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The Use of Narrative in Understanding how Cancer Affects Development: The Stories of One Cancer Survivor

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Abstract

Although cancer disrupts development, the experience of having cancer is often understood using developmental theories that do not assume serious illness at an early age. This article presents a narrative analysis of one patient's story of survivorship. She tells three interrelated stories: how others have reacted to her illness; her struggles to understand her illness; and how it has changed her priorities. Taken together, her stories comprise an account of how the experience has affected her development. Her story is an example of how individuals integrate unusual life events into their development. It suggests that focusing more on how unusual life experiences contribute to development may expand and enrich our understanding of developmental processes.

Keywords

cancer; development; narrative; young adult

In the summer of 1995, I set out to explore the thoughts, feelings, and perceptions of a young adult cancer survivor, 'Z'. As she told me of her illness, recovery and subsequent relapse, her story did not fall within the parameters of what was considered 'normal development' for a person her age. For example, at her young age she confronted issues of life and death.

Z's participation in the study enabled a greater focus on what 'normal development' means and its function in society. Ideas about normal development generate expectations of what should be accomplished by certain ages. In the field of psycho-oncology, for example, the needs and interests of young cancer patients are often understood by comparing them to their healthy peers (see Holland & Rowland, 1982, for an overview of psycho-oncology). While this approach has undoubtedly been quite useful, some believe it limits understanding of what it is like to have cancer (Frank, 1992). In some ways developmental theories do a disservice to the young by providing a template to view their experience, thereby providing a limited view of unusual life experiences.

Gergen and Gergen (1986) once noted that developmental theories tell a story. Like any story, developmental theories involve an orderly sense of progression towards a positive endpoint, and events are causally related. Like many of the grand narratives that characterize modern society, developmental theories purport to explain universal processes, i.e. what can be expected or accomplished at certain ages. These theories are readily accepted and pervade society. As such, developmental theories constitute a 'dominant social narrative'

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which reflects social norms and values (Murray, 1997; White & Epston, 1990). Having illness at a young age contradicts the dominant narrative of normal healthy development. What happens when your life falls outside the 'dominant narrative', or course of normal development? What happens when conventional ideas about progress are disrupted by illness (Bury, 1982; Radley, 1995)?

In the interview, Z talks about what it's like to have an unusual life experience. Narrative analysis lends itself readily to a richer understanding of Z's account. First, the conceptualization of Z's talk as a narrative may lead to a broader understanding of what she is trying to say. Frank (1992) advocated the use of narrative to understand suffering and illness. He contended that the language of medical and social scientific discourses about human suffering was inherently limited by its function: to manage a disease or to accomplish a patient intervention. Second, many of the generic processes around the motive for telling a narrative are present in Z's account (Chamberlain, personal communication, 2000). People tell narratives to express what it's like to have an experience that contradicts dominant narratives (White & Epston, 1990), and Z is no exception. Narratives are often used to describe how individuals use stories to understand, organize, and integrate unusual life experience (Bruner, 1990; Gee, 1985; Mishler, 1986; Murray, 1997; Radley, 1995; Reissman, 1993), particularly to understand and assimilate illness experiences into one's life (Radley, 1995).

Last, general ideas about how narratives are constructed are present in Z's talk. The narrative construction of one's experience is often influenced by social context (Mishler 1986, 1992; Murray, 1997; Paget, 1983). In Z's narrative, it is possible to detect how social and cultural expectations of the ill influenced her. Contextual factors, such as the purpose of the interview (Mishler, 1986; Murray, 1997), the motives of the speaker (Baumeister & Newman, 1994; Mishler, 1986), or 'the author's life history' (Murray, 1997, p. 16) influence what gets produced in an interview (Baumeister & Newman, 1994; Mishler, 1986; Murray, 1997; Paget, 1983). Two contextual factors influenced the production of awareness and knowledge in our interview. First, Z knew that I had a sibling who had survived rigorous treatments for cancer. We shared a greater familiarity with the ups and downs of treatment. Thus, my 'life-history': concerns, experiences, and interests shaped the interview, as did the participant's (Gentile, personal communication, 1997; Paget, 1983). Second, I had framed the interview as an opportunity for Z to tell her point of view of having cancer at a young age. I also stated the potential benefit to patients, and this possibility seemed very important to Z. Z expressed interpersonal motives for telling her story: she wanted her participation to help others facing cancer and to provide information (Baumeister & Newman, 1994). I felt similarly. My stated rationale for the study was that young adults with cancer could best inform and help others in the same circumstances. These two factors—our overlapping experiences and shared objectives—laid the foundation for our alliance as cancer survivor and sibling of cancer survivor. This alliance, or feeling of mutual empathy and regard, was palpable throughout the interview.

Z tells three interrelated stories to understand her experience with cancer. She tells the story of how others reacted to her illness, her struggles to understand her illness, and how it has changed her priorities. In short, Z tells how cancer affected her development and how she struggled to create an identity for herself as a young person recovering from a life-threatening experience. Three main themes re-emerge and intertwine throughout the conversation, comprising her main story of how cancer has affected her life. She accomplishes her story by setting up a series of conceptual tensions/conflicts that re-emerge throughout the talk: (1) her friends' lack of understanding versus her need for their feedback; (2) whether or not to integrate her illness experience as part of her identity; and (3) feeling more mature versus wanting to be like her peers. Each of these is explored in

turn, as well as the temporary resolution that Z was able to reach in the course of our conversation.

Interview transcripts were reviewed to identify themes (Ely, Anzul, Friedman, Garner, & Steinmetz, 1991). Then, each theme was explored by analyzing extracts from the interview and quotes that run throughout the interview. Texts were selected and examined for their narrative structure, as well as how that structure was used to accomplish the function of the talk (see Chamberlain, Stephens, & Lyons, 1997, p. 699, for a review; Labov, 1972; Labov & Waletzky 1967). Narrative analysis may focus on the kind of narrative genres used (Gergen & Gergen, 1986; Reissman, 1990), how meaning is conveyed to the listener (Paget, 1983; Reissman, 1990), and how the listener herself participates in creating the text and content of the interviews (Gentile, personal communication, 1997; Mishler, 1986; Paget, 1983). The discussion concludes by summarizing how the three themes relate to and support each other.

At the time of our interview, Z had been in remission for one year. She was first diagnosed with Hodgkin's disease in her late 20s and received treatment for it. She suffered a relapse following treatment and received a bone marrow transplant,¹ which led to remission. During this process she quit her job in the business field and began nursing school.

The need for feedback versus a collusion of silence

Early in the interview Z tells a story about her experience of having cancer at a young age:

It's a bummer because last night I was thinking,

'I wonder what my friends thought. I wonder if they ever thought, "is she going to die?"'

You know, no one's ever said, 'we were worried that you might die'.

I mean, I know that my *family* was worried that I might die,

but none of my friends have ever said anything,

except one girlfriend who said, that after seeing my skin get better and my weight go up, she said, 'you know, you finally don't look sick anymore'.

And I said, 'did I look sick?'

and she said, 'you did look sick sometimes'.

And I said, 'you know, you're the first person who has ever said that and I'm glad you said that. Because everyone just kind of just shakes it off like its no big deal.'

In the first line, Z orients (Labov, 1972; Labov & Waletzky, 1967) the listener to her mood in the story—she is reflective, feeling a bit down, and frustrated. She also orients the listener to the time of day and what she is doing (Labov, 1972, p. 364). In saying, 'I wonder what my friends thought. I wonder if they ever thought, "is she going to die?"' Z summarizes the content of her narrative. She is frustrated and puzzled by the lack of feedback and validation from her peers about her cancer. Yet, this feedback is so influential that when someone observes that she looked sick, she sounds skeptical: 'did I look sick?' Indeed, the feedback of her healthy peers appears to have reassured and helped her. Her story ends on a positive

¹The focus of this article is on Z's experience of having had cancer, but having endured the bone marrow transplant is a significant factor in her experience. Bone marrow transplantation is a risky and exhausting procedure for treatment-resistant cancer. It involves bringing the patient to 'near death' by destroying virtually all bone marrow cells, both cancerous and healthy. This process is followed by an infusion of healthy bone marrow cells to allow for normal body function.

note: 'I'm glad you said that'. In the evaluative clause, 'Because everyone just kind of just shakes it off like its no big deal', Z conveys the point of her story: for some reason, no one has pointed out the obvious to her, that she looked sick, and that her illness was a big deal. Using the word 'just' twice emphasizes how trivialized she feels. Unfortunately it is just this kind of feedback that Z needs to validate her feelings, or she runs the risk of believing that her cancer was 'no big deal'.

The importance of this topic to Z is evident in the number of times she revisits the issue. In the following passage, Z discusses the lack of 'real talk' about her illness. Further, in this example I actively participate in constructing the interview, by encouraging and supporting a stronger emotional response from Z:

C: don't you think that its strange about this whole thing, though—that so many times you know, where you have to make other people feel comfortable about it [...]

Z: it is, it is. like you can't just have it and let people see it. you do. like even when people came to the hospital to visit

C: uh-huh

Z: you kind of felt like—you had to be up, you had to be ok,

C: right

Z: yeah, that's true. I never really thought about that. yeah, that's really true you do have to excuse me, make it seem like its just kind of—like tonight, I know people are going to come up to me and ask, how are you feeling? but they really don't want to know—how I'm feeling

C: right. there's a big difference between what they want to hear and what you really feel.

Z: if I came out and said, 'this sucks, I'm pissed, I really hate this crap'

C: right

Z: they'd say, oh, I'll see you later [laugh]

C: I'm going to get a drink, can I get you one?

Z: *exactly* [laughter]. They'll say, oh ____—____ is my nickname—____ needs a beer! I have a lot of anger, too.

Two individuals sharing the same experience shaped this conversation. As the interviewer, I encouraged her to tell her story (Mishler, 1986) and was thus influencing the structure of our talk. My analysis of this moment was influenced by Paget's (1983) reflections on the covert and overt meanings of her question to an interviewee, 'how old are you?' When I said, 'there are so many times when you have to make other people comfortable about it', I was thinking of my own efforts to answer questions about my sibling as people expected and not as I felt. Z immediately agreed with the statement and also went so far as to say that she had not really focused on that idea herself. This idea, however, and my obvious support of her feelings (as seen in my short affirmations of her comments and my clarifying her comment, 'there's a big difference between what they want to hear and what you really feel') created a convivial atmosphere where Z brightened up and used less formal language; 'this sucks, I'm pissed, I really hate this crap'. Later, I fully engaged in the sardonic humor of her story by stepping into it and picking up on her tone, 'I'm going to get a drink, can I get you one?' At this moment, we were perfectly in sync. Z responded to my interjection with emphasis and reciprocal humor: '*exactly*' [laughter] they'll say, oh ____ — ____ is my nickname—____

needs a beer! I have a lot of anger, too'. Finally it is possible that our informal shared interlude and understanding encouraged Z to make another disclosure about her anger, something she might not have disclosed if we hadn't experienced that moment or if I hadn't volunteered my own personal observations.

Later Z returns to the issue:

I could tell that she [friend] didn't want to deal with it [Z's illness] anymore.

Because when I bring it up, she really changes the subject.

So I'm kind of running out of people outside of my family to talk to.

Part of her anger may be fueled by her wish and need for feedback from peers. It is difficult to make sense of cancer at a young age when there are so few comparisons. The phenomenon of feeling interpersonally isolated after cancer (Maher, 1982; Rowland, 1989; Shanfield, 1980; Siegel & Christ, 1990) may be particularly acute for young people. Many ill young adults have noted that they do not feel understood by their healthy peers, who avoid discussing the experience with them (Rowland, 1989). In the first story, Z thanked the friend who told her she looked sick. Later, she re-emphasizes the importance of such feedback by relishing the story of a more overtly supportive friend:

One of my really good friends called me and said, 'I'm really proud of what a good job you did'. And it was really funny the way he said it, he said, 'you never let your goals go away, you always had a plan of what was going to happen, as soon as you got out of the hospital. And I think he helped me feel—that was the first person who acknowledged it. It made me feel really good.

Instead of being given time and companionship to discuss and reflect on her illness, Z feels pressured to just 'get on with my life'. She comments: 'I think people don't understand and because I think it's been a year, people don't want to deal with it anymore. Because I think, it's been a year, get on with it, quit thinking about it, get on with your life. That's what I've been getting from the people around me'. Instead of 'slowing down' to listen about her experiences and insights, the world—inhabited by young adults focused on future life goals—spins by. Z comments: 'everyone's gone forward, and I'm still running to catch up with everybody'. In the following passage, she describes the kind of conversation she craves but never receives:

I think I would want someone to—no one's ever asked me—how do you *really* feel.

You know, I mean, I know my friends do not see the changes, I just don't—probably

because I am not around them that much anymore.

But you know, how do you really feel? Are you scared? What's it like to think about death and stuff.

Because no one's ever asked me those questions.

I mean—my parents, my family, I think they'd be afraid to ask me.

In the first line Z describes her problem—no one asks about her feelings or experience. She lists the questions rapidly, thereby emphasizing her need to hear and discuss them. By doing so, she also implies the simplicity and obviousness of these questions.

Why do we collude?

Z's talk about what she does not hear from others reflects social expectations about young people who are ill. As noted above, society does not easily accommodate a person's transition from patienthood. Society expects her to return as soon as possible as a functional and productive individual (Smith, 1981, p. 89).

Z's story makes a broader statement about how our society and culture minimizes the experience of illness by silencing the sufferers, what Frank (1992) referred to as a '... cultural denial of suffering' (p. 483). Smith (1981) observed, 'Like the inevitability of death, the possibility of illness is frequently denied in modern society' (p. 2). Z's story describes how this silence is achieved: there were no questions. Goffman (1952) wrote about how society finds ways to mute intense feelings to ensure that life runs smoothly and that norms don't get violated. Briefly, social roles sometimes act as 'coolers', with the function of helping others to live with and to accept difficult situations, intolerable feelings or events. Such individuals may be invested with more authority to make the task easier, such as a doctor or psychologist (Goffman, 1952). Frank (1992) gave an example of how one doctor tried to 'cool' out a patient's feelings about her career by offering sleeping pills (p. 478). Z had a similar experience: she was offered antidepressants but refused. She said, 'There's no chemo to cure the blues and the worrying. I don't need a pill. I know why I feel this way'. It is also possible that cancer is fearsome because its causes are mysterious (Blaxter, 1983), and it is this fear that fuels silence. At the end of her story (in the last sentence), Z speculated that her friends were probably 'scared' by the prospect of talking about the possibility of death:

But I think—we're so young and when you have your mortality in front of you and your friend has cancer it kind of makes everyone else feel kind of uncomfortable.

White and Epston (1990) suggested that when someone has an experience that contradicts dominant narratives, he or she might experience personal discomfort or disease, which prompts them to seek therapy (pp. 14–15). Z describes feeling oppressed, alienated, and unsure by the collusion of silence around her. She observes, 'Because people don't recognize you like you want to be recognized—you just—everything is just kind of pent up inside because you're not supposed to feel that and its not healthy for us—its more healthy to let it all out, than to keep it all in'.

As an interviewer/listener, at times I replicated the dynamic that existed on a social level. Several times during the interview, I noticed that I changed the subject or did not ask any further questions when Z discussed her fears and feelings. While part of me was concerned about the clinical and ethical issues and did not want to probe too deeply, I also noticed that sometimes I changed the subject when I felt uncomfortable. For example, at one point I asked Z directly how she was doing with the interview and was quite surprised by her ease and openness. I commented, 'it must be—I imagine that it must be tough for you to talk about all these things'. Without missing a step, Z responded, 'actually, it's not'. By not engaging more fully to understand the experiences and perspectives of young adults with cancer, are we protecting ourselves from dealing with how our own lives would change if we thought we were going to die?

Here, the role of interviewer/listener played a key role in eliciting and providing support to a storyteller with a mysterious and difficult story to tell (Gentile, personal communication, 1997; Mishler, 1986; Paget, 1983; Reissman, 1992). In summarizing Mishler's (1986) earlier observations, Reissman (1992) stated, 'Narrative analysis is particularly well suited to understanding the process of making sense of difficult experiences because it lays bare the interpretive work narrators do in collaboration with listeners' (p. 233). By being the

audience for her story, I was helping her to tell it. 'By creating words about the experience it is possible to reduce the fear induced by silence' (Murray, 1997, p. 17).

How to understand or integrate the illness experience?

Z discussed how her friends' silence affected her. When I began this study, I did not expect this finding to be so critical. This silence sends a variety of unspoken messages. As noted earlier, it oppresses feelings and thoughts. Silence may also create the perception that we do not care, as Z speculated. Even more frightening, it implies that the illness must be pretty bad if nobody wants to discuss it. For young adults, having cancer is not a shared experience. The lack of peer validation compounded her confusion about the experience. When one suddenly recovers from a life-threatening illness, there is uncertainty about how one should behave. Should I feel that it was truly as bad as everyone thinks it is? Am I minimizing my experience? What was it like to confront my mortality? As Siegel and Christ (1990) put it, 'there are no clear expectations or norms regarding how the cancer survivor should act, feel, or be treated by others' (p. 386). Further, Maher (1982) identified recovery from illness as an alienating experience. She observed that uncertainty and ambivalence characterized the recovered patient's state of anomie.

Z's uncertainty about how to interpret her experience is depicted in how she moves between her own interpretations and then to other people's construction of her experience. First, she states:

sometimes I do minimize it.

I think, I really do and I think that that's because it helps me.

And another thing kind of because I wasn't at death's door.

I wasn't really really sick from the transplant, I you know,

I think maybe I am overreacting,

I was only in for 18 days, I only threw up a couple of times, um you know,

I was running—jogging two weeks out of the hospital.

A few lines later, Z juxtaposes her reaction to her doctor's comment, 'you've been through a *catastrophic illness*':

Z: but even like Dr. __ said, 'you've been through a *catastrophic* illness, but you don't—I don't understand the depths of what I've been through, I don't think.

C: You don't think so?

Z: you know, I think that the other day, I'm like—wow.

C: what do you mean by depth?

Z: well its like, the deepness of having cancer and that, you can die from that and cause I guess I never really thought about the dying part and I think I just—don't understand death. Don't want to understand death, and don't want to die [laugh]. But a lot of other people that say that I'm at one with death, you know, I'm like, 'right'.

The effects of this contradiction are puzzling to Z. She concludes that she does not comprehend the significance of her illness. But by discussing the topic, she has successfully charted out a range of possible responses to consider. The issue of how cancer impacted her life remains open and unresolved and may become clearer to Z with time. This appears to be a temporary but appropriate resolution.

How to integrate the illness experience as part of identity

Questions of how cancer affected Z's life led directly into questions of how it affected her personhood. She commented, 'I don't know to what extent it's part of my identity'. Z did not address this issue directly. Instead, she used a metaphor in the following passage:

Z: But I sometimes feel like (?) and um—well my biggest thing too, and this is real important to me, I told my mom—is that I don't want to be a poster cancer child. You know, it's sometimes—I feel that way.

C: ____ says that. What does that *mean*?

Z: well it's like you know, you're the cancer patient, and you go through this, and be careful ____, or Z might not be feeling that well,

C: oh,

Z: you know, or she's been through this great thing. Let's put her up on a poster ... you know, it's great that you've gone through this and you've done really well, but you want to be known for like ____ the engineer, or the entrepreneur, and I want to be known as the nurse and like not not ... and I know it's going to be a stigma if people find out, you know, it's like the nurse who had CANCER! Like WOW ... which is true I mean it goes together and it *is* going to make me a better nurse. But it's like you know I don't want to be known as someone who was a cancer patient, I want to be known as someone who, so I'm trying to get rid of that stigma. To be a really good cardiac nurse, or something.

C: right.

Radley (1995) noted that we often use metaphors to organize or understand an indescribable experience that is difficult to articulate. With illness, Radley commented that 'metaphor (might) play a significant role in the construction of illness' (1995, p. 118). By comparing a difficult life experience with a more mainstream 'domain of experience' (Lakoff & Johnson, 1980, cited in Radley, 1995, p. 113) it becomes easier to reflect on the former, to evaluate and integrate it into one's life. So what was Z trying to say about her illness experience in this metaphor?

Z's choice of the metaphor 'poster child' signals the conflicts she experiences about how to integrate the cancer experience into her life and identity. 'Poster child' refers to well-known, commercialized posters portraying a young person with a given disease. These posters were used to promote public awareness to fight or to contribute to fighting the disease. Z uses this metaphor to emphasize how deeply cancer has been imprinted on her identity, to the point where she feels she has been marked as a representative of Hodgkin's disease. Further, she comments that the association with having had cancer stigmatizes her. Poster children are of course usually associated with what they advertise and as such are one-dimensional. In using this metaphor Z is able to say what she wants and does not want.

Z clearly states that she does not want to be perceived only as a cancer survivor. This statement creates some ambivalence because surviving cancer is an accomplishment. Part of her ambivalence is also fueled by her awareness that using her experience as a cancer survivor will enrich her expertise as a nurse and increase her empathy for suffering. Thus, while she does not want to be thought of only as a successful representative of the cancer survivor population, she is also aware that it will always be part of her life experience, with its positive and negative attributes. In her use of metaphor, Z is also able to state what she wants. She does want to move away from being closely associated with cancer, to becoming known more as a woman looking for a suitable life partner, a caring nurse, and a loving sibling and daughter. Z does not state these wishes or goals directly during our interview,

but by using this popular culture, easily understood metaphor she communicates them successfully.

Changed perspectives versus wanting to be like everybody else

As mentioned earlier, three assumptions characterize any narrative, whether it is a children's story or a dominant social narrative (in this case the story of normal development): evaluative endpoints, causal connections, and orderly progression (Gergen & Gergen, 1986). Z's story violates all three assumptions. For one, the desired and expected developmental goal for young people is to achieve identity and intimacy (Erikson, 1963). While in treatment, Z did not pursue a relationship or other developmental milestones, such as a career (Rowland, 1989). She expressed frustration about the situation, stating: 'I feel like my life has just been stopped'. When we talked, she seemed to be struggling to decide what goals she should pursue. Second, youth and cancer are not causally connected. Last, Z's development during the previous five years (during treatment) did not appear to have been linear or progressive. She cycled through the same phases: detecting cancer, treatment, recovery, and relapse. How does she make sense of this given that her experience is outside most developmental narratives?

As noted earlier, having an experience that does not 'fit' or that is not represented in popular narratives may elicit discomfort or personal conflict (White & Epston, 1990). Z compared her life with those of her peers and expressed frustration about what was missing in hers: relationships, career, and a more carefree approach to life. Z stated, 'Because that bothers me—not having a relationship, too. It's been a year. And then, it's like, it's *only* been a year'. Here, the poignancy and the dilemma of being a young cancer survivor became evident: she wants to be like everyone else, yet she knows that the experience sets her apart.

Z realized that she was different physically and psychologically. Bone marrow transplantation had physically aged her: as a consequence of the transplant she experienced menopause, and had to take estrogen to begin menstruating again. Physical side effects include low energy levels, fatigue, and infertility. She said, '[I] feel like a 50 year old in a 30 year old body'. Psychologically, Z found it harder to talk to her peers not only because they did not share the same experiences, but also because she realized that her priorities had changed. She observed that her friends' concerns were focused on socializing and volleyball, while her concerns extended beyond their 'little bubble'. In the following passage, she starts by observing that she is on a 'different maturity level', and then compares their concerns:

Z: What this does to you, from going through all this, you find that um you're definitely on a different maturity level than your other friends when it comes to things,

C: such as?

Z: um well like my friends will talk about um they're really into—their volleyball. and it's like, gee, well did you know who the President of the United States is, you know, did you know there's a war in Bosnia,

C: uh-huh,

Z: things like that. and you just—because you've been through all this, those types of things are to me—are more of an interest because these people are going through a hard thing, too.

C: right, right,

Z: you know, but they don't talk about stuff like that. and it's like, or politics, or—the stock market, sometimes. but most of it with them is like—their social things. and I get bored. and so that's another thing.

C: you're less wrapped up—in yourself.

Z: yeah, yeah. and also if I were to start talking about nursing, and stuff—they don't understand. um but I have met a girl who hangs out with these people—she's a nurse practitioner—so she and I will go off, and talk about nursing. And I think she's relieved—to have someone she can talk to—but it's just—I think the whole thing that gets me—is the lack of knowledge about the world is about—in their own little bubble.

C: well—how do you feel that going through all this has helped to reconstruct your view of the world from what it was before?

Z: I just think what I've really learned—is that there's a lot of suffering in the world. That's something that—yeah. I think that's the main thing that I've learned. Because a lot of people that you know like the homeless—I notice the homeless more—I notice needy people more. And that there's people out there that really need help. More than anybody, really I think, will ever realize. And um and you know, you just hear terrible stories that make yours sound like—it was nothing.

Z states that having cancer has caused her to reevaluate her lifestyle and to change her priorities. She feels that she is 'questioning' her life in a way she had not before. She explains that her increased sensitivity and interest in helping people led her to change careers from personnel recruiting to nursing. Smith (1981) reported that most (66 percent) of the seriously ill patients she interviewed expressed a shift in values and priorities (p. 24), typically away from materialistic values and towards more humanistic ones (p. 26). Siegel and Christ (1990) also observed that such shifts were accompanied by an increased 'focus on establishing meaningful personal aspirations rather than merely adopting the dominant societal goals' (p. 387). Despite the pain and discomfort of being outside the dominant narrative, Z makes something meaningful out of her experience by stating what she has gained. She emphasizes the importance of her increased awareness, changing priorities and how that enriched her life.

Linking the themes together

In the previous sections I have attempted to explicate and clarify the disparate yet interconnected themes of Z's story. Here I try to relate them together to present a coherent story.

In Z's story, she creates meaning out of her cancer survivorship by laying out a sense of related stories that organized her experience. Each of these stories focuses on a central conflict. In the first, she talks about her friends' silence and lack of openness to discussing her illness and its effects on her. Underneath this story is another subtext: Z is disappointed in her friends, but still wants their feedback. By telling us what she does not hear, Z is able to say what she needs to hear. Z's story also reflects and evokes social influences by what she does not say, experience, or hear from others. Further, because being sick at a young age is not part of the dominant narrative of what it means to be young, Z expresses how that makes her feel. Z also struggles with identity issues in her narrative. She is conflicted about whether or not to integrate her illness experience as part of her identity. She tries to understand the impact of having a life-threatening illness, with no satisfying resolution. Possibly this issue will become clearer as her life progresses. In the interview she is able to reflect on some possibilities for identity construction: she poses the metaphor of 'poster child', which aptly summarizes her complete, past identification with having cancer and her

desire to reintegrate different aspects of her life and interests in moving away from this identification. Last, Z is conflicted between feeling more mature as a result of her experience versus wanting to have a life like her peers. Z addresses this conflict by enumerating the ways that her personal priorities have shifted.

A final note

At the point in time when I interviewed her, Z was in a kind of ‘hiatus’ from mainstream developmental trajectories. However, her narratives suggested that this was a period of personal growth for her, a possibility that has been noted before for cancer patients (Smith, 1981, p. 53). Her account of having an experience that contradicts the dominant social narrative of ‘normal development’ suggests that we need to expand our ideas of what constitutes ‘normal’ development. In other words, focusing more on how unusual life experiences contribute to development may enrich our understanding of developmental processes.

Challenging and/or adverse experiences like illness or war may contribute to subsequent development in unexpected ways (Galatzer-Levy and Cohler, 1993). Galatzer-Levy & Cohler (1993) explained how such events play a role in how the person experiences him-/herself. Many Second World War veterans, while acknowledging the horrors of war, reflected that it had impacted them positively: by helping them to mature; expanding their world views; increasing their appreciation for others; and for giving them a sense of direction in life (Terkel, 1984).

Z’s desire to help others and the way her priorities shifted with an increased focus on making her life as personally meaningful as possible suggests that having cancer was a significant experience that influenced how Z wanted to live her life and how she related to others. For example, Z expressed a renewed concern and commitment to help others following her illness. Z reprioritized what was most important and meaningful to her and took action to achieve new personal or professional goals. Her responses suggest that illness experience can significantly impact psychological development (Galatzer-Levy & Cohler, 1993; Smith, 1981). Shanfield (1980) and Siegel and Christ (1990) both commented that illness seemed to ‘permanently’ change the way former patients regarded themselves and their own lives.

Second, Z’s shifts in perspectives and personal choices reflect an attempt to create meaning out of her illness. Similarly, Shanfield (1980) observed that the way that former patients changed their priorities ‘suggests the creative use of the crisis of illness’ (p. 133). Z’s account reemphasizes the idea of development as a continual, open-ended sequence of meaning-making that occurs throughout the lifespan (Carlsen, 1988; Kegan, 1982). A renewed focus on our ability to find meaning in life events (Carlsen, 1988; Kegan, 1982) out of overwhelming situations would also enhance developmental theories.

Last, incorporating unusual life experiences into our ideas of ‘normal development’ may help those struggling in the margins. As Z’s narrative expresses, it can be a difficult, alienating experience. Clinicians and social scientists need to talk candidly and directly to the ill (Frank, 1992). Thus, the concept of being ill would not be reified as an abnormal, temporary situation but would expand our ideas of what is considered ‘normal’ in our society.

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Biography

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