

CURED & CHRONIC

newsletter

"Cured & Chronic" promotes culture of long-term cancer survivorship

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EDITORIAL

Cancer survivorship: a need for international collaboration

— Vittorio Mattioli —



The considerable progress in cancer care occurring over the past few decades in surgery, chemotherapy, radiotherapy, and adjuvant therapies and our ever-growing knowledge base in all areas along the cancer research continuum

have undoubtedly led to greatly improved clinical outcomes. In fact prognosis has improved for most cancers: the overall five-year relative survival after cancer is over 60% in most developed countries due to early detection and improved treatment.

This has resulted in an estimated population of over 36 million cancer survivors in the developed world alone, corresponding to a population prevalence of about 3.5%: Europe nearly 14 million; Canada and the US: nearly 14 million; South-Eastern Asia: nearly 8 million; Oceania nearly 1 million. The absolute number of cancer survivors is predicted to increase nearly threefold over the next few decades, while the number of cancer deaths is expected to double.

However, the growing number of individuals surviving cancer, and the facility with which modern technology allows us to communicate our thoughts, feelings, and experiences, has also meant that we have stopped viewing cancer in a purely clinical sense and have begun to develop an awareness of the human being behind the disease. More often than not, those who receive a diagnosis of cancer now, no longer ask themselves how long they have to live, but rather how well they can expect to live from that moment onward. This shift in thinking from cancer survival to cancer survivorship has led to a notable increase in research on life beyond cancer in recent years. From 1971 to the present day, the body of literature in the US and EU has grown to over 18,000 papers, reviews, articles, citations, etc. on the key words cancer survivors and cancer survivorship, even if translation of this knowledge into practice is still poor and insufficient. Yet despite the growing body of scientific literature on cancer survivorship, many questions remain regarding how to assess, treat, and prevent survivorship-related problems. Indeed, the complex array of potential risks, problems, and long-term effects cancer survivors face and the methods to control them are just beginning to be explored and understood.

Continued on page 2

THE INTERVIEW Susan Leigh: an incredible life experience

My journey through cancer as nurse and survivor

Susan Leigh, RN, BSN, Founding Member of the National Coalition for Cancer Survivorship, is both a cancer survivor and a nurse cancer survivorship consultant in Tucson, AZ, USA. For this reason she lives an experience double, indeed, a once in a lifetime. For over 40 years she has been fighting with strength and tenacity a disease, repeatedly defeat, and repeatedly returned to manifest. For over 40 years, with her daily work as a nurse, she has been helping many cancer survivors to fight their daily battle. A story that combines all things: cancer, care, survivorship. A story that is worth to tell.

- Dear Susan, is a great honor for me to make this interview with you. Thanks a lot for giving me such an invaluable privilege. As you know, we met for the first time in May 2008, on the occasion of the international conference that I organized in Bari on the topic. "Life beyond cancer. Survivor: Person, not Patient anymore". Since then we met a couple of times in the United States, but despite these few meetings, between us is born a great esteem and friendship, and I followed you in your journey through cancer.

I know that your disease began in 1972. Can you tell briefly our readers when you found out the disease and what was so far its course?

"First of all, I wish to thank you, Dr. Mattioli, both for your warm friendship and also for your initial interest in the emerging field of cancer survivorship. Participating in the 2008 survivorship conference in Bari was surely one of my most memorable and cherished experiences as an advocate and oncology nurse, and we both have Dr. Pamela (PJ) Haylock to thank for this opportunity. I just wish there had been more time to explore your beautiful country!"

Raising awareness about the continual impact that cancer has on increasing numbers of survivors throughout the world has been a personal and professional mission of mine for over 4 decades. As you noted, I was originally diagnosed with Stage II a-e Hodgkin lymphoma in 1972 at the age of 24. As I had recently returned from a year's tour of duty in Vietnam as a young Army nurse, I was fortunate to have access to health care through our Veteran's Administration here in the United

States. Since oncology was such a neophyte specialty at that time, there were extremely limited sites that offered treatment in 1972, and Tucson, Arizona, was not one of them. Consequently, I was referred to Stanford University Medical Center in Northern California where Dr. Henry Kaplan had developed the radiation therapy protocol for treating my type of lymphoma. Also, Dr. Saul Rosenberg was instrumental in refining the chemotherapy regimens for Hodgkin's, thus making Stanford a dynamic hub for researching and treating this disease.

I could not have been more fortunate! Due to my extralymphatic disease in my left lung (along with mediastinal mass), I was treated with both chemotherapy (MOPP) and total nodal radiation. While these early treatments were incredibly difficult with severe side effects and no

effective symptom control, I had this new sense of hopefulness that my disease might be controlled or even cured. And "hope" is what propelled me forward to get through the treatments and eventually become an oncology nurse, also a new specialty in nursing in the mid-1970's.

Since my initial diagnosis, I have had episodes of remarkably good health interspersed with late effects from treatment. I have been diag-

nosed and treated for breast cancer (1990-91), bladder cancer (1995), and more recently, lung cancer (2016). I also take medication for hypothyroidism; went into premature menopause at the age of 24; have noticeable muscle atrophy and weakness throughout my upper chest and neck; have a partially paralyzed left vocal cord; and am currently dealing with multiple cardiac issues. Due to both external and internal muscle and vascular atrophy of my upper thorax, I am considered "high risk" for open heart surgery, and instead have had 7 stents inserted. I also had a heart attack even though I was taking anticoagulants, and am now living with congestive heart failure. But I am NOT complaining! If I had not received those original treatments 45 years ago, I would not be here to tell you about my life as a long-term survivor! So my mission is to raise awareness about the continuing issues and risks that many survivors face so that they have access to early diagnosis and interventions when needed."

Continued on page 4-5

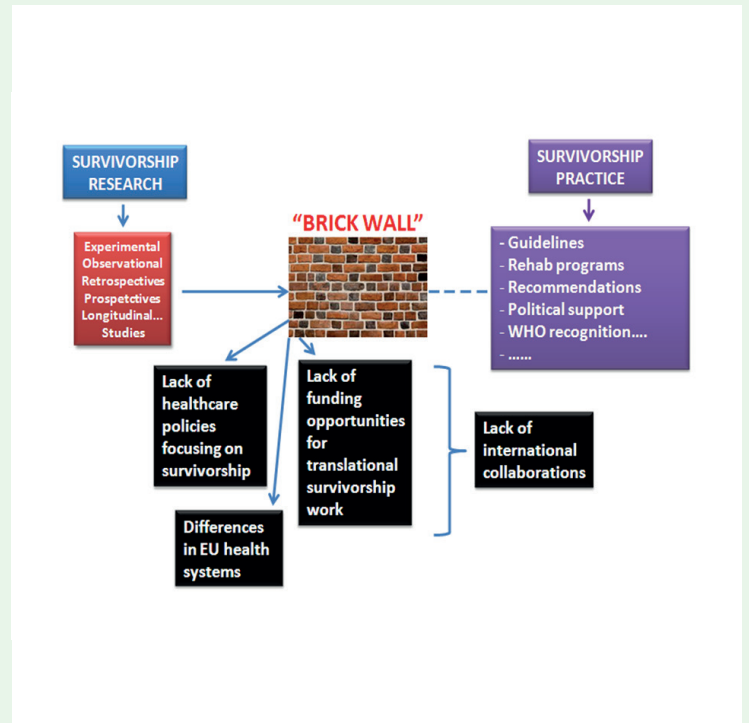


Research and Practice

Follows from page 1

Moreover, the degree to which these issues are becoming recognized varies greatly both across and within international geographic regions. Some countries are quite advanced with respect to the awareness and management of survivorship issues whereas others are just beginning to recognize and address the unique problems and concerns that cancer survivors face after the completion of their primary adjuvant treatment. Even in countries with more advanced approaches, there are few evidence-based recommendations for the management of cancer survivors, and experts have not reached consensus on the structure, content, and development of survivorship care guidelines. As a result, there are still many differences among countries regarding the research and practice in this field, which may be explained, in part, by the specific social and cultural factors that influence and shape the unique survivorship care scenarios for every country. International differences in health care systems and delivery are also notable. Many countries in Europe, such as France, Italy, and the United Kingdom, offer free access to public health care, whereas the United States does not, potentially contributing to limitations in access to quality cancer care for poorer individuals and those without adequate health care coverage. However, compared with European countries, the commitment of patient advocacy is traditionally stronger in the United States, which has led the way in promoting the application of research findings into practice. With increasing focus on the issues of long-term cancer survivorship in clinical care, public policy, and research initiatives, Europe and the United States are trying to respond in an even better and more targeted manner to this change in the health trajectory of patients diagnosed with cancer, with the main objective being to meet the needs of these individuals. As with many areas of cancer research, survivorship research is often fragmented throughout Europe and the rest of the world, leading to unnecessary overlap, wasted resources, and missed opportunities. If we were to imagine the ideal infrastructure with which to implement results from research on cancer survivorship into practice, it could look something like a smooth flow of knowledge from the various research areas into practice, at the personal, national, and global level, and experience from practice feedback to the table ready for new research projects (fig. 1).

However, despite the growing body of scientific literature on cancer survivorship, very often the transfer of this knowledge into consolidated survivorship programs and care planning is hindered by a series of obstacles and barriers which constitute a type of brick wall blocking progress (fig. 2).



This is the reason why the international collaboration can be a positive resource to overcome many of these obstacles and problems, involving clinicians, nurses, psychologists, healthcare planners, policy makers, stakeholders, and patients association in order to:

- develop a better understanding of key issues in cancer survivorship research and practice;
- promote high quality survivorship care and research; encourage inter-institutional collaborations to avoid overlap and speed up the transferral of research results into practice;
- develop and share a cross-cultural plan of research, knowledge, comparison, education and dissemination;
- push for increased focus on issues of cancer survivors, with a view to developing guidelines in the various areas.

In conclusion, to fill more rapidly the differences of both knowledge and practice in cancer survivorship, we need to learn from each other; international collaboration with a shared cross-cultural plan of research, knowledge, comparison, education and dissemination would encourage inter-institutional projects to avoid overlap and speed up the transferral of research results into clinical practice to better meet the needs of cancer survivors.

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Partners of young breast cancer survivors

Emotional needs and stress

— Maria Giovanna Pescarenico —

The AIRTUM report published in 2014 provides the readers with a chapter on psychosocial needs and well-being concerns of both long-term cancer survivors, and chronic cancer patients.

In this report, among other things, it's written: "in the review of studies concerning cancer survivors, several sources indicate that 20-30% of patients consistently report problems such as physical symptoms,

reduction of quality of life (QoL), psychological distress, sexual, relational and interpersonal problems". On this matter, the document of the European Union Council, published on 23rd June 2008, already reported a clear invitation to the Member States to take into consideration "the psychosocial needs of patients and to improve QoL of cancer patients through programs of psychological support rehabilitation".

The growing body of the scientific literature has shown that cancer affects not only patients but also caregivers, partners, family members, and close friends; many research studies demonstrated that a significant percentage of cancer caregivers has many unmet needs, frequently more than the patients they care for.

Primary caregivers (in most cases partners) of patients diagnosed with lung, urological, or gastro-intestinal cancer, compared with cancer patients, presented a higher level of both stress ($p < .01$) and anxiety scores ($p < .01$) (Sklenarova H. et al. 2015).

Otherwise, only a small percentage (<10%) of partners/family members of long-term breast, prostate and colorectal cancer survivors had high levels of anxiety and/or moderate or strong unmet needs (Turner D. et al. 2013).

Dr. Annunziata M.A. summarized exhaustively, in C&C Newsletter of 2016, the impact of disease on the survivors' family members. The article of Borstelmann N et al, presented at ASCO 2017

Cancer Survivorship Symposium, evaluated both the psychosocial concerns and mental health in partners of young survivors of early stage breast cancer (diagnosed at age < 40 yrs). Partners were invited to participate in a one-time survey, aimed to assess the psychosocial concerns including QoL, coping, social support, financial insecurity, partnership concerns, parenting

concerns, anxiety and depression. 289 partners, with median age 43 yrs, and median time since diagnosis 62 months, responded to the survey. 250 partners completed the questionnaire of anxiety evaluation (HADS), and of these 106 (42%) had anxiety. In the multivariate analysis, only the maladaptive coping was significantly associated with anxiety ($p < .01$). The Authors emphasized that caregivers' anxiety could have implications for both their own and survivors' health and QoL (QoL), and concluded that it would be necessary to develop constructive coping strategies to help partners to deal with cancer events.

Young breast cancer survivors

(aged < 50 years) and their partners are at higher risk of relationship distress and poor psychological adjustment than older age couples. Recently Cohee et al. (2017) confirmed that partners of younger breast cancer survivors fared worse on social constraints, intrusive thoughts and depressive symptoms, than partners of older breast cancer survivors. In Italy breast cancer survivors are about 700.000, but people "affected" by breast cancer are much more. Anxiety and depression are almost always present and assessed in cancer survivors, and this is reason why it should not be underestimated the psychological status of partners and/or patient's family, carefully to young couples. Psychotherapy and presence of psychologist/psycho-oncologist as member of the cancer care team, should be the standard in good clinical practice. But any member of cancer

care team can make immediate steps to understand the psychosocial needs of partners and families of patients. Borstelmann suggest a "small thing": to ask partner "how are you doing?".

These simple words can be the beginning of an important conversation about the relationship between the patient and his/her partner.

To achieve the highest standards of health and QoL for cancer patients, it is desirable that "Psychosocial

cancer care should be recognized as a universal human right"

(International Psycho-oncology Society): psychological well-being of cancer patients, their partner and family members should be considered in a public health program.

“
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a “small thing”:
to ask partner
“how are you doing?”

Borstelmann N et al J Clin Oncol 35, 2017 (suppl 5S; abstr 184)

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As Medical Executive of Oncology, she manages the outpatient clinics of both Oncology and Breast ultrasound, and the Oncology Day Hospital.



The most frequent aftereffects

Follows from page 1

- **The word survivor has often a semantic difference of opinion among the authors/people of the two sides of the Atlantic sea. Beyond the simple semantic interpretation, the term survivor may include a series of concerns, often little known in clinical practice, as well as not defined in care plans yet. What is your personal perspective on this issue as oncology nurse, and survivor?**

“For years no one paid much attention to the continuing struggles that plagued cancer survivors. Simply keeping patients alive for longer periods of time was major progress, especially since cancer had such a grim history. So, psychosocial trauma was usually a non-issue and often ignored, and physical symptoms not related to cancer were minimized or dismissed. Many of us were told to “be thankful that you are alive,” and to focus on the positive rather than the negative fallout from the cancer experience. But this was easier said than done. Over the past 4 decades, multiple issues surrounding the collateral damage from cancer and its treatments have been identified. These cancer-related issues can range from mild discomfort or inconvenience to major life-threatening emergencies. Consequently, physical survival is no longer the only measure of success, and oncology practitioners now include “quality of life” concerns in their research, treatment planning and follow-up care.

Obviously, it is good news that earlier diagnosis and better treatments are improving survival. The not-so-good news is that increased longevity increases our chances to develop other cancers and aftereffects from treatments. These aftereffects can be long-term or lingering, such as, neuropathy that continues indefinitely after chemotherapy treatment ends. They can also be late or delayed as seen in long-term Hodgkin’s survivors who develop breast cancer after mantle radiation. Although many survivors are fortunate to survive with minimal trauma, many others live with varying degrees of suffering, both physical and psychosocial. Below is a list of possible aftereffects that might influence life after cancer. This list is by no means complete.

Physiologic aftereffects:

System specific: Organ damage or failure

- Cardiac (e.g., cardiomyopathy, coronary artery disease, pericardial effusion)
- Pulmonary (e.g., fibrosis, pneumonitis)
- Endocrine (e.g., hypothyroidism, sterility, premature menopause)
- Vascular (e.g., stroke, arterial stenosis, transient ischemic attack, avascular necrosis)
- Compromised immune system (e.g., decreased immune function, increased risk for infection)

Second malignancy

- Recurrence of primary malignancy.
- Cancer associated with primary malignancy (e.g., ovarian cancer after primary breast cancer)
- Cancer associated with past therapies (e.g., breast cancer after chest irradiation)

Functional changes

- Decreased energy
- Incontinence
- Lymphedema
- Pain
- Neuropathies
- Fatigue
- Amputations
- Cataracts
- Dental caries

Cosmetic changes

- Lymphedema
- Amputations, including mastectomy
- Ostomies
- Weight gain and weight loss
- Skin or hair alterations

Psychosocial aftereffects:

- Psychologic: fear of recurrence, chronic anxiety, uncertainty about future, fear of dependency, survivor guilt, post-traumatic stress disorder, depression, anger, concerns about body image
- Social: change in social roles, creating or maintaining relationships, distress within family unit
- Financial: employment discrimination, insurance, out-of-pocket expenses, ability to work
- Spiritual: creating “new normal” or rediscovering self, questioning the meaning of illness and life after cancer, changing sense of hope and future, change in relationship with organized religion and/or God, surviving existential crisis and need to give back
- Sexual: can be a combination of physiologic, psychologic, social, or spiritual effects.

Numerous challenges now confront healthcare communities and delivery systems around the world. Who will take responsibility for caring for this increasing population of cancer survivors, and how will funds be allocated to pay for this extra care? While these complicated questions are now being debated in the U.S. and other developed countries, I also am aware that there are many people around the world who still have limited or no access to basic cancer care. They don’t even have the luxury of understanding the types of problems listed above.”

- So far cancer survivorship is an issue not yet highlighted by the WHO, even if there’s a wide body of literature on this concern. However in 2008, cancer survivorship, was recognized by NIH/NCI as part of the cancer control continuum, with the paper of Julia H. Rowland “Cancer survivorship: rethinking the cancer control continuum”, published in Seminars in Oncology Nursing.

You, who lived, in US, the first steps of cancer survivorship with Renilda Hilkemayer and Fitzhugh Mullan, might you provide our readers with the details of both the pioneering age of cancer survivors and the founding of patients associations and advocacy?

“Throughout the 1970’s and 1980’s, cancer treatments were changing so dramatically that so were our

expectations for survival.

We saw “dying from cancer” shift to “living with cancer,” and new sets of needs were identified that spawned the growth of community programs and advocacy organizations.

I am most familiar with the work of Dr. Fitzhugh Mullan as I was fortunate to be one of the founding members of the National Coalition for Cancer Survivorship (NCCS). In 1986, Dr. Mullan, a cancer survivor and officer in our National Public Health Service, was instrumental in creating this new organization, along with Catherine Logan who was also a survivor and a community activist in Albuquerque, New Mexico. NCCS was initially meant to coordinate the widespread and diverse activities that were serving patients both during treatment and beyond. It also hoped to create a comprehensive clearinghouse to share educational materials, to promote research in the area of survivorship, and to advocate for the needs of cancer survivors on a national level. Dr. Mullan had written the ground-breaking article, *Seasons of Survival: Reflections of a Physician with Cancer*, (New England Journal of Medicine, 1985) that started much of this exploration into surviving cancer in stages (acute, extended, permanent) and paying more attention to the consequences of treatment as patients lived longer. Others are now refining and adding to this model of staging in

order to better reflect changes and advancements in treatment, care and survival. Although NCCS first introduced the concepts of survivor and survivorship back in 1986, there is still confusion and no consensus as to their definitions. NCCS originally defined survivor as “from the time of its discovery and for the balance of life, and individual diagnosed with cancer is a survivor” (original NCCS charter). The goal was for cancer survivor to replace cancer victim, as the term victim was seen as being powerless, weak, or helpless. So it became a philosophical argument that patients could be empowered to live the best life possible no matter what the circumstance or stage of survival. Over the past decades, this terminology has been transformed to include other descriptive labels, such as, thriver, victor, sufferer, conqueror, advocate, or activist. While survivor has become a “love it or hate it” term, I actually consider the arguments over semantics a sign of progress, and individuals can call themselves whatever they prefer. But when dealing with physical survival and medical consequences of treatment, more specific parameters are needed so that healthcare providers are able to deliver appropriate follow-up care. Thus, the concept of survivorship may help in this respect as long as it is defined to fit a specified population. Survivorship is now embedded in most cancer care. While NCCS defines it as a dynamic concept “the experience of living with, through, or beyond cancer” healthcare providers have taken a different approach by defining survivorship as a static and distinct stage of survival.

Currently, the most popular use of the term is when describing the phase that follows the end of primary treatment and deals with post-treatment care and issues. But we must remember that this is hardly a homogeneous population.

Continued on page 5

The perspective of a long-term survivor

Follows from page 4

It is not just for survivors who are free of disease after 5 years. Survivors may also continue on maintenance therapy; eventually recur with the original cancer; develop secondary malignancies; live with cancer as a chronic illness; or be diagnosed with lingering or late effects. Survivorship also encompasses a huge list of psychosocial and other quality of life issues that can also include palliative care and end of life. So it has become an important and complicated concept to include in cancer care. While NCCS is still considered the primary architect of the concept of adult survivorship, it is only one of many organizations here in the U.S. with a focus on patient advocacy. Historically, as quality of life issues became more important to survivors and caregivers, individuals and communities responded by developing support groups, hotlines, publications, networking opportunities, and resource centers. Since the 1990's, local and national advocacy organizations increased dramatically, especially ones that focused more on specific types of cancer. Multiple breast cancer groups continue to compete against each other as they unite around different missions: education, support, research, clinical trials, fundraising, advocacy, or environmental issues. And advocates often turn into activists as they organize, network, march, and raise their collective voices to be part of health care debates. No longer silent, the voices of cancer survivors here in the United States are now included in public policy discussions that affect the lives of those who are living with, through or beyond cancer. And in this respect, NCCS has become a major leader in the public policy arena."

- On last February 14th-15th were presented in Malta the three years EU Joint Action CanCon (Cancer Control) key results in presence of EU policy makers, stakeholders and partners. CanCon Guide, officially titled "European Guide on Quality Improvement in Comprehensive Cancer Control", is the main delivery of the Joint Action, aimed to help to reduce not only the cancer burden throughout the EU but also the inequalities in cancer control and care that exist between Member States. The Guide is meant for governments, parliamentarians, health care providers and funders, and cancer care professionals at every level. A special focus was made in the WP8 on cancer survivorship, rehab, palliative and end of life care.

I remember well the book milestone published by IOM in 2006 "From Cancer Patient to Cancer Survivor. Lost in transition". This report highlighted the many concerns of cancer survivors. Since then, many Scientific Societies and/or Public/Private Associations have become aware of these issues. As, to your knowledge, what has changed since then in public health systems to meet the needs and improve the quality of life of these people, cured of cancer, but not from long-term or late sequelae of the disease?

"I will approach the discussion from the perspective of a long-term survivor who continues to need specialized survivorship care, and also as an ad-

vocate who still counsels survivors.

What follows is the list of the essential components of survivorship care that are summarized in the 2006 report, "From Cancer Patient to Cancer Survivor. Lost in Transition."

1. Prevention of recurrent and new cancers, and of other late effects.
2. Surveillance for cancer spread, recurrence, or second cancers: assessment of medical and psychosocial late effects;
3. Intervention for consequences of cancer and its treatment, for example, medical problems such as lymphedema and sexual dysfunction; symptoms, including pain and fatigue; psychological distress experienced by cancer survivors and their caregivers; and concerns related to employment, insurance and disability; and
4. Coordination between specialists and primary care providers to ensure that all of the survivor's health needs are met.

Although it has been over a decade since this report was published, progress toward implementing this type of care has been slow. It certainly is not due to interest, but rather to the complexity of the issues. Personally, I believe that:

- General awareness about survivorship has increased dramatically within the oncology community, but how to incorporate interventions is incredibly difficult. Pilot projects that are creating and assessing different models of survivorship care need more funding, yet money for this type of research is scarce. Julia H. Rowland at the Office of Cancer Survivorship at our National Cancer Institute (NCI) is an important resource for anyone interested in this type of work, and can help researchers find appropriate resources.

- Prevention needs more attention. Secondary prevention is meant to decrease the impact of the original cancer diagnosis, and is increasing in importance as the survivorship continuum expands and new risks and threats to health are identified. New screening guidelines are being developed in order to detect disease or treatment-related problems, but many more are needed. For example, earlier mammography after mantle radiation is now well-established for young Hodgkin's survivors, yet it is seldom included in lists of risk factors for breast cancer. Fortunately, the National Comprehensive Cancer Network (NCCN) has been gradually adding guidelines for long-term follow-up for a number of years now, as are survivorship care plans (SCP's).

- Tertiary prevention is meant to soften or decrease the long-term effects of disease or treatment, and thus plays a huge role in long-term survival. Survivors can live for years trying to manage lingering or late effects of treatments. Examples are living with lymphedema, infertility or peripheral neuropathy. Improving quality of life for survivors is now a challenge for clinicians and caregivers, and must be considered when treatment decisions are initially made. And prevention research not only needs more funding opportunities, but it also needs more interest and respect in the research community.

- Psychosocial issues, such as, suffering from fear of recurrence or debilitating post-traumatic stress

disorder, have been identified as barriers to recovery. More social workers, counselors, navigators, and advocates are needed to deliver both in-patient and out-patient services to hospitals and clinics. Unfortunately, this is the least funded area of cancer care, and many community programs must depend upon volunteers and foundations to offer support services.

- While the numbers of long-term survivors increase, few services exist that focus on adequate follow-up for this population. Once a person has completed initial treatment, follow-up with the oncology team gradually decreases. Often survivors who seemingly do well and have no signs of recurrence will eventually be followed by their primary care providers (PCP's or GP's) who have limited knowledge about guidelines and risk factors for survivors. Thus, the IOM report emphasizes the need to collaborate more effectively with PCP's and other non-oncology specialists. One way to assist with this coordination is to develop SCP's. These plans will hopefully:

- Summarize and communicate what transpired during cancer treatment;
- Record known and potential late effects of cancer treatments with their expected time course;
- Promote a healthy lifestyle to prevent recurrence and reduce the risk of other comorbid conditions;
- Prevent fragmentation of care as well as improve the efficiency of care

The development and implementation of survivorship care planning is an on-going experiment here in the U.S. While the American College of Surgeons Commission on Cancer wants all accredited programs to implement treatment summaries and SCPs, the dates for providing these plans keeps being extended as feasible delivery models are being tested. We now have a number of computer-generated templates that can start the process for survivorship care planning. But most of them focus mainly on historical treatment summaries. Much less attention is given to the part of the care plan that individualizes present and future management by focusing on health maintenance, health promotion, education, resources, and support services. Obviously, this is incredibly time consuming and requires the right personnel to develop and deliver this type of material.

Fortunately, we now have more opportunities to collaborate and share information about these survivorship issues. Care planning templates can be found through such sites as ASCO, Oncolink, and Journey Forward. Also, two national programs now meet regularly to share the latest in survivorship research and follow-up care. They are the Biannual Cancer Survivorship Research Conference through the NCI Office of Cancer Survivorship, and the new Cancer Survivorship Symposium co-sponsored by ASCO, ACP and AAFP.

Thank you for the opportunity to share my thoughts on survivorship. I hope this information is helpful."

interviewed by Dr. Vittorio Mattioli, MD

Androgen Deprivation Therapy in patients with prostate cancer and quality of life

— Paolo Tralongo —

Prostate cancer is the most common cancer among elderly men. The American Cancer Society estimates that in the US for 2017 are expected about 161.360 new cases and 26.730 deaths around. The incidence is steadily increasing in the last decade, mainly due to the diffusion of the test for PSA. The etiology of prostate cancer is the result of a complex interaction between genetic factors (responsible for the familiar and the different incidence in human races) and environmental (dietary factors, carcinogens present in the environment). Older age and the presence of biologically active androgen hormones circulating in the blood and prostate tissue still represent the most relevant causal factors. Survival rates for prostate cancer according to the most recent data, when including all stages of prostate cancer, are: 5-year relative survival rate is almost 100%; 10-year relative survival rate is 98%; 15-year relative survival rate is 95%. Despite the survival data are quite encouraging is necessary make some observations on how adverse events affect the quality of life. The androgen deprivation therapy (ADT) is a commonly prescribed treatment that reduces an-

drogens, such as testosterone, to castrate levels in an attempt to slow the progression of the tumor and improve overall survival in men with locally advanced disease, and appropriately selected metastatic. Despite the improvement in survival, research has consistently reported a number of adverse effects associated with the use of ADT including deterioration of musculoskeletal health, an increase of cardiometabolic risk, sexual disorders and a reduced quality of life. A growing body of evidence indicates that ADT may also negatively affect cognitive functions.

The precise mechanism by which androgen deprivation leads to skeletal muscle atrophy is not well understood, but is a result of an imbalance between muscle atrophy activation and muscle growth factors. ADT leads to profound hypogonadism with castrate levels of circulating testosterone and estradiol, and, although such levels are not observed in aging men in general, ADT may potentially be considered a unique accelerated model for studying male aging and frailty. Clinical data, accumulated over the years have indicated that ADT was associated with potentially serious side

effects, including an increased risk of cardiovascular morbidity and mortality. In particular, patients with pre-existing CVD appeared to be at risk for developing cardiovascular events with ADT. Men undergoing ADT, who have pre-existing risk factors for CVD are at increased risk of adverse cardiovascular outcomes than those without pre-existing risk factors. It has been suggested that the risk of cardiovascular and cardiac events can be stratified on the basis of the patient's cardiac history, and symptoms can develop immediately after starting ADT. In patients without established cardiovascular risk factors, ADT can promote the development of proatherogenic metabolic abnormalities, such as glucose intolerance, dyslipidemia, increased adiposity.

The common alterations for men's sexual health include erectile dysfunction, changes in penis length and girth, pain with sexual activity, ejaculation and orgasm. Among these, erectile dysfunction is often cited as the main concern of men after treatment for prostate cancer. Cognitive decline is part of normal aging, particularly in the areas of information processing speed, memory, reasoning, reaction time and spatial abilities.

However, in men with PCA treated with ADT, the rate of decline in these processes seems to be accelerated. In addition, the use of ADT was associated with an increased risk of nearly twice to developing Alzheimer's disease, with the risk increases with duration of treatment. The available evidence indicates that ADT adversely affects cognitive domains of verbal, visual, spatial and working memory, spatial reasoning and spatial ability, psychomotor and visual-motor function, the auditory learning, executive function and processing speed, with the most significant effects on visual-motor skills. In conclusion the adverse effects of ADT may be more pronounced in the elderly population, especially those with lower functional status and increased comorbidities. It is important to consider the specific benefits and risks for each treatment modality as they apply to the elderly because of the greater risk in both short and long term.



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The image of the body and the role of self-compassion for the psychological well-being in breast cancer survivors

— Maria Antonietta Annunziata —

The body image is a psychological construct which captures perceptions, emotions, and attitudes that a person holds towards his/her own body.

Cancer treatments affect the body in various ways, directly or in form of side effects. In oncology, the physical damage may be temporary or permanent, sudden or gradual, visible or not visible (e.g., regarding internal organs), and may include functional implications or disability. It can affect organs with important symbolic value and/or connected, more than others, to the personal identity (e.g. reproductive organs). In summary, it's a psychological dimension of the experience of oncological disease, which varies according to the clinical characteristics of the disease, its stage, and the effects of treatments. A distorted body image, as well as the inability to integrate the bodily changes resulting from the disease, can adversely affect the social functioning (intimate relationship) with

implications in terms of functioning and quality of life (QoL). The body image can also interfere with the course of both disease and treatment, influencing the therapeutic adherence/compliance, determining decisions aimed to minimize the damage (real or perceived) of the bodily integrity, rather than the health. The body image can be perturbed in each different phase of the illness experience (from diagnosis to long-term survivorship or progression). Furthermore the troubles associated with the body image can occur, or worsen, in remission, when energy and attention of the patients are moving from the treatment and its effects to the resumption of normality. In oncology, many studies focused on body image assessment of women undergoing mastectomy or quadrantectomy, because either the breast cancer is the most frequently diagnosed type of cancer among women, or, in general, it's assumed that women, more than men, care about their appearance and body. A poorer body

image is significantly associated with mastectomy, young age at diagnosis, low QoL, mental and psychological distress.

About one-third of breast cancer survivors manifest distress, directly related to a disturbed body image, even after the successful treatments completion, and it remains stable over time and is associated with chronic fatigue and worst QoL, both generically correlated to the disease. The Self-Compassion (SC) is the ability to accept and to show kindness towards oneself.

In theory, during the emotional suffering caused by the body changes, most probably, self-compassionate individuals react to them with tolerance, awareness, understanding and kindness towards themselves. It's an inner resource that can positively impact on coping processes, as mediation of the adverse effects of rapid changes of body image in the suffering. In the wide international literature on cancer concerns, Przewdzicki et al. were the first to investi-

gate the relationship between body image disorders, SC and psychological distress, confirming the association between body image troubles, SC, and psychological distress, and demonstrating, unequivocally, that SC has a significant impact on anxiety and psychological distress. In fact psychological distress is associated with a greater body image disturbances, and lower levels of SC, while breast cancer survivors, with higher SC, experience less distress.

In conclusion, the body image is a crucial psychological construct for the overall well-being, and high levels of SC can have a potential protective role in women at risk of experiencing body image disturbances.



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FINANCIAL HANDSHIPS EXPERIENCED BY CANCER SURVIVORS:
A SYSTEMATIC REVIEW



Alice CK et Al.
Abstract

Background:

With rising cancer care costs, including high-priced cancer drugs, financial hardship is increasingly documented among cancer survivors in the United States; research findings have not been synthesized.

Methods:

We conducted a systematic review of articles published between 1990 and 2015 describing the financial hardship experienced by cancer survivors using PubMed, Embase, Scopus, and CINAHL databases. We categorized measures of financial hardship into: material conditions (eg, out-of-pocket costs, productivity loss, medical debt, or bankruptcy), psychological responses (eg, distress or worry), and coping behaviors (eg, skipped medications). We abstracted findings and conducted a qualitative synthesis.

Results:

Among 676 studies identified, 45 met the inclusion criteria and were incorporated in the review. The majority of the studies (82%, n=37) reported financial hardship as a material condition measure; others reported psychological (7%, n=3) and behavioral measures (16%, n=7). Financial hardship measures were heterogeneous within each broad category, and the prevalence of financial hardship varied by the measure used and population studied. Mean annual productivity loss ranged from \$380 to \$8236, 12% to 62% of survivors reported being in debt because of their treatment, 47% to 49% of survivors reported experiencing some form of financial distress, and 4% to 45% of survivors did not adhere to recommended prescription medication because of cost.

Conclusions:

Financial hardship is common among cancer survivors, although we found substantial heterogeneity in its prevalence. Our findings highlight the need for consistent use of definitions, terms, and measures to determine the best intervention targets and inform intervention development in order to prevent and minimize the impact of financial hardship experienced by cancer survivors.

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EFFICACY OF MEANING-CENTERED GROUP PSYCOTHERAPY FOR CANCER SURVIVORS:
A RANDOMIZED CONTROLLED TRIAL



Van der Spek N et Al
Abstract

Background:

The aim of this study was to assess the efficacy of meaning-centered group psychotherapy for cancer survivors (MCGP-CS) to improve personal meaning, compared with supportive group psychotherapy (SGP) and care as usual (CAU).

Method:

A total of 170 cancer survivors were randomly assigned to one of the three study arms: MCGP-CS (n = 57); SGP (n = 56); CAU (n = 57). The primary outcome measure was the Personal Meaning Profile (PMP; total score). Secondary outcome measures were subscales of the PMP, psychological well-being (Scales of Psychological Well-being; SPWB), post-traumatic growth (Posttraumatic Growth Inventory), Mental Adjustment to Cancer (MAC), optimism (Life Orientation Test-Revised), hopelessness (Beck's Hopelessness Scale), psychological distress (anxiety and depression, Hospital Anxiety and Depression Scale; HADS) and quality of life (European Organization for Research and Treatment of Cancer Quality of Life Questionnaire; EORTC QLQ-C30). Outcome measures were assessed before randomization, post-intervention, and after 3 and 6 months of follow-up (FU).

Results:

Linear mixed model analyses (intention-to-treat) showed significant differences between MCGP-CS, SGP and CAU on the total PMP score, and on (sub) scales of the PMP, SPWB, MAC and HADS. Post-hoc analyses showed significantly stronger treatment effects of MCGP-CS compared with CAU on personal meaning (d = 0.81), goal-orientedness (d = 1.07), positive relations (d = 0.59), purpose in life (d = 0.69); fighting spirit (d = 0.61) (post-intervention) and helpless/hopeless (d = -0.87) (3 months FU); and distress (d = -0.6) and depression (d = -0.38) (6 months FU). Significantly stronger effects of MCGP-CS compared with SGP were found on personal growth (d = 0.57) (3 months FU) and environmental mastery (d = 0.66) (6 months FU).

Conclusions:

MCGP-CS is an effective intervention for cancer survivors to improve personal meaning, psychological well-being and mental adjustment to cancer in the short term, and to reduce psychological distress in the long run.

Psychol Med. 2017 Apr 4

The european guide on quality improvement in comprehensive cancer control

National Dissemination Meeting in Bari

— Francesco Giotta —

May 12th will take place in Bari the National Meeting for the dissemination of the European Guide of Recommendations & Policy Papers of the CanCon Project. The European Guide on Quality Improvement in Comprehensive Cancer Control (CanCon) is the result of an EU joint action aiming to contribute in different ways to reducing the cancer burden in the EU.

This joint action was co-funded by Participating Member States and Organizations, Institutes, Universities and the European Commission, and the Guide was carried out through a three-year study conducted by top experts in 25 countries and 126 partner organizations.

The CanCon project started in February 2014 and the results were presented in a final conference held in Malta on 14th-16th of February 2017. The quality improvement of cancer care is at the heart of the CanCon Guide. It will be reached by focusing on the patient's experience, care and health services organization, delivery and accessibility.

The Guide includes a detailed survivorship care plan and evidence-based recommendations on cancer screening programmes for the EU Member States.

This is the main outcome of the joint action.

The Guide's authors stressed the concept that besides saving money and time, the effective cancer con-

trol increases quality of life.

Currently about 2.6 million people in Europe are annually diagnosed with cancer, but more and more cancer patients are overcoming the disease.

Therefore greater attention needs

to be given to access to care, early diagnosis, rehabilitation, and survivorship.

One of the most important result of this work is the Survivorship Care Plan, which should become a routine part of patients' files and care plan process, ever since the diagnosis of cancer has been set.

The complexity, multidisciplinary and longitudinal nature of cancer care requires a systematic and structured approach where key informa-

tion on the cancer patient needs to be noted.

The Guide is the key document to be communicated so that one of the major responsibilities of CanCon dissemination is spreading and promoting cancer control information

and knowledge, and diffusion to policymakers, Member States and relevant stakeholders.

The implementation of these recommendations is the next step so that we do not want the Guide to be just another book on the shelf.

The dissemination strategy is based on the strategic planning and network analysis, that is an evolving process.

Similarly continuous evaluation of communication is essential, it is

an ongoing process which can be achieved by promoting events on website, social media and in professional/stakeholder circles, national and regional meetings.

The implementation of these recommendations must ensure the following goals:

- quality based cancer screening programmes;
- better integration of cancer care;
- community-based cancer care approaches;

-providing concerted efforts in all aspects of survivorship, including palliative care.

CanCon is also an ambitious challenge in order to decrease inequalities and increase quality of care and shift from how long to how well cancer patients lives, and in conclusion aims at preventing cancer and enhancing the cancer consciousness, helping the Member States to place cancer firmly on their national public health agendas, and improve national situations by applying and adapting recommendations in the Guide.

CanCon brochure is available both as digital and printable format: www.cancercontrol.eu/uploads/images/Guide/pdf/CanCon_Guide_FINAL_Web.pdf.



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BARI Friday, 12th May 2017 - Conference Hall

Chairmen: A. Delvino, V. Mattioli, F. Giotta



CanCon
Cancer Control Joint Action

**National Meeting for
Dissemination of
Recommendations & Policy Papers**

