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Self-Advocacy and Cancer: A Concept Analysis

Teresa L. Hagan, BSN, RN, BA and

Department of Acute and Tertiary Care, The University of Pittsburgh School of Nursing.

Heidi S. Donovan, PhD, RN

Department of Acute and Tertiary Care, The University of Pittsburgh School of Nursing.

Abstract

Aim—This paper is a report of an analysis of the concept of self-advocacy among individuals with cancer to clarify its meaning, to differentiate this meaning with related concepts and to unify understanding of the concept in cancer research and practice.

Background—Cancer survivors are increasingly required to assume an active role in their healthcare. A thorough analysis of how survivors advocate for themselves is a crucial aspect in supporting survivors' ability to engage and manage their care throughout all stages of cancer survivorship.

Design—Walker and Avant's eight-step process of conducting a concept analysis was used.

Data Sources—PubMed, PsycINFO and CINAHL databases were searched for articles, reviews, editorials and gray literature directly addressing self-advocacy.

Review Methods—A broad inquiry into the literature from 1960 – 2012 that produces a definition of self-advocacy. Model and contrary cases of self-advocacy demonstrate the concept's application and intricacies.

Results—Antecedents to self-advocacy include particular personal characteristics, learned skills and attainable support. The essential element of self-advocacy and what differentiates it from related concepts, is the internalization of these antecedent resources into self-advocacy thoughts and actions while incorporating personal values and priorities in a way that upholds the survivors' goals and beliefs. A full realization of self-advocacy facilitates a cancer survivor attaining a strong self-concept, sense of control and adaptation to a life with cancer.

Conclusions—Self-advocacy is a process of internalizing skills and resources to act in a way that supports survivors' needs and goals.

Keywords

self-advocacy; advocacy; cancer survivorship; nursing; concept analysis

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Correspondence concerning this article should be addressed to Teresa L. Hagan, 336 Victoria Building, 3500 Victoria Street, Pittsburgh, PA 15211, USA; tlh42@pitt.edu.

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Introduction

Cancer survivorship, as defined by the National Cancer Institute, consists of ‘the health and life of a person with cancer until the end of life’ (2012). Survivorship care increasingly emphasizes patient participation and patient-centeredness throughout all these stages, expecting survivors to be willing and able to engage in complex decision-making (Clark 1996), Peppercorn *et al.* 2011, Rose *et al.* 2008). Yet many survivors have difficulty making informed decisions that incorporate their needs and wants, especially when the ramifications are substantial and choices themselves are uncertain. Self-advocacy has been broadly defined as an assertiveness and willingness to represent one’s own interests when managing a life threatening disease (Brashers *et al.* 1999). While self-advocacy is often touted as an important skill for cancer survivors (Walsh-Burke & Marcusen 1999), there is no clear or consistent understanding of what the concept is or how to support it.

Background

Three global trends have created a need to better understand the phenomenon of self-advocacy within cancer survivorship: 1) an increasingly complex medical system; 2) the movement of cancer care to a chronic care model; and 3) the emphasis on survivor self-determination (Gaard & Schrager 2007). Survivors must not only navigate obstacles associated with each phase of survivorship, but also the obstacles associated with a fragmented health care system (e.g. communication with multiple health care providers [HCPs]; employment, financial and insurance concerns). Survivors now have access to an unprecedented variety and depth of information and support, but are then faced with an additional barrier of how to use these resources in ways that promote useful information exchange and understanding between survivors and HCPs (Lee *et al.* 2010, Skalla *et al.* 2004). Moving from an acute to a chronic care model (Hewitt *et al.* 2006, McCorkle *et al.* 2011) and a greater focus on patient participation, HCPs need to support survivors as central actors in their care consistent with the ethical principles of self-determination and autonomy (Taylor 2009).

A critical dilemma arises within cancer survivorship: cancer care grows more complex while the need for survivors to advocate for themselves grows more essential and burdensome (Pinch & Parsons 1992, Taylor 2009). Self-advocacy training has been presented as a mechanism by which survivors can tackle this essential, but overwhelming demand for increased pro-activity.

Self-advocacy has been broadly studied in other patient populations with strong evidence that it is a modifiable skill capable of impacting patients’ health outcomes and quality of life. Jonikas *et al.* (2011) conducted a randomized controlled trial teaching self-advocacy skills to adults with serious mental disabilities and concluded that participants receiving the intervention reported significantly higher levels of self-advocacy, hopefulness and environmental quality of life and lower levels of symptom burden compared with the control group. Test and colleagues (2005) reviewed 25 self-advocacy intervention studies and found that each of the interventions and educational curricula improved self-advocacy skills among individuals with disabilities. These findings support the potential application of self-advocacy in oncology as a target for intervention capable of improving patient outcomes.

In cancer survivorship, however, self-advocacy currently lacks both the conceptual clarity and constituent focus needed move self-advocacy from a vague but in vogue mandate into a concrete model capable of guiding clinical interventions among survivors. Without a clear understanding of what self-advocacy is and how it is achieved in the context of cancer survivorship, the healthcare professions risk placing the burden of self-advocating onto patients without providing the corresponding guidance on how to do so. Such an obligation,

while intending to bolster patient autonomy, self-determination and self-management, may overwhelm patients and counter-intuitively reinforce the paternalistic relationship self-advocacy is intended to overturn (Feeg 1995).

This concept analysis aims to: 1) define the phenomenon of self-advocacy in the context of cancer survivorship; 2) differentiate this meaning from related concepts; and 3) create a unified understanding of the concept in cancer practice and research.

‘Concepts’ are mental representations of reality used to represent a human phenomenon. The exploration of a concept establishes its essential components to provide research and clinical clarity. Multiple methods of concept analysis exist, most based on Wilson’s method of defining concepts (1963). We used Walker and Avant’s methodology to discover how the meaning of self-advocacy developed and to produce a shared, common meaning of the phenomenon of self-advocacy. This analytic style includes eight steps (Table 1) intended to streamline an abstract idea into a more tangible concept that can be universally applied and understood (Walker & Avant 2010). Beginning with a broad inquiry into the concept’s wide-ranging uses and essential aspects, the resulting conception of self-advocacy provides clear definition of the concept for use in the literature. To overcome critiques that this approach is reductionist (Morse 1995), Risjord 2009, Rogers 2005), real-world exemplars are employed as model and contrary examples of self-advocacy to illustrate the concept’s definition and highlight its complexities and uniqueness in this patient population (Duncan *et al.* 2007). Knowingly, concepts are expected to change and the result of this analysis will not be a finished product, but one anticipating future iterations.

Data Sources

To capture the full breadth of self-advocacy, an extensive, systematic, cross-disciplinary review of the literature was conducted. An original review of cancer survivorship literature revealed a surprising lack of well-defined research. Since self-advocacy’s central tenets derived from research with patients with HIV/AIDS, disabilities and mental health populations, the literature search was extended to include references outside of the cancer literature that specifically measured or discussed self-advocacy. PubMed, PsycINFO and CINAHL were searched using the keywords ‘self-advocacy’ or ‘advocacy’ and ‘cancer’ or ‘survivorship’ in varying combinations. Abstracts of research studies and reviews, editorials, conference abstracts and books published in English from 1960 – 2012 were reviewed. Abstracts of research studies and reviews, editorials, conference abstracts and books published in English from 1960 – 2012 were. Reference lists of relevant articles were essential to finding additional articles and books and the concept originated. The selection process primarily focused on adults, though adolescent/young adult cancer survivorship was also considered as relevant to the goals of the concept analysis. Attention was given to ensure inclusion of multiple ethnic and cultural perspectives. This search resulted in a total of 2,872 pieces of literature. Abstract review identified 103 relevant articles that are included in this analysis. The primary reason for exclusion was not mentioning self-advocacy. This frequently occurred because of our decision to include the broad search term ‘advocacy’ as MeSH terms and article indexing do not include self-advocacy as a distinct term.

A literary synthesis process was used to capture all of the conceptual dimensions of self-advocacy available in the literature according to Walker and Avant’s methodology. Articles were reviewed both for a broad portrayal as well as a detailed description of self-advocacy. All relevant articles were read once and then grouped into sub-categories based on patient population (cancer vs. other) and whether or not self-advocacy was the primary focus of the article. Articles that presented a more thorough description of self-advocacy and that

considered cancer survivors provided more relevant information and were considered more instrumental to the overall findings. Through this process of synthesis and comparison, a clear conceptualizations of the phenomenon emerged. A flowchart of data review and analysis is illustrated in Figure 1.

Results

Identifying All Uses of the Concept

Self-advocacy is a charged word, evoking strong and varied connotations depending on the context it is used. ‘Advocacy’ comes from the Latin word ‘advocates,’ meaning ‘one who is summoned to give evidence’ (Gates 1995). *The Oxford English Dictionary* defines an advocate as ‘one called upon...to defend or speak for’ another (Simpson 1989).

The concept of ‘self-advocacy’ refers to a distinct type of advocacy which an individual or group supports and defends themselves either as a collective or as singular persons (Forster 1998). The concept first originated in research on the ethical and legal rights of adolescent, HIV/AIDS and disability populations. In the HIV population, Brasher *et al.* (1999) defined self-advocacy as patients taking a participative stance in healthcare interactions and becoming ‘activists’ in managing their illness. Similarly, in the disability population Vessey and Miola (1997, pg. 53) defined the concept as ‘the ability to seek, evaluate and use information to promote one’s own health’. Disenfranchised populations experiencing undue inequalities began to utilize the concept of self-advocacy as a form of emancipation. Historically, self-advocacy has included both a reflective assessment of a population’s needs, an active movement towards emancipation and building agency in individuals (Caldwell 2010), Rogers & Pilgrim 2008).

While previous attempts at defining and measuring self-advocacy among cancer survivors have adapted models from the HIV/AIDS and disability populations (Goodley 1998), 2005, Hermansen-Kobulnicky 2008), such attempts failed to distinguish the unique dimension of self-advocacy in cancer survivorship. Therefore, while this analysis recognizes the roots of self-advocacy lie outside cancer survivorship, it argues that cancer survivors’ experiences are distinct and future research requires defining this phenomenon from this population’s perspective.

Defining Attributes

The defining attributes of a concept represent a cluster of qualities most frequently associated with the concept in the literature. Such elements help differentiate self-advocacy from related concepts and allow for easy identification of self-advocacy in action. Self-advocacy’s defining attributes (Figure 2) represent internalizing and leveraging the antecedents of self-advocacy into efforts to manage the challenges associated with cancer in a way that upholds the survivors’ personal goals and beliefs. These attributes can be categorized into three categories:

Thoughts and cognitions—Self-advocates are able to *create a ‘new normal’* where they adjust and accept life with cancer as an aspect of their life rather than a temporary deviation (Zebrack 2001). Self-advocates are also able to *prioritize their needs and wants* during the varying phases of survivorship (Clark 1996), Gray *et al.* 2005, Leigh 2006). Thirdly, self-advocates hold an underlying sense of *empowerment*, defined as a sense of command over the obstacles related to cancer (Davison & Degner 1997, Gibson 1991).

Actions for self—Self-advocates can assert themselves to gain command of their healthcare experience. These actions include *navigation of the healthcare system* so that they

receive the most appropriate care available. This includes knowledge of who and how to contact when a problem arises, such as a bothersome side-effect or an unreturned phone call (Levangie *et al.* 2011, Martin *et al.* 2011). Also, self-advocates build *teamwork with their healthcare providers* where both parties openly communicate, share information and check for mutual understanding (Casarett *et al.* 2002, Shapiro *et al.* 2009). Additionally, self-advocates *make informed decisions* after collecting and analyzing information from multiple sources (Allen *et al.* 2007, Hoffman & Stovall 2006, O'Hair *et al.* 2003). Finally, self-advocates may *engage in mindful non-adherence*, making informed decisions not to follow or to make modifications to recommendations based on an educated understanding of the issue and personal preferences (Brashers *et al.* 1999, Sinding *et al.* 2010). Rather than being a naïve rejection of treatment or deviant behavior, this is a reasoned decision based on rational choices drawn from patient preferences, beliefs and values.

Utilization of resources—Self-advocacy consists of survivors' involvement with people and groups that support their own interests and often the interests of the larger survivor population. Self-advocates may *seek out and provide social support* through individual relationships and support groups to share personal experiences and learn from others'. Survivor-advocates are a new genre of patient advocates who use their shared experiences to assist each other in navigating life with cancer. Similarly, *membership in cancer-related groups* indicates a survivors' personal identification as a member of a larger cancer community and presents an opportunity to gain support through their cancer experience. Finally, self-advocacy may extend to *acting to advance cancer awareness, policy and research* through involvement in personal and public service opportunities, cancer non-profit agencies (Bastian 1998), Koon *et al.* 2009, Norton 1998), political lobbying, using personal narratives to increase awareness and spur action (Hoffman & Stovall 2006) and contributing to oncology research efforts (Andejeski *et al.* 2002). These actions may come from personal needs or from altruistic intentions to 'give back' and are indicative of survivors' understanding and ownership of their cancer and may ultimately benefit the individual through a symbiotic relationship.

Related Concepts

Self-advocacy is often confused with the concepts of self-efficacy, self-management and self-empowerment. Self-efficacy is defined as the belief in one's ability to perform a specified skill, such as making a difficult decision or communicating with a health care provider (Bandura 1977). By contrast, self-advocacy incorporates not only a survivor's confidence in her ability, but the internal motivation and urgency behind his or her behavior. A second concept, self-management, refers to a survivor's ability to manage the realities of living with cancer and involves completion of skills and tasks. This concept primarily focuses on educating survivors in adhering to a disease management plan (Barlow *et al.* 2002, Cimprich *et al.* 2005, Foster *et al.* 2007). On the other hand, self-advocacy originates with the survivors' intentions to stand up for his or her values throughout all choices. Unlike self-efficacy and self-management which primarily focus on enacting behaviors to improve outcomes, self-advocacy entails the underlying activation of survivors' values and so has implications not only for the survivors' cancer care but also for the broader well-being of the survivor (O'Hair *et al.* 2003).

A third related concept, self-empowerment, is most closely related to self-advocacy and includes the survivor's process of gaining power and control over aspects of his or her cancer experience (Mok 2001, Rafael 1995). While self-empowerment is included in the defining attributes of self-advocacy, it is not sufficient to encompass the entirety of this phenomenon, primarily because self-advocacy has an action-orientation where the process

of self-advocating leads the survivor acting on his or her own behalf in the face of a challenge or threat.

Antecedents

According to Walker and Avant, antecedents are events that must occur or characteristics that must be in place prior to the occurrence of the concept. While each factor in each category is not essential for self-advocacy to occur, each factor does influence the extent to which one can become a self-advocate. While survivors may come to their cancer experience possessing these characteristics, skills and resources, many of these antecedents can also be learned or improved over time (Walsh-Burke & Marcusen 1999). Antecedents of self-advocacy recognized in the literature include three categories of resources that support the self-advocacy process:

Personal characteristics—Personal characteristics are the attitudes, beliefs and traits which predispose survivors to advocate for themselves in thought and action. A level of *personal awareness* of one's needs, values and priorities is required to be an effective self-advocate (Park *et al.* 2009). Only by stepping back to reflect on the impact cancer has on one's life and identity can a survivor discern the needs, values and priorities for which he or she would like to advocate. Secondly, an internal *drive to overcome*, control, or own negative experiences and an *openness to try new experiences* have been associated with self-advocacy (Osborne *et al.* 1999). These are necessary characteristics for survivors as significant effort and adjustments may be required to manage symptoms, make role adjustments, or plan for end of life.

Learned skills—Learned skills enhance a survivor's ability to perform the necessary tasks of cancer survivorship including navigating the healthcare system, working with healthcare providers and making informed decisions. *Communication skills* are recognized as essential instruments of self-advocates. The ability to effectively receive and convey information to the healthcare team, family and friends requires proficiency in articulating needs, negotiating solutions and mediating conflict (Hoffman & Stovall 2006, McConigley *et al.* 2011, Wolf *et al.* 2005). Furthermore, *information-seeking skills* allow survivors to explore second opinions, manage side effects and find support (Clark & Stovall 1996, Radina *et al.* 2011). *Problem-solving skills* equip survivors to readily address new challenges by identifying and selecting appropriate solutions (Tesauro *et al.* 2002).

Attainability of support—Availability of resources to provide support, advocacy and community throughout survivorship is the third category of antecedents. *Informal support* refers to access to social support from family and friends in the form of emotional, tangible and informational support that is specific to the unique needs of the survivor. Such support acts as a foundation for the survivor to initiate the process of self-advocacy. *Formal support* refers to the presence of established support groups and organizations that provide opportunities for survivors to connect with other survivors, help others 'going down the same path,' and make changes to the delivery of cancer care (Lythcott *et al.* 2003, Meneses *et al.* 2010, Zeigler *et al.* 2004). The availability of *cancer advocacy groups* is an example of formal support resources, which are established to advocate for cancer survivors at a local or national level, but also benefit individual survivors (McCabe *et al.* 1995, Norton 1998). As an antecedent to becoming a self-advocate, survivors must have access to these support resources to take advantage of them to meet their personal needs prior to actively participating and leading in these groups (Conlon *et al.* 2010, Temple 2002).

Each of these antecedents represents steps toward self-advocacy. While each may facilitate a survivor becoming a self-advocate, the presence of antecedents alone does not guarantee the

process of self-advocacy. The key feature of self-advocacy is the survivors' ability to internalize personal characteristics, skills and support resources into actions to support personally relevant goals.

Consequences

Consequences are the events or incidents that occur as a result of a concept. As an outcome of self-advocacy, survivors face the challenges of survivorship with improved outcomes both directly and indirectly into the future (Clark & Stovall 1996, Hoffman & Stovall 2006). Immediate outcomes may include improved symptom management, adherence, satisfaction with care and quality of life along with decreased healthcare utilization (Hibbard & Cunningham 2008, Jonikas *et al.* 2011, Mutchler *et al.* 2011, Pickett *et al.* 2010, Ramsay *et al.* 2009, Wiltshire *et al.* 2006). Beyond such proximal outcomes, self-advocacy ultimately is hypothesized to improve individual's self-concept, control and a strengthened sense of autonomy (Brashers *et al.* 1999, Leigh 2006, Morris *et al.* 2011, Shapiro 2009, Zebrack & Landier 2011).

Model Case and Contradictory Case

The final steps in Walker and Avant's process include designing model and contrary cases to explicitly embody how the concept of self-advocacy among cancer survivors occurs. Actual accounts of both self-advocacy and non-self-advocacy have been taken from an ongoing randomized clinical trial (NIH R01 NR010735) to form substantive exemplars. The Written Representational Intervention To Ease Symptoms (WRITE Symptoms) is a web-based symptom management intervention for women with recurrent ovarian cancer (Donovan *et al.* 2007). Survivors interact with research nurses over web-based message boards and as part of the intervention are asked to describe their experiences with trying to get better control over their symptoms. The message boards of two participants, 'Judy' and 'Anne' (pseudonyms), demonstrate how the concept of self-advocacy occurs in real-world situations.

Self-Advocacy—As described below, Judy's message board entries describing her experiences with gaining control over her symptoms of nail toxicity, memory problems and sexuality demonstrate the presence of all three categories of antecedents and the essential internalization process of self-advocacy:

1. *Leveraging personal characteristics into self-advocacy thoughts and cognitions.* Judy's posts suggest that she has several personal characteristics that enhance her ability to be a self-advocate including: a high level of personal awareness, a drive to overcome challenges, an openness to trying new things ('I'm willing to give it a try; glad you gave me some alternatives...I can try') and a sense of optimism ('I'm hopeful') that things will improve over time. She harnesses these inherent traits and directly applies them to specific actions meant to improve her cancer- and treatment-related symptoms. She makes statements such as 'will maintain my strategies to continue to decrease my nail discomfort' reflecting confidence that her efforts will lead to improved symptom control. She inherently 'owns' her symptoms and demonstrates initiative by coordinating her own, personalized goals for each of her symptoms. At one point in the intervention, Judy recognizes her need to 'be more mindful' in managing her discomfort. She shares her past participation in a mindfulness class 'which started me on my 'don't forget to breathe, stay in the moment, etc., etc. 'journey' in the face of future uncertainties related to her disease. She *prioritizes* her life and recognizes what accomplishments she needs to focus at the given time.

2. *Turning learned skills into actions for self.* Judy's posts describe impeccable communication, information-seeking and problem-solving skills. She leverages skills developed as a licensed social worker into an assertive and cooperative relationship with her HCPs to find solutions to her symptoms. She states, 'I don't have any difficulties talking to the doctor ...and I have frequently emailed the clinical trial nurse with questions, etc. I think that I have my own concept of the word 'team' ....' Throughout her posts, Judy's *communication skills* stand out in her skillful description of her symptom experience and its impact. 'I'm less concerned about sounding like I'm complaining because I see myself as 'reporting''. A skilled *information seeker*, she researches options and finds information about cotton gloves and tea tree oil to manage her nail problems. She has built *teamwork* with her HCPs, referring to her team collectively as 'we' and she feels in charge of her treatment. Her *problem-solving abilities* become apparent as she addresses the chemotherapy-induced nail toxicities that are not being adequately addressed. She makes and follows through on a plan to work with her team to alleviate this symptom and then chooses one of several recommended strategies to carry out. She feels capable of making *informed decisions* and even turns down certain nail toxicity medications after carefully weighing the risks and benefits to her (i.e. *mindful non-adherence*):

I feel like my body is one big repository for drugs so if I can do without [taking additional medications], I prefer to (That is not to say that I'm going to suffer rather than take something....I've never been opposed to 'better living through chemistry).

3. *Making use of available support.* Judy makes use of her support systems through *reaching out* to her husband for help in trying some new strategies for her memory problems and becoming a *member of the support group*. She makes plans to seek out advice from her support group as she transitions out of her job. 'I talk about my new life in my support group...and will bring up the issue of not working in my support group the next time we meet''. She takes advantage of resources at the *non-profit agency* where she attends a speaker's series and takes mindfulness classes.

In response to her severe and distressing cancer-related symptoms, Judy ends up advocating for herself in a way that gives her a renewed self-concept and hope for the future with a better sense of control over cancer and chemotherapy's symptoms: 'It seems like it has been a long time since I have felt so happy and free'.

Non-Self-Advocacy—Another participant, 'Anne', illustrates how the absence of self-advocacy's antecedents or an inability to internalize skills and resources into self-advocating actions can lead to poorer outcomes. Anne feels that having to deal with her symptoms is 'worse than death' and while she dreams of getting back to life, has difficulty developing a plan to achieve a new, more positive normal: 'I would like to get on with my life and maybe return to work, but the peripheral neuropathy and fibromyalgia I incurred with chemo and the lack of [my oncologist] treating these conditions makes that impossible'.

Anne's personal characteristics, lack of learned skills and lack of support put her at risk for increased symptom distress. She possesses a *drive to overcome* her symptoms: 'I wish I could get back to normal', but lacks the *personal awareness* and *openness to try new strategies* for symptom management: 'The only things I have tried are Cymbalta which does not work and B6 which also does not work. I do not want to take Neurontin because I don't like the side effects of it'. In terms of learned skills, Anne's message board posts do not reflect *information-seeking* or *problem solving skills*. The *communication* between her and her healthcare team has broken down as she adamantly blames her oncologist for her

recurrent cancer and distrusts their recommendations: 'I am so totally aggravated with these side effects I could scream. And especially since my oncologist does not think it is his responsibility to treat them. After all, I did get these side effects and current medical problems from *his* treatment'. She does not *seek out information* or work through *problem-solving* to manage her cancer-related pain even with repeated efforts by the WRITE Study research nurse to provide her with strategies to help her: 'Anyway I did check out [recommendations] and of course did not find anything to help.' Anne does not accept from the research nurse to connect her with support resources to assist her with symptom financial and support needs.

Considering Anne's lack of antecedents to self-advocacy, her difficulty in self-advocating is not surprising. Instead of *creating a 'new normal'*, taking *ownership* of her cancer and feeling *empowered*, her *thoughts and cognitions* seem stuck in feeling victimized by the cancer and her healthcare team and unable to move out of a state of passivity and regret. She is *unable to effectively navigate the healthcare system, make informed choices* that benefit her, or *build teamwork with her care team*. Anne does not mention any availability or use of outside support groups or organizations. She does not indicate having a source of support or encouragement. Without the key attributes of self-advocacy she continues to struggle with poorly managed symptoms and feels hopeless and frustrated. She states:

'I am...totally aggravated and out of options. I feel like I have to be a couch potato for the rest of my life to keep these problems at bay ...That's what I meant when I said I should have not had treatment. I don't like this life I am forced to live. It is depressing most of the time and makes me angry and anxious the rest of the time. I can't seem to find a good pace - it's either too little or too much.'

Comparing Judy and Anne's examples of self-advocacy and non-self-advocacy clearly distinguish how self-advocacy is a process requiring not only the presence or acquisition of resources and healthcare-related skills, but the crucial step of self-reflection and internalization of the process of self-advocacy to overcome the obstacles presented by cancer and its treatment.

Empirical Referents

Empirical referents are instances that by their existence demonstrate the occurrence of a concept (Walker & Avant 2010). Self-advocacy, defined by a fervent internalization and activation process on the part of cancer survivors, is yet to be objectively operationalized and measureable (Hermansen-Kobulnicky 2008). Still, a clear activation process is almost certainly present when the defining attributes are observable and therefore represents a means by which self-advocacy can be recognized and potentially measured.

Discussion

The concept of self-advocacy, as derived from this systematic synthesis of the literature, is a process of internalizing and activating resources into actions to overcome cancer- and treatment-related obstacles. When fully realized, this process extends beyond the skills-based and situation-focused concepts of self-management and self-efficacy to a person-based advocacy. Self-advocacy becomes a personal journey where survivors assess and tackle the challenges of cancer on their own terms, thus producing a patient-driven model of individualized care (Peppercorn *et al.* 2011).

The proposed conceptual model represents an integrated understanding of the previous uses of self-advocacy in the literature. Survivors may self-advocate in a wide range of issues, including both physical and emotional needs or even in larger social and political arenas. This model is not limited to a single phase of survivorship and should accommodate a wide

range of experiences and challenges (Miller *et al.* 2008, Muraca *et al.* 2011). The elements in this model are similar to key elements of a model of self-advocacy in the disabilities literature that successfully guided intervention research to improve patient outcomes (Test *et al.* 2005). This suggests that self-advocacy could also be a productive target for intervention among cancer survivors.

Nurses and other medical professionals can use the concept of self-advocacy in both clinical and research capacities as a way of understanding how best to provide patient-centered support in a mutually beneficial way throughout the survivorship continuum (Haylock *et al.* 2007). Instead of viewing nurses as competing with principles of self-advocacy, a synergistic view sees nurses playing a key role in promoting survivors' self-advocacy by assessing and valuing patient preferences and assisting survivors navigate their care (Gallagher *et al.* 2009, Mahlin 2010).

Limitations

Limitations to this model are also noted. This analysis was unable to consider related concepts (e.g. health literacy, locus of control, coping) not directly presented in the current self-advocacy literature. While such concepts may be similar to self-advocacy and assist in understanding the dimensions of self-advocacy, no such direct link is currently in the self-advocacy literature. Future research must compare the conceptual and clinical differences between these concepts.

Conclusion

This analysis defines self-advocacy as a developmental process where survivors leverage personal strengths, skills and resources to achieve personally relevant goals. Unlike related concepts, this phenomenon requires deeply personal engagement to stand up for his or her beliefs and needs particularly when met with opposition. Given the critical and global importance of this process across all survivors' experiences, the concept of self-advocacy must be transformed from a buzz-word into a well-defined framework for action. This concept analysis is a first step in realizing self-advocacy's potential as a means of understanding and building survivors' ability to and engagement in managing their cancer.

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References

1. Allen JD, Kennedy M, Wilson-Glover A, Gilligan TD. African-American men's perceptions about prostate cancer: implications for designing educational interventions. *Social Science, Medicine*. 2007; 64(11):2189–2200. [PubMed: 17399877]
2. Andejeski Y, Bisceglia IT, Dickersin K, Johnson JE, Robinson SI, Smith HS, Visco FM, Rich IM. Quantitative impact of including consumers in the scientific review of breast cancer research proposals. *Journal of Womens Health and Gender-Based Medicine*. 2002; 11(4):379–388.
3. Bandura A. Self-efficacy: toward a unifying theory of behavioral change. *Psychological Review*. 1977; 84(2):191–215. [PubMed: 847061]
4. Barlow J, Wright C, Sheasby J, Turner A, Hainsworth J. Self-management approaches for people with chronic conditions: a review. *Patient Education and Counseling*. 2002; 48(2):177–187. [PubMed: 12401421]
5. Bastian H. Speaking up for ourselves: The evolution of consumer advocacy in health care. *International Journal of Technological Assessment in Health Care*. 1998; 14(1):3–23.

6. Brashers DE, Haas SM, Neidig JL. The patient self-advocacy scale: measuring patient involvement in health care decision-making interactions. *Health Communication*. 1999; 11(2):97–121. [PubMed: 16370972]
7. Brody DS. The patient's role in clinical decision-making. *Annals of Internal Medicine*. 1980; 93(5): 718–722. [PubMed: 7212484]
8. Caldwell J. Leadership development of individuals with developmental disabilities in the self-advocacy movement. *Journal of Intellectual Disability Research*. 2010; 54(11):1004–1014. [PubMed: 20731755]
9. Casarett DJ, Karlawish JH, Byock I. Advocacy and activism: missing pieces in the quest to improve end-of-life care. *Journal of Palliative Medicine*. 2002; 5(1):3–12. [PubMed: 11839222]
10. Cimprich B, Janz NK, Northouse L, Wren PA, Given B, Given CW. Taking CHARGE: a self-management program for women following breast cancer treatment. *Psycho-Oncology*. 2005; 14(9):704–717. [PubMed: 15651055]
11. Clark E, Stovall E. Advocacy: the cornerstone of cancer survivorship. *Cancer Practice*. 1996; 4(5): 239–244. [PubMed: 9004569]
12. Clark, EJ. Imperatives for quality cancer care: access, advocacy, action and accountability. Silver Spring, MD: National Coalition for Cancer Survivorship; 1996.
13. Conlon A, Gilbert D, Jones B, Aldredge P. Stacked stigma: oncology social workers' perceptions of the lung cancer experience. *Journal of Psychosocial Oncology*. 2010; 28(1):98–115. [PubMed: 20391068]
14. Davison BJ, Degner LF. Empowerment of men newly diagnosed with prostate cancer. *Cancer Nursing*. 1997; 20(3):187–196. [PubMed: 9190093]
15. Donovan HS, Ward SE, Song MK, Heidrich SM, Gunnarsdottir S, Phillips CM. An update on the representational approach to patient education. *Journal of Nursing Scholarship*. 2007; 39(3):259–265. [PubMed: 17760800]
16. Duncan C, Cloutier JD, Bailey PH. Concept analysis: the importance of differentiating the ontological focus. *Journal of Advanced Nursing*. 2007; 58(3):293–300. [PubMed: 17474918]
17. Feeg VD. Nursing: the last bastion of patient advocacy. *Pediatric Nursing*. 1995; 21(2):108–199.
18. Forster R. Patient advocacy in psychiatry: the Austrian and the Dutch models. *International Social Work*. 1998; 41(2):155–167. [PubMed: 11660656]
19. Foster C, Brown J, Killen M, Brearley S. The NCRI cancer experiences collaborative: defining self-management. *European Journal Oncology Nursing*. 2007; 11(4):295–297.
20. Gaard S, Schrager S. Empowering patients with a written agenda. *Wisconsin Medical Journal*. 2007; 106(8):449–451.
21. Gallagher A, Horton K, Tschudin V, Lister S. Exploring the views of patients with cancer on what makes a good nurse: a pilot study. *Nursing Times*. 2009; 105(23):24–27. [PubMed: 19624053]
22. Gates B. Advocacy: whose best interest? *Nursing Times*. 1995; 91(4):31–32. [PubMed: 7862570]
23. Gibson CH. A concept analysis of empowerment. *Journal of Advanced Nursing*. 1991; 16(3):354–361. [PubMed: 2037742]
24. Goodley D. Supporting people with learning difficulties in self-advocacy groups and models of disability. *Health, Social Care in the Community*. 1998; 6(6):438–446. [PubMed: 11560613]
25. Goodley D. Empowerment, self-advocacy and resilience. *Journal of Intellectual Disabilities*. 2005; 9(4):333–343.
26. Gray RE, Fergus KD, Fitch MI. Two Black men with prostate cancer: a narrative approach. *British Journal of Health Psychology*. 2005; 10(Pt 1):71–84. [PubMed: 15826335]
27. Haylock PJ, Mitchell SA, Cox T, Temple SV, Curtiss CP. The cancer survivor's prescription for living. *American Journal of Nursing*. 2007; 107(4):58–70. [PubMed: 17413737]
28. Hermansen-Kobulnicky CJ. Measurement of self-advocacy in cancer patients and survivors. *Supportive Care in Cancer*. 2008; 16(6):613–618. [PubMed: 18386073]
29. Hewitt, ME.; Greenfield, S.; Stovall, E. The National Cancer Policy Board (U.S.). Committee on Cancer Survivorship: Improving Care and Quality of Life. Washington, DC: National Academies Press; 2006. From cancer patient to cancer survivor : lost in transition.

30. Hibbard JH, Cunningham PJ. How engaged are consumers in their health and health care and why does it matter? *Research Briefs*. 2008; (8):1–9. [PubMed: 18946947]
31. Hoffman B, Stovall E. Survivorship perspectives and advocacy. *Journal of Clinical Oncology*. 2006; 24(32):5154–5159. [PubMed: 17093279]
32. Jonikas JA, Grey DD, Copeland ME, Razzano LA, Hamilton MM, Floyd CB, Hudson WB, Cook JA. Improving propensity for patient self-advocacy through wellness recovery action planning: results of a randomized controlled trial. *Community Mental Health Journal*. 2011 in press. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/22167660> (accessed 10 February 2011).
33. Kahana E, Kahana B, Kelley-Moore J, Adams SA, Hammel R, Kulle D, Brown JA, King C. Toward advocacy in cancer care for older adults: survivors have cautious personal actions but bold advice for others. *Journal of the American Geriatrics Society*. 2009; 57(Suppl. 2):S269–S271. [PubMed: 20122027]
34. Koon KP, Soldak T, Gralow JR. Breast cancer advocacy: changing perceptions. *Salud Pública de México*. 2009; 51(Suppl. 2):s323–s328. [PubMed: 19967289]
35. Lee CJ, Gray SW, Lewis N. Internet use leads cancer patients to be active health care consumers. *Patient Education and Counseling*. 2010; 81(Suppl.):S63–S69.
36. Leigh S. Cancer survivorship: a first-person perspective. *Cancer Nursing*. 2006; 29(Suppl. 2):12–14. [PubMed: 16779949]
37. 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 in Cancer*. 2011; 19(9):1367–1378.
38. Lythcott N, Green BL, Brown ZK. The perspective of African-American breast cancer survivor-advocates. *Cancer*. 2003; 97(Suppl. 1):324–328. [PubMed: 12491496]
39. Mahlin M. Individual patient advocacy, collective responsibility and activism within professional nursing associations. *Nursing Ethics*. 2010; 17(2):247–254. [PubMed: 20185448]
40. Martin LT, Schonlau M, Haas A, Derosé KP, Rosenfeld L, Buka SL, Rudd R. Patient activation and advocacy: which literacy skills matter most? *Journal of Health Communication*. 2011; 16(Suppl. 3):177–190. [PubMed: 21951251]
41. McCabe MS, Varricchio CG, Padberg R, Simpson N. Women's health advocacy: its growth and development in oncology. *Seminars in Oncology Nursing*. 1995; 11(2):137–142. [PubMed: 7604192]
42. McConigley R, Holloway K, Smith J, Halkett G, Keyser J, Aoun S, Monterosso L. The diagnosis and treatment decisions of cancer patients in rural Western Australia. *Cancer Nursing*. 2011; 34(4):E1–E9. [PubMed: 20885301]
43. McCorkle R, Ercolano E, Lazenby M, Schulman-Green D, Schilling LS, Lorig K, Wagner EH. Self-management: enabling and empowering patients living with cancer as a chronic illness. *CA: A Cancer Journal for Clinicians*. 2011; 61(1):50–62. [PubMed: 21205833]
44. Meneses K, McNeas P, Azuero A, Jukkala A. Development of the Fertility and Cancer Project: an Internet approach to help young cancer survivors. *Oncology Nursing Forum*. 2010; 37(2):191–197. [PubMed: 20189924]
45. Miller K, Merry B, Miller J. Seasons of survivorship revisited. *The Cancer Journal*. 2008; 14(6):369–374. [PubMed: 19060601]
46. Mok E. Empowerment of cancer patients: from a Chinese perspective. *Nursing Ethics*. 2001; 8(1):69–76. [PubMed: 16010910]
47. Morris BA, Campbell M, Dwyer M, Dunn J, Chambers SK. Survivor identity and post-traumatic growth after participating in challenge-based peer-support programmes. *British Journal of Health Psychology*. 2011; 16(3):660–674. [PubMed: 21199541]
48. Morse JM. Exploring the theoretical basis of nursing using advanced techniques of concept analysis. *Advances in Nursing Science*. 1995; 17(3):31–46. [PubMed: 7778889]
49. Mosen, DM.; Hibbard, J.; Sobel, D.; Remmers, C. Is patient activation associated with better health outcomes for adults with cardiovascular disease?; Paper presented at the 13th Annual HMO Research Network Conference; 2007.
50. Muraca L, Leung D, Clark A, Beduz MA, Goodwin P. Breast cancer survivors: taking charge of lifestyle choices after treatment. *European Journal of Oncology Nursing*. 2011; 15(3):250–253.

51. Mutchler MG, Wagner G, Cowgill BO, McKay T, Risley B, Bogart LM. Improving HIV/AIDS care through treatment advocacy: going beyond client education to empowerment by facilitating client-provider relationships. *AIDS Care*. 2011; 23(1):79–90. [PubMed: 21218280]
52. National Cancer Institute. Dictionary of cancer terms. 2012. Available at: <http://www.cancer.gov/dictionary?cdrid=445089>(accessed 13 June 2012)
53. Norton L. Breast cancer advocates in clinical research: a trialist's perspective. *Breast Disease*. 1998; 10(5–6):51–59. [PubMed: 15687585]
54. O'Hair D, Villagran MM, Wittenberg E, Brown K, Ferguson M, Hall HT, Doty T. Cancer survivorship and agency model: implications for patient choice, decision making and influence. *Health Communication*. 2003; 15(2):193–202. [PubMed: 12742770]
55. Osborne RH, Elsworth GR, Kissane DW, Burke SA, Hopper JL. The Mental Adjustment to Cancer (MAC) scale: replication and refinement in 632 breast cancer patients. *Psychological Medicine*. 1999; 29(6):1335–1345. [PubMed: 10616939]
56. Park CL, Zlateva I, Blank TO. Self-identity after cancer: 'survivor', 'victim', 'patient' and 'person with cancer'. *Journal of General Internal Medicine*. 2009; 24(Suppl. 2):S430–S435. [PubMed: 19838845]
57. Peppercorn JM, Smith TJ, Helft PR, Debono DJ, Berry SR, Wollins DS, Hayes DM, Von Roenn JH, Schnipper LE. American society of clinical oncology statement: toward individualized care for patients with advanced cancer. *Journal of Clinical Oncology*. 2011; 29(6):755–760. [PubMed: 21263086]
58. Pickett SA, Diehl S, Steigman PJ, Prater JD, Fox A, Cook JA. Early outcomes and lessons learned from a study of the Building Recovery of Individual Dreams and Goals through Education and Support (BRIDGES) program in Tennessee. *Psychiatric Rehabilitation Journal*. 2010; 34(2):96–103. [PubMed: 20952362]
59. Pinch WJ, Parsons ME. The Patient Self-Determination Act: the ethical dimensions. *Nurse Practitioner Forum*. 1992; 3(1):16–22. [PubMed: 1450780]
60. Radina ME, Ginter AC, Brandt J, Swaney J, Longo DR. Breast cancer patients' use of health information in decision making and coping. *Cancer Nursing*. 2011; 34(5):E1–E12. [PubMed: 21116176]
61. Rafael AR. Advocacy and empowerment: dichotomous or synchronous concepts? *Advances in Nursing Science*. 1995; 18(2):25–32. [PubMed: 8585705]
62. Ramsay J, Carter Y, Davidson L, Dunne D, Eldridge S, Feder G, Hegarty K, Rivas C, Taft A, Warburton A. Advocacy interventions to reduce or eliminate violence and promote the physical and psychosocial well-being of women who experience intimate partner abuse. *Cochrane Database of Systematic Review*. 2009; 8(3):CD005043.
63. Risjord M. Rethinking concept analysis. *Journal of Advanced Nursing*. 2009; 65(3):684–691. [PubMed: 19222666]
64. Rogers A, Pilgrim D. 'Pulling down churches': accounting for the British Mental Health Users' Movement. *Sociology of Health, Illness*. 2008; 13(2):129–148.
65. Rogers, BL. *Developing nursing knowledge: philosophical traditions and influences*. Philadelphia: Lippincott; 2005.
66. Rose C, Stovall E, Ganz PA, Desch C, Hewitt M. Cancer Quality Alliance: blueprint for a better cancer care system. *CA: A Cancer Journal for Clinicians*. 2008; 58(5):266–292. [PubMed: 18768677]
67. Shapiro CL, McCabe MS, Syrjala KL, Friedman D, Jacobs LA, Ganz PA, Diller L, Campbell M, Orcena K, Marcus AC. The LIVESTRONG Survivorship Center of Excellence Network. *Journal of Cancer Survivorship*. 2009; 3(1):4–11. [PubMed: 19169829]
68. Shapiro M. Life in the balance: my journey with breast cancer. *Salud Pública de México*. 2009; 51(Suppl. 2):S361–363. [PubMed: 19967294]
69. Simpson, J.; Weiner, E., editors. *The Oxford English Dictionary*. 3rd ed.. Oxford UK: Clarendon; 1989.
70. Sinding C, Hudak P, Wiernikowski J, Aronson J, Miller P, Gould J, Fitzpatrick-Lewis D. 'I like to be an informed person but...': negotiating responsibility for treatment decisions in cancer care. *Social Science, Medicine*. 2010; 71(6):1094–1101. [PubMed: 20633970]

71. Skalla KA, Bakitas M, Furstenberg CT, Ahles T, Henderson JV. Patients' need for information about cancer therapy. *Oncology Nursing Forum*. 2004; 31(2):313–319. [PubMed: 15017447]
72. Taylor K. Paternalism, participation and partnership: the evolution of patient centeredness in the consultation. *Patient Education and Counseling*. 2009; 74(2):150–155.
73. Temple SV. The advocacy movement in gynecologic oncology. *Seminars in Oncology Nursing*. 2002; 18(3):231–235. [PubMed: 12184046]
74. Test DW, Fowler WM, Brewer DM, Wood CH. A content and methodological review of self-advocacy intervention studies. *Council for Exceptional Children*. 2005; 72(1):101–125.
75. Test DW, Fowler CH, Wood WM, Brewer DM, Eddy S. A conceptual framework of self-advocacy for students with disabilities. *Remedial and Special Education*. 2005; 26(1):43–54.
76. Vessey JA, Miola ES. Teaching adolescents self-advocacy skills. *Pediatric Nursing*. 1997; 23(1): 53–56. [PubMed: 9137022]
77. Walker, LO.; Avant, KC. *Strategies for theory construction in nursing*. 5th ed.. Boston: Prentice Hall; 2010.
78. Walsh-Burke K, Marcusen C. Self-advocacy training for cancer survivors: the Cancer Survival Toolbox. *Cancer Practice*. 1999; 7(6):297–301. [PubMed: 10732527]
79. Wilson, J. *Thinking With Concepts*. New York: Cambridge University Press; 1963.
80. Wiltshire J, Cronin K, Sarto GE, Brown R. Self-advocacy during the medical encounter: use of health information and racial/ethnic differences. *Medical Care*. 2006; 44(2):100–109. [PubMed: 16434908]
81. Wolf MS, Chang CH, Davis T, Makoul G. Development and validation of the Communication and Attitudinal Self-Efficacy scale for cancer (CASE-cancer). *Patient Education and Counseling*. 2005; 57(3):333–341. [PubMed: 15893217]
82. Zebrack B. An advocate's perspective on cancer survivorship. *Seminars in Oncology Nursing*. 2001; 17(4):284–287. [PubMed: 11764714]
83. Zebrack B, Landier W. The perceived impact of cancer on quality of life for post-treatment survivors of childhood cancer. *Quality of Life Research*. 2011; 20(10):1595–1608. [PubMed: 21452086]
84. Zeigler L, Smith PA, Fawcett J. Breast cancer: evaluation of the Common Journey Breast Cancer Support Group. *Journal of Clinical Nursing*. 2004; 13(4):467–478. [PubMed: 15086633]

Summary Statement

Why is this research needed?

- Clinical, research and political mechanisms encourage survivors to advocate for themselves.
- The overwhelming, ongoing challenges of cancer survivorship demand that survivors self-advocate.
- To date, no clear definition of self-advocacy has been provided in the literature from which to build ways of supporting self-advocacy among survivors.

What are the three key findings?

- A concise definition of self-advocacy is proposed which explicates the process using clear antecedents, defining attributes and consequences.
- Real-life examples of self-advocacy from a web-based symptom management intervention for cancer survivors demonstrate the lived processes of self-advocacy among cancer survivors
- Conceptual clarity identifies the unique potential of self-advocacy and becomes the first step in promoting future clinical and research focus on improving this phenomenon.

How should the findings be used to influence policy/practice/research/education?

- The proximal and long-term patient outcomes of self-advocacy can be improved by increased understanding of the process of self-advocacy.
- Nursing's role as patient advocates may be enhanced with a better understanding of how cancer survivors advocate on their own behalf.

Figure 1. Data analysis flow chart. This chart illustrates the distribution of articles reviewed in the concept analysis.

Figure 2. Model of self-advocacy and cancer survivorship. This figure depicts the results of the concept analysis of self-advocacy in a flow chart.

Table 1

Eight Steps of a Concept Analysis

1.	Select a concept
2.	Determine the purpose of the analysis
3.	Identify all uses of the concept
4.	Determine the defining attributes
5.	Construct a model case
6.	Construct a borderline and contrary case
7.	Identify antecedents and consequences
8.	Define empirical referents