

Flinders Centre for Innovation in Cancer

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The Roles of Survivors in Shaping Care that Works: Phil Kerslake

Introduction

My name is Phil Kerslake and I'm a cancer survivor. I'm here from New Zealand to talk about the potential roles of survivors in helping shape survivorship care that will work.

Cancer survivorship care is generally viewed as the responsibility of the medical profession, so why do we need to consider cancer survivors – laypeople – for shaping and helping deliver some of these services?

Well two reasons. Firstly, if our goal is, as it must be, to deliver survivor-centric care, who better to inform the shape and content of that care than the survivors themselves?

Secondly, the medical profession just doesn't have the resources to do everything it needs to and it's going to have even less resource in the future, at a time when it's required to deliver more. There are plenty of forecasts predicting this world-wide (e.g. Lin and Donehower, 2010).

In the May 2009 issue of Journal of Oncology Practice, Shulman et al noted for the US context; that the number of internal medicine trainees going into primary practice was decreasing progressively.

Together with the acute shortage of medical oncologists and oncology nurses forecast globally for the near future, and with the inadequate preparation of Primary Care Providers, at this point anyway, to address complex cancer survivorship care; we are facing an increasingly critical resourcing problem (Shulman et al, 2009).

Current service gaps

So extra resourcing will be required from outside of the medical profession if survivorship care is to gain momentum and cancer survivors, appropriately selected, inducted, trained and applied to their tasks, know the domain they would be sought to volunteer in, in ways those who had never experienced cancer could not.

Something to consider relevant to the possible nature of survivors' roles is, where if anywhere are the gaps in survivorship care currently? What's not being done that needs doing?

Well, circumstances might indicate the *Lost in Transition* report was itself “lost,” because in 2013, eight years after the report and seventeen years after the Office of Cancer Survivorship was formed by the National Cancer Institute in USA, with the mandate to improve the length and quality of life of all those diagnosed with cancer, there are still few cancer centres internationally that have adopted survivorship care plans in any capacity (National Cancer Institute, 2012).

And, from those programs created and operational, the National Cancer Institute is doubtful of *any* survival benefit [*based on research to date such as that undertaken by Kattlove & Winn (2003)*] having been shown and sceptical, if I read the tone of a 29 August 2012 *Research Funding Opportunity Announcement* right (National Institutes of Health, National Cancer Institute, 2012 - extract follows), that the medical profession has made genuine efforts to apply survivorship care to its intended purpose.

To quote: ‘*Preliminary research suggests survivorship care planning may be related to improved compliance with recommended medical surveillance, reductions in duplicate health care procedures, and improvements in patient confidence about and preparedness for follow-up care. However it is unclear whether survivorship care planning demonstrates added benefit when compared to usual care.*’

What are survivors indicating they want and need from their care?

More research needs to take place on survival benefits, particularly once survivorship care plans are more widely adopted. However I submit that from many, perhaps most survivors’ perspectives the real promise in survivorship care is less related to morbidity than we might imagine, and more related to psychosocial issues.

Peoples’ needs will differ, but for many, *quality* of life restoration is their principal concern after the emotional, spiritual, existential, social and economic trauma the cancer and its treatments created for them.

For instance in a 2007 study by the Institute of Medicine presented by Hewitt et al (2007), survivor focus groups and interviews of people engaged in a survivorship care program found:

- They were enthusiastic about the prospect of receiving follow-up care plans
- They were satisfied with post-treatment medical care, but felt their psychosocial needs were not met
- They considered that counselling should be a part of follow-up care
- Those who had attended support groups praised them for the information and emotional support, however most had not been directed to support groups by their doctors

Clearly these survivors' needs post-treatment were very much in the psychosocial domain. In New Zealand I regularly engage with other cancer survivors and this is the consistent message I get.

For them it is about addressing the myriad of potential survivorship challenges we know to be common: regaining their sense of meaning, purpose and direction is a key one; re-building their self-image; not having to live in fear all the time; not wanting to feel like an outsider amongst their family, friends and colleagues; addressing sexuality and fertility problems and restoring damaged relationships at home and in the workplace.

Speak with any group of recent cancer survivors and you will find in many sub-clinical yet for them, debilitating psychosocial suffering that needs support. I use the word 'support' advisedly because more often than not medical intervention and treatment will be neither required nor wanted. People don't want to be coddled; they just want support.

Hewitt et al's 2007 reported findings are consistent with many other studies showing that patients want but don't get psychosocial support *during* treatment either (i.e. Ganz and Hahn, 2008). The Lost in Transition report speaks about cancer survivors' care needs becoming lost in the transition from patient to survivor. People's wider care needs can equally be said to have been lost in transition from healthy citizen to cancer patient – something I believe we must examine concurrent with addressing the gaps in survivorship care.

There's an argument to be made therefore, in terms of priorities, that rather than cramping the lives of survivors logistically and emotionally with lifelong regimes to manage their life quantity at the expense of the quality of their lives, perhaps care that is deemed to be working for survivors will focus firstly on empowering them with knowledge and psychosocial support to enable them to move forwards with their lives (J. Kane MD, personal communication, December 2012).

Peer Navigator roles

Accepting if you will my argument that psychosocial support is a common, notable gap in both in-treatment care and survivorship care, then of the numerous roles volunteer survivors could play and are currently playing, I'm going to underscore one I feel would deliver most value in helping address these issues for cancer survivors. It's one you will certainly have heard of: the *Peer Navigator*.

There are many different adaptations of Peer Navigator roles worldwide and they are certainly not all created equal. With most, veteran cancer survivors are paired up with novices. An attempt is often made to match type and stage of cancer. The "Navigators" are volunteers who've received training, sometimes in basic counselling, and are debriefed regularly in groups in order to refine their skills (J. Kane MD, personal communication, December 29, 2012).

Currently, Peer Navigators across programs are mostly employed during the in-treatment period. However I consider their engagement *after* treatments potentially, equally valid, and much needed.

The Genesis and modus operandi of WeCARE!

Of the many Peer Navigator programs globally, I am going to briefly overview the characteristics of the Peer Navigator role within the WeCARE! Community-Based Breast Cancer Peer Navigator Program at the National Cancer Institute-designated UC Davis Cancer Center, at the University of California, in Sacramento, USA. Having examined and compared it with various others, I consider it a well constructed program that might be emulated as an invaluable component of our survivorship care programs, once we establish them.

Information about WeCARE can be found in various Papers, however I also exchanged online with the program's creator, Dr Marlene von Friederichs-Fitzwater, between 3rd and 24th January 2013, to establish a more complete picture of her program.

Firstly I want to share with you in her own words, the personal life story of Dr von Friederichs-Fitzwater. As eminent as she clearly is, using my Layperson's licence I'll refer to her by her Christian name while relating the program information that she shared with me in our personal communications.

"In the late 1970s I was in my master's program, intending to continue graduate studies in journalism and mass media, when I learned I had cervical/uterine cancer at the age of 39. I was a single mother of four sons, sole breadwinner, working and going to school and unprepared to deal with the worsening prognosis. I was surprised to learn that my doctors were even less prepared in terms of the psychosocial and emotional issues. My questions of what would my 15-year-old son, still at home, do without my care and supervision, how would we live without my income, why did I feel so overwhelmingly sad with the loss of my uterus and the ability to have children when I did not intend to have more anyway, etc. were never addressed. In fact, they were dismissed as "unimportant" by my physician. As my prognosis got worse, my health care providers, my family, even some of my friends began to withdraw. The sense of isolation was immense. I did not know anyone else my age with cancer. I was lost in time and space. I vowed that if I survived, I would do something to make it better for others having a similar experience." Marlene M. von Friederichs-Fitzwater, Ph.D., M.P.H., Associate Professor, Haematology & Oncology, Department of Internal Medicine, University of California.

So Marlene's earlier encounter with cancer and her essentially disregarded and dismissed psychosocial suffering became the genesis of this program for cancer patients and survivors alike. Providence?

Shortly after going to UC Davis School of Medicine full time in 2005, Marlene was asked to develop and direct an Outreach Research & Education Program for the UC Davis Comprehensive Cancer Center.

She first did a year of research – interviews and focus groups with cancer patients and survivors and traveling around the United States to see what other cancer centres were doing. Then she developed the WeCARE! (Coach, Assist, Respect, Empower) Cancer Peer Navigator Program.

WeCARE! recruits cancer survivors two years or more out of treatment, who are carefully trained as cancer peer navigators (AKA "cancer coaches") and then matched with newly diagnosed cancer patients on a one-to-one basis for three to six months (or through active treatment and beyond).

In its 6th year and reported to be immensely successful, the program measures anxiety levels, confidence of patients in communicating with their physicians and problem-solving and coping skills of patients at baseline, 30, 60 and 90 days.

Marlene believes this element of the process is the key to empowering patients and helping them improve their problem-solving coping skills; skills that will serve them well through their cancer experience and into survivorship.

Medical people can be reticent about having laypeople systematically engaging with their patients on matters related to their care. What makes WeCARE! unique in the existing cancer peer navigation world, is that there is a well-tested cognitive/behavioral model at its core – the COPE model (an acronym for Creativity, Optimism, Planning and Expert information) – based on solid theory and research.

They train the cancer Peer Navigators in this model and they then coach newly diagnosed cancer patients with it.

Importantly, WeCARE! and the cancer Peer Navigator roles are not about "rescuing" or "taking care of" the patients. The loss of control that comes with a cancer diagnosis can be traumatic, so the WeCARE! approach gives some of that control back to patients and helps them engage more actively in their own treatment. It empowers rather than coddles.

Some of the program's Peer Navigators are already coaching patients into the survivorship phase and Marlene considers that the model could easily have a discreet focus at that end of the cancer care continuum. Guiding patients into finding a "new normal" as they deal with the long-term side effects of treatments is critical, she believes.

Marlene sees the possibility too of cancer survivor Peer Navigators working with patients at the end of treatment to actually develop and maintain their cancer survivorship care plan, acknowledging however that this would need more thought, research and discussion.

How might we identify and engage volunteer survivors?

To develop and operate a peer navigator program, or any other survivorship care program involving volunteer survivors, you first need to attract and secure a willing cluster, and that's not always easy.

WeCARE! uses a variety of approaches. They use their own publications that go out into the community. They use newspapers, mostly feature stories but also display advertisements. They give presentations to cancer support groups and sometimes radio and television interviews. And they engage with churches and community organisations, as well as using word of mouth.

Internationally, people are becoming increasingly innovative to identify, attract and secure the services of would-be volunteers. Organisational partnerships are sometimes favoured, focussing on new ways for the Health Sector to work with businesses. These can include:

- Corporate-sponsored volunteer vacations
- Release time for current employees
- Employee volunteer sabbaticals

The key seems to be to establish flexible and inclusive strategies (Australian Government, 2010). Many people in surveys not volunteering say this is not through lack of interest or motivation, but through lack of necessary time and/or competing priorities to do the volunteering and/or pre-requisite training. Measures to reduce such barriers therefore need to be included in volunteer prospecting strategies.

Consider our cancer support NGO's

It has long been my personal observation and bug-bear that in a majority of instances, the medical profession doesn't give our cancer support NGO's enough recognition for the roles they currently play and those they could play to a much greater extent, in feeding into cancer care right through the cancer continuum.

To quote my colleague Jeff Kane MD: "The perennial difficulty is in convincing the medical people that tumours are only one aspect of cancer and that the subjective emotional component is not only real and valid, but actually constitutes the person's suffering" (J. Kane MD, personal communication, December 29, 2012). Again, it's not all about morbidity.

Here in Australia you have some of the more creditable cancer support NGO's internationally as far as supportive care services are concerned. They're professionally operated, well resourced and capable of playing a significant role in both engaging volunteer survivors for Peer Navigator roles and for delivering psychosocial services tailored to the specific, individual needs of the survivors, as identified within their care plans.

I proposed earlier that we needed to look to address the psychosocial care needs of both in-treatment and post-treatment patients concurrently.

To do that successfully we need our oncology specialists to be adding psychosocial care, most of which could be delivered by the NGOs, to the treatment programs they devise for and in consultation with their patients. Such medical acknowledgement of the role psychosocial care should play in the total treatment process, and direct medical referrals to the NGOs for the support available, would be a crucial step forward in whole-person cancer care.

How do we prevent barriers to volunteer engagement?

The Australian National Volunteering Strategy Consultation Paper (Australian Government, 2010) found that over 25% of respondents indicated that feeling unwelcome in organisations prevented them from volunteering.

WeCARE also initially met with resistance from oncologists and surgeons about laypeople meeting with and talking to their patients before their first visit with them. But now, Marlene advises, they are her biggest champions.

The Doctors themselves report that new patients working with a Peer Navigator arrive at their first meeting with them better informed, less anxious and prepared to make better shared treatment decisions. The program has data that shows statistically significant improvements in disease and treatment knowledge, as well as improved problem-solving and coping skills.

So, with any similar program to be developed, it is the responsibility of the program developers and leaders to engage with the medical people while the program is in development on its intended purpose, and then be able to demonstrate its value when implemented to allay professional concerns and resistance.

Another barrier to survivor engagement can be tokenism. Many cancer survivor volunteers engaged by the Health Sector in a variety of roles internationally, comment that they ultimately found their presence largely or entirely tokenistic. Anecdotally, sometimes they felt they were invited simply so a consumer-engagement box could be ticked.

When engaging cancer survivors for volunteer survivorship care roles therefore, integrity must be shown through a genuine intent to involve them in meaningful work, and by empowering and enabling them to do the work they were recruited to do.

Any survivorship care program with a genuine intention of engaging survivors to play substantive roles will establish feedback mechanisms that allow for the survivors to share their perceptions of the effectiveness of both the program, and their own ability to make a contribution to it. The program should also include a feedback mechanism to let the volunteer know how they are assessed as performing against their role description.

Summary

In summary, I hope in this short paper I have shown you that cancer survivors, appropriately screened, recruited, trained and motivated, can be invaluable contributors to the delivery of survivorship care that works.

In most cancer centres internationally, survivorship care plans remain an unfulfilled promise. However volunteer survivors' engagement in substantive roles such as Peer Navigators, have been shown to integrate perfectly with the treatment and care programs.

I consider the Peer Navigator role, within a program that is well conceptualised, constructed and operated, to offer real potential as a crucial component of survivorship care. Integrated into a comprehensive survivorship care program, Peer Navigators can support new survivors as they seek to address their psychosocial suffering, thereby contributing to the effectiveness of the overall program.

Cancer survivors indicate time and again that their psychosocial needs were neglected as part of standard clinical care (i.e. Ganz and Hahn, 2008).

It is eminently sensible therefore that we address this in-treatment care omission as we establish programs to support patients through survivorship. In so doing we will move much closer to whole-person treatment that is focused on the individual with cancer, rather than on the illness they are afflicted with.

Thank you for your attention and I am happy to take any questions or comments you might have for me.

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References

- Australian Government (2010). National Volunteering Strategy Consultation Report. http://www.dpmc.gov.au/publications/national_volunteering/docs/consultation_report-national_volunteering_strategy.pdf.
- Earle, C.C. (2006). Failing to plan is planning to fail: improving the quality of care with survivorship care plans. *Journal of Clinical Oncology*, Review Article, Volume 24, Number 32, November 10, pp. 5112 – 5116.
- Ganz, P.A. and Hahn, E.E. (2008). Implementing a survivorship care plan for patients with breast cancer. *Journal of Clinical Oncology*, Review Article, Volume 26, Number 5, February 10, pp. 759 – 767.
- Hewitt, M.E., Bamundo, A., Day, R., and Harvey, C. (2007). Perspectives on post-treatment cancer care: Qualitative research with survivors, nurses, and physicians. *Journal of Clinical Oncology*, Volume 25, Number 16, June 1, pp. 2270 – 2273.
- Kattlove, H., and Winn, R.J. (2003). Ongoing care of patients after primary treatment for their cancer. *CA: A Cancer Journal for Clinicians*, 2003; 53; 172 – 196.
- Kerslake, P.T. (2010). The history and possible future of survivorship care. Presentation to the *Survivorship Forum - from discharge, through follow-up and beyond*, Cancer Society of New Zealand and Central Cancer Network, 1 December 2010.
- Lin, J. and Donehower, C. (2010). Make quality cancer survivorship care possible in the era of workforce shortage. *Journal of Oncology Practice*, Volume 6, Issue 1, pp. 52 – 53.
- Macvean, M.L., White, V.M. and Sanson-Fisher, R. (2008). One-to-one volunteer support programs for people with cancer: a review of the literature. The Cancer Council Victoria, *Patient Education and Counseling*, 2008, 70(1): pp. 10 – 24.
- Mayer, D.K., Gerstel, A., Leak, N. L. and Smith, S. K. (2012). Patient and Provider preferences for survivorship care plans. *Journal of Oncology Practice*, Volume 8, Issue 4, pp. e80 – e86.
- National Cancer Institute (USA: 2012). A Closer Look: A tough transition: Cancer survivorship plans slow to take hold. *NCI Cancer Bulletin*, June 26, Volume 9, Number 13.
- National Institutes of Health, National Cancer Institute (2012). Examination of survivorship care planning and impact [R21]. Research Project Grant. <http://gents.nih.gov/grants/guide/pa-files/PA-12-12-274.html>. Posted August 29, 2012.
- Oeffinger, K.C., and McCabe, M.S. (2006). Models of delivering survivorship care. *Journal of Clinical Oncology*, Volume 24, Number 32, November 10, pp. 5117 – 5124.
- Rowland, J.H., Hewitt, M., and Ganz, P.A. (2006). Cancer survivorship: A new challenge in delivering quality cancer care. *Journal of Clinical Oncology* (Overview), Volume 24, Number 32, November 10, pp. 5101 – 5104.
- Shulman, L.N., Jacobs, L.A., Greenfield, S., et al. (2009). Cancer care and cancer survivorship care in the United States: Will we be able to care for these patients in the future? *Journal of Oncology Practice*, 27, pp. 2489 – 2495.
- Synthesis*: A publication of the UC Davis Cancer Center. (2009, Spring/Summer Issue). Navigating the first days of breast cancer.

About the presenter

Phil Kerslake is a 53-year-old, New Zealand-based, seven-time lymphoma survivor (both Hodgkin and non-Hodgkin). Phil's education in the art, science and practice of coping with cancer and its treatments for best outcomes began 34 years ago when he was diagnosed with an 'incurable' lymphoma in 1979 at age 19. His first lymphoma symptoms actually appeared when he was just a 14-year-old school boy.

Phil shares what his personal experience and extensive enquiry over decades has led him to believe with patients, health care and support professionals. He has presented to over 130 forums in NZ and Australia. He has a mission to help reduce patient suffering by empowering them with knowledge and hope. He advocates for empathetic, patient-centric service delivery with all those professionals who interface with patients in the medical system.

A volunteer patient-advocate for over 20 years, Phil was awarded an international Re-Building Lives Award in Vienna, Austria in 2007 for his work. He was appointed as New Zealand's first International Hero of Hope for 2011/12 by the American Cancer Society.

Phil's Cancer Society of New Zealand-endorsed patient support book Life, Happiness... & Cancer has been arguably New Zealand's foremost psychosocial support resource for patients and their carers since its first publication in early 2006 (now in its 4th print).

Described by the Cancer Council Australia as '*A book that can make a real difference in the lives of cancer patients from all walks of life and one I would certainly recommend to patients to incorporate as part of their recovery process*' (*CancerForum*, November 2007, Volume 31 Number 3, pages 181 – 182), Life, Happiness... & Cancer is also now published in Australia (2008), Africa (2010) and Poland (2010).

Publishers of *Life, Happiness... & Cancer* (2010) in Australia: Fontaine Press: Web <http://www.fontainepress.com/>

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