



HHS Public Access

Author manuscript

J Cancer Educ. Author manuscript; available in PMC 2017 June 01.

Published in final edited form as:

J Cancer Educ. 2016 June ; 31(2): 375–381. doi:10.1007/s13187-015-0828-x.

Patient Education vs. Patient Experiences of Self-advocacy: Changing the Discourse to Support Cancer Survivors

Teresa L. Hagan, BSN, RN and

University of Pittsburgh School of Nursing, 336 Victoria Building, 3500 Victoria Street, Pittsburgh, PA 15261

Elizabeth Baldys, PhD

University of Pittsburgh Department of Linguistics, 2816 Cathedral of Learning, Pittsburgh, PA 15260

Abstract

A growing emphasis on patient self-advocacy has emerged in the public discourse on cancer survivorship. This discourse shapes patients' conceptualizations about self-advocacy and in turn influences their health care attitudes and behaviors. The purpose of this discourse analysis is to explore the language of self-advocacy by comparing a published self-advocacy guide with the lived experiences of women with ovarian cancer. Data sources include 1) a self-advocacy patient education guide published by the National Coalition for Cancer Survivorship and 2) transcripts of focus groups conducted with ovarian cancer survivors. Discourse analysis techniques were used to take a close look at the language used by both to uncover the meaning each group ascribed to self-advocacy. Challenges and inconsistencies were noted between the patient education guide and transcripts including viewing self-advocacy as a skillset to assert one's needs as opposed to a means by which to preserve a positive attitude and maintain a trusting relationship with health care providers, respectively. Some women saw themselves as self-advocates yet struggled to locate relevant health information and hesitated to upset their relationship with their health care providers. This analysis highlights tensions between the discourses and points to ways in which patient education materials can be adjusted to support cancer survivors in advocating for their needs according to their unique situations and preferences.

Keywords

Self-advocacy; discourse analysis; patient education; cancer

Background

The term "self-advocacy" is infused within the cancer survivorship literature encouraging survivors (defined as any individual with a history of a cancer diagnosis) to stand up for themselves. This message of "fighting" and "speaking up" for yourself is delivered by several authorities and organizations [1–6]. For patients, self-advocating provides an

Correspondence: Teresa L. Hagan, tlh42@pitt.edu, Phone: 412-624-4101, Fax: 412-383-7227.

opportunity to get their needs met, voice personal preferences, and maintain a level of control over their lives. For providers, self-advocacy suggests patient competence in managing and preventing health problems. Given the uniform support of self-advocacy, it is easy to understand how the language of self-advocacy has come to permeate the discourse of cancer survivorship. Table I lists several diverse definitions of self-advocacy. While the significance of self-advocacy is not questioned, such diverse conceptualizations of self-advocacy may send confusing or inconsistent messages to the cancer survivors who are intended to benefit from self-advocacy.

Public discourse shapes the normative expectations and actions of cancer survivors, setting a standard by which survivors are judged to either self-advocate or not. A key example of this discourse is the patient education guide published by the National Coalition for Cancer Survivorship (NCCS) – “Self-Advocacy: A Cancer Survivor’s Handbook”. This guide is intended to inform cancer survivors in how to advocate for their needs and preferences [19]. It represents the “collective wisdom” of the NCCS on how self-advocacy can improve cancer survivors’ quality of life. This manual is the only free, publically available patient education tools to support self-advocacy. It remains unclear how this discourse of self-advocacy is experienced by cancer survivors.

Without a critical review of how these discourses are understood by cancer survivors, the discourse of self-advocacy can inadvertently disenfranchise the cancer survivors most in need of the benefits of self-advocacy. The purpose of this discourse analysis is to compare how self-advocacy is described in the NCCS self-advocacy handbook and among ovarian cancer survivors in order to understand the discrepancies between the two and provide recommendations on how to improve self-advocacy patient education.

This analysis attempts to answer three research questions:

1. How does the NCCS handbook present self-advocacy to cancer survivors?
2. How do the ovarian cancer survivors’ transcripts (both what they say and how they say it) describe self-advocacy?
3. How do the NCCS handbook and cancer survivors’ transcripts compare and contrast in their respective discourses of self-advocacy?

Methods

Sample

Data for this qualitative discourse analysis came from two sources: 1) the NCCS self-advocacy handbook and 2) transcripts of a focus group study of women with ovarian cancer. The handbook is a free, 36-page patient education booklet published by the NCCS and is intended for use by all cancer survivors. The 2nd edition of this handbook was selected because it is popular, publically-available patient education materials specifically designed to increase cancer survivors’ abilities to self-advocate. The researchers downloaded the handbook from the NCCS website after receiving permission from the NCCS organization leaders.

Audiotapes were taken from 13 women recruited from a local ovarian cancer advocacy group participating in five focus group discussions. Self-advocacy is critical for the ovarian cancer population because of the poor prognosis, lack of screening tests, high rate of recurrence, and intense treatment options. During each focus group session, women were asked three broad questions with the goal of understanding their lived experience of self-advocacy: (1) “How do you go about trying to manage your symptoms?”, (2) “What does the word “self-advocacy” mean to you?”, and (3) “Is there anything more you can tell me about self-advocacy or the process of managing your symptoms that you think I should know?”. Sample demographics represented the ovarian cancer population with an average age of 51.31, mostly White (92%), educated (78% with at least an associate’s degree), and married (46%). Participants received a \$10 gift card at the end of the study. Transcripts from each focus group were transcribed verbatim with transcription notations and reviewed by both authors. More complete descriptions of the methods and sample are in the original manuscript [20].

Taking a critical approach to language, discourse analysis is a method that considers elements of language and communication, even as seemingly inconsequential as a pause, as meaningful and rooted in social practice. Through discursive speech, speakers produce and reproduce larger circles of belief and meaning, such as their opinion of self and others, political beliefs, and the social norms that guide our everyday life. As such, even within a few conversations, evidence for larger trends and beliefs can be elucidated along with how participants in those conversations are orienting themselves toward the world, or in this case their medical state [21]. As such, many studies using discourse analysis as their core methodology have often used small sample sizes and in fact, some have focused on a single conversation. For in their discussion of framing and managing pediatric care, Tannen and Walleet [22] used only interactions between staff and one family over a three week period, and for their analysis focused only on one interaction.

After closely reviewing all transcripts, the researchers selected the dialogue of two women as representative of the entire sample because all of the major themes of the five focus groups were represented within their dialogue. One woman (alias Dorothy) was diagnosed 3 years ago, had 2 recurrences, and had active cancer at the time of the focus group. The other woman (alias Colleen) was diagnosed 8 years ago, had no recurrences, and did not have active disease. Dorothy is in her early 60s, and Colleen is in her early 40s. Both women are White and from small towns outside of a midsize Midwestern city.

Data Analysis

Discourse analysis is a type of qualitative research that involves a close analysis of written text or recordings of speech to identify social roles, identities, values, and power dynamics. By uncovering the underlying shared meaning of words, discourse analysis can reveal how social norms, power structures, and group identities are both formed and maintained through language [23].

With the three research questions in mind, two researchers (T.H. and E.B.) independently and systematically reviewed and sequentially analyzed the handbook and then the focus group transcripts. One researcher is a nurse, and the other is a linguist; neither is a cancer

survivor. Attention was given to the intentions, voice, and goals of the text according to critical discourse analysis methodology, as suggested by Johnstone [24]. The two researchers jointly derived definitions and discursive themes of self-advocacy for each source. Exemplar texts were selected to illustrate each theme. Comparisons and contrasts between the handbook and transcripts were used to highlight differences between each data source's understanding of self-advocacy. Any disagreements in themes and features were discussed until an agreement was made.

Results and Interpretations

Self-Advocacy Handbook

The NCCS handbook richly describes the crucial importance of self-advocacy for all cancer survivors, insisting on its critical role in assuring the cancer survivor thrives at every stage of the cancer trajectory. According to the handbook: "Self-advocacy...means that you arm yourself with the tools and skills necessary to feel comfortable about asserting yourself and communicating clearly about your cancer care needs" [19]. According to the handbook, by taking responsibility for one's care, a survivor gains control over not just cancer but his or her life. More than a mere recommendation, self-advocacy is described as an "*imperative*."

The majority of the handbook lists and describes the main elements of self-advocacy: (1) information seeking, (2) communication skills, (3) problem-solving, and (4) negotiation. Information-seeking skills are developed by survivors educating themselves "as thoroughly as possible" about cancer, treatment options, side effects, and support services. Communication skills help survivors have "thoughtful interactions" with others and avoiding misunderstandings. Problem-solving skills are similar to decision-making skills and help survivors approach problems with a team approach. Negotiation skills teach survivors to address "issues that are of personal importance" to get their needs met. Survivors are encouraged to apply these self-advocacy skills to the full spectrum of issues and concerns experienced by survivors including problems related to their health, financial, insurance, family, work, and additional concerns.

Ovarian Cancer Survivors Focus Group

Three overarching themes were derived to synthesize and summarize Dorothy and Colleen's experiences of self-advocacy as ovarian cancer survivors. The three themes include: 1) maintaining a positive attitude, 2) needing and being scared of information, and 3) connections with a health care team. The transcription key at the end of Table II describes the linguistic conventions found in the excerpts.

Theme 1: Maintaining a positive attitude—Maintaining a positive attitude consisted of using cognitive strength to continue living as if they did not have cancer. A positive attitude allowed women to maintain hope, stay strong in the face of uncertainty and physical pain, and remain connected to their pre-cancer identity.

In Excerpt 1 (Table II), Colleen refers to her "part" in self-advocacy as based on what seems to be a personal mantra that she lives by ("don't go quietly"). Colleen demonstrates that this phrase, or "motto" as she refers to it in line 2, is of vital importance to her by saying that she

has it “tattooed on [her] shoulder.” After Dorothy’s tag question (a question that immediately follows the other speakers statement without a break) in line 4, Colleen continues to explain what this motto means to her and places emphasis on the words “worth” and “down” in lines 5 and 6. For Colleen, as the interview shows, self-advocating is important for the maintenance of this motto; it allows her to fight, keep a sense of self-worth, and believe that she can overcome the cancer and “never go down.”

Dorothy repeatedly supports Colleen’s mantra with statements such as “That’s right” and “I hear you.” Dorothy also describes her own positive attitude as the foundation to how she stands up for herself. She states that she cultivates this attitude as her primary means to making it through her day without falling apart. Periodically, she breaks down and has serious doubts about her future: “I’m not a hero. I’m just getting through it...I have my boo-hoo times or I’m kneeling beside the couch and I’m praying” (Line 977–978). She forces herself out of these moments as a means of self-preservation; otherwise she believes these doubts and fears will overtake her and cause her cancer to spread.

Theme 2: Needing and being scared of information—Dorothy and Colleen both recognized a need for information related to cancer, but differed in their comfort level of finding and applying medical information to their situation. Colleen, while focused on maintaining her strong will and positive attitude, did not believe that researching information about her illness contributed to the way she self-advocated. Dorothy does not disagree with Colleen, but discussed her active approach to researchers.

In Excerpt 2 (Table II), Colleen admits that she “sucks” at the researching and learning about her disease through her own means (line 8). In line 9, Colleen uses the alveolar variant (“in” rather than “-ing”), at the end of the words “knowing” and “researching” to convey a stance of lacking knowledge about researching. Choosing a variant that signals this position, in conjunction with the repetition of the negative “suck” in lines 10 and 20, which is emphasized by an intensifier “really,” Colleen demonstrates that she does not use information gathering to self-advocate and sees this as a personal fault.

Colleen continues to give an explanation as to why she does not like to research on her own. In line 11, Colleen explains, “because I think if-if I know more I’ll. get. more. scar:ed.” Colleen believes she must explain why she does not perform information seeking as an act of self-advocacy. While she recognizes that other survivors believe information gives them control when, Colleen feels frightened. Dorothy also concurs with Colleen’s statement in line 13 (“Yeah, yeah. And it does”).

Instead of advocating through information seeking, Colleen puts her faith in her health care provider. She uses the casual phrase “my man” to refer to her doctor, suggestive of a casual, trusting closeness. She also uses a contracted and reduced form of “going to” in line 19. This again suggests Colleen has a causal relationship with her provider, and continues to take a stance of “less informed.” Taking this stance, by the reduced form of “going to” and the word choice of “my man,” backs Colleen’s assertion that her doctor is the one who has the information and tells her what she needs to know, not the other way around.

Theme 3: Connection with health care team—Connection with the health care team was a significant consideration for both women. In Excerpt 3 (Table II), Dorothy discussed her need to be proactive with her treatment plan after her cancer is suspected to have metastasized to her liver. Her personal example of self-advocating demonstrates that she is a part of her health care team, helping her providers find efficient means of providing her care.

In line 22, Dorothy explains her researching as being “proactive.” She repeats “I don’t” three times in lines 23 and 24, and explains she keeps tabs on her provider because she does not want “anybody to make a mistake.” This belief that the doctor will and could make a mistake, which is emphasized by Dorothy’s repetition, directly contrasts with Colleen’s belief that her doctor knows all.

Even though Colleen fully trusts her provider and Dorothy has learned to be more skeptical, both Colleen’s not looking up information and Dorothy’s seeking out information are driven by a need to protect themselves from harm. Colleen fears she will lose positivity and confidence should she know the odds or facts, whereas Dorothy believes if she does not research, she won’t get the best treatment.

Colleen’s use of footing shifts also demonstrates her standpoint. Footing shifts are one type of conversational micro-strategy that can be used by participants to signal the role they are playing within a conversation. The footing shifts between line 24 and 25 create a boundary between Dorothy and the health care team. Dorothy uses “I” in lines 32 and 33, which emphasizes her agency and responsibility to make certain there are no mistakes made. In lines 26 and 31, Dorothy also uses “they” to refer to the physicians and medical teams in charge of her surgery/care. This shift, between “I” and “they”, shows that while Dorothy believes she has responsibility for her treatment and care, she does not, in fact, align herself with the group that makes treatment decisions.

Given the complexities of these three transcripts, self-advocacy is clearly a complicated process and not understood the same way by both participants. While both women discuss self-advocacy as a way to maintain a positive outlook, to help battle cancer, and to maintain a sense of self-worth, the methods by which they accomplished this varied widely.

The handbook and focus group transcripts present different perspectives of self-advocacy. The handbook emphasized self-advocacy as a skillset by which cancer survivors gain control and power within the health care system. On the other hand, cancer survivors enacted self-advocacy as a process of promoting internal strength and connectivity with their health care team that allows them to overcome their cancer.

Definitions of self-advocacy are comparable across the self-advocacy handbook and cancer survivors’ transcripts. The handbook’s description of self-advocacy as a “commitment to shared responsibility with your medical team” is reflected in Dorothy and Colleen’s desire to have strong relationships with their teams, whether through fully entrusted deference or cautious acceptance of their power.

The transcripts and handbooks differed in three key areas. First, differences exist between presumptions of togetherness vs. separateness. Self-advocacy is portrayed as a method of

addressing power and information disparities between patients, providers, and the larger medical system. Survivors are encouraged to “arm” themselves with information, portraying the medical experience as a war in which patients must fight for themselves and enlist the medical troops to be on their side. However, in the transcripts cancer survivors expressed a fundamental need for trust and comfort with their health care providers made. Self-assertion might be a disruptive rather than productive action. Even though Dorothy admits to confronting her physician and medical team in Excerpt 3 as to their decisions, she also takes the stance of less knowledge. Moreover, Dorothy’s use of the reduced forms (e.g. ‘em for them) may indicate her discomfort in questioning her provider, or may be an attempt to avoid insulting the researcher (a nurse).

Secondly, self-advocacy was presented as prescriptive in the handbook and individualized in the transcripts. Even if the skills described in the handbook are necessary, they do not constitute the essence of self-advocacy described by the women. The survivors described contextualized situations in which they self-advocated at specific times, with key persons, and about personal concerns. They explicitly did not want to self-advocate all the time. Colleen felt uncomfortable and scared self-advocating (Lines 8 – 11), and Dorothy self-advocated out of fear of mistakes being made (Lines 22 – 24). Dorothy and Colleen self-advocated because they wanted to continue their positivity, maintain their self-worth, and fight the disease. Even though the two women differed in their methods of self-advocating, their reasons were fundamentally focused on their personal needs and not generally focused on a specific aspect of their health care. While at times their self-advocacy focused on explicit tasks, such as Dorothy’s ordering of CT scans (Lines 31 – 33), this was not the central way in which Dorothy saw herself as a self-advocate or even a task that she fulfilling or empowering.

The third major difference between how the handbook and transcripts portrayed self-advocacy was the necessity vs. the fear of health information. The handbook emphasized the need for cancer survivors to know, seek out, and scrutinize health care information. In order to conduct the essential skills of self-advocacy (information seeking, communication, problem-solving, and negotiating), the handbook instructs cancer survivors to educate themselves about their diagnosis (Page 8), their selection of health care providers and treatment plans (Page 9 – 13), and insurance (Page 14) among other aspects of cancer care. Yet, the cancer survivors reported engaging in information only when needed. Sometimes they purposefully avoided information to protect themselves from overwhelming or upsetting information. Trusting the doctor to know and provide information allows the survivor to avoid the burden of being in charge of her health and well-being.

Discussion

The results of this discourse analysis demonstrate that the recommendations for cancer survivors to self-advocate as demonstrated in the self-advocacy handbook, while a valuable process, are an extremely formidable task requiring significant personal understanding and investment. While the handbook focused on preparation, research, communication, and self-reliance, the women’s experiences emphasized the importance of mental attitudes of self-advocacy and the value of relationship-building with their health care teams.

These findings mirror research demonstrating how cancer survivors are hesitant to lead their care, engage in health information, and lead decision-making. Even if the value of self-advocacy is recognized as a positive ability, patients may lack the willingness or the capacity to fully participate the level expected of a model self-advocate [12, 25]. Individuals may also feel disenfranchised if they do not fit the cultural ideal of an involved, assertive, active cancer survivor [14]. Cancer survivors who are already marginalized face additional challenges in finding their voices [12] and having their needs and preferences met. Without addressing the core values and needs of the cancer survivors intended to benefit from self-advocacy skills, then attempts to build this capacity risk being ineffective. Rather, self-advocacy training should start from a place of knowing how and why self-advocacy matters to cancer survivors.

Because patient education materials define and distribute the current discourse of self-advocacy, they should be adjusted to reflect how and why cancer survivors self-advocate. Based on the results of this study, patient education materials should: (a) acknowledge self-advocacy's role as a strategic process cancer survivors' engage in to maintain a positive outlook on life; (b) recognize and accommodate survivors with varying levels of comfort with health care information; and (c) emphasize the need survivors have for connectivity with their health care team.

This article's limitations include a focus on one published patient education handbook and experiences of a limited number of ovarian cancer survivors. Findings do not represent all survivors' understandings of self-advocacy, but do provide insight into this under-examined area.

Self-advocacy remains a necessary part of being a cancer survivor. By adjusting patient education materials to include a richer description of the process of self-advocacy based on cancer survivors' experiences, then the discourse of self-advocacy and expectations of health care providers can be adjusted to reflect the struggles and needs of cancer survivors.

Acknowledgements

We thank Mary Urban and the National Ovarian Cancer Coalition – Pittsburgh for their support of this study and dedication to ovarian cancer survivors. We also thank the National Coalition for Cancer Survivorship for use of their handbook, "Self-Advocacy: A Cancer Survivor's Handbook" © 2013 National Coalition for Cancer Survivorship. All Rights Reserved. This material may not be reproduced, displayed, modified or distributed without the express prior written permission of the copyright holder. For permission, contact info@canceradvocacy.org.

Funding: The authors disclosed receipt of the following financial support for the research and/or authorship of this article: Funding was received by the National Institute of Nursing Research (T32 NR011972 and R01 NR010735) and the Judith A. Erlen Endowed Research Fund.

References

1. Agency for Healthcare Research and Quality. [Accessed July 1, 2014] Strategies to Reduce Health Disparities Web site. <http://archive.ahrq.gov/news/ulp/dispar/dispar6.htm>.
2. American Society of Clinical Oncology. [Accessed July 1, 2014] Being Your Own Advocate Web site. <http://www.cancer.net/all-about-cancer/newly-diagnosed/being-your-own-advocate>.
3. Cancer Treatment Centers of America. [Accessed July 1, 2014] Next Steps in Cancer Advocacy Website. http://www.cancercenter.com/community/newsletter/august_2010/.

4. Mattern, AL. [Accessed July 1, 2014] Words of wisdom: Cure: Cancer Updates, Research, and Education Web site. 2011. http://curetoday.com/index.cfm/fuseaction/article.show/id/2/article_id/1679.
5. Rechis, R.; Beckjord, EB.; Arvey, SR.; Reynolds, KA.; McGorlrick, D. [Accessed July 1, 2014] The essential elements of survivorship care: A LIVESTRONG brief. <http://livestrong.org/pdfs/3-0/EssentialElementsBrief>.
6. National Coalition of Cancer Survivorship. [Accessed July 1, 2014] What is Advocacy? Web site. <http://www.canceradvocacy.org/cancer-advocacy/what-is-advocacy/>.
7. Ainslie J, Hicks R, Drummond R, Blakey D, McKenzie MB. Simulated bone metastases: A case study of two patients with breast cancer. *Australas Radiol*. 1999; 43(3):365–368. [PubMed: 10901939]
8. Davies, NJ.; Batehup, L. [Accessed July 1, 2014] Self-management support for cancer survivors: Guidance for developing interventions. Self-Management Work stream NCSI/Macmillan Cancer Support. 2010. http://www.trustedwriter.com/documents/guidancefordevelopinginterventions_anupdateoftheevidence.pdf.
9. Hermansen-Kobulnicky CJ. Measurement of self-advocacy in cancer patients and survivors. *Supportive Care Cancer*. 2008; 16(6):613–618.
10. Hoffman B, Stovall E. Survivorship perspectives and advocacy. *J Clin Onc*. 2006; 24(32):5154–5159.
11. Clark E, Stovall E. Advocacy: The cornerstone of cancer survivorship. *Cancer Pract*. 1996; 5:239–244. [PubMed: 9004569]
12. Kahana E, Kahana B, Kelley-Moore J, et al. Toward advocacy in cancer care for older adults: Survivors have cautious personal actions but bold advice for others. *J Am Geriatr Soc*. 2009; 57(S2):S269–S271. [PubMed: 20122027]
13. Levangie PK, Santasier AM, Stout NL, Pfalzer L. A qualitative assessment of upper quarter dysfunction reported by physical therapists treated for breast cancer or treating breast cancer sequelae. *Support Care Cancer*. 2011; 19(9):1367–1378. [PubMed: 20652602]
14. Sulik, GA. *Pink Ribbon Blues: How Breast Cancer Culture Undermines Women's Health*. New York, NY: Oxford University Press; 2011.
15. Volk RJ, Jibaja-Weiss ML, Hawley ST, et al. Entertainment education for prostate cancer screening: A randomized trial among primary care patients with low health literacy. *Patient Educ Couns*. 2008; 73(3):482–489. [PubMed: 18760888]
16. Agency for Healthcare Research and Quality. [Accessed July 1, 2014] Strategies to Reduce Health Disparities Web site. <http://archive.ahrq.gov/news/ulp/dispar/dispar6.htm>.
17. Centers for Disease Control & Prevention. [Accessed July 1, 2014] A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies. <http://www.cdc.gov/cancer/survivorship/pdf/plan.pdf>.
18. Institute of Medicine. *Patient-Centered Cancer Treatment Planning: Improving the Quality of Oncology Care: Workshop Summary*. Washington D.C.: The National Academies Press; 2011.
19. Stovall, E. [Accessed July 1, 2014] Self-Advocacy: A Cancer Survivor's Handbook. In National Coalition for Cancer Survivorship Web site. http://www.canceradvocacy.org/wp-content/uploads/2013/01/Self_Advocacy.pdf.
20. Hagan TL, Donovan HS. Ovarian cancer survivors' experiences of self-advocacy: A focus group study. *Oncology Nursing Forum*. 2013; 40(2):140–147. [PubMed: 23454476]
21. Tannen D, Cynthia Wallat. Interactive Frames and Knowledge Schemas in Interaction: Examples from a Medical Examination/Interview. *Social Psychology Quarterly*. 1987; 50(2):205–216.
22. Wodak, R.; Michael, Meyer. *Methods of Critical Discourse Analysis*. London: England: Sage Publications; 2001.
23. Starks H, Trinidad SB. Choose your method: A comparison of phenomenology, discourse analysis, and grounded theory. *Qual Health Res*. 2007; 17(10):1372–1380. 2007. [PubMed: 18000076]
24. Johnstone, B. *Qualitative Methods in Sociolinguistics*. New York, NY: Oxford University Press; 2000.

25. Sinding C, Hudak P, Wiernikowski J, et al. "I like to be an informed person but ...": Negotiating responsibility for treatment decisions in cancer care. *Soc Sci Med.* 2010; 71(6):1094–1101. [PubMed: 20633970]

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Table I

Self-advocacy Definitions Within Cancer Survivorship

Author or Group	Definition of Self-Advocacy
<i>Cancer and Advocacy Organizations</i>	
American Society of Clinical Oncology [2]	“A positive experience and often gives a person a sense of control in a time of uncertainty.”
Cancer Treatment Centers of America [3]	“When you become an advocate in your cancer care, you become empowered to fight the disease.”
Cure Magazine [4]	“Key to long-term survival, including being willing to question experts if you don’t understand something.” Being active in treatment decisions and knowing all options; seeking second options and improving decision-making.
LIVESTRONG [5]	No definition given, but listed as an essential element of survivorship care delivery.
National Coalition for Cancer Survivorship [6]	“A way of taking charge in an otherwise portentous environment of diagnostic tests, surgery, radiation, chemotherapy, and doctors’ offices. From arming oneself with good information about their diagnosis, to seeking second opinions, to locating resources for identifying and obtaining support, to knowing how to ask the right questions — people with cancer can become self-efficacious. Personal empowerment can mean the difference between maintaining a positive future outlook and enhancing quality of life or feeling helpless and less certain of the desirability of survival.”
<i>Research Articles</i>	
Ainslie [7]	Proactivity by the patient. Promoting informed patients willing to participate in clinical management. Having higher expectations of obtaining answers to medical problems. Provides a sense of being in control over their own lives, improve quality of life, and turns hopelessness and helplessness into hopefulness. Leads to personalized and subjective outcomes for the patient.
Davies & Batehup [8]	Assertive communication skills to enhance the patient’s participation in planning his care.
Hermansen-Kobulnicky [9]	A mindset or set of beliefs as well as a set of behaviors which can be learned and demonstrated.
Hoffman & Stovall [10]	Arises from being an informed health care consumer. Involves collecting accurate medical information, seeking second opinions, locating and accessing support resources, asking questions and insisting on clear answers, and fighting for individual financial, insurance, employment, and privacy rights.
Clark & Stovall [11]	Begins with having competencies outlined in the aforementioned skill set, allowing individuals and/or their family and friends to be effective participant(s) with the healthcare team and significant others involved in cancer care.
Kahana et al. [12]	An awareness of, and responsiveness to, social changes in health care, including changing norms toward consumerism.
Levangie, Santasier, Stout, & Pfalzer [13]	Includes knowledge, motivation, denial, adaptation, and fear. Is particularly needed for long-term cancer sequelae.
Sulik, Cameron, & Chamberlain [14]	Consists of activities to support a particular agenda.
Volk [15]	The degree to which a “patient takes a participative stance in health-care decision making”. Reflected in definitions of informed decision making. Mastering and obtaining information about a cancer-related procedure.
<i>Policy Organizations</i>	
Agency for Healthcare Research and Quality	A skill used to address health care disparities, especially with people from cultures that equate assertiveness with rudeness.

Author or Group	Definition of Self-Advocacy
[16]	
Centers for Disease Control and Prevention [17]	A means of increasing preventative measures to reduce cancer incidence. A way of addressing public education among cancer survivors.
Institute of Medicine [28]	Cancer survivors “should be taught advocacy skills so they can tell their stories powerfully and succinctly”.

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Table II

Excerpts from Ovarian Cancer Focus Group Transcripts

Excerpt 1: Don't Go Quietly

1 Colleen (C): As far as my part in this is like
 2 my motto is "don't go quietly"
 3 like I'm- have tattooed on my shoulder,
 4 Dorothy (D): [Do you?
 5 you know you fight for all you're worth.
 6 you never go down.
 7 you know what I mean?

Excerpt 2: The Man's Going to Tell Me

8 C: Oh you know what I suck at doing that as-as far as like what you do
 9 Like with the-the uh knowin an researchin an everything.
 10 I really suck at that.
 11 Because I think if-if I know more I'll. get. more. scar:ed.
 12 Or [whatever you want to say
 13 D: [Yeah, yeah. And it does/]
 14 C: [So I- you know,
 15 I'm kind of like you know, Dr. XXXX's my man,
 16 he knows what's going on and he'll take care of me]
 17 D: [yeah [yeah yeah
 18 C: [if I really need =
 19 to know something the man's gonna to tell me.
 20 So I really suck at that.
 21 I leave that all in their hands.

Excerpt 3: Being on Top

22 D: Proactive is the word.
 23 Yeah because I don't want – I don't
 24 And I don't want anybody to make a mistake
 (Laughter)
 25 Like they're gonna have me go for um CT scans
 26 They want me to go for the abdomen because it's starting to get on my liver]
 27 C: [yeah
 28 D: and they don't know if it's because it's scar tissue
 29 Or do- is it spreading to the liver.]
 30 C: [mhmm
 31 D: Alright so at that point so they-they want me to get the pelvic and the abdomen.
 32 I says "but for this plan, it says you should also get the chest one
 33 so why don't I get all three of them done now instead of like waiting."
 34 C: yeah

- 35 D: You know that was another one of my questions
 36 [Like why don't you just throw that in there because it's so hard to contrast
 37 C: [yeah
 38 D: because I have such little vei:ns now [because they chemo's like eating them =
 39 C: [uh huh
 40 D: all up.
 41 you know that, let's do 'em all.
 42 So I wanna like,
 43 you know like "don't you have this idea already?"
 (Laughs)
 44 Like why am I coming up with this idea?
 45 Or tell me the reason why I'm not supposed to have it.
 46 C: Yeah
 47 D: You know so that's why I don't like- I like to be on top.
-

Transcription Key

- a. Punctuation reflects intonation, not grammar.
- b. [signs shows latching (second voice begins without perceptible pause) and bracket ([]) show overlap (two voices heard at the same time)
- c. Underline indicates emphatic stress
- d. = indicates the speaker continues
- e. : colon following a vowel indicates elongated vowel sound
- f. one period (.) within line indicates slight pause between words
- g. two periods (..) indicated pause in turn
- h. dotted underline denotes laughing while talking
- i. / indicates rising intonation word finally.