

Advice to patients undergoing stem cell transplant: Content analysis of survivor peer support narratives

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Abstract

Hematopoietic stem cell transplant survivors often share advice with patients undergoing this difficult treatment. We content analyzed narratives written by 59 transplant survivors given the opportunity to share advice with patients. Analyses described categories of advice they shared and evaluated their perceptions of the helpfulness of advice they had received. We found nine advice categories and evidence for variation in their perceived helpfulness, especially for advice to “be your own advocate,” “have someone you can rely on,” and “think positive.” Findings suggest the need to investigate how seemingly innocuous advice can be unhelpful and potentially distressing to some patients.

Keywords

content analysis, hematopoietic stem cell transplant, peer support, survivors’ advice, written narratives

Hematopoietic stem cell transplant (SCT) saves the lives of many hematologic cancer patients; however, many face painful and potentially life-threatening side effects, lengthy hospitalization, and a prolonged recovery with ongoing potential for complications (Blume and Krance, 2004; McQuellon and Andrykowski, 2009). Patients receive substantial information about transplant by their healthcare teams during treatment (Blume and Krance, 2004), but many seek additional information, especially from SCT survivors who can provide insight into the day-to-day experiences of SCT (i.e. peer support) (Blume and Krance, 2004; Rini et al., 2006).

Research on peer support benefits (Campbell et al., 2004; Dakof and Taylor, 1990; Hoey et al., 2008) suggests that it is a rich informational and supportive resource. Although some of this

information is provided in interpersonal interactions (e.g. in peer support programs), written narratives—in which survivors share experiential information, advice, and encouragement—are also common. Patients often seek written narratives of personal experience with illness and pass their experience to others in the form of written advice, particularly given the growing

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popularity of websites that allow patients both to seek and produce health information (Hardey, 2001).

Research indicates that SCT recipients highly value information and advice from SCT survivors. Learning about others' experiences with SCT can help them prepare for their own treatment and recovery, including potential problems not communicated by healthcare teams and possible ways to cope with them. Information from SCT survivors can also help SCT recipients manage uncertainty and distress, make treatment decisions, and communicate with their providers (Rini et al., 2006).

These potential benefits can only be realized if the content of written SCT survivor narratives is truly helpful. Yet, research suggests that information SCT survivors choose to share with others might not always be perceived as helpful and might be viewed as misleading, confusing, or distressing (Dunkel-Schetter et al., 1992; Goldsmith and Fitch, 1997; MacGeorge et al., 2008; Rini et al., 2006).

Variation in possible responses to SCT survivor narratives warrants additional research to guide development of methods to reduce harm and enhance potential benefits of peer support. A critical first step in understanding the potential for written SCT survivor narratives to serve as a beneficial resource for SCT recipients is to understand what kinds of advice survivors choose to share in their writing and, subsequently, what kinds of information are experienced as helpful or potentially harmful.

Accordingly, the goals of this study were twofold. The first was to describe types of advice that SCT survivors shared with SCT recipients when offered a chance to write a narrative to help others prepare for this treatment. Findings address the dearth of research on the content of advice that SCT survivors share with others in written peer support. The second goal was to evaluate the extent to which survivors differed in their perceptions of the helpfulness of various kinds of advice they received and wrote about in their narratives. We specifically explored whether some pieces of peer advice were commonly described in positive terms

(i.e. perceived as helpful), whereas others were described as potentially distressing.

Materials and methods

Participants and procedures

We content analyzed narratives written by 59 SCT survivors who completed a randomized control trial of a psychosocial intervention (Rini et al., 2014). Parent study participants ($N=315$) were English-speaking adults who had a successful SCT within 9 months to 3 years and who had at least mild survivorship problems in at least one of four domains: general distress (Derogatis, 1993), cancer-specific distress (Horowitz et al., 1979), health-related quality of life (Cella, 1997; McQuellon et al., 1997), and purpose in life (Scheier et al., 2006). Exclusion criteria are as follows: current substance abuse disorder, active psychosis, active suicidal ideation, or significant cognitive impairment. All parent study participants completed a baseline assessment that gathered information about sociodemographic and medical characteristics and psychosocial factors. Next, they were randomized into four groups. Participants in each group completed four brief structured writing sessions over 4 weeks, following group-specific instructions to describe their SCT experience. Data for the present study came from the last writing day (day 4) of two groups who were given the same instructions: to write an account of their SCT experience, including advice and encouragement they wished they received prior to their own transplant and thought would help others preparing for SCT. The other two writing groups wrote for themselves rather than writing narratives to share with others. The procedures were approved by the Institutional Review Boards at all sites.

Analysis strategy

We conducted an iterative, data-driven analysis to explore advice survivors shared in written narratives. We initially developed a topical codebook in a broad content analysis of all narratives from the four writing groups ($n=980$). Example codes

Table 1. SCT survivor sample characteristics (N=59).

	%	M (SD)
Sex: female	63	
Age (in years)		53 (13)
Race/ethnicity: non-Hispanic White	85	
Education: completed 4-year college degree or higher	66	
Type of transplant		
Allogeneic	54	
Autologous	46	
History of graft versus host disease (GvHD)	42	
Number of non-GvHD SCT complications		2.68 (1.7)
Months since transplant		20.7 (8.61)
Number of medical comorbidities		1.02 (1.12)

included “challenges” and “presence of direct advice.” Two coders (including the first author, YS) applied these codes to the narratives. For this study, YS read through writing day 4 narratives from the two targeted groups if they were previously coded as having a high amount of helpful advice, because these were particularly rich examples of advice that survivors offer. To be included in this “high advice” category, narratives had to meet two criteria as independently determined by the two coders: (1) a response of “yes” to the question, “Is direct advice given in the writing sample?” and (2) a response of “a lot” to the question, “To what extent would a reader learn something helpful from this writing sample, because of direct advice?” YS made line-by-line comments related to advice on 12 “high advice” narratives using ATLAS.ti 7.5 software. We used these comments to develop an inductive, data-driven codebook to capture recurring themes related to advice. YS then systematically coded 14 more “high advice” narratives until we determined that we had reached thematic saturation (the point at which new information ceased to emerge) (Morse et al., 2008).

To ensure there were no systematic differences in the type of advice offered by survivors in the “high advice” narratives versus other narratives, we coded a random sample of 25 percent of writing day 4 narratives from the two targeted groups that were previously coded as having any advice ($n=33$). We examined the coding results for code frequency and co-occurrence and used

these analyses to develop broader encompassing categories to describe common categories of advice. This exercise produced nine categories, which we label below using in vivo codes—survivor’s own words.

Results

Table 1 summarizes characteristics of the 59 participants. They averaged 53 years old (range: 19–79 years), comparable to parent trial participants ($M=54$ years) (Rini et al., 2014). Most were women, non-Hispanic White, and had completed a 4-year college education, also reflecting the parent trial’s sample. Over half underwent allogeneic SCT (i.e. using stem cells from a donor), and had undergone transplant less than 2 years prior to completing the study, on average. Their narratives averaged 569 words in length (range: 135–1343; $SD=256$).

We discovered nine advice categories that survivors frequently shared: (1) “Be your own advocate”; (2) “Have someone you can rely on”; (3) “Show compassion toward others”; (4) “Think positive”; (5) “Take things one step at a time”; (6) “Identify things that bring you peace”; (7) “Exercise”; (8) “Follow guidelines”; and (9) “It gets better.”

“Be your own advocate”

The most common advice ($n=36$) concerned the need for SCT recipients to advocate for

themselves by asking questions, getting second opinions, and asking for help. One woman wrote, "Be as involved in your own care as you can be. Gives you some ownership with what's going on, more in control instead of at someone's mercy" (P1, 58-year-old woman).

Six survivors described the importance of a second opinion:

Seek second and third opinions, and fast. Demand attention. Demand information. If you don't understand, ask again. If something doesn't sound right to you, ask someone else ... seek until you have all the answers you need to make informed, smart choices that support you and your health. (P3, 44-year-old woman)

This survivor expressed the belief that patients should play an active role in becoming informed about SCT.

Many survivors ($n=27$) wrote about how important it was to be knowledgeable about the disease, transplant, and recovery and how that knowledge helped them feel in control. One writer articulated that knowledge about her illness and treatment assuaged her anxiety, because she knew what to expect (P5, 44-year-old woman). Although survivors wrote about how "knowledge is power," a few ($n=4$) offered the caveat that information can also scare patients:

Be prepared. Read the materials you're given pre-transplant. Knowledge is a powerful weapon against fear. However, don't read too much! Searching online and for other materials can often be misinterpreted and downright scary. Stay away from that. (P6, 66-year-old man)

One woman implied that certain information such as mortality rates can be scary, but she offered a way to cope with it:

After you've learned the numbers and used them to make a plan, turn your back and completely ignore the numbers. There is only one number that matters to you: YOURS. You will experience either a 100% or a 0% survival rate. There is no such thing as an 80% survival. That's just a number. (P3, 44-year-old woman)

These quotes demonstrate the variability in how SCT survivors described advice about advocating for themselves; some wanted as much information as possible and others wanted only some kinds of information.

"Have someone you can rely on"

Survivors ($n=31$) wrote about how others were critical to their well-being during treatment and recovery. One survivor was thankful that her friend accompanied her to post-transplant appointments. Another noted that SCT recipients need emotional support during recovery, saying, "A good partner in this is very important. Someone who can listen to you when chemo makes you sick, or laugh with when your hair falls out" (P8, 65-year-old man).

In all, 13 survivors mentioned how important it was to talk to other SCT recipients, saying they provided information and helped them feel less isolated. One survivor communicated that other SCT recipients helped her feel supported above and beyond what loved ones could provide. Another elaborated on this distinction,

The most valuable help I received, besides the love of my family, was the support I got through online support groups ... I received mounds of encouragement from others who knew exactly what I was going through, and a ton of knowledge as well. It gave me a place to go where I was not the 'sick one' in a group of well people. I was not the 'outsider' in this group. It also allowed me to ask difficult questions, talk about my fears and vent without putting added stress on my family. (P5, 44-year-old woman)

Although many survivors wrote about the importance of relying on others, seven survivors expressed that it might not always be possible to count on others for support. For example, P10 (47-year-old man) wrote, "Be prepared to be disappointed by friends who disappear, maybe because they just don't know what to say or do, and maybe because they are afraid." Another survivor elaborated on this sentiment by writing about how the SCT

process caused conflict within her interpersonal relationships:

There were relationships I was trying to save prior and during treatment that I would have ended sooner ... Sometimes when you go through something so life-changing you realize that there are things you just don't want in your life but will hang on because you are under intense stress. Had someone pulled me aside and said "obviously this relationship is toxic and the fact that it is creating problems when you are at your lowest proves that," I would have probably stepped back earlier and realized I didn't want to include it my life. Major illness has a way of crystallizing things. (P3, 44-year-old woman)

These last two quotes reflect a counter to the advice to rely on others by highlighting how social relationships can add stress.

"Show compassion toward others"

Although many survivors described the importance of receiving support from others, four survivors wrote about how helpful it was to have others rely on them. One man advised that it can be therapeutic to help others because it provides a distraction:

Think about others. I've found this is the best way to take my mind off myself. (P6, 66-year-old man)

Another man wrote,

They [loved ones] need to be reminded every day how much you love them and appreciate the sacrifice they are making for you. Always try to be there for them as much as they are for you. If your experience is like mine you will find that this ordeal will bring you closer than you ever were before. (P18, 47-year-old man)

Thus, these writers urged others to provide support to loved ones, explaining that it took their mind off their own distress and fostered mutual support.

"Think positive"

Many survivors ($n=30$) urged others to maintain a positive attitude and avoid negativity. In

all, 10 participants described how their positive attitude contributed to their survival:

I avoided speaking to negative people and really stayed focused on the positive aspects of the outcome ... If possible, I suggest you avoid self-pity and the "why-mes" ... To me, staying positive and avoiding negativity from within and from others is what is keeping me alive today—because as soon as my will to live leaves, I know I'm a goner. (P10, 47-year-old man)

For P10, having someone there for him was not enough: he needed people around to be positive.

P11 (56-year-old man) wrote that it is important for SCT recipients to make the best of their difficult situation. P3 (44-year-old woman) provided an alternative view that left room for SCT recipients to experience and acknowledge negative emotions, but assert a positive attitude in the end: "Think positive. See the bright side. Kick and scream and cry, but then think positive again. Always." Another woman provided a different opinion: "My daughter says I always say I don't feel well when she calls—that I should have a more positive attitude. So I won't say how I feel as much" (P12, 65-year-old woman). In her case, advice to think positive silenced her. Another survivor also expressed her frustration about advice to think positively:

Lots of friends would say things like—"Just think positive!" whenever I voiced a doubt or concern. It became rather annoying—this was a real thing, happening to me, and I had a right to be concerned, educated, and even a bit worried. (P13, 46-year-old woman)

P20 (52-year-old woman) described how the advice to think positive can make some people blame themselves for being sick:

Your attitude did NOT cause your cancer! It didn't happen because you didn't laugh enough, or didn't have a positive enough attitude, or eat wheat germ, or whatever. It just happened—so go on now ... get rid of it!

For some survivors, the advice to think positive throughout the SCT process was beneficial,

but others ($n=3$) did not want to force a positive attitude and instead wanted to express all their feelings—good and bad.

“Take things one step at a time”

In total, 18 survivors explained how aspects of SCT were overwhelming, but advised that it helped to break daunting tasks into small steps:

The most important thing that I take away from this is when faced with all this before your transplant to take one day at a time. It is so overwhelming and depressing when you try to absorb the ordeal as a huge tidal wave that will just wipe you out. (P14, 49-year-old woman)

A few survivors suggested acknowledging small accomplishments: “Sometimes it wasn’t just day by day, but hour by hour or minute by minute. Praise yourself for any accomplishment no matter how small” (P15, 51-year-old woman). Another survivor explained that recovery is not a linear process and that step-by-step sometimes means taking a step back, but still moving forward overall.

“Identify things that bring you peace”

In all, 20 survivors wrote about how, despite the stress of SCT, it is important to find happiness where one can. P3 (44-year-old woman) advised others to “identify those things that help bring you peace, whether they are working, yoga, music, art, etc., and use them to help you cope.” Several survivors echoed this idea that it helped to stay busy with enjoyable activities.

Other survivors ($n=4$) wrote about how their SCT experience changed their expectations about what it means to live a happy life. One man eloquently illustrated this theme:

Start living and try to see your diagnosis as a wake-up call so that you begin prioritizing the people in your life that mean the most to you. You don’t miss the kids’ soccer games, begin volunteering to help at the next benefit, get involved in the lives of the people you love. No regrets—no messed up priorities. I walk my

daughter to school every day now. It means I get to work at 8:30 AM instead of 7:30 AM. Maybe it ends up costing me 20% in bonuses—but so what ... She can’t remember the money—but she will remember it was me walking her to school and the silly talks and games we played. (P5, 47-year-old man)

“Exercise”

Seven SCT recipients advised others to exercise as much as possible to keep busy and to promote recovery. P41 (55-year-old woman) offered this advice:

Start off with just a little exercise and allow it to increase naturally. Be consistent. Next thing I knew I was dancing again. Not like I used to but seventeen months post-transplant, I’m getting close; planning to be better than before.

Whereas some wrote about specific exercises for SCT survivors (e.g. yoga, low impact exercises), others encouraged survivors to get any kind of exercise, “even just move your arms and legs around or stand as much as you can” (P38, 36-year-old female). The advice to exercise during recovery was always written about in a positive light.

“Follow guidelines”

Nine survivors explained that patients will have a better chance of recovery if they follow their providers’ guidelines. P53 (53-year-old woman) poignantly described an important guideline for warding off infection:

Be very careful to stay clear from big crowds of people unless you wear your face mask. I got every cold, flu, infection that was in the air after coming home. Don’t be afraid to keep sick neighbors away, although they may be well meaning, they could kill you.

Others wrote about how critical it is to follow recommendations for hygiene, diet, and medications, and to attend doctor appointments—even when one feels better. Some survivors shared

instances when they were not careful about these things and described consequences (e.g. infections, hospitalizations).

"It gets better"

Finally, 12 survivors described how the experience is temporary and that life will get better. P48 (19-year-old man) shared, "When the process begins it gets better and easier because you're not as tense or afraid like when you start." One woman wrote about how the body will eventually heal: "I've lost my hair and watched it grow back. That is all reassuring. We can heal. The human body is pretty amazing" (P46, 53-year-old woman). Others wrote about how the physical discomfort and feelings of sadness and frustration eventually pass.

Co-occurring themes within narratives. In two narratives, survivors wrote about their conflicting feelings concerning the advice "be your own advocate" and how the advice to "think positive" can help survivors cope. For example, P3 wrote about the importance of gathering health information even when it is unpleasant, because it can help people carry out a plan for treatment and recovery, but to then use a positive mindset to "ignore the numbers." Her advice highlighted how some might feel that the advice to "advocate for yourself" can be both helpful and harmful. To her, that advice was helpful only when a person used positive thoughts to minimize negative emotions in response to frightening health information. P27—a 66-year-old male—similarly wrote about the importance of gathering health information but then using positive thoughts to prevent emotional harm.

Discussion

We investigated advice that SCT survivors shared about their experience to help others prepare for this arduous treatment, with the goals of identifying the kinds of advice survivors offered to peers and examining variation in how survivors described and valued different types

of advice. We found that not every SCT survivor described each advice category in the same way nor found each category helpful. There was particular variability in the way SCT survivors described and valued three categories: "be your own advocate," "have someone you can rely on," and "think positive."

Why might there be variability in descriptions and reactions to advice? In the case of the advice "be your own advocate," some survivors wanted to know every possible detail about SCT—good and bad—but others avoided potentially stress-inducing information. This variation may indicate that some individuals prefer not to take an active role in their care. For instance, one study found that over one-third of breast cancer patients preferred that their physicians make all medical decisions for them (Degner et al., 1997). Another reason for variation may be that some SCT survivors might not be aware that they can control their care or might not have sufficient psychosocial resources to manage the burdensome SCT process. Interestingly, two survivors advised others to seek health information—including unpleasant facts—with the caveat that it is important to maintain a positive attitude to minimize negative reactions to this information. Our findings suggest that the amount and kind of information given to people preparing for SCT should be tailored to individual needs.

For some participants, the advice to "rely on others" stood out because loved ones and other SCT recipients provided them with social support. Survivors wrote about the need for different kinds of support from various sources. Some survivors wrote about how other SCT recipients provided them with support that their family and friends could not provide, and this support was valued because it helped them feel less alone. This finding is consistent with research on peer support. For instance, cancer survivors have reported that communicating with other survivors provides a sense of belonging, an understanding of the same experience, useful information about cancer, and empowerment (Jefford et al., 2008; Ussher et al., 2006).

Likewise, several authors have argued that loved ones might be better suited for providing love and practical assistance, whereas peers might be better suited to provide empathetic understanding, information, and hope (Taylor, 2007; Thoits, 2011; Wortman and Dunkel-Schetter, 1979). It is likely useful for SCT recipients to have multiple support providers representing different perspectives and competencies. However, consistent with the idea that support can vary in its effectiveness (Rini and Dunkel Schetter, 2010), some survivors indicated that the advice to “rely on others” is problematic for people with ineffective support networks because they are stressed, scared, or unsure of what to do. Thus, it is also important to consider how the advice to “rely on others” might be harmful to survivors who do not have effective support.

Similarly, advice to “think positive” might be beneficial to some survivors as a coping strategy, but it might be unhelpful and perhaps even harmful to others. Researchers have argued that optimism can be beneficial for cancer survivors’ well-being (Hodges and Winstanley, 2012; Pinquart and Frohlich, 2009). American oncology culture often emphasizes the importance of hope in recovery (Del Vecchio Good et al., 1990). Scholars contend that in contemporary healthcare, patients are expected to adopt an optimistic attitude about their disease and that healthcare institutions will foster or instill hope in those who lack it (Brown, 2007; Petersen, 2015). In our study, some survivors did not want others to tell them to stay positive because they did not want to force untrue feelings. Holland and Lewis (2000) call this sentiment “the tyranny of positive thinking.” They argued that survivors who generally have a positive attitude in life will be more likely to approach cancer with a positive attitude than those who do not, but having a positive attitude does not guarantee survival. Furthermore, they posit that forcing a positive attitude can victimize survivors by implying that survivors whose cancer progresses are at fault for not thinking positively. It is important to recognize that optimism, especially

when unrealistic, can cause some patients harm—for example, by overhyping the benefits of certain treatments (Petersen, 2015). Our findings and existing evidence suggest there is not likely a one-size-fits-all approach about thinking positively.

The literature on illness narrative analysis can also shed light about why some cancer survivors might not find certain advice helpful. Frank (1993, 2003) contends that there are core narratives describing how survivors experience and respond to serious illness. Some survivors feel like part of a larger community of the ill and feel morally compelled to give back to the community by sharing their stories. For others, cancer does not define them and they can move on without incorporating the illness into their identity. Likewise, Bury (2001) argues that some people believe that something good came out of illness such as renewed value of life. Thus, survivors who feel that cancer has changed them in a positive way might better receive certain advice (e.g. “think positive”) compared to survivors who do not incorporate cancer into their identity.

Several limitations of this study must be underscored. First, the purposive sampling strategy of “high advice” narrative selection might have yielded a sample that is not representative of all SCT recipients; however, we attempted to minimize this bias by coding a 25 percent random sample of narratives that included any advice to other SCT recipients. Second, the results might not generalize to all SCT survivors, because most participants had relatively high income and were college educated although these characteristics are consistent with the population receiving SCT in the United States (Rini et al., 2014). Furthermore, all participants agreed to participate in a psychosocial intervention and results might not reflect the advice of people who would not participate. It is, however, promising that our results are consistent with several descriptive advice themes presented in other studies of adult cancer survivors (Civan and Pratt, 2007; Kahana et al., 2009; Meier et al., 2007).

Conclusion

This study provides valuable insight regarding the nature of advice that SCT survivors offer to peers on how to cope with the stress of SCT. It is vital to understand the advice that survivors felt was most important to pass on because SCT recipients value and seek out this type of information (Blume and Krance, 2004; Rini et al., 2006). Cancer survivors' reactions to cancer-related information and advice from peers are not well studied (Hartoonian et al., 2014; MacGeorge et al., 2008; Rini et al., 2006) nor is the potential for this kind of information to elicit negative responses. A particularly useful finding from this study is that some types of advice might be more likely to be viewed as unhelpful, or even harmful, than others. Nettleton argues that there is a range of emotional consequences to peer support advice: some will feel better informed or reassured from advice, whereas others will not feel this way and perhaps will learn information they would rather not have known (Nettleton et al., 2004). Potential negative responses to peer advice in this study could help explain why not all cancer survivors benefit from peer support programs (Campbell et al., 2004; Helgeson et al., 2000). As such, current findings may guide development of methods for helping caregivers and peer counselors provide effective advice that avoids worsening emotional distress and undermining coping efforts (Goldsmith and Fitch, 1997; MacGeorge et al., 2008). We propose that the question of whether a particular type of advice will be perceived as helpful or not is likely to be both a function of the advice itself and characteristics of the recipient. Research to investigate these possibilities would enable tailored delivery of information in peer support programs to harness advice that meets survivors' unique informational needs.

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