

Response to “Rethinking Assumptions about Cancer Survivorship”: A nursing disciplinary perspective

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Abstract

In response to our social science and humanities colleagues' paper, Rethinking Assumptions about Cancer Survivorship (Ristovski-Slijepcevic & Bell, [2014]. CONJ, 24(3), p. 166), we offer a nursing disciplinary perspective on some of the dominant messages purported to underpin cancer survivorship. We illuminate points of disjuncture within their paper, using nursing's disciplinary lens to describe and explain the complexities inherent in the cancer survivorship experience and its implications for clinical practice. Opportunities for collaboration with our social science and humanities colleagues are outlined to foster synergistic knowledge development that will, ultimately, improve the care of those living with, through, and beyond cancer.

We thank our social science and humanities colleagues for the invitation to engage in dialogue about this important topic. As three oncology nursing doctoral students, we agree that how we understand and talk about cancer survivorship is worthy of further dialogue among health professionals and communities of scholars. Our social science and humanities colleagues' assessment and interpretation of the dominant messages shaping cancer survivorship care (i.e., cancer is a choice, surviving cancer is an accomplishment, and cancer makes you a better person) is thought provoking and, at times, somewhat provocative. Similarly, the notion that life after cancer is a narrow set of experiences is a message that oncology health professionals might find equally perplexing. In this article we choose to capitalize on these statements as an opportunity to develop a collegial conversation about nursing's contribution in

promoting optimal health in cancer survivorship. In the spirit of building good will and lively dialogue, we respond to the challenge offered in the article when the authors noted, “We therefore seek to offer oncology care professionals some thoughts about the sorts of messages that might be unintentionally conveyed to patients, drawing on insights from scholarship informed by social science and humanities perspectives” (Ristovski-Slijepcevic & Bell, 2014, p. 166).

To take up this challenge, we have chosen to illuminate points of disjuncture within the article that merit further discussion. We offer an alternative angle of vision on these various points of disjuncture, using nursing's disciplinary lens to describe and explain the complexities inherent in the cancer survivorship experience and its implications for clinical practice. Finally, we explore opportunities for collaboration with our social science and humanities colleagues that will synergistically contribute to knowledge development intended to positively impact care for people and their families experiencing cancer.

Defining survivor(ship)

Our social science and humanities colleagues very astutely point out that the evolving term survivorship lacks conceptual clarity within the literature. If we take the position that words do, indeed, shape the phenomenon (Foucault, 1970; Rose, 1998), then we must use caution in how we use the term *survivorship*. To this end, we would like to clarify the difference between the terms *survivor* and *survivorship*, as used within a nursing context, and offer some clinical nursing practice implications of using these terms. In the research literature beyond the confines of the social sciences and the humanities, there has been a great deal of progress in refining and finding agreement regarding the common usage of these definitions. We fully acknowledge this is a body of knowledge that continues to evolve. Thus, it is important that we work from the most current knowledge in such a rapidly developing field.

Most researchers and clinicians use the term *survivorship* to refer to the phase in the cancer trajectory that begins after primary cancer treatment ends, and this phase continues throughout the remainder of one's life (Hewitt, Greenfield, & Stovall, 2006; Rowland, Hewitt, & Ganz, 2006). *Survivor*, in its simplest form, may refer to a person (and his/her family) who has received a cancer diagnosis (National Coalition for Cancer Survivorship, 2014). Both terms are necessary to fully appreciate the interplay between a phase or point in time (*survivorship*), and the experience of these points in time through an individual's own unique perspectives (*survivor*). The experience of living as a survivor is shaped and influenced by a variety of structural, environmental, social, economic, personal factors that layer and intersect during the survivorship phase of the cancer trajectory. Our social science and humanities colleagues have identified one dimension (i.e., the social constructions of survivor[ship]) within a myriad of dimensions that shape this experience for infinitely complex individuals living with cancer.

While we acknowledge that how health care professionals use terms such as *survivor* is important, from a nursing perspective what takes *central* priority is how individuals perceive and interpret the term *survivor* in relation to their own experience and preferences. Individuals' perspectives regarding who is a cancer *survivor* are highly varied and may impact how the individual engages with

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health care professionals and the health care system (Little, Paul, Jordens, & Sayers, 2002; Park, Zlateva, & Blank, 2009). These perspectives range from those who identify as survivors from the time of diagnosis and throughout the rest of their lives, to some who call themselves “thrivers” at the point of completion of primary cancer treatment. Still others completely reject the notion of survivor, equating the label with having survived a traumatic event (Bell & Ristovski-Slijepcevic, 2013; Bellizzi & Blank, 2007; Deimling, Bowman, & Wagner, 2007; Ehrenreich, 2001; Kaiser, 2008; Khan, Harrison, Rose, Ward, & Evans, 2011; Khan, Rose, & Evans, 2012; McGrath & Holewa, 2012; Zebrack, 2000). We recognize that scientists, scholars and survivors of privilege, in particular upper and middle class white women with breast cancer (see for example, Ehrenreich, 2001; Segal, 2012; Sulik, 2013) constitute predominant voices in the literature on exploring the meaning of survivor(ship). This can thereby marginalize the voice of “the other” within this survivorship discourse and, so, we would caution against superficial interpretation and acceptance of these findings without further introspection. It is important to consider the context within which this knowledge has been developed and published to fully appreciate its applicability to complex individuals across a multitude of cancer types, gender, socioeconomic and other socially constructed locations.

For every person who rejects the notion of *survivor*, there are likely as many who do feel triumphant and embrace the term as meaningful and helpful. Still others land somewhere in between (Park et al., 2009). Understanding the individuals’ perspective regarding the affiliation or rejection of the term *survivor*, reasons underpinning this perspective, and exploring if there is a preference for another term is an essential and foundational aspect of care provided by professional oncology nurses. As nurses, we do not privilege or exclude one term over another, nor are we driven by a disease-focused model that labels people according to their tumour/cancer status—what drives our clinical interactions and language use with individuals and families are their perceptions, beliefs, values, and goals.

Messages don’t always translate into practice

The survivorship messages (i.e., *cancer is a choice*, *surviving cancer is an accomplishment*, and *cancer makes you a better person*) outlined by our social science and humanities colleagues are not new and have been documented in the social science and lay literature for almost two decades. If these messages are, indeed, so pervasive and harmful, why are we not seeing them being taken up as consistently problematic for all survivors within the clinical setting and research? Why don’t all survivors feel overwhelmed by the idea of taking responsibility for preventing their cancer recurrence or not achieving some sort of a personal transformation as a result of surviving cancer, as implied in this article by our social science and humanities colleagues? Our own review of the literature, as well as our nursing lens, leads us to believe that these messages may not be taken up into clinical practice as readily as suggested, and they may not affect everyone equally (see for example, Laranjeira, Leão, & Leal, 2013; Park, Chmielewski, & Blank, 2010; Sherman, Rosedale, & Haber, 2012).

The line of reasoning within the article by our social science and humanities colleagues makes the assumption that nurses and other health care professionals are directly or indirectly communicating and/or implying survivorship messages, as a standard part of their practice. While we appreciate this perspective at a theoretical level, from our viewpoint this represents a leap in logic from presenting a deconstruction of some of the messages underpinning cancer survivorship to health care professionals actually consciously (or unconsciously) applying these messages in practice and indirectly

or directly communicating these to survivors. We cannot comment on the practices of other health disciplines. Instead, we offer an oncology nursing perspective on how these messages are in fact *purposefully* considered within the interactions and communication environment among nurses, survivors and their families.

Nursing’s mandate regarding collaborative care of people living with cancer

Nurses draw upon a variety of sources of knowledge to inform their practice, and this knowledge is often co-created with individuals to contextualize to their unique and complex situation (Doane & Varcoe, 2005; Johnson & Ratner, 1997; Purkis & Bjornsdottir, 2006; Thorne, Canam, Dahinten, Hall, Henderson, & Kirkham Reimer, 1998; Thorne & Sawatsky, 2014). We believe that people are inherently unique and are shaped by a multitude of factors that layer and intersect to influence their survivorship experience. As nurses, we carefully consider an individual’s personal health values, beliefs, and goals while exploring how history, politics, social context, economics, ideologies, and other structural factors influence the opportunities for people to enact their agency to achieve their health goals. It is within this dialectic of supporting the individual toward their personal health goals while also trying to shape and influence factors that might maximize those health goals where the aforementioned messages are addressed. For example, it is within the nurse’s therapeutic domain to explore feelings such as “not living up to expectations”, “feeling responsible for my cancer development or recurrence”, or “not feeling transformed by having had cancer”. As oncology nurses, we routinely anticipate and support patients and families through the emotional and psychosocial sequelae of living with, through, and beyond cancer. We are aware of the societal expectations placed on survivors and how this might not be congruent with what they are actually experiencing. Despite other social signifiers saying, “you’ve done it—completed your treatment—you have beaten cancer,” nurses recognize that for many people completing cancer treatment is filled with anxiety and fear rather than jubilation and triumphant feelings. Nurses have, within their practice, the ability to anticipate a potential mismatch between societal expectations, such as those conveyed within the “messages” identified above, and the individual’s actual experience. In fact, it is a professional nursing mandate to elevate this beyond the theoretical level to take action by acknowledging an individual’s concerns, and developing an individualized action plan in collaboration with the individual to actively address their specific concerns. The messages offered by our social sciences and humanities colleagues may be one source of knowledge to inform how nurses and health care professionals view a phenomenon, but never a sufficient knowledge source upon which to make decisions or direct the care of complex individuals during the survivorship phase.

Communication as a critical nursing competency

We agree with our social science and humanities colleagues that the manner in which health care professionals communicate about cancer survivorship with survivors plays a role in shaping their experiences. As our colleagues astutely pointed out, “language and terminology is not neutral and descriptive, but actively constructs the way we think about phenomena” (Ristovski-Slijepcevic & Bell, 2014, p. 167). As nurses, we acknowledge that a health care professional’s ability to effectively and sensitively communicate with a survivor and their family has a huge impact on the cancer care experience. Communication is considered a foundational clinical skill of nurses and other health care professionals. The ability to communicate effectively is honed through years of intricately weaving together theories, research, ethical reasoning, experiences, and

critical self-reflection about patient care experiences along with the nurses's own capacity for therapeutic communication. That nurses imply blame or undue accountability to survivors by suggesting that cancer is a choice, or that their "unhealthy" lifestyle choices directly influence their cancer outcomes, may risk offending professional oncology nurses who may view this as a significant affront to their intention, education, experience, and skill.

Communication is a messy and infinitely complex human interaction that involves much more than the influence of a singular message (Albrecht, Penner, Cline, Eggly, & Ruckdeschel, 2009; Carlson, Feldman-Stewart, Tishelman, & Brundage, 2005). Words can help or harm. What matters is how we *interact* with patients and families, using words and language as *shared* understandings and interpretations of phenomena such as cancer recurrence and what it means to be a survivor *from the survivors' perspective* (Epstein & Street, 2007; Thorne, Hislop, Armstrong, & Oglov, 2008). Acknowledging shared understanding is a central tenet of nursing practice. A growing body of interdisciplinary research led by nurses describes and explains, from people undergoing treatment as well as from the survivors' perspective, what helpful and unhelpful communication looks like across the cancer trajectory (see, for example, Feldman-Stewart, Brundage, Tishelman, & Dunn, 2005; Schofield & Butow, 2004; Thorne, Hislop, Kim-Sing, Oglov, Oliffe, & Stajduhar, 2014; Thorne & Stajduhar, 2012).

What can I do to prevent or delay my cancer from coming back?

This is a common question nurses get from survivors as they finish their primary cancer treatment. With a goal of promoting optimal health and drawing on the most current evidence on cancer recurrence prevention after treatment, nurses may review diet, exercise and other lifestyle interventions (e.g., smoking cessation, sun safety) with individuals. While our social science and humanities colleagues state that there are "inadequacies in the [lifestyle] evidence base and a tendency to oversell the role of lifestyle in tertiary prevention" (Ristovski-Slijepcevic & Bell, 2014, p. 167), our assessment is that there exists convincing consistent national and international data, synthesized into evidence-based guidelines, supporting that exercise and diet may promote healthful living and reduce cancer recurrence risk (Brunet, Sabiston, & Meterissian, 2012; Campbell, Stevinson, & Crank, 2012; Courneya & Friedenreich, 2011; Davies, Batehup & Thomas, 2011; Kushi et al., 2012; Ligibel, 2012; Loprinzi & Lee, 2014; McNeely et al., 2006; Milne, Gordon, Guilfoyle, Wallman, & Courneya, 2007; Pollard, Eakin, Vardy, & Hawkes, 2009). A landmark report co-authored by several organizations offering a global metasynthesis of over 17,000 lifestyle research papers provides recommendations on food, nutrition, and physical activity centred on cancer prevention for both cancer-free individuals and those who have completed cancer treatment (World Cancer Research Fund/American Institute for Cancer Research (WCRF/AICR), 2007). American consensus guidelines regarding exercise specific to cancer survivors have been established, offering an overarching "exercise prescription" with modifications specific to each cancer type (Schmitz et al., 2011). Besides possibly reducing the risk of recurrence, exercise offers survivors added benefits of improving mood, feelings of well-being, and feelings of being in control and of doing "something" to improve their health. Exercise can also reduce pain, improve fatigue, and improve cardiovascular fitness (Courneya & Friedenreich, 2011). Many cancer survivors have other complex chronic diseases for which exercise and lifestyle modification is an important health promotion and disease management strategy (Tsai, Morton, Mangione, & Keeler, 2005). Healthful living also garners an opportunity for families to support each other while taking on new health-promoting behaviours together.

Regardless of disease state (cancer/no cancer/other diseases), nurses play a role by offering support and coaching on health promotion activities that are both meaningful and feasible to individuals and families. The goal of nursing is to promote optimal health that takes into consideration physical, psychological, emotional, financial, social, practical, and spiritual needs of people within their social context. We believe that assessment of the current lifestyle state for cancer survivors and its associated relevance to the individual and family in our care provides a strategy to communicate this information in a way that promotes optimal health. This can only be judged in the clinical moment by clinicians who understand and appreciate the uniqueness of the survivor as an individual. Nurses do not "sell" lifestyle advice as implied by our social science and humanities colleagues but, rather, nurses have a moral imperative and mandate to sensitively present the *most current* evidence (as well as other relevant sources of knowledge) to support individuals in making decisions *that are right for them* about actions that they may take toward preventing a cancer recurrence. There are no right or wrong choices when it comes to taking on lifestyle behaviours, but rather what is most important is finding those options that are most meaningful and useful to the individual to meet their health goals.

The siloed nature of research (and practice)

As our social science and humanities colleagues point out, it is important for oncology health care professionals to attend to the social context of cancer and its complex meanings. We wholeheartedly agree, but add that it is equally important not to focus exclusively on this social context or to extract it from the broader context of individuals that includes other dimensions such as the physical, psychological, practical, and spiritual. Nursing's disciplinary lens views these contexts as inextricably linked and co-influencing each other within the context of survivors and their personal support systems.

Interdisciplinary and intradisciplinary collaboration begins by becoming knowledgeable about the contributions of one's colleagues, and by seeking areas of convergence and disjuncture. Foucault's (1982) notion of dividing practices exemplifies this, cautioning health care professionals from working in silos due to the self-limiting result around questioning and actively engaging in dialogue about ontological or epistemological assumptions undergirding health care (Dzurec, 2003). Without active questioning and critique among and between health care professionals and (social science and humanities) researchers, opportunities for addressing the practice implications of any given theory may be missed, as well as opportunities for considering ways to foster collaborative initiatives that ultimately impact the care of people living with cancer. We appreciate that our social science and humanities colleagues have begun this process of moving out of silos and encouraging interdisciplinary engagement through offering the opportunity to respond to this article (Ristovski-Slijepcevic & Bell, 2014).

While our social science and humanities colleagues suggest that "...the oncology community remains unaware of this [social context of cancer] literature..." (Ristovski-Slijepcevic & Bell, 2014, p. 166), we point out that nurses do not discriminate when it comes to using various types of research and knowledge in their practice or research endeavours. We celebrate the multidisciplinary thinking that must happen to solve complex clinical problems. With a pragmatic end in view to impact people and their health at the practice level, nursing's epistemological structure necessitates a multiplicity of sources of research, knowledge, and perspectives to be used. We quite purposefully borrow theory and research from sociology, anthropology, the humanities, medicine, and other scholars to inform care and research. Many of the

qualitative research methodologies upon which we draw were initially developed within social science. Many nursing scholars have studied extensively in the fields of anthropology, sociology, and the humanities during their doctoral work, bringing these perspectives and partnerships back into the theoretical core of nursing. To say that nurses are not using or benefitting from research from the social sciences and humanities is far from the truth! In fact, we shamelessly “borrow” theories and research generated by our social science colleague scholars and put them to work to solve complex clinical problems within a nursing disciplinary framework. Theories from the social sciences and humanities standing alone, or deconstruction of the aforementioned “messages” in and of themselves, can never fully inform the care for the infinitely complex and unique individuals. As a foundation toward finding clinical solutions for complex individuals, nurses employ pragmatic frameworks and a holistic view of people that includes, but is not limited to, their social context.

Opportunities for collaboration

With these points of disjuncture illuminated in response to the challenge laid out for us by our social science and humanities colleagues, we offer a nursing disciplinary perspective on how we may collaborate with our social science and humanities colleagues to improve the care of people living with cancer. Our perspective is that nurses and social scientists/humanities scholars have very different, yet complementary, foci and goals. It is important to be clear on these similarities and differences so that we may capitalize on opportunities to synergistically work together. In this way, the different disciplines might collate a variety of angles of vision in reference to cancer survivorship that better illuminates the complexities associated with living with, through, and beyond cancer.

In contrast to the social scientist’s purpose to theorize or create theory, nurses theorize in order to act (Thorne & Sawatsky, 2014). Theories rarely tell us about how to individualize or enact care. This action requires a disciplinary framework and internal logic

structure that can take up theories and “limber them up” to be useful for pragmatic *action*. Theories become tools toward a pragmatic end within a nursing disciplinary framework. Nursing is oriented to the “so what”—we focus on the “what does this theory/narrative/ideology mean for practice”?

We see opportunities for collaboration with our social science and humanities colleagues to develop theories that are embedded in the everyday realities of clinical practice and useful to solve clinical problems. Some examples might include an exploration of the social, political, historical and other structural barriers that prevent survivors from achieving optimal health after primary cancer treatment. Another example might include identifying effective approaches to minimizing the negative impact of those (and other) messages outlined by our social science and humanities colleagues. With an action orientation in view, social scientists, humanities scholars, and nurses may bring together their unique perspectives and skills to improve the quality of life of survivors.

Conclusion

In the spirit of lively dialogue, we have taken up our social science and humanities colleagues’ challenge to critically explore some messages purported to underpin cancer survivorship. Through nursing’s disciplinary lens, we have illuminated various points of disjuncture within our colleagues’ argument with the goal of offering an applied clinical perspective on the implications of taking a singular social context view of individuals living with cancer. People, including those living with cancer, are infinitely complex. As nurses within an applied discipline, we strive to appreciate and respect this complexity while also considering their unique physical, psychological, practical, spiritual, and emotional needs. As our social science and humanities colleagues would undoubtedly agree, the holistic vision that enhances our work at the individual survivor level can also serve us well as we theoretically scaffold our united disciplinary approach to providing the best care possible to survivors and throughout the cancer care trajectory. ❏

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