer screening and management. *Cancer* 76:167-177, 1995
7. Madden M, Fox S: Finding answers online in sickness and in health. Washington, DC, Pew Internet and American Life Project. www.pewinternet.org/PPF/r/183/report_display.asp
8. Festinger L: A theory of social comparison processes. *Hum Relat* 7:117-140, 1954
9. Taylor SE, Lobel M: Social comparison activity under threat: Downward evaluation and upward contacts. *Psychol Rev* 96:569-575, 1989
10. Wortman CB, Dunkel-Schetter D: Interpersonal relationships and cancer: A theoretical analysis. *J Soc Issues* 35:120-155, 1979
11. Helgeson VS, Mickelson KD: Motives for social comparison. *Pers Soc Psychol Bull* 21:1200-1209, 1995
12. Bennenbroek FTC, Buunk BP, Stiegelis HE, et al: Audiotaped social comparison information for cancer patients undergoing radiotherapy: Differential effects of procedural, emotional and coping information. *Psychooncology* 12:567-579, 2003
13. Rotter JB: *Social Learning Theory and Clinical Psychology*. Englewood Cliffs, NJ, Prentice Hall, 1954
14. Bandura A: Vicarious and self-reinforcement processes, in Glaser R (ed): *The Nature of Reinforcement*. New York, NY, Academic Press, 1971, pp 228-278
15. Cialdini RB, Trost MR: Social influence: Social norms, conformity, and compliance, in Gilbert DT, Fiske ST, Lindzey G (eds): *The Handbook of Social Psychology* (ed 4). New York, NY, McGraw-Hill, 1998, pp 151-192
16. Denberg TD, Melhado TV, Steiner JF: Patient treatment preferences in localized prostate carcinoma: The influence of emotion, misconception, and anecdote. *Cancer* 107:620-630, 2006
17. Baile WF, Aaron J: Patient-physician communication in oncology: Past, present, and future. *Curr Opin Oncol* 17:331-335, 2005