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Dissemination and Translation: A Frontier for Cancer Survivorship Research

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Abstract

As the field of survivorship research grows, the need for translation is imperative to expand new knowledge into arenas that directly impact survivors. This commentary seeks to encourage research focused on dissemination and translation of survivorship interventions and programs, including practice-based research. We overview diffusion, dissemination and translation in the context of cancer survivorship and present the RE-AIM and Knowledge to Action frameworks as approaches that can be used to expand research into communities. Many academic, governmental, and community-based organizations focus on cancer survivor. Future survivorship research should contribute to harmonizing these assets to identify effective interventions, maximize their reach and adoption, and integrate promising practices into routine care.

Background

The field of cancer survivorship has steadily progressed from gaining recognition as a distinct phase of the cancer experience toward achieving a better understanding of the multifaceted challenges associated with cancer and its treatment. Cancer survivorship research has elucidated late and long-term impacts of cancer and has led to interventions and changes in practice intended to improve quality of life and health outcomes of cancer survivors. For example, survivorship researchers and pediatric oncologists collaboratively developed the Children's Oncology Group (COG) Long-Term Follow-Up Guidelines to inform the screening, surveillance, and management of adverse effects related to childhood cancers (¹). Another example is the recent publication of 2 studies related to breast cancer. One study showed that arm resistance exercise did not increase lymphedema and another showed that early-stage cancer axillary lymph node dissection did not offer survival benefits over sentinel lymph node dissection (^{2, 3}). These new findings have the potential to

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significantly alter the prevalence of lymphedema, a dreaded sequelae of breast cancer, as well as debunk misconceptions about how it is affected by exercise. Research has also shown the impact of psychosocial, informational, and behavioral interventions on cancer survivors (4–8).

Although this progress has been promising, advances in cancer survivorship need to be replicated and translated into community settings where 85% of cancer patients are treated (9). Replicating interventions will move the science forward by confirming that benefits persist in real-world settings. This is particularly true for communities with poor health care access or which serve patients who have a limited understanding of cancer and its potential consequences. Therefore, the next important step in the progression of survivorship research is to investigate how to best disseminate and translate emerging evidence. Dissemination research focuses on effective methods to influence target groups to receive, accept, and use information and interventions (10). Translation is the process of ensuring effective and widespread use of science-based programs, practices, and policies (11). Dissemination and translation are of utmost importance because they extend the value of original research by connecting findings into actions and programs that impact individuals on a larger scale.

The goal of this article is to encourage the conduct of more relevant practice-based research that can inform and improve care of survivors. After reviewing survivorship research in the context of diffusion, dissemination, and translation, we introduce 2 practical frameworks, RE-AIM and Knowledge to Action (K2A), to support the “uptake” of research by practitioners (11, 12). Finally, we describe challenges, opportunities, and suggested future directions for the dissemination and translation of survivorship research.

Survivorship Research in the Context of Diffusion, Dissemination, and Translation

Dissemination is a complex process that goes far beyond the publication of results. Traditionally, clinical and social scientists focus on testing the value of interventions in carefully chosen and controlled environments (efficacy). Once completed, however, there are often limited expectations and support for testing the effect of the interventions in everyday practice (effectiveness). A reason for this disconnect is that the theory, skills, and experience required to disseminate evidence-based practices are distinct from those needed to develop and test novel interventions. The terms *diffusion*, *dissemination*, and *translation* are all relevant to this process, but each term has a unique meaning (13).

Diffusion

Diffusion theory is largely based on the work of Everett Rogers, a rural sociologist who identified elements that influence the spread of a new idea and described factors that ultimately influence its adoption or rejection (14). These factors include the relative advantage of the innovation over the status quo, its compatibility into one’s current life or work flow, the perception of how simple or complex it would be to adopt, the feasibility of testing the innovation before it is fully adopted, and the visibility of the change to other observers (14). Diffusion theory relates to the current state of cancer survivorship research

because the premise of preventing and addressing the late and long-term effects of cancer and cancer treatment is a relatively new idea in the medical care model. Furthermore, the adoption of survivorship interventions requires cancer survivors and/or their providers to change current practices.

Dissemination

In contrast to the passive, uncontrolled spread of diffusion, *dissemination* implies a more strategic approach to encouraging the adoption of new ideas and practices (15). In dissemination science, the focus shifts from change occurring due to the attributes of an innovation itself, to a more active, deliberate strategy for encouraging change in a targeted group. Considerations for dissemination of interventions include social context, resources, leadership, timing, and preferred channel of delivery (13). In some ways, principles of dissemination mirror those used in marketing, as they focus on preferred information channels of potential adopters, refining interventions through pretesting research, and supporting decisions to adopt and maintain change through trials, support, and technical assistance (16). Using the earlier example of COG guidelines, companion patient education materials, *Health Links*, were developed and made freely available online as a potential dissemination tool (17).

Translation

As a concept, translation covers the spectrum from basic discovery to developing interventions, developing guidelines, changing practice through diffusion and dissemination, and evaluating outcomes of changed practices (18–20). Translation research emerged to address the gap between discovery science and effective practice because many innovations developed through academic research do not reach practitioners, and if they do, adoption is often sporadic and slow (21–23). Translation maintains a strong focus within basic science and is concerned with all aspects of research on testing interventions for acceptability and adoption into practice (24). Much of the survivorship research has focused on determining efficacy of interventions. A next step is to expand cancer survivorship research to address translational issues concerning whether and how research findings relate to practice (25). Table 1 highlights some of the differences between what is valued in research versus practice.

To illustrate diffusion, dissemination, and translation of a survivorship intervention, consider survivorship care planning, a major recommendation of a 2005 Institute of Medicine (IOM) Report, *From Cancer Patient to Cancer Survivor: Lost in Transition* (26). A cancer survivorship care plan is a written summary of critical information needed for a survivor's long-term care, including cancer type, treatments received, potential late effects of the cancer or treatments, recommendations for medical follow-up, and information related to health promotion and psychosocial resources (26–28). Care plans are seen as valuable for educating survivors and their caregivers about their cancer care and future health concerns, as well as facilitating coordination between oncology, primary care, and available support services (29). Within the context of diffusion and factors that lead to adoption of a new practice, survivorship care plans may be seen as having advantages over current practice by providing the survivor and primary care provider with better information on the diagnosis,

treatment, and potential consequences of cancer⁽³⁰⁾. However, the oncology practitioner, who likely would be responsible for creating survivorship care plans for each patient, may view it as a complex, time-consuming process that does not easily fit into workflow and has not yet been proven effective or useful⁽²⁹⁾. With regard to dissemination, professional societies such as the American Society of Clinical Oncology and the Oncology Nursing Society actively encourage the use of survivorship care plans through educating providers on their objectives and core elements and providing templates to ease integration into practice. If dissemination is successful, there will still be a need for translation as best practices in survivorship care planning may differ by practice setting, recipient's health literacy, and intended use of the document⁽³⁰⁾.

Frameworks for Research Translation: RE-AIM and Knowledge to Action

Two frameworks that researchers and organizations should consider for translating research into practice within communities are RE-AIM and K2A^(11, 12).

RE-AIM provides a framework for effectively implementing science into “real-world” settings^(12, 31, 32). It provides a comprehensive approach to research translation by identifying 5 components essential for creating and evaluating effective, generalizable, and sustainable interventions^(31, 32). These components are (i) Reach: the number of people impacted by the intervention, including those most in need; (ii) Efficacy/effectiveness: the intervention's impact on quality of life and outcomes, including those which are negative or unintended; (iii) Adoption: the number of institutions willing and able to implement the program; (iv) Implementation: the quantity and quality of delivering intervention components; and (v) Maintenance: the extent in which the intervention becomes routine practice at the institutional level, and the measurement of long-term effects on health outcomes at the individual/population level^(12, 31-33). RE-AIM's multilevel design allows programmatic intervention at both the participant (Reach, Effectiveness, and Maintenance) and institutional (Adoption, Implementation, and Maintenance) level^(12, 31, 32). The framework also addresses both internal (Efficacy and Implementation) and external (Reach and Adoption) validity⁽³³⁾. RE-AIM is particularly relevant to the translation and dissemination of cancer survivorship research because as a relatively new field, this tool provides a systematic, standardized approach to applying the research.

The K2A framework outlines several high-level processes necessary to translate chronic disease research. The K2A schematic identifies 3 phases: (i) Research: testing of interventions to determine effectiveness and appropriateness for translation; (ii) Translation: developing actionable resources and supporting structures for implementing interventions; and (iii) Institutionalization: maintaining the intervention as an established activity⁽¹¹⁾. Key features of the K2A framework include recognizing that intentional decisions are needed to translate research and adopt interventions, relationships between the practice communities and researchers are inherent to successful translation, and evaluation underpins the entire translation process⁽¹¹⁾.

Challenges and Opportunities

The components of these frameworks highlight challenges to bridging the divide between survivorship research and practice. Reach identifies the challenge of defining a community to target for translation, which for survivorship can mean many different groups such as cancer survivors, their family members, clinical providers, and organizations focused on survivors. Reach should also address the sparse representation of minority and economically disadvantaged participants because survivorship research in diverse cultural settings is limited⁽³⁴⁾. In addition, for all populations, it is important for researchers to report both uptake and attrition in studies, to allow potential users to assess the generalizability of reported findings. Organizations that provide care to survivors may not share the same features as the original research setting. Because the adolescence of the field of survivorship, the evidence base for effectiveness of interventions and programs is small. Thus, research that specifically addresses translation, as discussed in the K2A continuum, is warranted because individual communities may require different approaches to foster change due to their unique composition, beliefs, and experience. Translation needs to address how a community makes health decisions as well as its broader cultural, economical, historical, and political context⁽³⁵⁾. Adoption and implementation of an intervention or new practice often depends on its feasibility and community readiness⁽³⁶⁾. Context and adaptability of innovations become very important for scientific knowledge to be translated into practice and policy. To be maintained and to achieve institutionalization, survivorship science must shift toward and achieve both internal and external validity⁽²³⁾.

In response, there is growing consensus to incorporate both practice-based and research-based evidence in evaluating the best approach when choosing among interventions. Green and colleagues concluded that health science research would improve its influence on policy, professional practice, and public impact if the research questions ask “How can we make science more practice-based?” rather than “How can we make practice more science-based?”⁽²³⁾. To do so, the health research agenda should be determined by the needs of patients and populations through researcher–practitioner collaborations with resource allocation proportionate to the magnitude of the task^(23, 37).

Dissemination and translation research should be a 2-way street. There are many survivorship interventions and programs that are being widely used, but have not been evaluated. The development, dissemination, and adoption of such materials and activities often precede research because they seem to meet the needs of the community. These programs and the lessons learned from their evolution should inform the survivorship research agenda. An advantage to doing so is that materials developed with and for a targeted survivorship community may possess an inherent sociocultural context that will ultimately influence its feasibility and acceptance.

How do we track progress in translation? Measuring outcomes is critical for decisions about adopting or continuing interventions and common measurements are necessary for evaluating comparative effectiveness. There is a definite need to use and further develop methodology related to disseminating efficacious survivorship interventions. Recognizing that public health practice is an ideal environment to better understand and address

challenges related to external validity, one method to consider is community-based participatory research. Community-based participatory research is a collaborative process that seeks input and engagement of the targeted community in the development of research questions, data collection, intervention development, and evaluation (38). Another approach to inform the feasibility of survivorship interventions is economic research because to encourage adoption, interventions will ideally have high reach at low cost (13). Our earlier example of survivorship care planning shows this need because the cost of preparing and delivering care plans is currently not covered by most medical insurers. In response, several community hospitals in Colorado are using patient navigators to promote and deliver survivorship care plans; and this has provided an opportunity to evaluate the feasibility and comparative costs of alternative dissemination routes for care planning (B.C. Risendal; personal communication). Finally, a non-traditional but potentially relevant approach to dissemination and measurement of survivorship interventions is continuous quality improvement (CQI). Through continually identifying, measuring, and attempting to improve processes toward a stated outcome, CQI can identify expectations and be responsive to the unique needs of a targeted community (39). The application of any of these methods would contribute greatly to the field of survivorship.

Future Directions

As we strive toward the goal of delivering evidence-based, coordinated cancer care and empowering survivors to lead healthy lives, we should consider the many assets currently available. Nonprofit organizations serving survivors; comprehensive cancer control coalitions within each state, tribe, and territory; and influential individuals within targeted communities can all be enthusiastic allies in dissemination with attention toward sustainability (40, 41). Figure 1 illustrates key partners who are vital to the advancement of cancer survivorship. Future work in survivorship needs to focus on weaving these assets together. One such example is 2 CDC-supported pilot projects being conducted at academic and community cancer clinics to determine the feasibility and impact of implementing survivorship care plans developed by a collaboration of nonprofit and private organizations and based on IOM guidance (26, 28, 42). A second asset is the growing amount of research and number of researchers focused on treatment improvements, rehabilitation, late effects, and psychosocial support related to cancer survivorship. These resources make now an ideal time to embrace dissemination and translation research and begin to address the challenges of integrating research and practice. Researchers and program planners should use available resources and tools to increase translation. For example, Cancer Control P.L.A.N.E.T. (planning, implementation, and evaluation of evidence-based cancer control interventions) is a website designed for public health planners to access cancer control resources such as evidence-based interventions and programs and for researchers to locate programmatic partners (43). Current research networks and funding mechanisms for the dissemination and translation of cancer survivorship interventions include the Agency for Healthcare Research and Quality's ACTION Network, the Prevention Research Centers program within Centers for Disease Control and Prevention, and National Cancer Institute's Designing for Dissemination initiative (44-46). If investigators are encouraged to report their work in the

RE-AIM framework (¹²), program planners may be better equipped to decide which survivorship interventions work best in their community.

In conclusion, timely and effective translation of research to public health practice is paramount in supporting the nearly 12 million cancer survivors currently living in the United States (⁴⁷). This overview highlights many theoretical and practical approaches to making research and interventions more relevant at the community level. As our depth in knowledge about cancer survivorship grows, it should be equally broad. A shift toward increasing research on dissemination and involving targeted communities in the development of research questions and the translation of results could have an enormous impact on ensuring the relevance and adoption of survivorship interventions.

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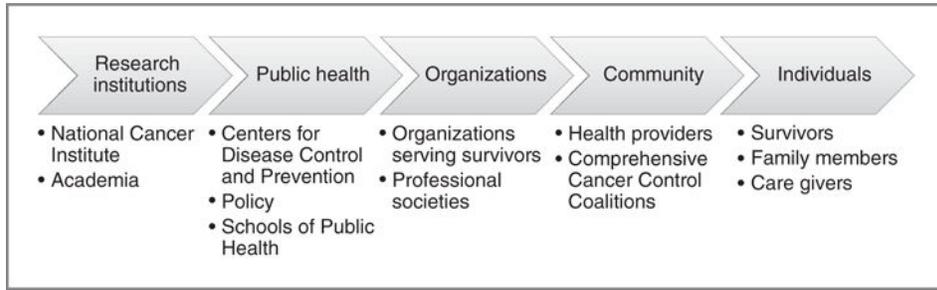


Figure 1.
Key partners in the dissemination and translation of cancer survivorship research.

Table 1

Comparison of factors valued in research versus practice

Research	Practice
Theoretical framework	Cost
Funding available	Reach
Previous research	Relative advantage
Study design	Uptake
Methodology	Policy support
Inclusion/exclusion criteria	Culture
Isolation of key variables	Organizational
Validity	Targeted population
Controlled setting	Feasibility
Defined outcome	Adaptability
Fidelity	Practicality
Reproducibility	Personnel
Internal validity	Simplicity
Reporting of selected results	Sustainability
Efficacy	Communication Trust External validity Effectiveness

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